



## 2020 NATIONAL CARER SURVEY, TASMANIAN FINDINGS REPORT

MAY 1, 2021

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## About Carers Tasmania

Carers Tasmania Ltd is the Peak Body for unpaid carers in the state. The organisation was formed in 1993 in response to the need for greater focus on carers at a state-wide level. Since then, the organisation has grown to be the pre-eminent authority on unpaid carers, providing a comprehensive range of peak and service delivery outcomes.

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 the government.

A carer is a family member or friend who provides unpaid care and support for individuals, family members or friends who may be living with physical disability, mental health, alcohol, and drug problems, be aged or frail or living with a life limiting illness. The caring role mostly goes unrecognised and unpaid because it is generally embedded in everyday family relationships.

Caring can involve tasks such as dispensing medication or providing reminders, assisting with domestic or personal care activities such as cooking and shopping, showering, or feeding, attending appointments, advocacy, supporting the implementation of strategies recommended by specialists, providing encouragement or support to attend family and social events, school, or work, and/or emotional support and supervision.

In Tasmania, the estimated number of carers is approximately 80,100<sup>i</sup>. Tasmania has the highest ratio of carers (1:6) and the most dispersed, given the regionalised nature of the state.

Carers Tasmania's 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 do not go to plan and do what we say we will.

**Quality every time**— we do not accept 'good enough' because carers deserve our very best every time.

**Speed that matters**— we are agile and do not 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.

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## List of abbreviations

Auslan	Australian Sign Language
CALD	Culturally and Linguistically Diverse
FS	Hawthorne Friendship Scale
GP	General Practitioner
IWB	International Wellbeing Group
K5	Kessler Psychological Distress Scale (5 items)
K10	Kessler Psychological Distress Scale (10 items)
LGBTQI+	Lesbian, gay, bisexual, transgender, queer, intersex and other sexuality, sex, and gender diverse
LOTE	Language other than English
N	Number of respondents
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
PWI	Personal Wellbeing Index
SDAC	Survey of Disability, Ageing and Carers
TAS	Tasmania
HACC	Home and Community Care
COVID 19	Coronavirus
CHSP	Commonwealth Home Support Program
HCP	Home Care Package

## Foreword

Carers Tasmania is delighted to release the results of the 2020 National Carer Survey for Tasmania. The 2020 survey represents a collaborative partnership between each of Australia's state and territory carer association to conduct the survey nationally for the first time.

2020 was a challenging year for all Australians. We have been impacted by and responded to the unprecedented strain of the Coronavirus pandemic which saw Tasmanian carers in lock down caring for some of Tasmania's most vulnerable people whilst managing considerable restrictions placed on service delivery across the community service sector.

Tasmania has approximately 80,100 carers, which represents 15.5 % of the Tasmanian population. This is the highest per capita rate of carers of all Australian states and territories<sup>ii</sup>.

Carers Tasmania would like to extend their recognition and gratitude to the Tasmanian carers who took the time to respond to the survey and in so doing have provided information to guide Carers Tasmania in representing carers views and advocating for improvements in services and support to Tasmania's carers.

David Brennan

CEO

Carers Tasmania

April 2021

## Executive Summary

The National Carer Survey is conducted every two years to understand the experience of carers and find out how services and supports for carers can be improved. In 2020 the survey was conducted nationally across all Australian states and territories. More than 8,500 carers from across Australia including 1,024 (12%) from Tasmania completed the survey between April and June 2020 when many Tasmanians were in lockdown due to the Coronavirus (COVID-19) pandemic.

The survey also coincided with Carers Tasmania acquiring a wholly owned entity, Care to Serve Ltd, through which carer services are provided. Care2Serve (trading name) is one of ten national organisations providing Carer Gateway services within the Integrated Carer Support Service reform from the Commonwealth. Care2Serve also delivers Home and Community Care (HACC) on behalf of the Tasmanian Government's Healthy Tasmania initiative. The National Disability Insurance Agency (NDIA) recently contracted Care2Serve to provide Community Connector services for ageing unpaid carers of someone with disability.

Carers were asked to complete 75 questions which asked carers to share their opinions and experiences of their caring role. Participants were asked about:

- the caring relationship
- their caring role
- services and support
- paid work
- their health and wellbeing
- carer demographics

1024 surveys were received in Tasmania comprising 735 online and 289 in hardcopy



## 2020 National Carer Survey: Key findings for Tasmania

- The oldest survey respondent was 93 years of age.
- 92.6% were current carers and 7.4% were former carers.
- The typical respondent was a female primary carer with a median age of 61 and a household income below \$49,999 per year.
- The typical person being cared for was an adult male (median age 55) with physical disability who is not able to be left alone for more than a few hours.
- The average number of hours spent caring per week was eighty hours.
- The average number of years in a caring role was 12.65.
- Nearly half of the carers who responded were experiencing moderate to high levels of distress, and 81% were feeling some degree of isolation.
- Carers reported they had 11.92 hours per week for themselves and 42.8% reported that they never got time out from their caring responsibilities.
- Over 50% of carers reported that when accompanying a care recipient for a visit to a general practitioner or hospital they were not asked about their personal needs and there are insufficient support options and facilities for carers (seating, overnight rooms, transport support).
- Only 22.4% of carer were currently employed. These carers felt emotionally drained when they finished work and that this impacted on them in their caring role.
- Most respondents (58.2%) were primary carers, those individuals providing the most support to the person(s) they care for.
- More females (74.9%) than males (24.7%) responded to the survey, reflecting the larger proportion of primary carers in the overall population who are female.
- Respondents were most likely to care for their child, including adult children (45.1%), and/or partner (37.0%) and one in four respondents (25.9%) cared for more than one person.
- The most common group of people being cared for by survey respondents were people with physical disability (36.1%), followed by people with a chronic condition (29.2%) and people living with a mental illness (26.4%).

### Tasmanian Carers

### Spotlight on Tasmanian Carers

- Tasmanian carers were most likely to be female and aged over 65 years of age.
- They are mostly not in the labor force.
- They speak English and have completed year twelve or a higher academic qualification.
- Most have a household income below \$49,999 per year.
- They are most likely to be providing care to partner or parent with a physical disability, or one who is frail or aged.

The Australian Government's Survey of Disability, Ageing and Caring (SDAC)<sup>iii</sup> data indicated that there are approximately 80,100 carers in Tasmania. Based on the SDAC data over 10% of Tasmanian carers responded to the National Carer Survey. 1024 Tasmanian carers responded to the survey representing carers from all three Tasmanian regions (see Figure 1).



Figure 1: Number of carers in each region responding to the 2020 National Carer Survey

Table 1 provides a comparison of the 2020 National Carer Survey Data for Tasmania, Australian population estimates and the SDAC data for Tasmania. Tasmanian carers are more likely to be female, older and either not in the labour force or unemployed than their national counterparts.

		2020 National Carer Survey Tasmanian Data		Tas Population estimate (SDAC 2018) (proportions of person's %)	Population estimates (ABS 2019a)
		N	Valid %		% of population
<b>Total carers</b>		948	-	80,100	2.65 mil
<b>Primary carer</b>				33	
<b>Gender</b>	Female	551	74.9	51.7	57.3
	Male	182	24.7	47.4	42.7
	Non-binary/other	3	.1	Not provided	Not provided
<b>Age</b>	Mean (years)	61.4	-	-	51.2
	Up to 24 years (Young carers)	10	1.3	7.0	7.0
	25 to 64 years	298	49.8	56.0	56.0
	65+ years	392	49.0	34.0	34.0
<b>Education</b>	Bachelor or higher	171	23.5	18.1	25.6
	Certificate/diploma	259	35.5	32	34.3
	High school	148	20.3	Not provided	11.9
	< High school	151	20.7	Not provided	28.0
<b>Employment</b>	Employed	189	22.4	46	53.7
	Unemployed	56	6.6	40	3.3
	Not in labour force	600	71.0	52.5	42.9
<b>Disability*</b>		222	31	15.5	32.1

\*% age of carers who had experienced any long-term illness or disability themselves during the last 12 months.

Table 1: Demographic characteristics of Tasmanian sample

The youngest Tasmanian carer responding to the survey was twelve years of age and the oldest carer was 93. The mean age of all current carers in Tasmania was 61 in comparison to 51 nationally. 49% of Tasmanian carers were aged over 65 years.

### Cultural Background

Most (82%) of Tasmanian carers identified their cultural background as Australian (see Figure 2).

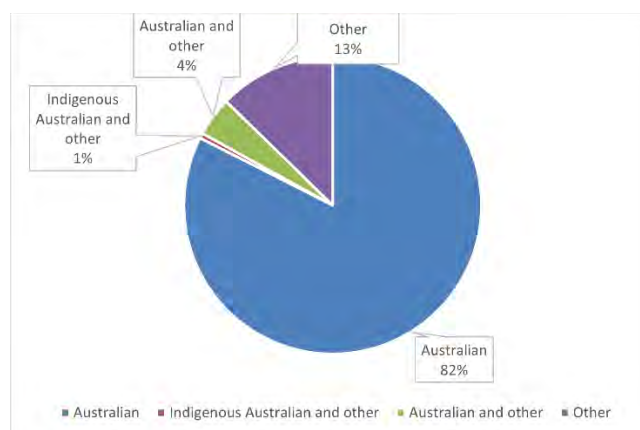


Figure 2: Cultural background of Tasmanian carers

Four percent of carers spoke a language other than English. The most common languages spoken other than English were Polish and German (9.7% of carers), French, Dutch, Tai, Bengali, and Nepali (all 6.5%).

### Education

Carer were asked about the highest level of education they had attained. 36% of carers held a Certificate or Diploma which was on par with national data. However, 20.3% of Tasmanian carers in comparison to the national figure (11.9%) had only completed High School (year 12 or equivalent). Most carers (91%) were not currently enrolled informal education.

### Household income

Carers were asked about their annual household incomes prior to tax. 64.7% of carers had an income of less than \$60,000 per year and 27.2% of carers had a household income of less than \$30,000 per year which is considerably less than the minimum wage in Australia of \$38,521 per year.

There was more than twice as many female carers (76.5% of all female carers) than male carers (23.5%) receiving less than the minimum wage (See Figure 3).

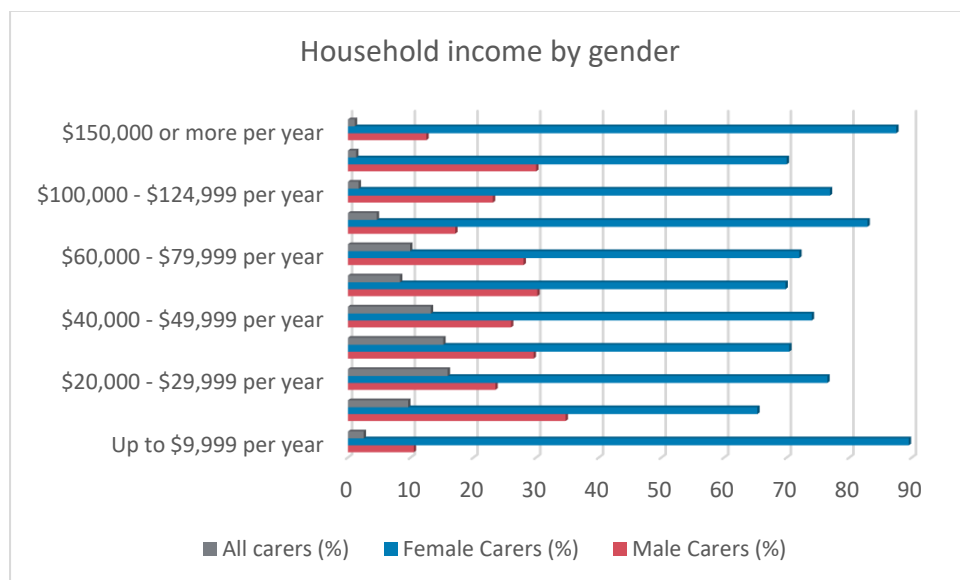
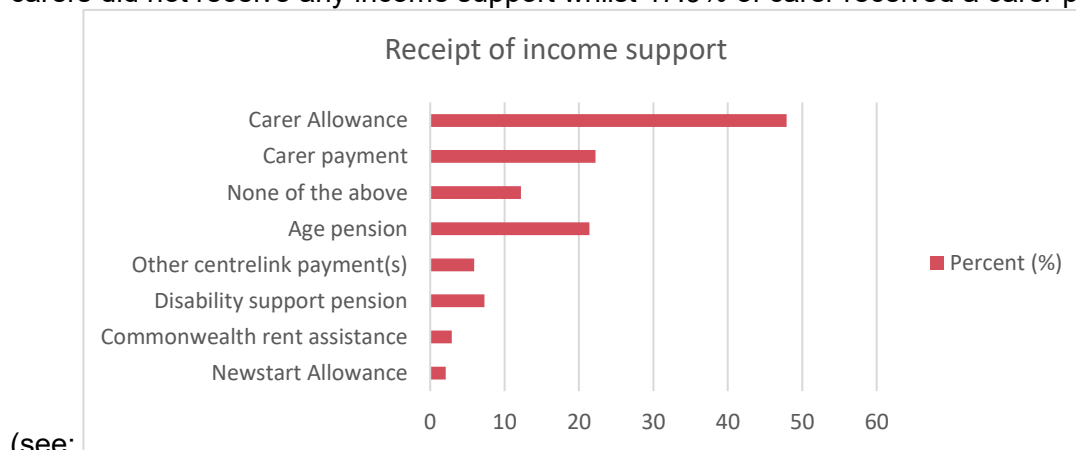


Figure 3: Gross household income by gender

### Financial Supports

Carers were asked if they received any financial support from the Government. 12.2% of carers did not receive any income support whilst 47.9% of carer received a carer payment



(see:

Figure 4).

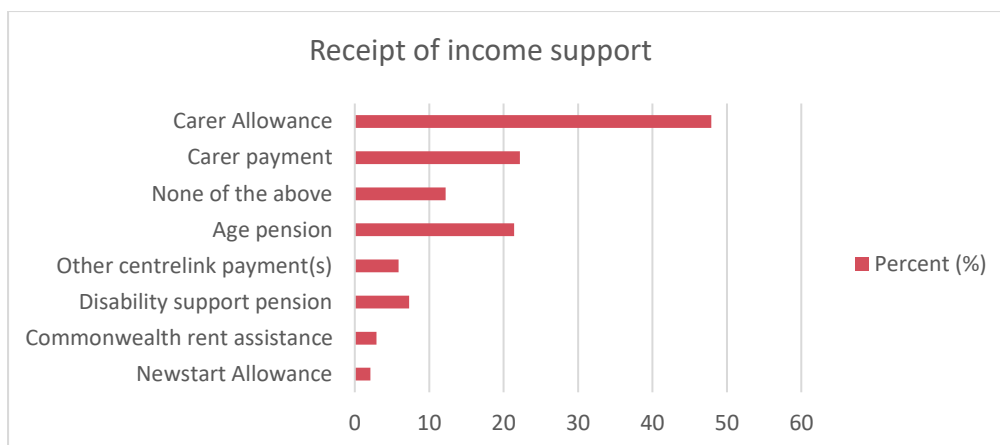


Figure 4: Income support received by carers.

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*Once my daughter moved into her home for over 63 days a year, I lost all carers payments/allowances. I care for her directly most weekends, also get called on in emergencies regularly by carers. Carers payment/allowance has been my only contribution to family finances for many years and when it stopped I was very depressed as I felt I was nothing. It felt like the government did not recognise the many hours of care I still put in and I felt like the high intensity care I still provide isn't important, and still feel the government regards me as useless*

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Carers experience trepidation and stress around being in receipt of payments if the care arrangements change due to the person, they care for dying, or having to move into a care facility.

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*There are many carers who dread what will happen to them after the person they care for dies. They are looking at JobSeeker (Newstart) and the financial commitment taken on in consideration of their career - e.g., rent or mortgage - they could lose their home. For many they have lost contact with career/work and are emotionally and physically long-term exhausted."*

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Carers were asked about the types of financial stress that they had experienced in the last twelve months. Figure 5 shows the number of carers and the type of financial stress they have experienced. 23.5% of carers were unable to raise \$2,000 in a week for something important. 16.6% of carers spent more money than they received in a month. Carers also reported seeking financial help from family and friends (9.4%), being unable to pay registration or insurance on time (8.9%), having to pawn or sell something (8.7%), not being able to pay gas, electricity, water, or telephone bill on time (10.6%), seeking assistance from welfare/community organisations (5.8%) and in some cases being unable to heat or cool their home (3.9%) and going without food (5%).



Figure 5: Carer's experience of financial stress.

Financial distress varied dependent on household size and participation in the labour force. Unemployed carers reported the highest rate of financial distress when compared to their working peers and those voluntarily out of the workforce. Just under half of all respondents experienced at least one form of financial stress in their household in the year prior to completing the survey (See Table 2).

	Household size					Labour force participation		
	1 person household (n=63)	2 person household (n=422)	3 person household (n=116)	4 person household (n=57)	5 or more person household	Employed (n=174)	Unemployed (n=55)	Not in labour force (n=545)
No experience of financial distress in past 12 months	55.6%	65.2%	49.1%	35.1%	19.0%	48.9%	29.1%	60.6%
One financial stress experience in past 12 months	14.3%	15.6%	14.7%	19.3%	22.2%	19.5%	12.7%	16.3%
Two financial stress experience in past 12 months	12.7%	8.1%	5.2%	15.8%	9.5%	9.8%	7.3%	7.9%
Three financial stress experience in past 12 months	7.9%	3.3%	3.4%	7.0%	15.9%	6.9%	7.3%	4.2%
Four financial stress experience in past 12 months	9.5%	7.8%	27.6%	22.8%	33.3%	14.9%	43.6%	11.0%

Table 2: Financial stress and distress by household size and labour force status

Carers reported that they were regularly paying for medicines (46%), health services and equipment (21%), transport (36%) and insurance (22%) for the care recipient. Financial stress may be attributed to the high rate of expenditure on the costs of care. Carers were

asked about the financial contribution they made to the cost of caring. Almost half of all carers paid for medicines (46%), health services and equipment (21%), insurance (22%) and transport (36%) (See Figure 6).

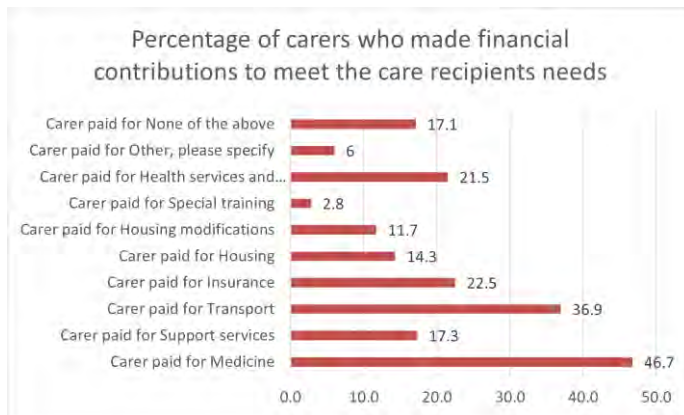


Figure 6: Percentage of carer making contributions to meet carers needs.

## The Caring Relationship

Care provided by families and friends occurs in the context of an existing relationship and is often part of a loving relationship. The issues, needs and challenges faced within a care relationship differ depending on the nature of the relationship, as well as the age, gender, health of both the carers and the person receiving care, the nature and severity of the condition or illness of the person being cared for, cultural expectations, the resources available within the family unit or care network, and the capacity to access external support.

People have very different values, expectations, and experiences of caring and being cared for. For some people, caring is an extremely positive experience, while for others it is stressful and difficult. Care relationships also change over time and involve different decision points and support needs depending on where people are at in the caring trajectory.

Carers were asked how their caring role had affected their relationships with the person they care for and other family and friends. Many felt socially isolated and had lost their friendship circles. Others felt a loss of intimacy in their relationship with the person receiving care. Increasingly the care relationship becomes transactional rather than affirming and sustaining.

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*I am 73 and have Chronic Fatigue Syndrome which mostly manifests as mental fatigue. My energy levels have declined until now I feel exhausted most of the time. My wife did have a loving, generous nature. Now, although she is not aggressive, I am constantly badgered with inane questions and irrational behaviours caused by various obsessions. I am too tired to show kindness or consideration and I cannot cope. I am in the process of applying for permanent residency for her at a nursing home. One of the obsessions is social phobia and consequently she doesn't want to see anyone at all under any circumstances. Because of this, although they are sympathetic, her friends, family and my children stay away and anyway, are either too far away or have their own problems.*

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255 respondents were both current and former carers. A former carer is a partner, relative, friend or neighbour who has completed their caring role because of the death of the person they were supporting or because the carer no longer has any involvement in caring. There were 76 respondents who were former carers only.

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*It effects the time I have to spend with my other family members. It affects the relationship I have with my partner and the time we have to even talk or engage with each other.*

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## Key Findings for Tasmania

- Care recipients were more likely to be male.
- Most respondents were caring for one person with little or no assistance from other family members or friends.
- The most common group of people being cared for by respondents were people with physical disability, followed by people with a chronic condition and people who were frail and aged.
- The typical person being cared for was an adult son with physical disability who is not able to be left alone for more than a few hours.
- Most respondents provide 40 or more hours of care per week, and more than half had been caring for 10 years or more.

This section outlines the Tasmanian results of the National Carer Survey relating to the person/people being cared for because of their needs arising from a disability, chronic condition, mental ill health, or advanced age.

The relationship between the care giver and care receiver is depicted in Figure 7. Eighty percent of carers care for only one person. Where there was only one care recipient the care providers were either a partner or spouse (45.7%) or adult children (33%). 13.2% of carers were caring for a parent or parent-in-law, 2.6% caring for a brother or sister and 1.6% caring for a friend.

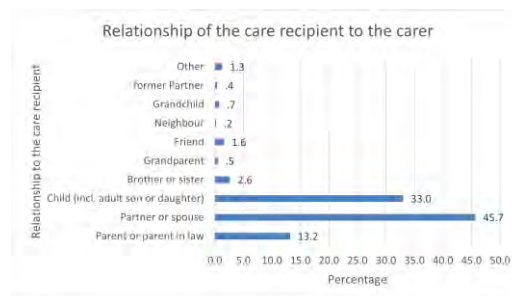


Figure 7: Represents the relationship of the care recipient to the carer.

13.6% of carers are caring for two people and 5.4% are caring for three or more people. Carers who are caring for one person are most commonly providing care to a partner or spouse (45.7%) or child (33%).

Carers who are caring for more than one person are most likely to be caring for a child including adult sons and daughters (91%), parent or parent-in-law (46%) or partner of spouse (20%) (See Figure 8).

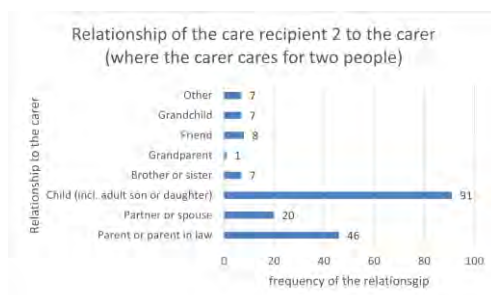


Figure 8: Represents the relationship of the second care recipient to the carer.

## Who is being cared for?

Males accounted for 55% of people being cared for and females (45%) (See Figure 9).

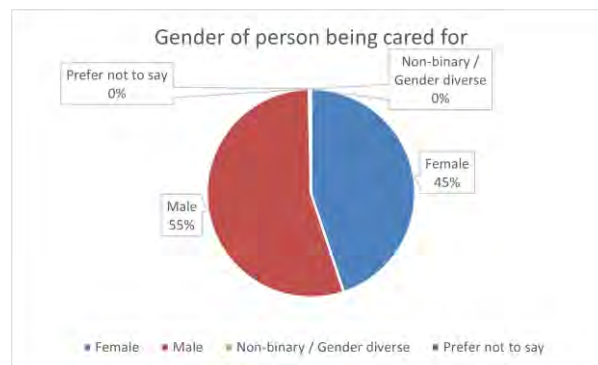


Figure 9: Gender of care recipient

The cultural background of the care recipient in 81.5% of cases was Australian (see Figure 10) and English was the most common language spoken (see Figure 11).

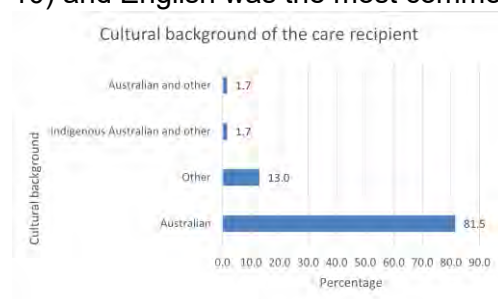


Figure 10: Cultural background of the care recipient

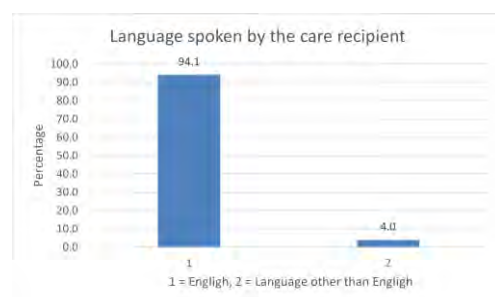


Figure 11: Language spoken by the care recipient.

Aboriginal and Torres Strait Islander people represent 4.6% of the Tasmanian population<sup>1</sup>. Only 5.6% of care recipients identified as Aboriginal and Aboriginal and Torres Strait Islander (See Figure 12).

<sup>1</sup> [Aboriginal and Torres Strait Islander Population Tasmania](#), 2016 Census data summary

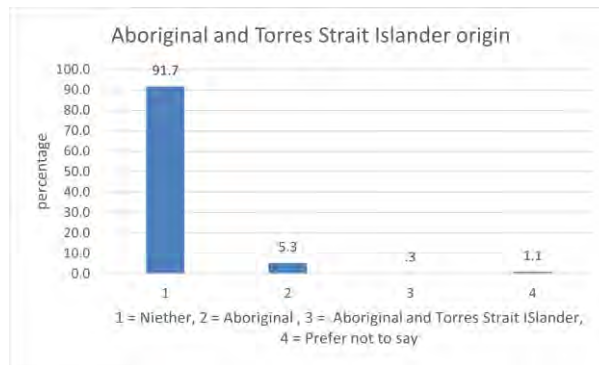


Figure 12: Aboriginal or Torres Strait Islander origin

Figure 13 represents a breakdown of the primary conditions, illnesses, or disabilities of the care recipient 1 (CR1) by Tasmanian respondents to 2020 National Carer Survey.

Respondents were most likely to be providing care for person with a physical disability (38.6%) or a chronic health condition (28.3%), 24.6% were aged or frail. Respondents to the survey were able to include multiple conditions. It is likely that comorbidity such as mental illness and an alcohol and drug dependency or chronic health condition and frailty due to ageing is present in some care recipients.

188 or 19.8 % of all carers who responded to the survey were caring for more than one person. Of those caring for more than one person the care recipient 2 (CR2) was most likely to be a male child (including adult child). The mean age of the CR2 was 40.89 years and the most prevalent condition was Autism Spectrum Disorder (58), frailty due to ageing (50), mental illness (47) and chronic health condition (42) (See Figure 14).

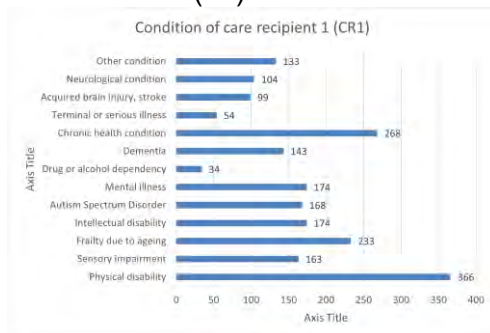


Figure 13: Condition experienced by care recipient 1 (CR1)

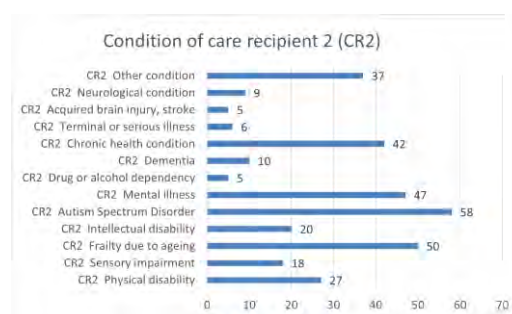


Figure 14: Condition experienced by care recipient 2 (CR2)

Most care recipients (81.9%) lived in the same household as their carer (see Figure 15). In instances where the carer was caring for more than one care recipient the second care recipient was likely (65%) to also live with the carer.

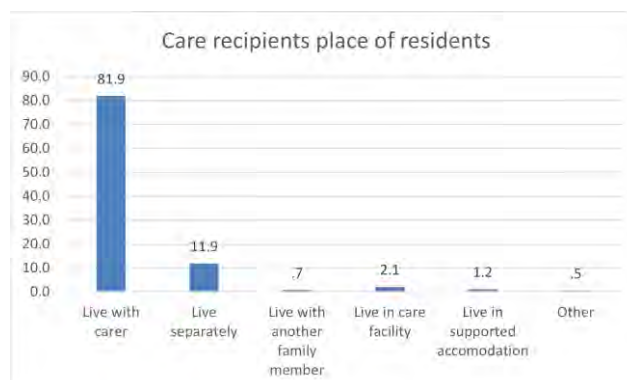


Figure 15: Care recipients place of residence.

Carers were asked if they received help taking care of the care recipient from other family members or friends. 56.6% reported that they were the only providers of care whilst 36.3% had some help with care some of the time (See Figure 16).

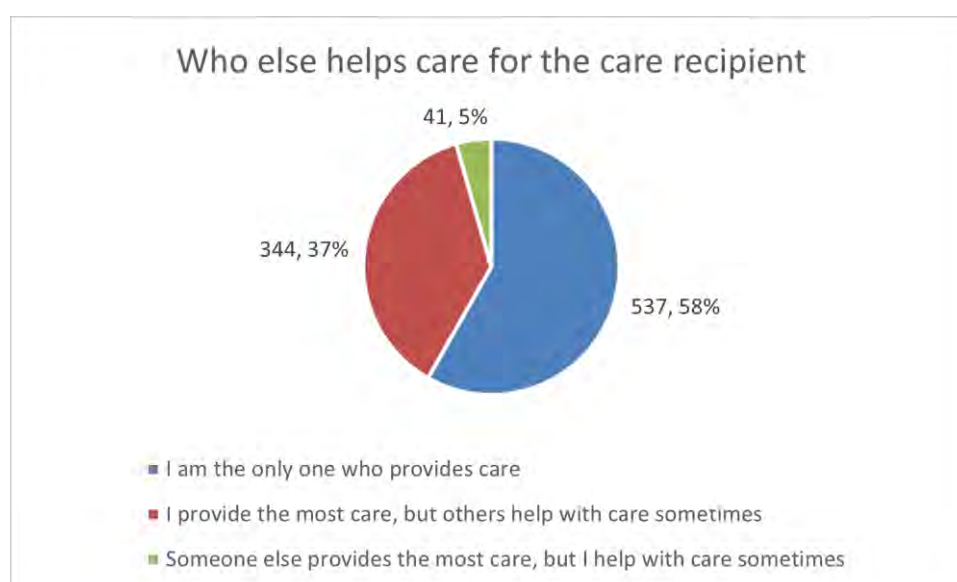


Figure 16: Help received by carer.

Carers were asked if they were able to leave the person they cared for alone, and if so for how long. In 37% of cases care recipients were only able to be left alone for a few hours at a time and a further 21.4% were unable to be left alone at all. 13.8% of care recipients were able to be left alone for less than an hour. Figure 17 represent the length of time the care recipient can be left alone.

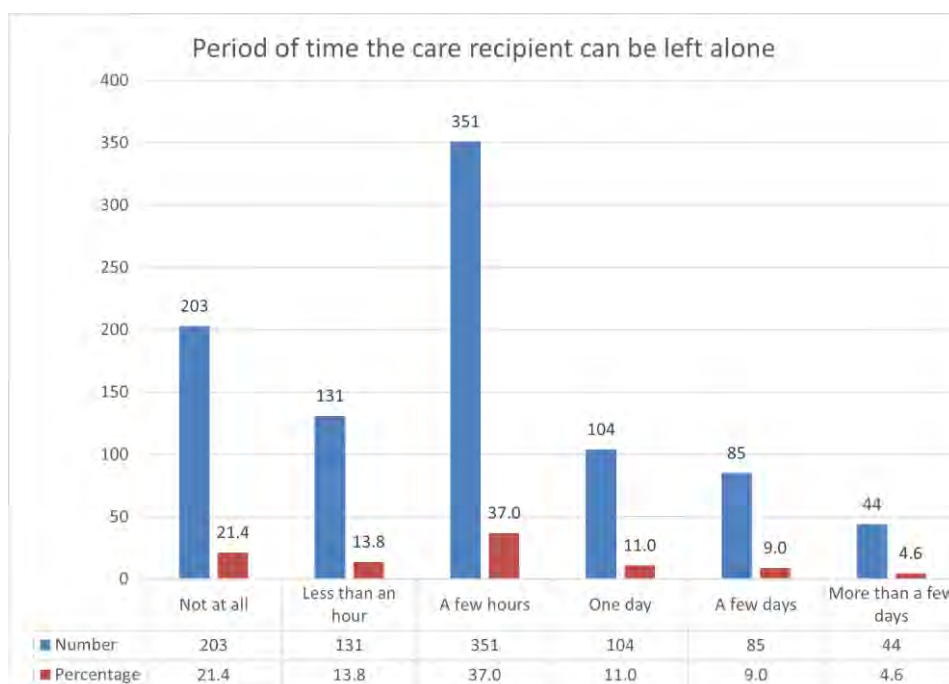


Figure 17: Length of time care recipients can be left alone.

The mean number of hours spent by carers in the caring role was 83.83 hours per week. 97.2% of carers had been in a caring role for more than two years and the mean length of time carers had been in the caring role was 12 years.

## The caring role

Many carers do not realise the significance of their caring role and view it as a normal, unnamed part of their life.

The caring role and the tasks undertaken by carers varies depending on the nature of the caring role, who they are caring for and the type of illness experienced by the family member or friend receiving care. How care is provided includes:

- General household and daily living tasks including cooking, cleaning, dishes, washing, ironing, grocery shopping, and gardening.
- Personal care such as dressing, washing and toileting.
- Emotional care such as providing emotional support and companionship. Supporting a disabled sibling such as playing with them, assisting those with nonverbal skills.
- Family care such as looking after younger siblings, getting them to and from school and to activities.
- Medical care and management including giving medications and injections and changing dressings, help with medical appointments by accompanying a parent to a Doctor's appointment and acting in a support and advocacy role.
- Physical care walking, moving around, pushing a wheelchair, organising, or providing transport to appointments.
- Financial care and support such as managing the family budget, attending to financial transactions.

Carers were asked about the type of support they provided for the person they cared for (See Figure 18 **Error! Reference source not found.**). Over 70% of carers were checking on the care recipient to see if they were okay. 9.4% provided transport, 78% helped with

household chores including cooking, cleaning, and shopping. 79% were providing transport to appointments or assisting them with navigating public transport systems. 75.6% provided administrative support. Other areas where carers provided support were in personal care (58.9%), communication (assisting with reading, writing, or helping the care recipient articulate themselves in conversation), advocacy (54%), organising finances (58%) and cognitive and emotional tasks (66%).

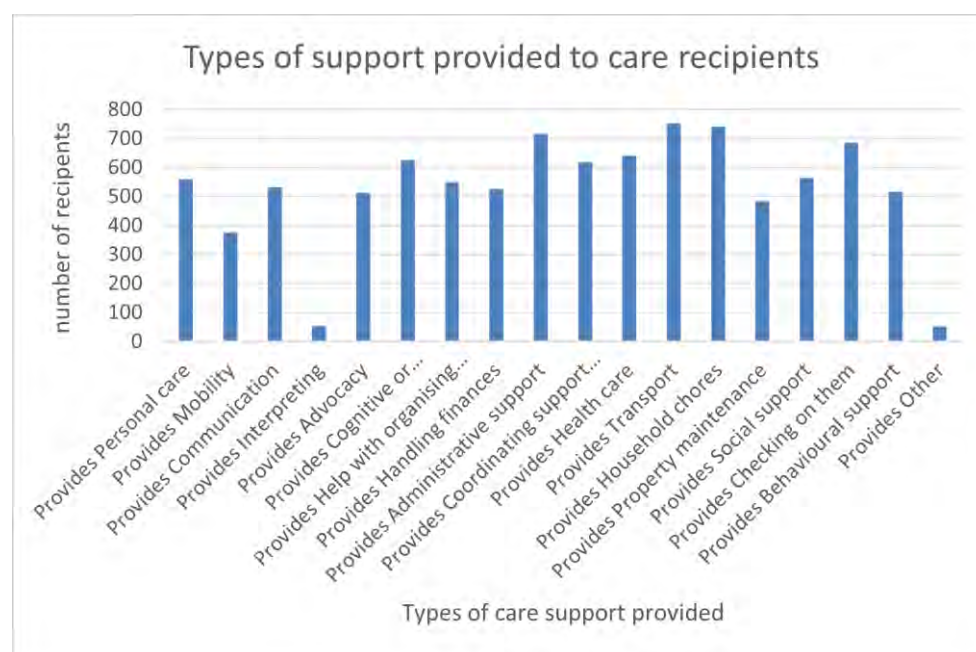


Figure 18: Type of support provided by the carer.

Carers were asked if they felt confident that they had the necessary skills for what they were doing in their caring role. Most carers 33% felt confident in their caring role. The level of confidence varied from somewhat confident (20.4%) to very confident (22%) with only 2.1% of carers not feeling confident in their role as carer.

Carers frequently experience feelings of isolation, resentment, and anger in their role as carer and commented that their relationship had *“transformed the husband/wife relationship to carer and care recipient”*. Carers also commented on their lack of time for themselves, and having no energy left.

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*“We are now more isolated- not helped by current pandemic. At first, I felt resentful and angry, now accepting although sometimes resentful. He depends on me totally, even when he does not recognise me and shows how much he loves me. It is an honour and privilege to be able to care for him. He is a lovely-although difficult at times-man-It has isolated us from some of our friends. My role is now a carer rather than a partner”.*

---

The caring role affected the carer care recipient’s relationship with several carers commenting that they felt socially isolated and rarely had time to see other family members and friends.



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*No longer in a loving relationship once a carer. Relationship becomes defined by the caring role. Family relationships are affected as frequently the care recipients' needs take precedence over the rest of the family.*

---

Carers also commented that they were experiencing poverty, and significant financial hardship and in some cases had ended up with no savings or superannuation.

---

*"As I am getting older, I find it more difficult to constantly be providing emotional and practical support. I worry a great deal about what is going to happen when I am no longer able to give support or simply, I am no longer here. Other family members help but I know they are not going to be able to provide the support I am currently giving."*

---

Care recipients with psycho-social disabilities and mental illness present a challenge to carers as the external presentation of the care recipient often masks their internal world. People do not understand how an individual that presents his/herself as articulate, talented, attractive, and capable can also have a mental illness.

---

*Since mental illness can be episodic, my experience currently is atypical of my total experience, as my son is currently able to live well enough independently. But in the first 10 years, the stress and grief and financial loss was quite considerable and many of my responses to this survey would have got reversed answers, back then.*

---

#### When the caring role ends

The caring role may change over time with some current carers also being former carers to another care recipient (see Table 3). Twenty five percent of current carers had also been former carers and 7.4% of respondents were no longer in a caring role. The median number of years former carers had spent in a caring role was nine years.

Carer Status	Count	%
Former carer only	76	7.4%
Current carer	948	92.6%
Current and former carer	255	24.9%

Table 3: Current and former carer status.

53.9% of former carers had ceased in the role of carer more than a year ago. This was due to the care recipient dying (28), someone else taking over the caring role (12), because they could no longer continue in a caring role (14) or for other reasons (23) (See Figure 19).

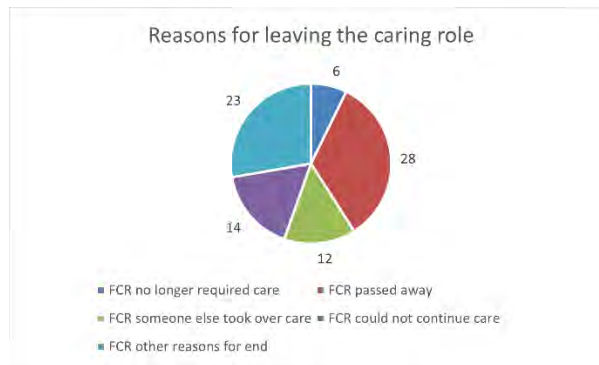


Figure 19: Former carers reasons for ceasing care.

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*“There are many carers who dread what will happen to them after the person they care for dies. They are looking at JobSeeker (Newstart) and the financial commitment taken on in consideration of their career - e.g., rent or mortgage - they could lose their home. For many they have lost contact with career/work and are emotionally and physically long-term exhausted.”*

---



## Health and wellbeing of carers

### Key Findings for Tasmania

Nearly half of the carers who responded reported high or very high psychological distress.  
One third of respondents felt highly socially isolated.  
Carer wellbeing is considerably lower than that of the general population.  
Most respondents felt that their family members and friends recognised and valued their caring role, but less than one in five felt recognised and valued by government.

*The isolation that occurs with friends and family who wish not to participate with the person you are caring for EG visit only Easter, Christmas, Birthdays, Anniversaries.*

Carers were asked about the level of satisfaction in various aspects of their life (see Table 4). Most notably 60% of carers were very satisfied with their future security. However, 44% of carers were extremely dissatisfied with their feeling of safety and their standard of living (30%). Most carers had some level of dissatisfaction with their health, feeling of being part of the community and their life overall.

Level of satisfaction	Satisfaction with							
	health	achieving in life	standard of living	personal relationships	feeling of safety	feeling part of the community	future security	life overall
Extremely dissatisfied	11%	9%	30%	11%	44%	19%	23%	24%
Very dissatisfied	15%	7%	17%	6%	15%	10%	10%	13%
Moderately dissatisfied	13%	8%	14%	6%	10%	10%	10%	12%
Slightly dissatisfied	11%	8%	10%	6%	6%	9%	8%	11%
Neither satisfied or dissatisfied	17%	22%	16%	16%	13%	31%	20%	16%
Slightly satisfied	9%	10%	4%	9%	4%	6%	7%	7%
Moderately satisfied	8%	12%	4%	9%	2%	8%	5%	7%
Very satisfied	8%	12%	3%	11%	3%	6%	60%	3%
Extremely satisfied	8%	13%	3%	26%	3%	11%	11%	7%

NB: percentages have been rounded

Table 4: Percentage of carers and level of carer satisfaction

*Creates social isolation as we exist on the margins of society mainly within the disability sector. Family and friends gradually distance themselves.*

The 2020 National Carer Survey included three validated scales designed to measure health and wellbeing. The domains measured were subjective wellbeing (the Personal Wellbeing Index), psychological distress (Kessler 5-Item Scale of Psychological Distress) and social connectedness (the Friendship Scale). It should be noted that these health and wellbeing measurements are likely to have been impacted by widespread restrictions on gathering and public movement in many parts of Australia at the time the Survey was conducted, due to the first wave of the COVID-19 pandemic. Results should therefore be interpreted carefully.

## Personal Wellbeing

The Personal Wellbeing Index (PWI, Cummins et al. 2003, IWB 2013) measures satisfaction with life across seven domains, which can either be assessed individually, or collectively as an overall indication of personal wellbeing. Values are calculated to be expressed in the range from 0 to 100% for each domain and the overall index. Table 12 shows the mean scores for the overall index and for each of its domains, as well as a comparison to the scores calculated for the general population of Australia (the 'normative mean', obtained from Khor et al., 2020).

Tasmanian survey respondents reported low levels of satisfaction in health, achieving in life and community connectedness. 70% of respondents were satisfied with their standard of living and 74.6% felt personally safe (see Table 5).

---

*At times isolation, boredom, anger and resentment. Our whole lives have been taken away by a muscle wasting condition. Seldom go out - too difficult. And fed up [with] friends and relatives telling us what we "should" do.*

---

Dimension	2020 Tas Carer Survey mean (%SM) (N=)	2020 normative mean (Kohr et al 2020) (%SM)	Difference (%points)
<b>PWI</b>	60.6	75.3	-14.7
<b>Standard of living</b>	69.6	78.2	-8.6
<b>Health</b>	55.3	74.4	-19.1
<b>Achieving in life</b>	54.9	73.4	-18.5
<b>Personal relationships</b>	59.6	79.3	-19.7
<b>Personal safety</b>	74.1	79.6	-5.5
<b>Community connectedness</b>	56.1	71.2	-15.1
<b>Future security</b>	58.3	71.2	-12.9

Table 5: Carers PWI score in comparison to the general population.

## Psychological distress

Psychological distress was measured using the Kessler 5-Item Scale of Psychological Distress (K5), which is categorised to indicate low to moderate (score of 5 – 11), or high to very high levels (score of 12 – 25) of negative emotional experiences by people in the previous four weeks prior to completing the survey.

Carer's levels of psychological distress ranged from low/moderate to high/very high. The lowest score was five and the highest 23 and the mean score on the K5 was 10.03 indicating a moderate level of psychological distress amongst carers. 64% of carers reported low to moderate distress levels. Of interest is a higher prevalence of psychological distress in carers than recorded in previous surveys which may be attributed to the COVID-19 pandemic.

---

*It is soul destroying, lonely and sometimes thankless work. People often say chirpily 'you must look after yourself' not realising there are no options to do that when your loved one is still at home. Family/spouse carers become*

---

*invisible in time. People don't want to hear the challenges you face so you learn to not talk about issues to avoid people's eyes glazing over with compassion fatigue. I would rather jump off a bridge than undertake the carer role again and certainly will never ask anyone to care for me.*

---

Carers were asked several questions relating to their experience of relationship during the previous four weeks. 66% of carers felt that they were able to relate to others at least half of the time. 48.3% of carers felt isolated from other people about half of the time during the previous four weeks. 62% reported having someone to share feelings with and felt that they were isolated from other people and 50% felt that they had someone they could share feelings with.

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*Although there are services for carers I feel very alone in my personal and social life.*

---

Carers were asked how easy it was to get in touch with others when needed during the previous four weeks. 35% of carers felt that they were almost always able to get in touch with someone when needed. Figure 20 depicts the overall level of social connectedness felt by carers over a four week period. 23.9% of carers felt highly socially connected, a further 19.4% felt some social connection and 17.9% felt socially isolated.

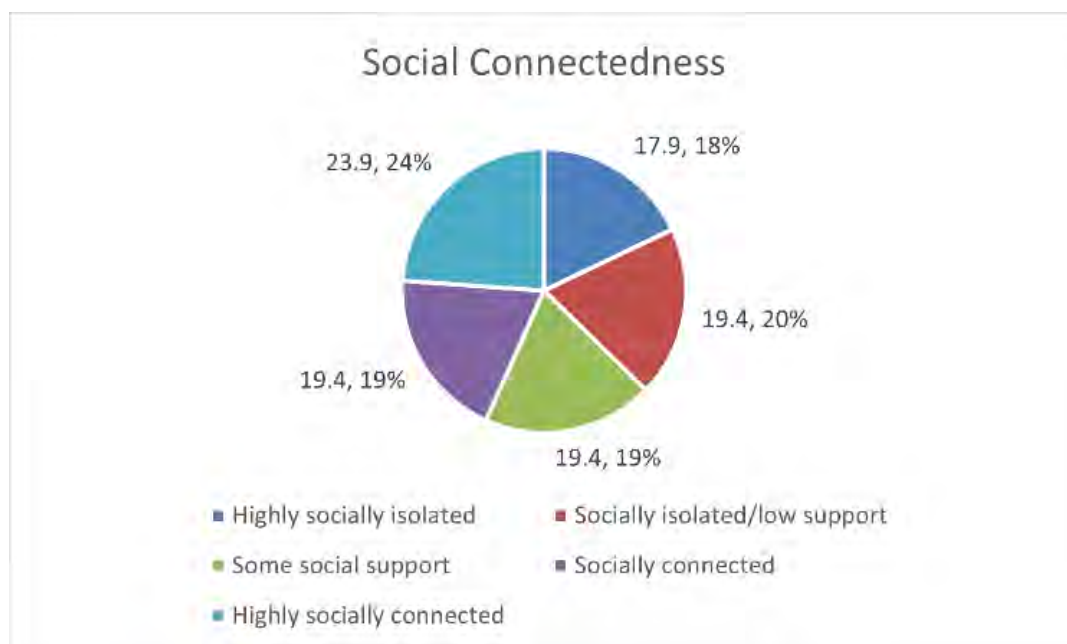


Figure 20: Experience of social connectedness

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*I have had poor mental health before, during, and after my role as carer for my elderly grandmother. I did not feel entitled to access respite services as my grandmother's personal care needs were minimal. While I recognise now that I should have sought support and would have the skills and confidence now to do so, I was unable to then. I'm not sure how this could have been overcome.*

Maybe as a requirement of getting the Centrelink Carer's Pension there should be a review of the caring role and how the carer and care recipient are coping, if adjustments need to be made, and plans going forward e.g. services to access.

## Paid work

Carers were asked about their paid work and the impact that their caring role had on their employment. 189 carers responded to the question relating to employment status (See Table 6). 71% of survey respondents were not in the labour force and the average age of those not in the labour force was 66 years. This would suggest that many are of retirement age. 71% of those not in the labour force were women and 28.4% men.

		Employed (%)	Unemployed (%)	Not in labour force (%)
<b>Total (N=845)</b>		22.4	6.6	71
<b>Age (Mean)</b>		51.0 years	54.5 years	65.9 years
<b>Gender</b>	Female (N=600)	82.7	80.0	71.5
	Male (N=202)	16.8	18.2	28.4
	Non-binary (N=1)	0	0	0.2
<b>Education</b>	Bachelor or higher (N=189)	36.7	20.0	20.0
	Certificate/diploma (N=285)	45.8	47.3	31.5
	High school (Yr. 12 or more) (N=163)	11.3	21.8	23.2
	Less than high school (Yr. 12 or equivalent) (N=160)	6.2	10.9	25.3
<b>Disability (N=783)</b>		23.5	52.7	30.8

Table 6: Education and employment status of carers

55.9% of respondents were in permanent employment (part time or full time), a further 14.9% on either a part time or full-time fixed term contract and the remainder either casually employed (18.6%), self-employed (8.0%) or an independent contractor (0.5%) (See Figure 21).

*“You didn’t ask about my salary? Only partners? I do not want to be treated benevolently I would like to be treated as holding an important role in society”.*

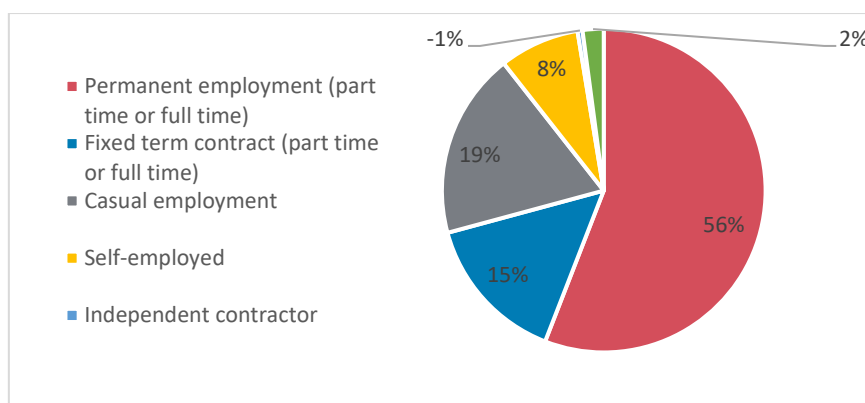


Figure 21: Employment status of carers

Carers were asked about flexibility in their workplace and the working arrangements available to them to accommodate their caring role (See Table 7).

Type of flexibility	Count	%
<b>Flexible start/finish times</b>	83	43.9%
<b>Working from home</b>	39	20.6%
<b>Job sharing</b>	7	3.7%
<b>Paid personal leave (from the ten accruable days per year) to be used for sick leave and/or carers leave</b>	62	32.8%
<b>Paid carers leave in addition to the 10-day entitlement</b>	27	14.3%
<b>Unpaid carers leave (from the 2 days most workers are entitled to)</b>	19	10.1%
<b>Additional unpaid carers leave granted by employer</b>	13	6.9%
<b>Annual Leave (holidays)</b>	65	34.4%
<b>None of the above</b>	28	14.8%
<b>Other flexible work arrangements</b>	24	12.7%

Table 7: Flexible working arrangements used by carers.

Over 60 % of carers had access to either flexible start and finish times or the ability to work from home. Many (32.8%) took paid personal leave to enable them to undertake their caring role. Carers were then asked about the impact of their work on their caring role. 46% of carers felt that they were often so emotionally drained when they finished work that it impacted on their ability to provide care. 46.6 % of respondents felt that they missed work activities due to the amount of time that they needed to spend caring and 32.5% felt that their caring responsibilities impacted on their capacity to concentrate in their job. 47.2 % of respondents felt that they were able to develop close friendships in their job.

---

*When I was caring for my grandmother my mental health suffered as I never had a break from my role, and felt alienated from my peer group who were pursuing marriage and work (I cared for my grandmother aged 21 - 28).*

---

Carers were asked about the impact that their caring role had on their employment. Carers reported experiences such as having to quit work or reduce their hours of work in order to undertake their caring role. Figure 22 depicts the most common impacts of caring on employment.

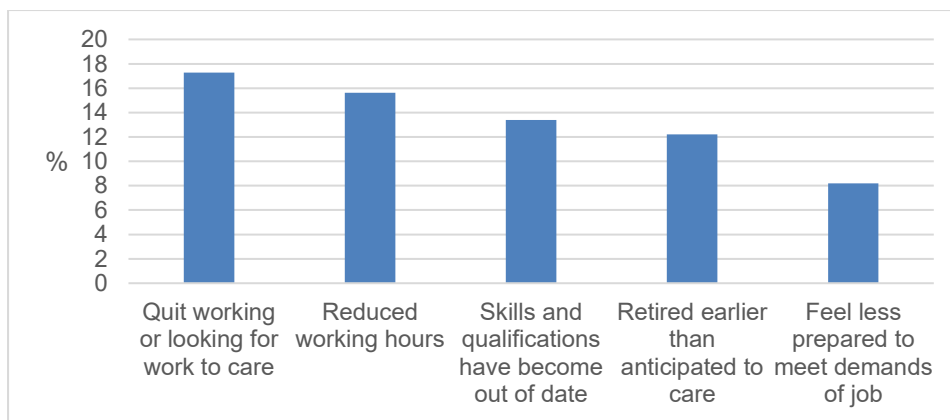


Figure 22: Most common impact of caring on career trajectory.

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*There are many carers who dread what will happen to them after the person they care for dies. They are looking at JobSeeker (Newstart) and the financial commitment taken on in consideration of their career - e.g. rent or mortgage - they could lose their home. For many they have lost contact with career/work and are emotionally and physically long-term exhausted.*

---

## Carers Confidence in using the internet.

Carers were asked about their level of confidence in using the internet to find information, access online support services and to stay in contact with friends and family. The level of confidence varied across the activity the carer was undertaking. Overall carers were confident in accessing online support services, using the internet to find information about caring and staying in contact with family and friends (see Figure 23, Figure 24, Figure 25).

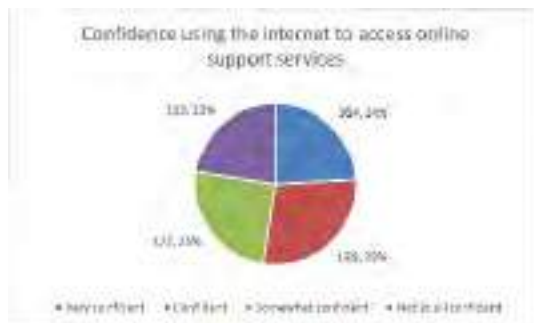


Figure 23: Carers confidence in using the internet for online support services

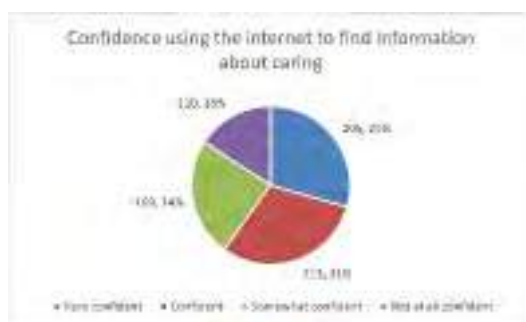


Figure 24: Carers confidence in using the internet to find information.

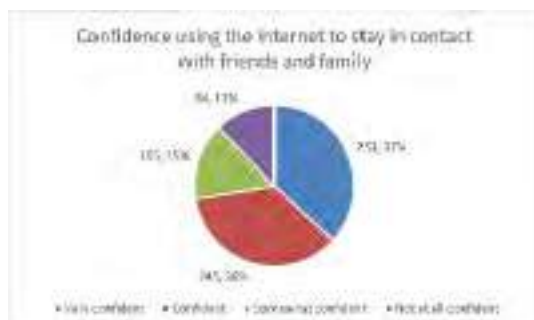


Figure 25: Carers confidence in using the internet to stay connection

## Services and support

Aged care services are designed for people over the age of 65 years (or over 50 years of age for Aboriginal and Torres Strait Islander Australians). These services include home support (cleaning, community transport, aged care services) via the Commonwealth Home Support Program (CHSP), Home Care Package (HCP) designed for those with more complex needs (personal care, nursing and allied health services, assistive technology and social support services). Aged care services may be funded privately or via an aged care package or other government funded service.

The National Disability Insurance Scheme (NDIS) provides government funded services to people under the age of 65 years who have significant or permanent disability.

The following section outlines carers response to a number of questions relating to their use of these services.

### Key Findings for Tasmania

- 172 respondents were caring for someone with a Home Care Package (Level 1 to 4), 157 with a Commonwealth Home Support Programme (CHSP) and 273 respondents were caring for an NDIS participant.
- Aged care and NDIS services were much less likely to meet carers' needs than the needs of the people they were caring for.
- The mental health services most used by people being cared for were private psychologists and psychiatrists.
- Respondents found accessing information about aged care, disability, and mental health and carer support services difficult, and coordinating those services complex and time consuming.
- Long waiting periods to access services or assessment were a common challenge across all service types.
- Carers were particularly unlikely to be asked about their own needs when accompanying the person, they care for to the GP, a hospital, or community service.
- Carers reported having limited time away from the caring role, and most are constantly thinking about their caring responsibilities when undertaking other activities.

### Aged Care Services

Nearly half (45.7%) of respondents indicated that nobody they cared for currently needed aged care services (See Figure 26).

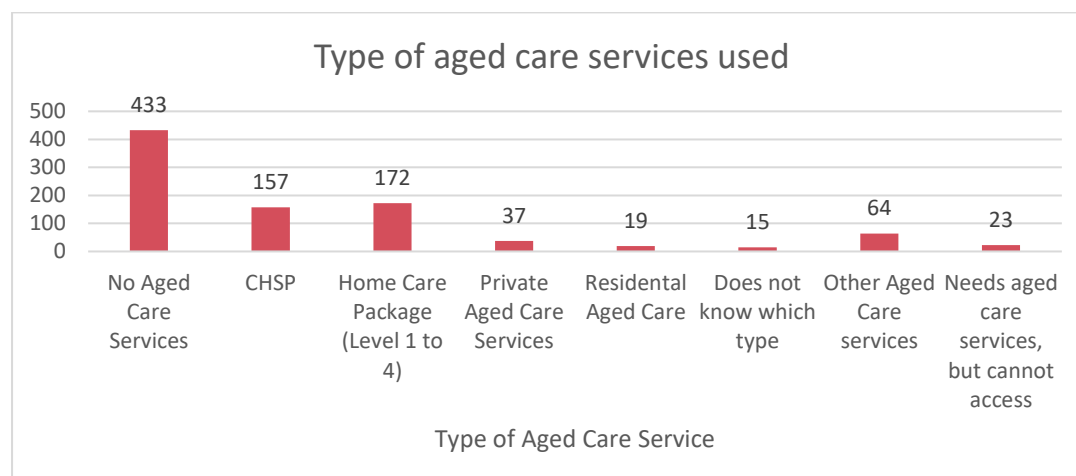




Figure 26: Types of Aged Care Service provided to care recipients.

Care recipients in 18% of cases had a government funded Home Care Package (Level 1, 2, 3 or 4) and a further 16% used entry level, aged care services subsidised by the Commonwealth Home Support Program (CHSP). Fewer than 10% indicated that the older person they were caring for were accessing residential aged care (2%) or other aged care services (6.8%).

---

*I totally feel that when it all boils down, we have to accept it and get on with it. Although on paper it appears, we are acknowledged and assisted we definitely are not. We are encouraged to keep our elderly at home, but are not assisted physically, mentally, or financially, it's most certainly the hardest job I've had.*

---

Carers of people using aged care services were asked to respond to a range of statements about the nature, quality and impacts of those services on themselves and the person they care for. Over half (61%) had been provided with all the information they needed as carers. Under half of all respondents (46%) were asked about their needs as a carer (See Figure 27 and Figure 28) when accessing aged care services.

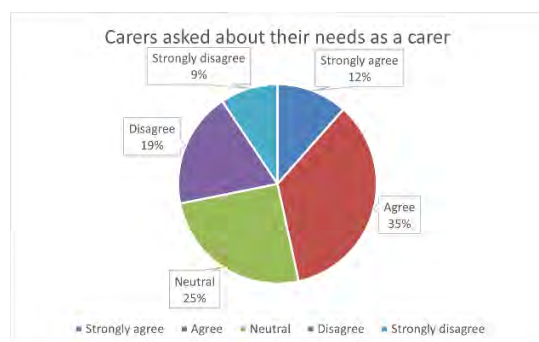


Figure 27: Needs as a Carer

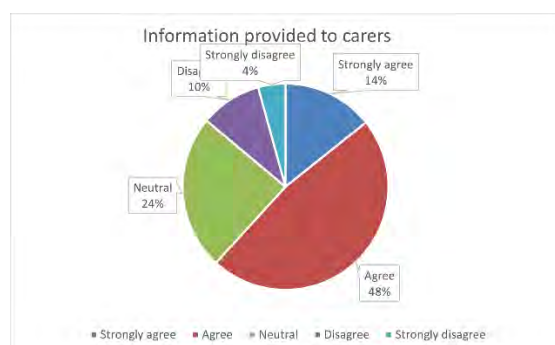


Figure 28: Provide information.

65% of carers felt that the aged care services received by the person that they cared for enabled them to have a break from providing care. Although carers were able to have a break from their caring role by utilising aged care services only 42% of carers were able to keep their job or return to work having finished in their caring role (See Table 8).

	Aged Care Services (%)
Giving break from providing care	44.7
Enabling to stay in work	27.2
Meeting Care Recipient Needs	53.5

Meeting Carer Needs	40.9
Meeting Quality and safety expectations	52.1
Easy to organise	42.6
Care Recipient not eligible	3
Services at a lower level that required	7.5
Long waiting periods for assessment	5.4
Long waiting periods for service	10.2
Not available locally	2.8
No culturally appropriate services available	.8
Quality or safety concerns	4.1
Cost too high	4.7
Difficult to find information	8.0
Takes too much time/energy to organise	7.6
Care recipient did not want services	7.7
Other	5
None	9.4

Table 8: Aged care services and level of satisfaction of care

53.5% of carers felt that the needs of the person they cared for were being met and 52.1% of carers felt that their expectations for quality and safety of care were being met.

#### National Disability Insurance Scheme (NDIS)

The care recipients of 43% of carers were not receiving services from the National Disability Insurance Scheme (NDIS) and 29% had a NDIS plan. Just under 5% of care recipients although needing NDIS support had not been able to access these services at the time of the survey. A further 1.3% used disability services outside of the NDIS.

Carers commented that the *NDIS focus[ed] only on the recipient [were] not interested in [the] needs of carers*. Some carers reported feeling pressured to apply for NDIS funding by service providers.

---

*Was pressured to apply for NDIS because our current service is underfunded and there is more funding in NDIS. Was turned down and needed to provide more information. Still haven't gotten this information to NDIS because it is causing too much emotional upset to deal with it.*

---

Many carers were able to access the supports and services that were required through the NDIS however others reported long, and drawn-out waiting periods and challenges having the care recipients needs met.

---

*We have been trying to get a home mod done so that my son's wheelchair will fit through the doorways of our home. This has been ongoing for 5 years. We have days where we cannot get him out of bed. We have had so many reports done, gone through rule changes, been told all our information was lost due to the portal crashing, our story has had to be repeated over and over due to staff changes - it is exhausting!*

---

Carers were asked a number of questions about the supports provided through the NDIS. Whilst 44.6% of carers felt that the care recipients' needs were being met only 24.6% of carers felt that their needs were being met (see Table 9).

	NDIS Services (%)
Giving break from providing care	37.8
Enabling to stay in work	25.4
Meeting Care Recipient Needs	44.6
Meeting Carer Needs	24.6
Meeting Quality and safety expectations	43.8
Easy to organise	28.3
Care Recipient not eligible	3.9
Not enough funding	5.8
Services outside the NDIS not available	4.0
Services at a lower level that required	5.8
Long waiting periods for assessment	8.1
Long waiting periods for service	8.5
Not available locally	7.4
No culturally appropriate services available	.3
Cost/Co-payments too high	3.7
Difficult to find information	11.6
Takes too much time/energy to organise	9.9
Care recipient did not want services	4.1

Table 9: NDIS services and level of satisfaction of care

Carers were asked about their experiences with the NDIS and other disability services. Figure 29 reflects how common a range of key challenges were among carers accessing aged care services with or on behalf of the person(s) they care for.

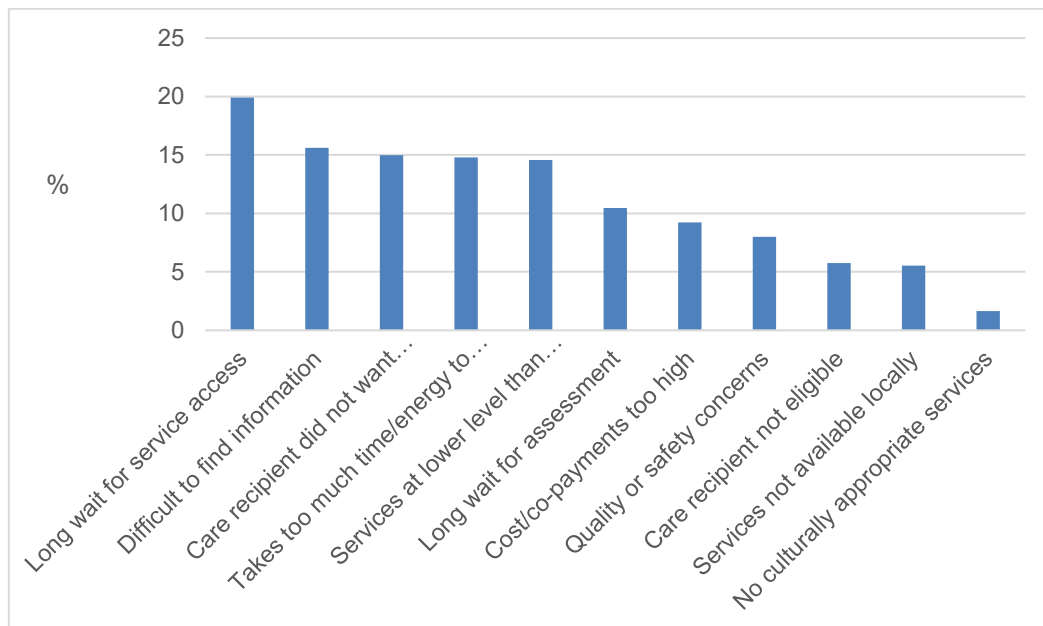


Figure 29: Challenges when accessing aged care services.

The local area coordinator (LAC) / NDIS planner...

*We have a wonderful LAC and a great team of therapists, but we have lost valuable time in early childhood just waiting...*

Local Area Coordinators (LAC) are employed to assist individuals with understanding and accessing the NDIS. A LAC is frequently the main point of contact for the NDIS and will connect people with disability to support services, activities in their community and other government services. The role of the LAC also included working directly with communities to encourage accessibility and inclusiveness for all people living with a disability.

Carers were asked about their experiences with LAC when providing care for NDIS recipients. Approximately 45.9% of carers reported that then were asked about their needs as a carer and similarly 47.1% said that they were provided with information.

Carers were asked if they had any comments to make regarding the NDIS. Several commented on their frustration with LAC and the process of developing NDIS plans for the recipient.

---

*LAC being unfriendly, won't listen to needs, makes up the plan to suit herself make her job easier. Do Not know where to go or who to speak to get a new LAC.*

---

### NDIS Plans

NDIS Plans outline the individual goals for the NDIS recipient and the supports that are required to achieve those goals. Carers were asked about how the support included in the care recipients NDIS plan impacted on them. 50.6% of carers were able to have a break from their caring role and 34.3% were able to stay in work as a result of the supports and services that were provided to the care recipient through the NDIS.

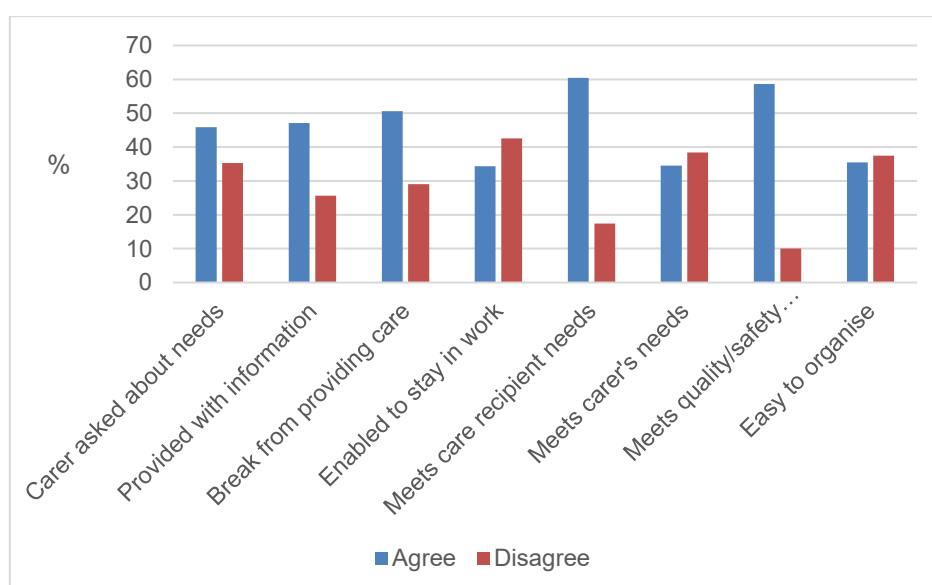


Figure 30: Carer inclusion and supports in the NDIS.

Carers were asked to comment on their experience with NDIS Plans. Some expressed that they *have been extremely happy with our NDIS plans and how they have been organised*. Other's experiences were not so positive expressing more challenging experiences.

---

*NDIS Planner has been extraordinarily difficult to contact and telephone support/communication with/ from them has been non-existent to date apart from one email which has remained unanswered/ followed up.*

---

### Challenges with the NDIS and other disability services

Many carers faced challenges when accessing disability services. Carers provided comments on their overall experience with the NDIS.

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*Really quite disgusted by the whole process which was demeaning... It felt like charity and made us feel like beggars. We do now have a reasonable 2-year plan which is used for psychiatric, counselling, OT and exercise physiologist at this point. Nothing for social needs. He never leaves the house, and he's 28 and relies on me for all of his emotional, social and prompting for even basic hygiene. It's very difficult and exhausting. Sorry to sound so negative. I love them both dearly, but caring at this level, while working part time as well in disability, is the toughest gig I've ever had on my plate.*

---

Figure 31 reflects how common a range of key challenges were among carers accessing disability services with or on behalf of the care recipient.

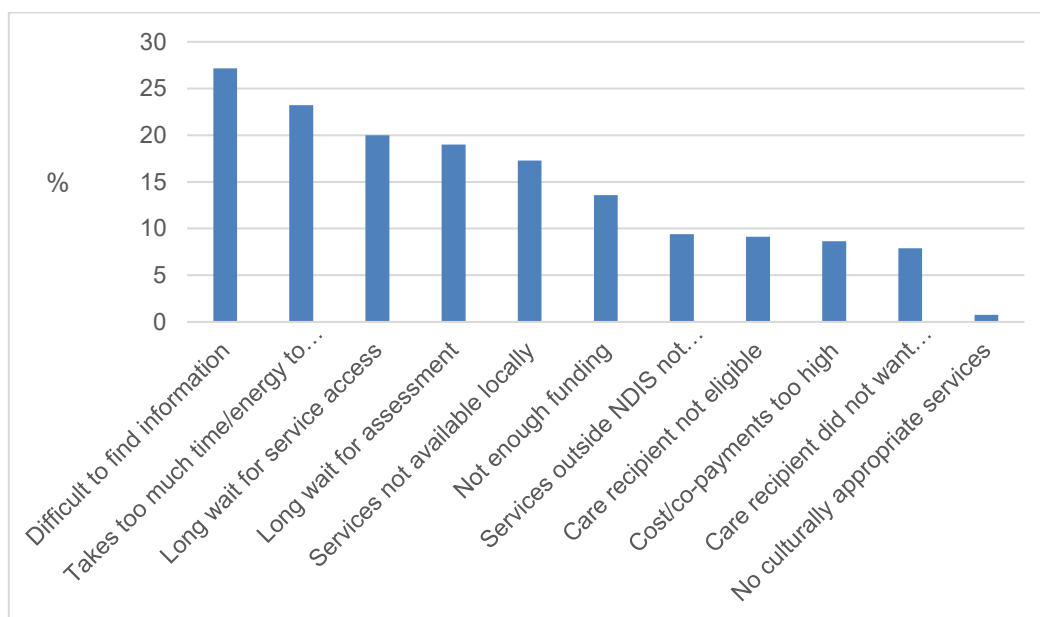


Figure 31: Challenges with accessing disability services.

### Mental health services

Carers of people accessing mental health services were asked to respond to a range of statements about the nature, quality and impacts of those services on themselves and the person they care for. Carers were asked about their experiences with mental health services, whether they cared for someone who uses mental health services, including government funded community services, hospital services and Medicare subsidised clinical

support (e.g., psychology appointments) that assist people experiencing mental ill health or living with a mental illness (See Figure 32: Mental Health Services being accessed ).



Figure 32: Mental Health Services being accessed.

33.9% of carers said that they were asked about their individual needs when accessing mental health services with a care recipient. 41.6% of carers were provided with information that would assist them in their caring role. A smaller percentage of carers (20.6%) felt that mental health services available to the care recipient enabled them to have a break from their caring role and 14% were able to stay in work as a result of the services available (Figure 33).

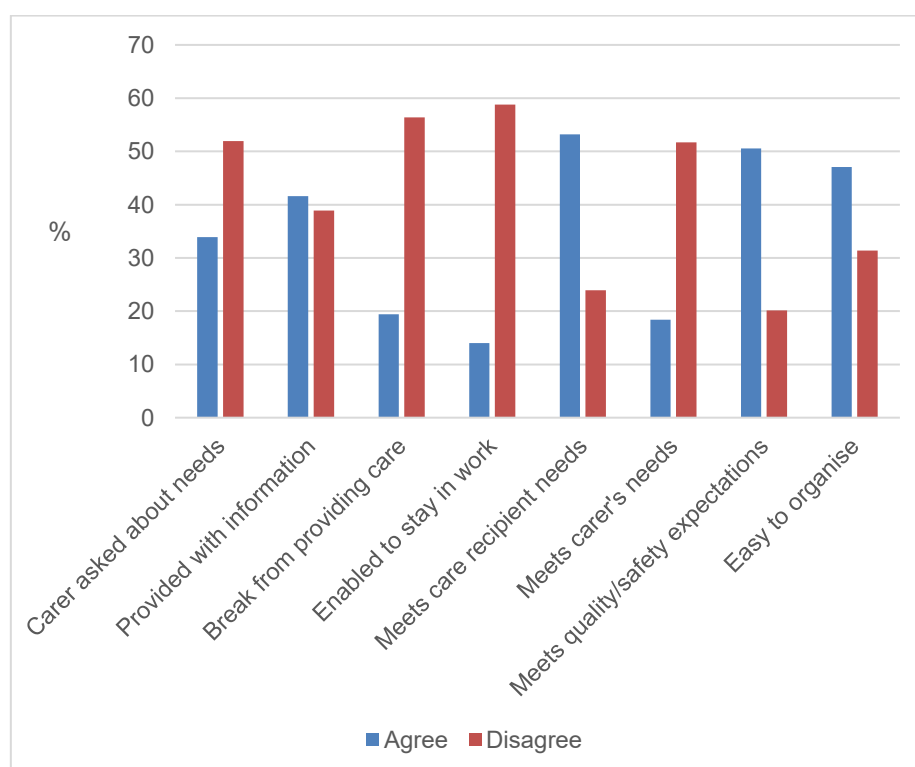


Figure 33: Carer inclusion and support in mental health services

Carers of people accessing mental health services were asked whether they or the person they care for had experienced any of a range of commonly reported challenges when accessing mental health services.

---

*NW Tasmania has appalling mental health care. we travel to Launceston. We previously used to go to Melbourne.*

---

Some carers reported a lack of understanding from providers of the needs of the care recipient.

---

*The agency refused to accept the person because he was agitated and distressed during a preadmission interview. The staff member took this behaviour as a personal insult and not part of the behaviour of someone who is unwell, anxious and afraid and refused admission. This resulted in suicidal behaviour, a period of homelessness and a great deal of distress for the patient and family (including myself) until we could persuade the person to seek treatment again.*

---

Of the carers surveyed 51.6% were not caring for someone who required mental health services. Of the 48.4% of care recipients who were accessing mental health services. 5.9% were using hospital based mental health services as an admitted patients or accessing services through out-of-hospital care. A further 15.5% was seeing a private psychologist or psychiatrist and 4.5% were using community mental health service such as drop in clinics, or rehabilitation programs.

---

*After four calls to the ambulance service my Son was finally admitted to hospital for 8 weeks, he was discharged, one week later he was admitted to the psyche ward after attempting suicide by overdose. He also while in hospital the first time tried to take his life twice, the nursing staff were unaware, and my Son was laying by the bed with a plastic bag on his head while the nursing staff discussed whether they should locate him as he wasn't in bed. They decided no. He also cut at his left wrist after taking off his id tag and I was the only one that noticed.*

---

A small percentage of care recipients (4.6%) needed mental health services but had been unable to access them.

---

*Was to see a psychologist was on waiting list but psychologist died and was not referred to another.*

---

Carers reported that the mental health services provided were at a lower level than was required, there were long waiting periods for services, services were not available locally, were not culturally appropriate and the costs and co-payments were too high. The most reported challenge was the long wait for service access (25.5%) (see Figure 34).

---

*To provide full time care to a person with a mental illness means using all my savings to try to make their life a little better & then realizing that my money is gone & I am in debt.*

---

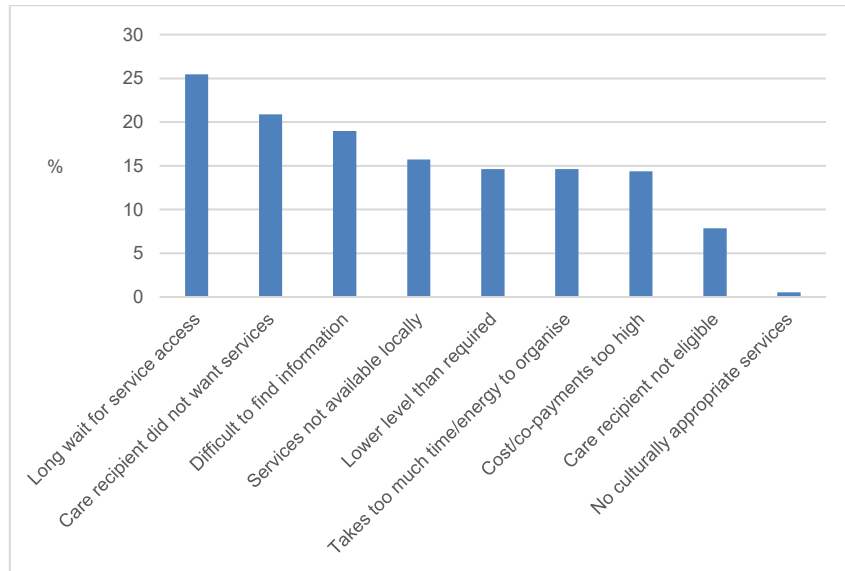


Figure 34: Challenges with accessing mental health services.

#### Hospital and GP Visits

Carers were then asked about their experiences when the person they care for accessed health services, including general practitioners (GP) or family doctors, community health services and services within hospitals.

---

*Psychiatrists and specialist doctors-finding me (carer) offensive for questioning over the types of medications differing from theirs and me being too overprotective and caring. Domestic and personal provider service personnel being under-trained, under-educated...I complained to HR who agreed and told me it was common to receive complaints ... Is Tas more of an exception than the rule i.e., "the mainland". Yes, I think so.*

---

Fifty percent of carers felt that the care recipient's general practitioner provided them (the carer) with information however, GPs did not tend to ask carers about their own needs for support (see Figure 35).



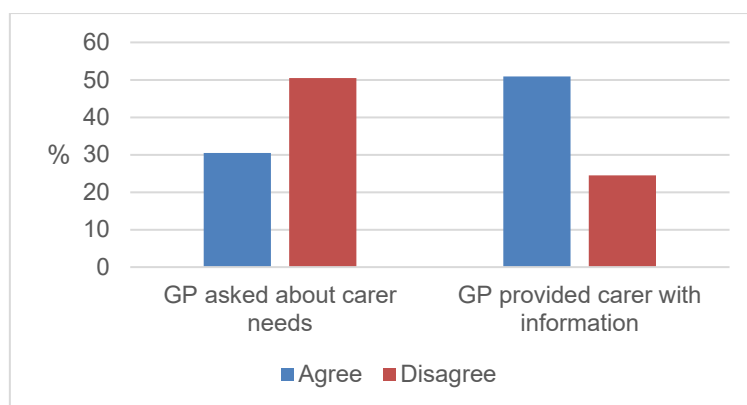


Figure 35: Carer inclusion and support by general practitioners (GPs)

---

*I objected to the Privacy Act where our family member was concerned, as most of the time she was unable to think clearly, and we were treated as if we didn't exist, when we asked for help.*

---

Carer's experiences with accompanying the care recipient on a visit to the hospital or community health service reflected their experiences with GPs with 50% of carers feeling that their needs were not considered however information was provided to the carer in 50% of cases (see Figure 36).

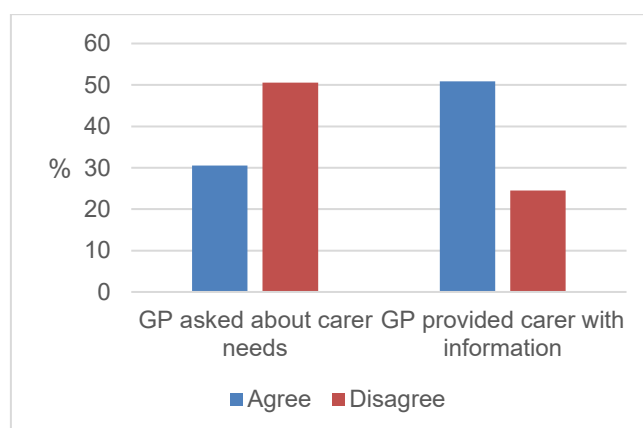


Figure 36: Carer inclusion and support by hospital and community health services

Respondents were asked to comment on their experiences with health services. Many commented that although staff were pleasant and supportive many of them needed more specialised training in aged care and training to better understand the needs of and how to communicate with people with dementia.

---

*All staff I enchanted at the Royal and St Johns need training and understanding of how to communicate with someone with Dementia. My experience is, mention the word dementia and everyone demeanour changes, it is absolutely shocking!*

---

Comments ranged from carers feeling they were *treated with extreme care and respect* to feeling unheard and unacknowledged.

---

*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.*

---

Many carers reported poor communication between medical practitioners (GPs and specialists) which resulted in an inconsistency of care. Pharmacists were spoken of positively:

---

*Specialist appointments once a year are a waste of time - achieves nothing - just ticking off another patient - like xmas cards - better off talking to pharmacist everyday if required.*

*I have been told to sedate my daughter next time she needs an X-ray, because she had a meltdown. When I asked for help because of being over stressed, the doctor stated "what do you have to be stressed about "in an inappropriate way. Another doctor told me to sign forms to take my sons rights away because his has autism. Having to fight for everything because there is no understanding of complex diagnosis.*

*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 on 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.*

---

Carers were also asked about support services that they were currently using and what they needed (See Figure 37). Carers were most in need of planned respite and carer specific face to face information sessions and workshops.

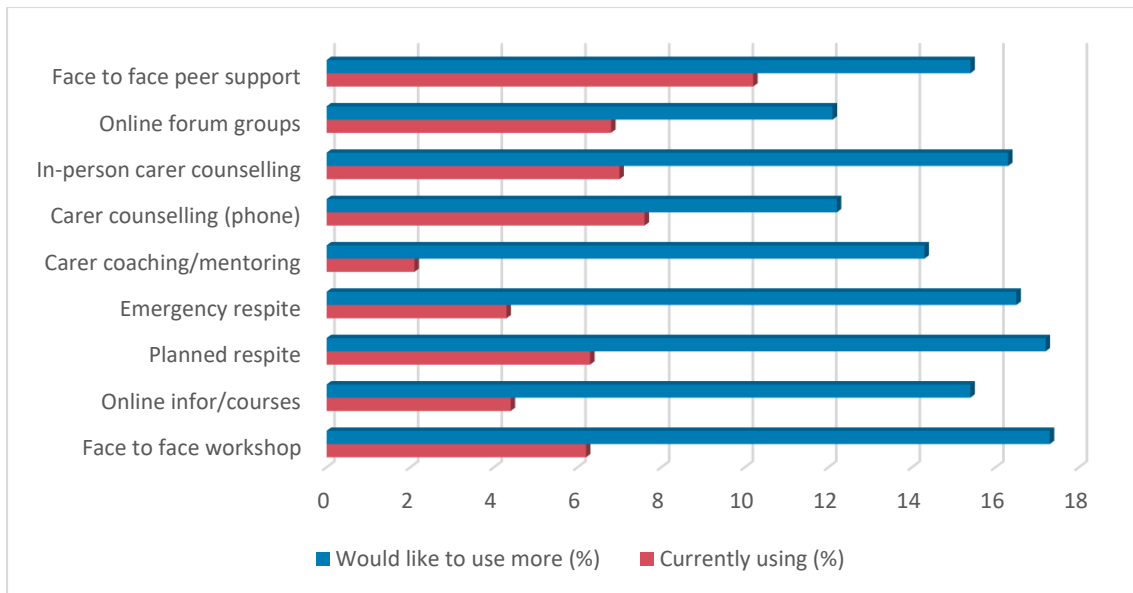


Figure 37: Use and demand for care support services

### Carer Gateway

The 2020 National Carer Survey was conducted between April and June 2020, concurrent with the launch of a range of new, in-person services under the National Carer Gateway. The Carer Gateway is an Australian Government initiative delivered in Tasmania through Care2Serve. Care2Serve offers practical information and advice to carers and help with access to services, supports, counselling and coaching services.

It was therefore timely to ask respondents about their awareness of these services, so that results can be compared in future years as the service system matures. Carers' current use of, need for, and the most common types of carer support services were also captured to allow for comparison over time, as the use of Carer Gateway services develop and other associated service reforms (e.g., in the aged care and disability sectors) progress.

---

*I haven't really found the help I need as a carer. I didn't feel I fitted in Carers Tas. I hate the name care2serve. I hate how everything is couched in terms of needing a break so you can care for loved one - motherhood type speak.*

*Do carers count as actual people with need for support as people not just so they can continue caring?*

---

Figure 38 depicts the percentage of Carers that were aware of the Carer Gateway. Although 63% of respondents had heard of the Carer Gateway only 13.8% of respondents had used the gateway to access services.



Figure 38: Awareness of Carer Gateway

Carers were asked to respond to several statements about their caring role and their capacity to take time out from caring and the quantity and quality of that time.

---

*Planned respite is too costly for pensioners. We are both full pensioners and it is with hardship to provide a break for me if I have to pay for his respite as although we own our own home there is still maintenance to be met as well as the usual ongoing costs.*

---

42.8% of carers felt that they never got time out from their caring responsibilities and 58.6% of carers felt they were able to take just enough time out from their caring responsibilities to keep going. Only 33% of carers felt they were able to take the time out from their caring role to relax and recuperate and slightly more (35.9%) were able to pursue their own goals and interests when they were taking time out.

Most carers were unable to disconnect from their caring role with 80.3% reporting that when they had time away from their caring responsibilities, they were still constantly thinking about the needs of the person they care for.

Carers felt that there were often long waiting periods to access services and that carer services were at a lower level than required, often not available locally and did not meet the needs of the carer. 8.9% of carers reported concerns about the quality or safety of the services available and 10.5% felt the costs of services including co-payments were too high. Carers also felt that it was difficult to find information about the services that were available and how to access them.

Carers were asked about their current level of awareness of the Carer Gateway (See Figure 39). 50% of respondents had heard of the Carer Gateway however they were not using it. A further 36% reported not having heard about the Carer Gateway.

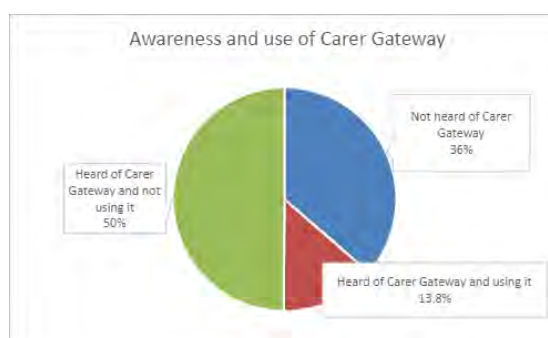


Figure 39: Awareness and use of the Carer Gateway.

Carers were then asked about their uptake of a variety of types of support services and if they were currently using them or if they would like to use more of the supports offered.

Some carers expressed that there were additional supports that could be offered to carers that were more practical and appropriate to their needs.

---

*From what I've seen, Carer Gateway doesn't provide the type of care I need. When my husband has been in the hospital, I would like to have an overnight room available to me and/or I would like transport home. I've been left standing at bus stops in the middle of the night hoping the bus will take me home. You don't know how scary and lonely that is. If something happens to me, I would like to know that I can call on a person to check on my husband.*

---

Areas of greatest need for carers were face-to-face workshops and information, planned and emergency respite and counselling. Whilst the Carer Gateway offers these supports there are other stressors carers face on a day-to-day basis that could be alleviated through additional supports.

---

*At home, I've got a mountain of paperwork to deal with, but there are no services to help with that. I can have the lawn cut for \$50 or get the house cleaned for \$100 but I can't get anyone to sit down with me for a day and make some progress on the paperwork so that my stress level can go down so I can deal with my husband's situation better.*

---

## Conclusion

This summary report has provided an overview of the Tasmanian results from the 2020 National Carer Survey. A valid sample of 1024 current and former carers of diverse circumstances and backgrounds responded to the survey, resulting in important insights into the health and wellbeing of Tasmanian carers. The survey responses also provided insight into the impacts the caring role has on carers.

The results presented provide an informative snapshot of Tasmanian Carers during the COVID-19 pandemic and offer a detailed analysis of carers health and wellbeing and their experiences of inclusion and support.

The findings of this report will be used by Carers Tasmania to advocate for improved services and supports for carers and most importantly the need for carer recognition.

## Appendix A: 2020 National Carer Survey Questionnaire



# 2020 NATIONAL CARER SURVEY

Thank you for taking the time to complete this survey. By sharing your opinions and experiences, you will help the National Network of Carer Associations advocate for greater recognition and support of carers across Australia. Please take the time to read the enclosed Participant Information and Consent Form prior to participating.

There are two ways you can complete the survey:

- 1) Online via the website <http://bit.ly/2020NationalCarerSurvey> by **30 June 2020**
- 2) By completing this form and returning it in the reply paid envelope provided, no later than **30 June 2020**

The survey should take you approximately 20 minutes depending on your responses. You can leave any question blank if it does not apply to you, or if you would prefer not to answer. Your responses will be anonymous.

At the end of the survey, you will be asked whether you would like to be contacted for a follow-up study on the long-term effects of caring in 2022. You can participate in this survey regardless whether you choose to be part of the follow-up study.

**By completing and returning this survey you indicate that you have read the enclosed Participant Information and Consent Form, that you voluntarily agree to participate, and that you are at least 16 years of age.**

If you have any questions about this survey, please contact the Carers NSW Research Team on (02) 9280 4744 or email [research@carersnsw.org.au](mailto:research@carersnsw.org.au).

### SCREENING QUESTIONS

1. **In which state or territory do you live?**

<input type="checkbox"/> Australian Capital Territory	<input type="checkbox"/> New South Wales
<input type="checkbox"/> Northern Territory	<input type="checkbox"/> Queensland
<input type="checkbox"/> South Australia	<input type="checkbox"/> Tasmania
<input type="checkbox"/> Victoria	<input type="checkbox"/> Western Australia
  
2. **Do you look after someone (or help look after someone) who has a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal or serious illness, or who needs care due to ageing?**

<input type="checkbox"/> Yes ( <b>go to Question 3</b> )
<input type="checkbox"/> Not currently, but I have in the past ( <b>go to Question 3</b> )
<input type="checkbox"/> No (unfortunately you do not fit our respondent profile. Thank you for your interest.)
  
3. **Is/was the person you care(d) for a family member, friend or neighbour?**

<input type="checkbox"/> Yes ( <b>If you currently provide care please go to Question 4, if you no longer provide care please go to Question 18</b> )
<input type="checkbox"/> No, I care for the person(s) as paid work (i.e., nurse, support worker) (Unfortunately you do not fit our respondent profile. Thank you for your interest.)
<input type="checkbox"/> No, I care for the person(s) as a formal volunteer (Unfortunately you do not fit our respondent profile. Thank you for your interest.)

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## SECTION 1: THE CARING RELATIONSHIP

### 4. How many people do you care for? \_\_\_\_\_

The following questions are about the person/people you care for because of their needs arising from a disability, chronic condition, mental ill health or advanced age. If you care for more than one person, please complete both columns, thinking about the **two** people you provide the **most** care for.

#### PERSON 1

##### 5. What is this person's gender?

- ☐ Female  
☐ Male  
☐ Non-binary / gender diverse  
☐ Their gender identity isn't listed  
 They identify as: \_\_\_\_\_  
☐ Prefer not to say

##### 6. How old is this person?

\_\_\_\_\_ years

##### 7. What is this person's relationship to you?

They are my:

- ☐ Parent or parent in law  
☐ Partner or spouse  
☐ Child (incl. adult son or daughter)  
☐ Brother or sister  
☐ Grandparent  
☐ Friend  
☐ Neighbour  
☐ Other, please specify:  
 \_\_\_\_\_

##### 8. What is this person's cultural background? (e.g. Italian, Chinese, Australian, etc.)

\_\_\_\_\_

##### 9. Does this person speak a language other than English at home? (e.g. Vietnamese, Auslan)

☐ Yes, they speak

\_\_\_\_\_

☐ No, English only

#### PERSON 2

##### 5. What is this person's gender?

- ☐ Female  
☐ Male  
☐ Non-binary / gender diverse  
☐ Their gender identity isn't listed  
 They identify as: \_\_\_\_\_  
☐ Prefer not to say

##### 6. How old is this person?

\_\_\_\_\_ years

##### 7. What is this person's relationship to you?

They are my:

- ☐ Parent or parent in law  
☐ Partner or spouse  
☐ Child (incl. adult son or daughter)  
☐ Brother or sister  
☐ Grandparent  
☐ Friend  
☐ Neighbour  
☐ Other, please specify:  
 \_\_\_\_\_

##### 8. What is this person's cultural background? (e.g. Italian, Chinese, Australian, etc.)

\_\_\_\_\_

##### 9. Does this person speak a language other than English at home? (e.g. Vietnamese, Auslan)

☐ Yes, they speak

\_\_\_\_\_

☐ No, English only



**PERSON 1 (continued)**

**10. Is this person of Aboriginal or Torres Strait Islander origin?**

- ☐ No
- ☐ Yes, Aboriginal
- ☐ Yes, Torres Strait Islander
- ☐ Yes, both
- ☐ Prefer not to say

**11. For what conditions / disabilities / illnesses does this person need your care?**

Please tick all that apply, even if the person you care for has not received an official diagnosis.

- ☐ Physical disability
  - ☐ Sensory impairment (e.g. loss of hearing or loss of vision)
  - ☐ Frailty due to ageing
  - ☐ Intellectual disability
  - ☐ Autism Spectrum Disorder
  - ☐ Mental illness
  - ☐ Drug or alcohol dependency
  - ☐ Dementia
  - ☐ Chronic health condition
  - ☐ Terminal or serious illness
  - ☐ Acquired brain injury, stroke
  - ☐ Neurological condition (e.g. epilepsy, Parkinson's disease, multiple sclerosis)
  - ☐ Other, please specify:
- 

**12. Do you and the person you care for live in the same household?**

- ☐ Yes
  - ☐ No, they live separately
  - ☐ No, they live with another family member or friend
  - ☐ No, they live in a care facility (e.g., nursing home)
  - ☐ No, they live in supported accommodation / a group home
  - ☐ Other, please specify:
- 

**PERSON 2 (continued)**

**10. Is this person of Aboriginal or Torres Strait Islander origin?**

- ☐ No
- ☐ Yes, Aboriginal
- ☐ Yes, Torres Strait Islander
- ☐ Yes, both
- ☐ Prefer not to say

**11. For what conditions / disabilities / illnesses does this person need your care?**

Please tick all that apply, even if the person you care for has not received an official diagnosis.

- ☐ Physical disability
  - ☐ Sensory impairment (e.g. loss of hearing or loss of vision)
  - ☐ Frailty due to ageing
  - ☐ Intellectual disability
  - ☐ Autism Spectrum Disorder
  - ☐ Mental illness
  - ☐ Drug or alcohol dependency
  - ☐ Dementia
  - ☐ Chronic health condition
  - ☐ Terminal or serious illness
  - ☐ Acquired brain injury, stroke
  - ☐ Neurological condition (e.g. epilepsy, Parkinson's disease, multiple sclerosis)
  - ☐ Other, please specify:
- 

**12. Do you and the person you care for live in the same household?**

- ☐ Yes
  - ☐ No, they live separately
  - ☐ No, they live with another family member or friend
  - ☐ No, they live in a care facility (e.g., nursing home)
  - ☐ No, they live in supported accommodation / a group home
  - ☐ Other, please specify:
-

**PERSON 1 (continued)**

**13. Do any other family members / friends help take care of this person?**

- ☐ I am the only one who provides care  
☐ I provide the most care, but others help with care sometimes  
☐ Someone else provides the most care, but I help with care sometimes

**14. How long can this person be left alone?**

- ☐ Not at all  
☐ Less than an hour  
☐ A few hours  
☐ One day  
☐ A few days  
☐ More than a few days

**15. On average, how many hours per week do you spend caring for this person?**

\_\_\_\_\_ hours per week

**16. How long have you been caring for this person?**

- ☐ Less than 1 year  
☐ \_\_\_\_\_ years

**17. Have you previously cared for anyone who you are no longer caring for?**

- ☐ Yes  
☐ No (Please go to Question 22)

**18. Please indicate who you have previously cared for, but are no longer caring for. If you cared for more than one person in the past, please think of the person you cared for most recently:**

- ☐ Parent or parent in law  
☐ Partner or spouse  
☐ Child (incl. adult son or daughter)  
☐ Brother or sister  
☐ Grandparent  
☐ Friend  
☐ Neighbour  
☐ Other, please specify: \_\_\_\_\_

**19. How long did you care for this person?**

- ☐ Less than 1 year  
☐ \_\_\_\_\_ years

**20. How long ago did this caring role end?**

- ☐ Less than a year ago  
☐ \_\_\_\_\_ years ago

**PERSON 2 (continued)**

**13. Do any other family members / friends help take care of this person?**

- ☐ I am the only one who provides care  
☐ I provide the most care, but others help with care sometimes  
☐ Someone else provides the most care, but I help with care sometimes

**14. How long can this person be left alone?**

- ☐ Not at all  
☐ Less than an hour  
☐ A few hours  
☐ One day  
☐ A few days  
☐ More than a few days

**15. On average, how many hours per week do you spend caring for this person?**

\_\_\_\_\_ hours per week

**16. How long have you been caring for this person?**

- ☐ Less than 1 year  
☐ \_\_\_\_\_ years

**21. Why did this caring role end?**

Please tick all that apply:

- ☐ The person I cared for no longer required care
- ☐ The person I cared for passed away
- ☐ Someone else took over the caring role; please tell us who (e.g. their child, sibling, or friend) \_\_\_\_\_
- ☐ I couldn't continue caring
- ☐ Other, please specify: \_\_\_\_\_

If you are a former carer, and you are not **currently** providing care for someone, please go to Question 40.

## SECTION 2: YOUR CARING ROLE

**22. Please tick all the types of support you provide to the person(s) you care for. Please also rank the 5 tasks that require the most effort from you (5 = most effort, 1 = less effort).**

Please tick all that apply.

	Tick	Rank
Personal care (e.g. eating, showering, dressing)	<input type="checkbox"/>	___
Mobility (e.g. walking, getting out of bed)	<input type="checkbox"/>	___
Communication (e.g. reading, writing, helping them articulate themselves in conversations)	<input type="checkbox"/>	___
Interpreting or translating for them from or into another language	<input type="checkbox"/>	___
Advocacy (e.g. helping them dispute a treatment or a decision)	<input type="checkbox"/>	___
Cognitive or emotional tasks (e.g. making decisions, managing difficult feelings)	<input type="checkbox"/>	___
Help with organising finances (e.g. helping them budgeting, assisting with online banking)	<input type="checkbox"/>	___
Handling their finances (e.g. making financial decisions for them, managing their accounts)	<input type="checkbox"/>	___
Administrative support (e.g. filling out forms, sending emails or making phone calls on their behalf)	<input type="checkbox"/>	___
Coordinating support services or care workers (e.g. finding and booking services, dealing with service providers)	<input type="checkbox"/>	___
Health care (e.g. assisting with taking medication, injections, or wound care)	<input type="checkbox"/>	___
Transport (e.g. driving them to appointments, taking public transport with them)	<input type="checkbox"/>	___
Household chores (e.g. cleaning, cooking, shopping)	<input type="checkbox"/>	___
Property maintenance (e.g. mowing lawns, cleaning gutters)	<input type="checkbox"/>	___
Social support (e.g. helping them to engage in relationships and in the community)	<input type="checkbox"/>	___
Checking on them, seeing whether they are okay	<input type="checkbox"/>	___
Behavioural support (e.g. dealing with behaviours such as aggression or social withdrawal)	<input type="checkbox"/>	___
Other, please specify: _____	<input type="checkbox"/>	___

31

23. Do you feel confident that you have the necessary skills for what you are doing in your caring role?

☐ Very confident   ☐ Confident   ☐ Somewhat confident   ☐ Not at all confident   ☐ Prefer not to say

24. Please tell us how your caring role has affected your relationships with the person you care for, your family or friends?

---

---

---

## SECTION 3: SERVICES AND SUPPORT

### 25. Does someone you care for currently use aged care services?

Please tick all that apply

Aged care services are services designed for people over the age of 65 years (or over the age of 50 years for Aboriginal and Torres Strait Islander Australians). They may be government funded or purchased privately.

- ☐ No, nobody that I care for currently needs aged care services (Please go to Question 28)
- ☐ Yes, someone I care for uses entry-level, aged care services subsidised by the Commonwealth Home Support Program (CHSP), such as cleaning, community transport, or basic in-home support
- ☐ Yes, someone I care for has a Home Care Package (Level 1, 2, 3 or 4), a government funded package of support that enables them to purchase aged care services, such as personal care, or respite
- ☐ Yes, someone I care for pays for aged care services privately, such as cleaning, or in-home support
- ☐ Yes, someone I care for lives in residential aged care, for example a nursing home or care facility
- ☐ Someone I care for is receiving aged care services, but I don't know which services they are using
- ☐ Other, please specify: \_\_\_\_\_ (Please go to Question 27)
- ☐ Someone I care for needs aged care services but is currently unable to access these services (Please go to Question 27)

### 26. Please indicate how much you agree with the following statements:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
<b>When the person I care for accesses aged care services...</b>						
...I am asked about my needs as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...I am provided with all the information I need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>The aged care services received by the person I care for...</b>						
...give me a break from providing care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...enable me to keep my job, or go back to work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...meet the needs of the person I care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...meet my needs as a carer (e.g. are available when I can't provide care)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...meet my expectations for quality and safety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...are easy to organise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



**27. Have you or the person(s) you care for experienced any of the following challenges with aged care services?** Please tick all that apply.

- ☐ The person I care for was not eligible for the required services
- ☐ The service received was at a lower level than what was required
- ☐ There was a long waiting period to get assessed
- ☐ There was a long waiting period to access services
- ☐ The services required were not available locally
- ☐ There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity)
- ☐ There were concerns about the quality or safety of the services
- ☐ The cost of services (including co-payments) was too high
- ☐ It was difficult to find information about what services were available and how to access them
- ☐ It took too much time and energy to organise the services
- ☐ The person(s) I care for did not want to use services
- ☐ Other, please describe: \_\_\_\_\_
- ☐ None of the above

Please leave any comments you might have on your experience with aged care services:

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**28. Does someone you care for currently receive support through the National Disability Insurance Scheme (NDIS)?** Please tick all that apply.

*The National Disability Insurance Scheme (NDIS) provides government funded services to people under the age of 65 years who have a significant or permanent disability.*

- ☐ No, nobody I care for currently needs disability services (Please go to Question 31)
- ☐ Yes, someone I care for has a National Disability Insurance Scheme plan (NDIS plan)
- ☐ Someone I care for needs the NDIS, but has not been able to access these services to date (Please go to Question 30)
- ☐ Someone I care for uses disability services outside of the NDIS (Please go to Question 30)
- ☐ Other, please specify: \_\_\_\_\_ (Please go to Question 30)
- ☐ I don't know (Please go to Question 30)

**29. How much do you agree with the following statements?**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
<b>The local area coordinator (LAC) / NDIS planner...</b>						
...asked about my needs as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...provided me with all the information I needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
<i>The supports included in the NDIS plan (for the person I care for)...</i>						
...give me a break from providing care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...enable me to keep my job, or go back to work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...meet the needs of the person I care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...meet my needs as a carer (e.g. are available when I can't provide care)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...meet my expectations for quality and safety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...are easy to organise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**30. Have you or the person(s) you care for experienced any of the following challenges with the NDIS or other disability services? Please tick all that apply.**

- ☐ The person I care for was not eligible for the NDIS
- ☐ The person I care for did not receive enough funding in their NDIS plan
- ☐ Services outside the NDIS (either in addition to, or instead of the NDIS) were not available
- ☐ There was a long waiting period to get assessed
- ☐ There was a long waiting period to access services
- ☐ The services required were not available locally
- ☐ There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity)
- ☐ The cost of services (including co-payments) was too high
- ☐ It was difficult to find information about what services were available and how to access them
- ☐ It took too much time and energy to organise the services
- ☐ The person(s) I care for did not want to use services
- ☐ Other, please describe: \_\_\_\_\_
- ☐ None of the above

Please leave any comments you might have on your experience with disability services:

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**31. Does someone you care for currently use mental health services?**

Please tick all that apply

Mental health services include government funded community services, hospital services and Medicare subsidised clinical support (e.g. psychology appointments) that assist people experiencing mental ill health or living with a mental illness.

- ☐ No, nobody I care for currently needs mental health services (Please go to Question 34)
- ☐ Yes, someone I care for uses hospital based mental health services as admitted patient or in out-of-hospital care
- ☐ Yes, someone I care for sees a private psychologist or psychiatrist
- ☐ Yes, someone I care for uses community mental health services, such as drop-in clinics, or rehabilitation programs
- ☐ Someone I care for needs mental health services but has not been able to access these services to date (Please go to Question 33)
- ☐ I don't know (Please go to Question 33)
- ☐ Other, please specify: \_\_\_\_\_ (Please go to Question 33)

**32. How much do you agree with the following statements?**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
<b>When the person I care for accesses mental health services...</b>						
...I am asked about my needs as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...I am provided with all the information I need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>The mental health services received by the person I care for...</b>						
...give me a break from providing care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...enable me to keep my job, or go back to work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...meet the needs of the person I care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...meet my needs as a carer (e.g. are available when I can't provide care)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...meet my expectations for quality and safety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...are easy to organise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



**33. Have you or the person(s) you care for experienced any of the following challenges with mental health services? Please tick all that apply.**

- ☐ The person I care for was not eligible for the required services
- ☐ The service received was at a lower level than required
- ☐ There was a long waiting period to access services
- ☐ The services required were not available locally
- ☐ There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity)
- ☐ The cost of services (including co-payments) was too high
- ☐ It was difficult to find information about what services were available and how to access them
- ☐ It took too much time and energy to organise the services
- ☐ The person(s) I care for did not want to use services
- ☐ Other, please describe: \_\_\_\_\_
- ☐ None of the above

Please leave any comments you might have on your experience with mental health services:

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The following questions are about when the person you care for accesses health services, including a general practitioner (GP) or family doctor, community health services and services within a hospital. Please indicate how much you agree with the following statements:

**34. How much do you agree with the following statements?**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
<b>When I accompany the person I care for to visit a GP...</b>						
...I am asked about my needs as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...I am provided with all the information I need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>When I accompany the person I care on a visit to the hospital or community health service...</b>						
...I am asked about my needs as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...I am provided with all the information I need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...there are sufficient support options and facilities for carers (e.g. seating, overnight rooms, transport support)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

35. Please leave any comments you might have on your experience with health services:

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36. Which of the following carer support services do you currently use?  
Which would you like to use more?

Support type	I am currently using this support	I would like to use this support more
Carer peer support (face to face carer support groups)	<input type="checkbox"/>	<input type="checkbox"/>
Online forums or groups	<input type="checkbox"/>	<input type="checkbox"/>
In-person carer counselling (counselling designed specifically to address challenges relating to the caring role)	<input type="checkbox"/>	<input type="checkbox"/>
Carer counselling over the phone	<input type="checkbox"/>	<input type="checkbox"/>
Carer coaching or mentoring (working on personal goals and resilience relating to the caring role, one-to-one)	<input type="checkbox"/>	<input type="checkbox"/>
Emergency respite (care in a facility or in the home provided when you are suddenly unable to provide care for a period of time)	<input type="checkbox"/>	<input type="checkbox"/>
Planned respite (care in a facility or in the home booked in advance so that you are able to participate in other activities or take a longer break from caring)	<input type="checkbox"/>	<input type="checkbox"/>
Carer specific online information or training courses	<input type="checkbox"/>	<input type="checkbox"/>
Carer specific face-to-face information sessions or workshops	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify:	<input type="checkbox"/>	<input type="checkbox"/>

37. Have you heard of the Carer Gateway?

- ☐ No
- ☐ Yes, and I have used it (e.g. called the 1800 number, visited the website, accessed services from a Carer Gateway Service Provider in my local area)
- ☐ Yes, but I have not used it

Please leave any comments you might have on your experience with the Carer Gateway:

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38. How much do you agree with the following statements:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
I never get time out from my caring responsibilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to take just enough time out from my caring responsibilities to keep going	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to take just enough time out from my caring responsibilities to keep on top of other responsibilities, e.g. household chores	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to regularly take enough time out from my caring responsibilities to properly relax and recuperate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to take enough time out from my caring responsibilities to pursue my own goals and interests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I have time away from my caring responsibilities I am still constantly thinking about the needs of the person I care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

39. Have you experienced any of the following challenges with carer support services? Please tick all that apply.

- ☐ The service received was at a lower level than what was required
- ☐ There was a long waiting period to access services
- ☐ The services I needed were not available locally
- ☐ The services available did not meet my needs (e.g. available when I needed them)
- ☐ There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity)
- ☐ I was concerned about the quality or safety of the services available
- ☐ The cost of services (including co-payments) was too high
- ☐ It was difficult to find information about what services were available and how to access them
- ☐ It took too much time and energy to organise the services
- ☐ I don't see myself as a carer
- ☐ My caring role is a private matter
- ☐ The person I care for does not think I need or want services
- ☐ There is not enough transport to the services
- ☐ I do not want or need any or more services to help me in my care role
- ☐ Service providers think the person I care for is the only one who needs help
- ☐ I can't organise another carer or respite to take enough time out
- ☐ None of the above
- ☐ Other, please tell us: \_\_\_\_\_

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## SECTION 4: PAID WORK

40. Which of the following have you experienced as a result of your caring role? Please tick all that apply:

- ☐ I have lacked the knowledge and confidence to apply for jobs effectively
- ☐ My skills or qualifications have become out of date due to time out of the workforce
- ☐ I feel less prepared to meet the demands of my job
- ☐ I have worked in a job lower than my skillset
- ☐ I reduced my working hours
- ☐ I changed industry/occupation
- ☐ I turned down a new job or promotion
- ☐ I quit working or looking for work to be able to care
- ☐ I retired earlier than anticipated to be able to care
- ☐ I could not find any jobs in my field that would allow me to continue with my caring responsibilities
- ☐ I have been denied an opportunity by an employer
- ☐ An employer has changed my working conditions
- ☐ None of the above
- ☐ Other, please specify: \_\_\_\_\_

41. What is your occupation? \_\_\_\_\_

42. Do you currently have a paid job?

- ☐ Yes
- ☐ No, but I am looking for work (Please go to Question 49)
- ☐ No, and I am not looking for work (Please go to question 50)

43. How many hours per week do you usually spend doing paid work?

\_\_\_\_\_ hours

*If you have more than one paid job, please refer to your main job (i.e. where you spend the most hours) in answering the following questions*

44. Which of the following apply to you?

- ☐ I am a permanent employee (either part time or full time)
- ☐ I have a fixed-term contract (either part time or full time)
- ☐ I have a casual job
- ☐ I am self-employed
- ☐ I am an independent contractor
- ☐ Other, please specify: \_\_\_\_\_

*If you are a former carer, and you are not currently providing care for someone, please go to Question 50.*

45. How much do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
I have to miss caring activities due to the amount of time I must spend on my job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often so emotionally drained when I finish work that it affects my ability to provide care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The behaviours that make me effective at work do not help me to be a better carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have to miss work activities due to the amount of time I must spend caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Because of my caring responsibilities, I have a hard time concentrating on my job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behaviour that is effective and necessary for me as a carer (e.g. being compassionate) would be counterproductive at work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

46. How much do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
The job allows me to plan how I do my work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The job involves performing a variety of tasks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The results of my work are likely to significantly affect the lives of other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The job involves performing relatively simple tasks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have the opportunity to develop close friendships in my job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



47. How much do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
<b>Being in paid work...</b>						
Helps me to understand different viewpoints and this helps me be a better carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Makes me feel good and this helps me be a better carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helps me feel personally fulfilled and this helps me be a better carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>My involvement in caring...</b>						
Helps me acquire skills and this helps me be a better employee	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Puts me in a good mood and this helps me be a better employee	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Encourages me to use my work time in a focused manner and this helps me be a better employee	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

48. Which of the following flexible working arrangements are you using in your current job to accommodate your caring role? Please tick all that apply.

- ☐ Flexible start / finish times
- ☐ Working from home
- ☐ Job sharing
- ☐ Paid personal leave (from the 10 accruable days per year to be used for sick leave and/or carers leave)
- ☐ Paid carers leave in addition to the 10 day entitlement
- ☐ Unpaid carers leave (from the 2 days most workers are entitled to)
- ☐ Additional unpaid carers leave granted by employer
- ☐ Annual leave (holidays)
- ☐ None of the above
- ☐ Other, please specify: \_\_\_\_\_

49. How much do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
<i>I had trouble finding work, because...</i>						
...my skills weren't recognised	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...it wouldn't be possible to respond to an emergency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...the type of work would have kept me from sufficiently checking on the person I care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...the demands on time would have been too high to keep up my caring role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...there wasn't enough support for carers by the prospective employer (e.g. lack of flexibility)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...it wouldn't be possible to take enough paid leave to keep up the caring role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## SECTION 5: YOUR HEALTH AND WELLBEING

50. Please indicate how satisfied you are with each of the following:

	Completely dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely satisfied 10
Your standard of living	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What you are achieving in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your personal relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How safe you feel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling part of your community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your future security	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your life overall	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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51. In the past 4 weeks, about how often did you feel:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Nervous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Without hope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless or jumpy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
That everything was an effort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
So sad that nothing could cheer you up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

52. How many hours per week do you have for yourself?

*"Time for yourself" is time where you can pursue activities of your choice - that are not related to caring responsibilities, work, or to household and other chores.*

\_\_\_\_\_ hours

53. How often have you experienced the following?

	Almost always	Most of the time	About half the time	Occasionally	Not at all
<i>During the past four weeks...</i>					
It has been easy to relate to others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt isolated from other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had someone to share my feelings with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Almost always	Most of the time	About half the time	Occasionally	Not at all
I found it easy to get in touch with others when I needed to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When with other people, I felt separate from them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt alone and friendless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



54. How satisfied are you with...

	Completely dissatisfied	0	1	2	3	4	Neutral	5	6	7	8	9	Completely satisfied	10	N/A
...your relationship with your partner?	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
...your relationship with your parents?	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
...your relationship with your children?	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
...your relationship with your friends?	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>

55. How much do you agree with the following statement?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
I feel that my caring role is recognised and valued by my community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that my caring role is recognised and valued by my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that my caring role is recognised and valued by my friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that my caring role is recognised and valued by service providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that my caring role is recognised and valued by the government	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

56. During the last 12 months, have you had any long-term illness or disability that has lasted, or is likely to last, at least 6 months, which has been made worse by your caring role?

☐ Yes (please specify: \_\_\_\_\_)

☐ If yes, what form of support would improve your health? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

☐ No

## SECTION 6: ABOUT YOU

57. How old are you? \_\_\_\_\_ years old
58. What is the postcode where you live? \_\_\_\_\_
59. What is your gender?
- ☐ Female
  - ☐ Male
  - ☐ Non-binary / gender diverse
  - ☐ My gender identity isn't listed. I identify as: \_\_\_\_\_
  - ☐ Prefer not to say
60. What is your cultural background? (e.g., Italian, Chinese, Australian, etc.) \_\_\_\_\_
61. Do you speak a language(s) other than English at home?
- ☐ Yes, I speak: \_\_\_\_\_ (e.g. Vietnamese, Auslan)
  - ☐ No, English only
  - ☐ Prefer not to say
62. Are you of Aboriginal or Torres Strait Islander origin?
- ☐ No
  - ☐ Yes, Aboriginal
  - ☐ Yes, Torres Strait Islander
  - ☐ Yes, both
  - ☐ Prefer not to say
63. What is the highest level of education you have completed?
- ☐ Less than high school (year 12 or equivalent)
  - ☐ High school (year 12 or equivalent)
  - ☐ Certificate / diploma
  - ☐ Bachelor degree or higher
  - ☐ Other, please specify: \_\_\_\_\_
64. Are you currently enrolled in any formal education?
- ☐ No
  - ☐ Yes – high school
  - ☐ Yes – TAFE / apprenticeship
  - ☐ Yes – university
  - ☐ Other, please specify: \_\_\_\_\_
65. Do you consider yourself to be:
- ☐ Lesbian, gay, or homosexual
  - ☐ Straight or heterosexual
  - ☐ Bisexual
  - ☐ Queer
  - ☐ Not listed, my sexual orientation is: \_\_\_\_\_
  - ☐ Prefer not to say

66. How confident are you...

	Very confident	Confident	Somewhat confident	Not at all confident	N/A
...using the internet to find information about caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...using the internet to access online support services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...using the internet to stay in contact with friends and family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

67. What is your household's yearly income (before tax)?

Please include your partner's and / or family members' typical income from all sources (e.g. wages, pension, investment income). Please tick your best estimate:

- ☐ Up to \$9,999 per year (\$1 - \$189 per week)
- ☐ \$10,000 - \$19,999 per year (\$190 - \$379 per week)
- ☐ \$20,000 - \$29,999 per year (\$380 - \$579 per week)
- ☐ \$30,000 - \$39,999 per year (\$580 - \$769 per week)
- ☐ \$40,000 - \$49,999 per year (\$770 - \$959 per week)
- ☐ \$50,000 - \$59,999 per year (\$960 - \$1,149 per week)
- ☐ \$60,000 - \$79,999 per year (\$1,150 - \$1,529 per week)
- ☐ \$80,000 - \$99,999 per year (\$1,530 - \$1,919 per week)
- ☐ \$100,000 - \$124,999 per year (\$1,920 - \$2,399 per week)
- ☐ \$125,000 - \$149,999 per year (\$2,400 - \$2,879 per week)
- ☐ \$150,000 or more (\$2,880 per week or more)
- ☐ Prefer not to say

68. Including you, how many people are living in your household?

- \_\_\_\_\_ Children under the age of 15
- \_\_\_\_\_ Children aged 15 to 18
- \_\_\_\_\_ Adults aged 18 to 64
- \_\_\_\_\_ Adults aged 65 and older

69. Do you receive any payments from Centrelink? Please tick all that apply

- ☐ Carer Allowance (currently \$131.90 per fortnight)
- ☐ Carer Payment (currently up to \$933.40 per fortnight for singles and \$1,407.00 for couples)
- ☐ Newstart Allowance
- ☐ Age Pension
- ☐ Disability Support Pension
- ☐ Commonwealth Rent Assistance
- ☐ Other, please specify \_\_\_\_\_
- ☐ I don't know
- ☐ None of the above

70. In the last 12 months, did any of the following apply to you? Please tick all that apply

- ☐ You would have been unable to raise \$2,000 in a week for something important
- ☐ You could not pay rent or mortgage payments on time
- ☐ You spend more money than you received in a month
- ☐ You could not pay gas, electricity, water, or telephone bill on time
- ☐ You could not pay registration or insurance on time
- ☐ You pawned or sold something
- ☐ You went without meals
- ☐ You were unable to heat or cool home
- ☐ You sought assistance from welfare/community organisations
- ☐ You sought financial help from friends or family
- ☐ None of the above

71. Did you need to pay for any of the following for the person(s) you care for at least once in the last 12 months?

- ☐ Medicine
- ☐ Support services
- ☐ Transport (including parking)
- ☐ Insurance
- ☐ Housing
- ☐ Housing modifications
- ☐ Special training
- ☐ Health services and equipment
- ☐ Other, please specify: \_\_\_\_\_
- ☐ None of the above

72. Are you a member / affiliate member of, or registered with, the Carers Association in your state or territory (e.g. Carers NSW, Carers WA...)?

- ☐ Yes
- ☐ No
- ☐ Don't know

73. Optional: Is there anything else you would like to tell us about your experiences as a carer?

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**You have finished the survey – thank you for your input!**

Remember, if you feel upset or have any concerns about anything from this survey, we strongly encourage you to call the Carer Gateway (1800 422 737, open Monday to Friday, 8am to 5pm), which will offer support and carer specific services in your area.

If you are in distress, please call Lifeline (13 11 14, open 24 hours, 7 days), or contact your local GP (<https://www.healthdirect.gov.au/australian-health-services>). In an emergency, please call 000.

If you wish to contact an Aboriginal or Torres Strait Islander Health Service, please contact the service nearest to you. A list of services is available under <http://healthinfor.net.ecu.edu.au/key-resources/health-professionals/health-workers/map-of-aboriginal-and-islander-health/medical-services/>.

**74. OPTIONAL: Please participate in the follow-up study in 2022 and help us track the impact of caring over time!**

If you agree to participate, we will contact you for the next carer survey in 2022. Your answers will be assigned a randomly generated unique identifier, allowing a comparison over time. No information identifying you personally will be stored in the dataset. Please refer to the accompanying Participant Information and Consent Form for details.

☐ Yes I would like to participate in the follow-up study!

Please provide your contact details below.

**75. OPTIONAL: As a thank you for participating in the survey, you can win an Apple iPad 32GB Wi-Fi**

The prize will be drawn on 30 July 2020, the winner will be contacted via email.

☐ Yes I would like to participate in the prize draw!

Please provide your contact details below.

**I want to participate in the follow-up study and/or the prize draw. My contact details are:**

Name

Email

Street address

## Appendix B: Participant Information and Consent Form

Department of Sociology  
Faculty of Arts  
MACQUARIE UNIVERSITY NSW 2109



Chief Investigator: Dr Lukas Hofstaetter  
Department of Sociology, Macquarie University & Carers NSW

### 2020 National Carer Survey (Project ID 6233) Participant Information and Consent Form

This is an invitation to participate in a study conducted as a collaboration of the National Network of Carer Associations with researchers from Macquarie University, The University of New South Wales, the University of Sydney, the University of Technology Sydney, and the University of Queensland. The purpose of the research is to identify and highlight carers' strengths and the challenges they face in caring for a family member or friend. This research is led by Carers NSW with funding from the NSW Department of Communities and Justice.

#### The research team:

A/Prof Hugh Bainbridge	UNSW	<a href="mailto:h.bainbridge@agsm.edu.au">h.bainbridge@agsm.edu.au</a>
Ms Kirsten Baird-Bate	Carer Representative	
Dr Margaret Boulos	Carers Victoria	<a href="mailto:Margaret.Boulos@carersvictoria.org.au">Margaret.Boulos@carersvictoria.org.au</a>
Ms Dianne Brookes	Carer Representative	
Dr Myra Hamilton	UNSW	<a href="mailto:m.hamilton@unsw.edu.au">m.hamilton@unsw.edu.au</a>
Dr Lukas Hofstaetter	Macquarie University & Carers NSW	<a href="mailto:lukah@carersnsw.org.au">lukash@carersnsw.org.au</a>
Ms Sarah Judd-Lam	Carers NSW	<a href="mailto:sarahj@carersnsw.org.au">sarahj@carersnsw.org.au</a>
Dr Jack Lam	University of Queensland	<a href="mailto:j.lam@uq.edu.au">j.lam@uq.edu.au</a>
Ms Marianne Lewis	Carers South Australia	<a href="mailto:Marianne.Lewis@carers-sa.asn.au">Marianne.Lewis@carers-sa.asn.au</a>
A/Prof Kate O'Loughlin	University of Sydney	<a href="mailto:kate.oloughlin@sydney.edu.au">kate.oloughlin@sydney.edu.au</a>
Dr Ahner Poon	UNSW	<a href="mailto:w.poon@unsw.edu.au">w.poon@unsw.edu.au</a>
Ms Cathy Thomson	UNSW	<a href="mailto:cm.thomson@unsw.edu.au">cm.thomson@unsw.edu.au</a>
Dr Melanie Zeppel	Macquarie University	<a href="mailto:melanie.zeppel@mq.edu.au">melanie.zeppel@mq.edu.au</a>

#### What we would like you to do:

If you choose to take part, you will be asked to complete the survey questionnaire. The survey is anonymous, and you do not have to answer any questions you do not want to. It should take approximately 20 minutes to complete the survey, which you can do at any time that suits you. Please complete the online survey or return the paper survey in the reply paid envelope provided by **30 June 2020**.

You will be asked questions on the following topics:

- Yourself (e.g. your age, gender, cultural background, employment)
- The person(s) you care for (e.g. their relationship to you, the level of care required)
- Access to services and support (e.g. what services are you using?)
- Your health and wellbeing (e.g. do you feel stressed?)

**By submitting a completed survey, you are indicating your consent to participate.**



At the end of this survey, you will have the option to register for participation in a follow-up study in 2022 by providing Carers NSW with contact details. These details will only be used to contact you for the follow-up study, and not for any other purpose. Your contact details will be stored in a separate database and will not be part of any analysis. If you do not wish to participate in the follow-up study you still can take part in the survey.

You can also choose to enter a prize draw. One participant from each state or territory can win an Apple iPad 32 GB WiFi. The prize draw will be conducted on **30 July 2020**, the winner will be contacted via email or post.

If you have any questions or would like assistance to complete the survey, please contact Carers NSW Research Team on (02) 9280 4744.

#### **Possible risks, inconveniences and discomforts**

It is not envisaged that you will experience any discomfort as a result of participating in this survey. However, if your participation raises any issues of concern or discomfort, you are encouraged to call either of these services:

**Carer Gateway**  
(8am – 5pm Monday to Friday)  
1800 422 737

**Lifeline Australia**  
(24 hours)  
13 11 14

In an emergency, call **Triple Zero 000**

**Lifeline Text**  
(6pm – Midnight, 7 days a week)  
0477 13 11 14

If you wish to contact an Aboriginal or Torres Strait Islander Health Service, please contact the service nearest to you. A list of services is available under <https://healthinfonet.ecu.edu.au/key-resources/health-professionals/health-workers/map-of-aboriginal-and-islander-health/medical-services/>.

Completing the survey is completely voluntary and you may withdraw your participation at any time. Any partially completed surveys will be excluded from the final analysis. Refusal to participate will not affect your relationship with Carers NSW or any of the collaborating universities.

#### **Benefits of the research**

This research will help to direct the advocacy and support work of the National Network of Carer Associations in Australia. Findings will be used to identify areas of greatest need amongst carers across Australia, and the particular needs of different carer groups (e.g., different geographic locations, different care recipient conditions, etc.). Survey results will be published in a report that will be made publicly available online, along with factsheets. Results will also be published in a number of peer reviewed journal articles and will also be presented at relevant conferences. Each member of the research team will have access to the information collected, however, as survey responses are anonymous, you will not be personally identified in any part of the research.

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email [ethics@mq.edu.au](mailto:ethics@mq.edu.au)). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

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<sup>i</sup> Australian Bureau of Statistics 2018 Survey of Disability, Aging and Carers (SDAC)

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- ii Australian Bureau of Statistics 2018 Survey of Disability, Aging and Carers (SDAC)
  - iii Australian Bureau of Statistics 2018 Survey of Disability, Aging and Carers (SDAC)