



# Quality of Life Audit 2019

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## FOREWORD

### An invisible and unpaid workforce

Providing 1.9 billion hours nationally or more than 74% of the assistance required by people with a disability, mental health problem, terminal illness, chronic medical condition or aged related frailty, carers are an invisible and unpaid workforce. Conservative estimates indicate the replacement value of unpaid care is equivalent to 3.8% of GDP. In Queensland, 474,300 people including children and young adults (1 in 11 of the population) will provide unpaid care and support to a family member or friend, the replacement value of which is estimated to be between \$10.2 and \$10.5 billion per annum.

While caring can be rewarding and brings about life affirming experiences, without appropriate support, it can have significant long term and inter-generational negative effects on the health, wellbeing, relationships, employment and social and financial inclusion of individual carers and caring families.

Australian and international research highlights the clear relationship between the unpaid carer and the diminished health and wellbeing of the individual carer. Caring relationships, particularly those of a longer duration or very intense responsibilities, can result in carers becoming separated and isolated from their immediate family and informal network (their herd) and their community (their tribe).

Humans are social beings. We need our social groups (our herd and our tribe) to nurture, sustain and protect us. Separated from our social groups, we cannot discover our personal identity and have no sense of belonging and we don't function well. When family and friends don't step up to the responsibilities of those herd relationships by ignoring or minimising when a herd member is in pain or need of support, the potential emotional damage is serious and the emotional consequences catastrophic, as the social isolation morphs into a sense of social exclusion and feelings of alienation.

When people feel isolated, they tend to feel cut off from their herd, and a natural part of that separation is to feel anxious. When people feel anxious, they tend to withdraw even further and become more isolated and self-absorbed, rather than reaching out for contact, which is generally speaking, one of the best antidotes for anxiety.

Isolated at home, in terms of personal relationships and family relationships, many carers are living in domestic situations below the suboptimal herd size and because of their caring responsibilities are not connecting with their tribe of community networks. The implication is clear. If carers are not feeling connected to a functioning herd and tribe, not feeling a part of a nurturing and functioning family and neighbourhood, friendship circle or workplace, the effect on their mental health is quite serious.

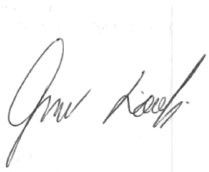
A healthy tribe is one in which the members are aware of and respond to the needs of individuals and families at risk of isolation and exclusion, such as carers and caring families, so that those individuals are invited to share in and contribute to the life of a community and in doing so the consequences of anxiety and depression are diminished.

Sadly, many of the respondents to this year's survey are experiencing the negative impact of not being a part of a nurturing and protective support network:

- 42% of respondents of working age believe that their caring role is not recognised or supported with their community and 46% of all respondents experience low role recognition and respect

- 39% are experiencing chronic anxiety, and 6% identify as completely anxious
- 19% are lonely most of the time
- 18% are very satisfied, and 32% believe that what they are doing is very worthwhile
- 30% identify as socially isolated

Carers Queensland remains committed to supporting Queensland's unpaid and invisible workforce through robust advocacy to government and industry, seeking to secure caring family-positive policy changes and system improvements, and additional funding for programs that will improve the quality of life of caring families throughout Queensland.



**Jim Toohey**  
Chair, Board of Governance  
Carers Queensland Ltd.



**Debra Cottrell**  
Chief Executive Officer  
Carers Queensland Ltd.

## QUALITY OF LIFE

### About Carers and Wellbeing

Measuring quality of life directs attention to the positive aspects of people's lives and extends traditional objective measures of health, wealth and social functioning to include subjective perceptions of wellbeing.

Studying wellbeing in a systematic and scientific way enables social scientists to identify the wellbeing of different population groups and the extent to which different factors influence how people feel about their quality of life. The Australian Centre on Quality of Life distinguishes two broad categories of wellbeing – subjective and objective wellbeing.

**Subjective wellbeing** considers an individual's satisfaction with their own life and can be broken down into emotional wellbeing (the emotional quality of a person's everyday experience) and life evaluation (the thoughts people have about their life). Subjective wellbeing is normally a positive state of mind. It is a long-lasting, deep sense of contentment, as opposed to the momentary burst of joy we experience when we laugh at a joke. Happiness is frequently used when referring to subjective wellbeing.

**Objective wellbeing** is concerned with the material conditions that affect a person's life, such as access to education and employment opportunities.

### Subjective wellbeing homeostasis

Research conducted by the Australian Centre on Quality of Life suggests that we are born with a baseline level of happiness or unhappiness, and whilst life events cause our baseline level to fluctuate, it is generally only a little. In a very similar manner to the maintenance of our body temperature, we are generally able to self-regulate our wellbeing. Our in-built neural mechanisms allow our feelings of wellbeing to fluctuate a little, but the homeostasis does its best to maintain such feelings relatively steady over time.

We maintain this baseline level of happiness or subjective wellbeing homeostasis, by drawing on a range of external and internal resources. External resources include personal relationships and money. Internal resources include our ability to find meaning in a bad event, and both enable us to cope with tough situations better. Failure of our homeostasis function on a chronic basis can result in a loss of positive wellbeing that can, for some lead to depression.

### Those at risk of lower wellbeing

Research conducted by the Australian Centre on Quality of Life in 2007 indicates that unpaid carers have the lowest wellbeing of any population group yet surveyed by the Centre. The average wellbeing score of the Australian population is between 73 and 76. The average score for carers was 58.4.

Carers most at risk of lower wellbeing are?

- sole parent carers
- female carers
- carers experiencing chronic pain
- carers carrying a chronic injury or injuries
- carers with intensive and/or prolonged caring responsibilities

## Factors affecting wellbeing

Many factors influence wellbeing including stress, chronic pain, not receiving treatment for a significant medical or psychological condition, where we live, housing tenure and security, income, employment, and the presence or absence of a life partner.

The provision of personal resources, such as money or relationships, can strengthen defences against negative experiences. Moreover, for someone who is experiencing homeostatic defeat, the provision of additional resources may allow them to regain control and restore their wellbeing.

## The things we can do to look after our wellbeing

1. connect with family and friends – spending time with people we care about makes us happier and healthier, they have the strongest influence on our happiness
2. save for a rainy day – having the money when things go wrong
3. get involved in the community – being involved with the local community is a great way to feel connected; it enhances our sense of belonging and security
4. engage in activities that provide a sense of achievement – we get a sense of achievement and drive when we do something good or useful
5. find a balance - between work, care responsibilities and leisure – this balance is different for each person

## METHODOLOGY

### Carers Queensland Liveability Audit

The data generated by the annual Quality of Life Audit is an integral component of our systemic advocacy work, promoting the importance of liveability in the development of effective national, state policies and the development of programs and services relevant to caring families. The survey acts as a barometer, measuring and reflecting the changing mood of Queensland's caring families as they adapt to significant changes in the disability, mental health and aged care sectors and in social welfare policy.

### Methodology

Initially launched in 2011, the Quality of Life Audit formed the benchmark estimate of the quality of life of carers in Queensland. It's issued as both a paper survey and electronically through the regional offices throughout the Carers Queensland website.

Each year since its inception, the survey includes different thematic questions, creating a deeper and richer portrait of the quality of life of caring families.

Issued on August 1, the survey was emailed to approximately 9000 individuals promoted through our social media platforms and newsletter, *Together*.

This year the thematic questions explored loneliness and social isolation, the impact of caring on carer health and wellbeing and the recognition of carers and respect for the caring role within the broader social care sector and community. The survey was completed by 569 eligible respondents.



## PART 1. PERSONAL DEMOGRAPHICS

### 1.1 Respondent Demographics

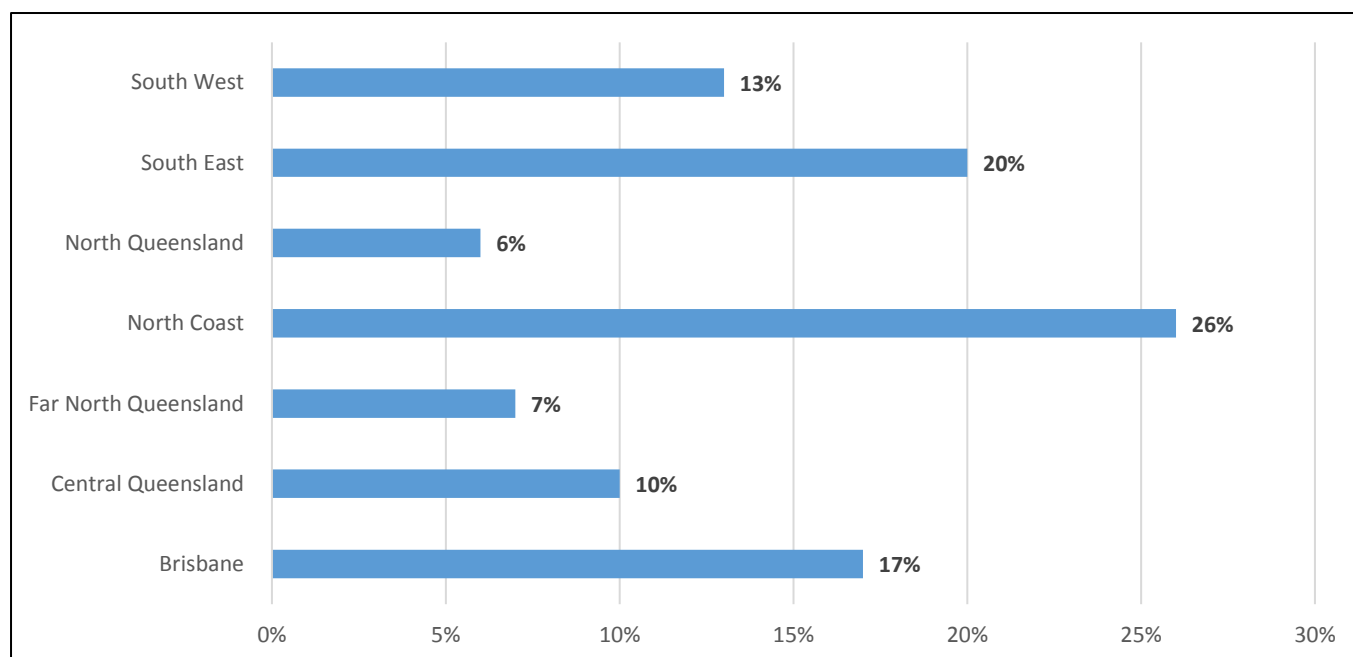
The 2019 responses closely reflect the 2018 survey responses across the personal demographic domains.

Of the respondents:

- 92% speak English as their first language
- 4% identify as Aboriginal and Torres Strait Islander
- 82% are female
- 74% are of working age
- 59% are reliant on Centrelink or personal saving
- 62% are married or in a committed relationship
- <1% are young adult carers
- 49% provide 12 or more hours of care and support per day
- 3% are attending a school or other educational institution
- 6% identify as sexually diverse and <1% as gender diverse

The geographic distribution of survey respondents closely reflects the state profile. The ABS Survey of Disability, Ageing and Carers 2015 estimates that 77,220 carers or 16% of the Queensland carer population live outside of Queensland's major cities.

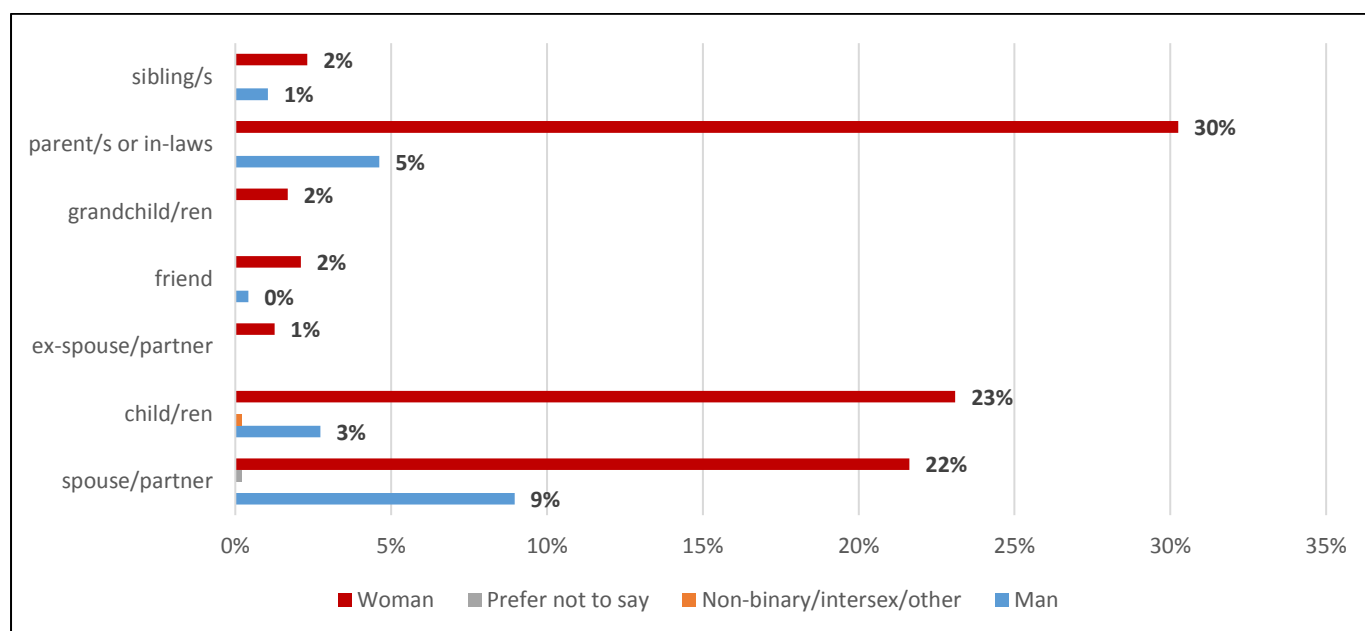
**GRAPH 1 – Respondent location**



The age and gender profile of the survey respondents closely reflects the national and state profiles.

- Nationally, 68.1% of primary carers and 55.5% of all carers are women. Among people aged 55 to 64 years, the number of female primary carers is almost double the number of male primary carers. The number of male and female primary carers 75 years and over, was similar.
- At the state level, 70% of primary carers and 56% of all carers are women.

GRAPH 2 – Carer gender by relationship to care, recipient,

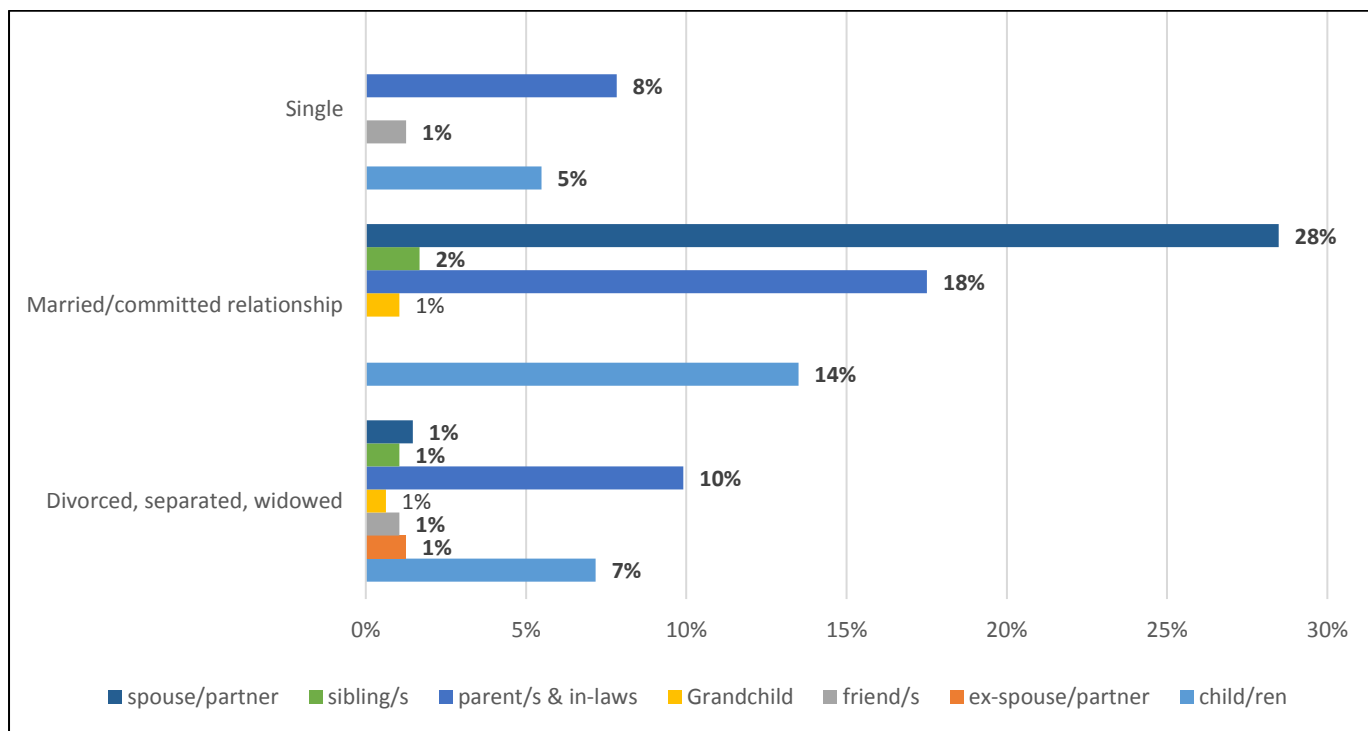


Analysis of the carer population highlights that people who are married or in a committed relationship are overrepresented against the general population. This reflects the most common carer relationship – that is where one spouse provides care and support to the other spouse. 1

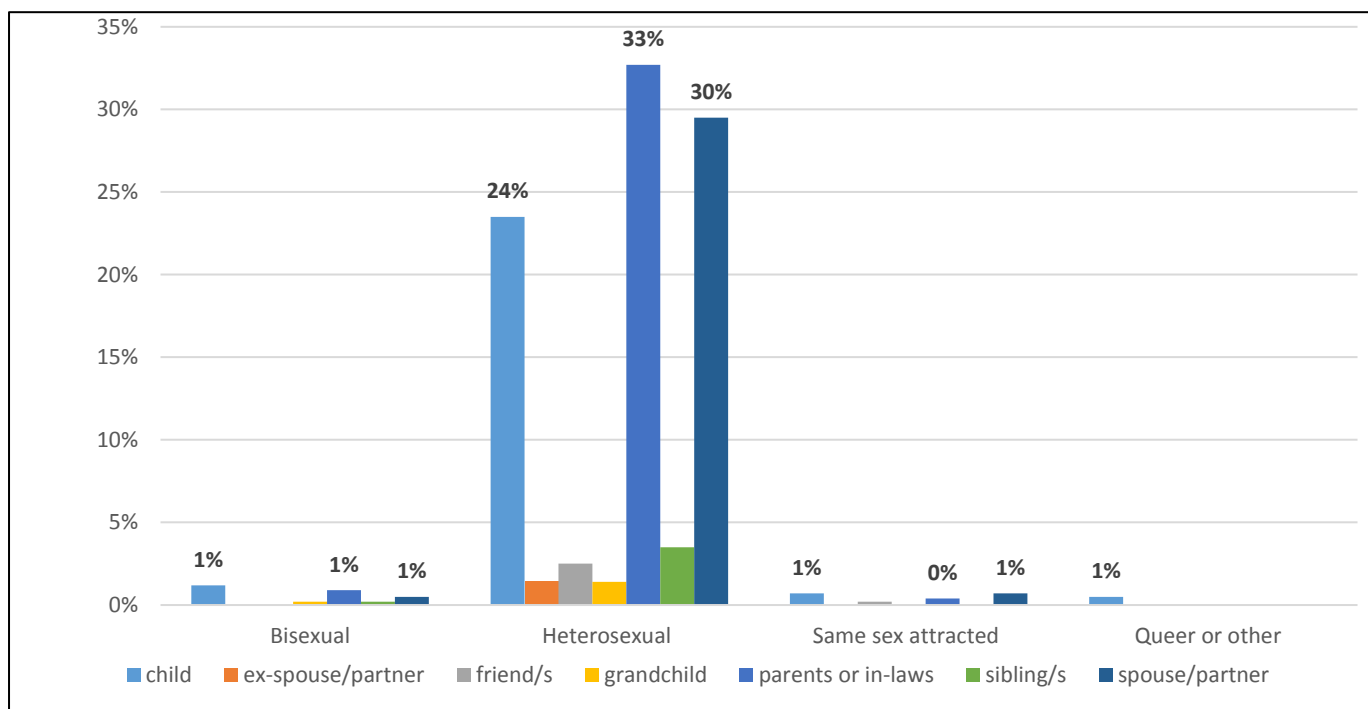
While the idea of creating a long term relationship that involves providing care and support for someone feels foreign to many divorced or separated heterosexual couples, in the lesbian gay, bisexual and queer communities these phenomena are more common.

*Of the survey  
62% of survey  
respondents are  
married or in a  
committed relationship  
and 1.5% care for an ex-  
spouse or ex-partner*

GRAPH 3 – Relationship between the carer and the care recipient



GRAPH 4 – Carer sexuality by the care recipient relationship

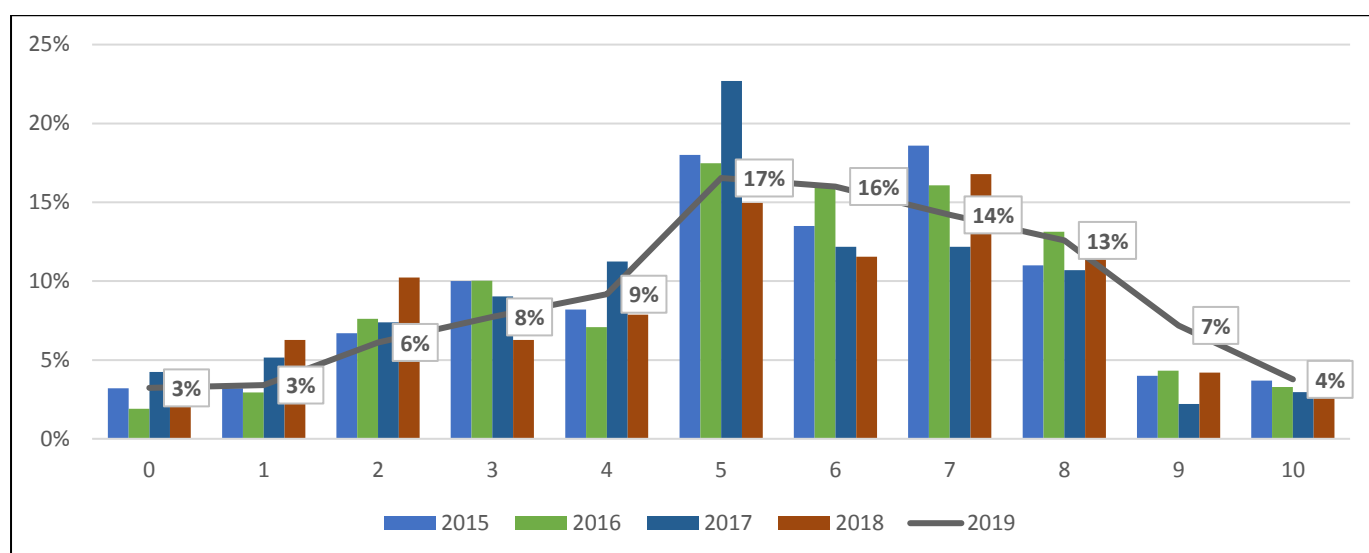


## PART 2. QUALITY OF LIFE INDICATORS

### 2.1 Quality of Life

While many survey respondents spoke of the value of support services, there are never enough to meet demand and carers frequently fill the void. Caring for a family member or friend can take a serious toll of the mental health and wellbeing of carers, their personal and family relationships, employment and income and social connection. Without the right support when needed, carers suffer from physical and emotional exhaustion, anxiety, loneliness and exclusion.

GRAPH 5 – Current quality of life (0 means completely dissatisfied and 10 means completely satisfied)

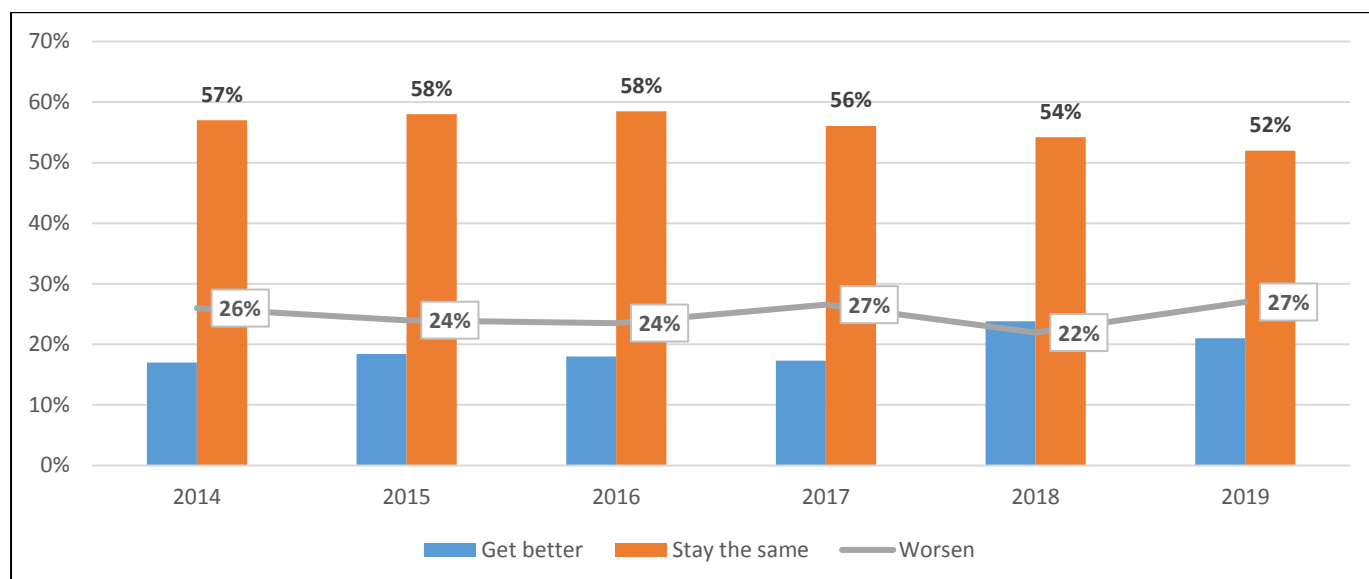


This situation is only like to worsen as Australia's population ages, and people live longer with better managed chronic and acute conditions. In real terms, this means that more people will require more care and support and for a longer period of time and much of that care and support will be provided by caring families.

Research has shown that carer wellbeing is influenced by the nature of the relationship between the carer and the person cared for (spouse/child/parent/sibling etc.) and the duration and intensity of the caring role.

Carers Queensland contends that without improved access to the appropriate support services at the right time, caring families will continue to experience a lower quality of life than other population groups.

GRAPH 6 – Future quality of life



- I have been suffering from depression and this year has been a struggle for me. After paying the mortgage and bills, there is nothing left over. I am continually exhausted and feel that life wasn't meant to be this hard. Some days are a real struggle.
- My health is down but I am not out. I try and keep doing exercise. Work hard to make sure I get decent meals for me and my spouse. By being frugal I can get the money to stretch so no unpaid bills or debts. I watch magpies bathing and drinking from an old baking tray I leave in the backyard with water in it for them. I grow some veggies. Overall I have much to be thankful for. I feel I am in an awful situation with no reasonable way out but at the moment I have a roof over my head, food in the pantry, a washing machine that works, a car that does what I need so I still think I am not badly off.
- I feel my quality of life score is low and lowering because I do not feel the person I care for is fully supported by the health and medical community nor am I heard fully by the medical community on behalf of whom I care for. This makes caring so difficult when the best medical care is not given to those who need it.
- It's absolutely s..t! My day starts at 6.30 am when I start the get-ready-for-school fight. After the school drop-off (11 yr.) I drive an hour for Mr. 4 to attend his therapy sessions 5 days a week. Due to the time and cost involved versus the benefit (1 hour at home) it is not feasible to travel home after dropping him off. However, at least once a fortnight, I have to drive home during the day to be available for the 11yr old's needs that the school can't control. I then battle through the afternoon doing what therapy needs following-up, before doing food prep, stopping the physical issues that arise when my back is turned for a second. I hand wash at night anywhere between 10 and midnight depending on who is asleep. Despite being medicated there are multiple wake ups from all of the children during the night which I have to attend to. I average 4 to 5 hours of broken sleep a night on a good night.

## 2.2 Income, housing affordability and standard of living

Australian research shows that at the aggregate level, carers experience a higher rate of poverty on all measures. Carers who have been caring for two years or more have higher poverty rates than non-carers and are more likely to be living in persistent poverty. This is particularly so for co-resident and primary carers.

Excessive inequality is harmful. When people on low incomes and wealth do not participate in society, they struggle to reach socially acceptable living standards. The nation's economic growth is diminished when people are too impoverished to participate effectively in the workforce or acquire the skills to do so.

The majority of people in the lowest 20% income quintile live in households that rely on Centrelink payments include sole parents, people of 65 years, and the unemployed.

In Queensland, 144,700 carers live in a household where the gross equivalised income is in the lowest 20% (87,200 carers aged 15-64 years and 37,500 carers aged 65+ years).

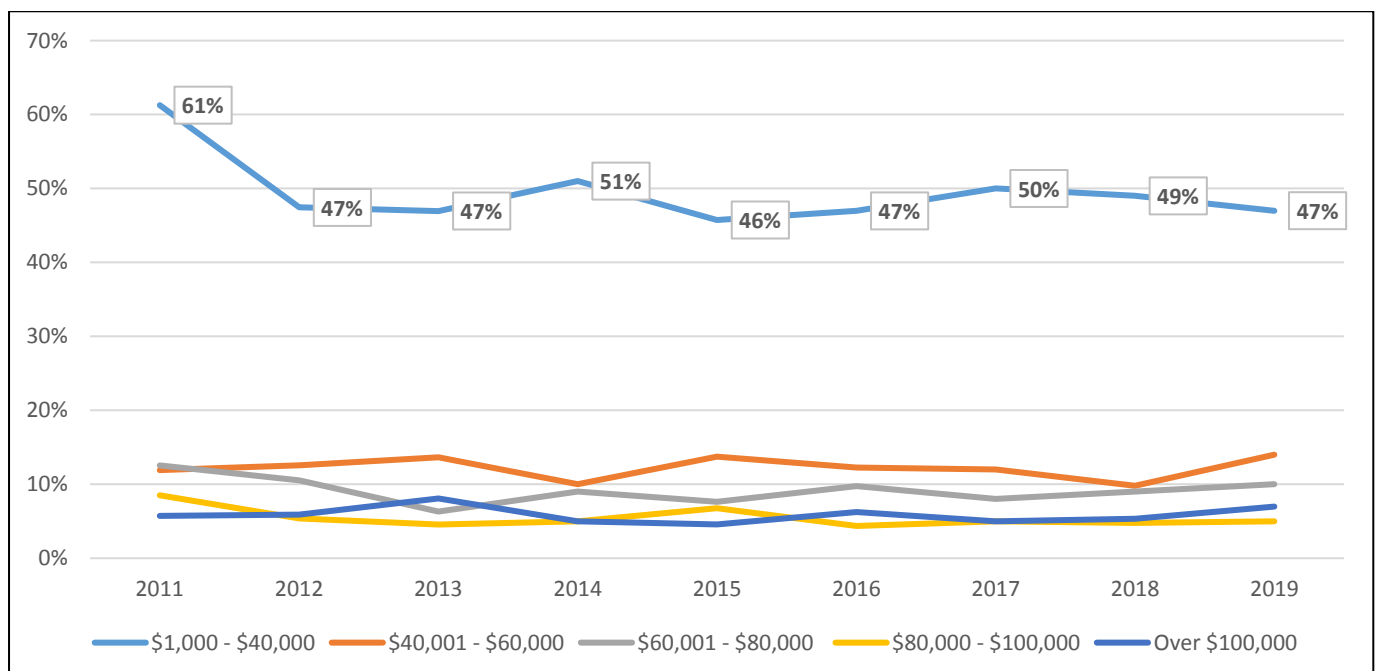
*Of the survey respondents:*

*59% rely on Centrelink or their own income*

*and*

*47% live in a household with a combined income of less than \$40,000 per year*

GRAPH 7 – Household income



*Of the survey respondents:*

*56% are satisfied with the ability to maintain their housing and purchase goods and services*

Data over seven years, reveals that whilst the wellbeing of men is highly linked to paid work, the wellbeing of women is highly linked to the capacity to manage it. Further, the research indicates that carers are almost twice as likely than the wider community to worry that their income will not be sufficient to meet expenses, the result of which is decreased wellbeing. The constant stress associated with a lack of money to pay for necessary goods and services is known to contribute to health problems and stress on family relationships.

Recent National Health Survey data revealed that anxiety and anxiety-related disorders are the most prevalent mental health condition (13.1%) and a similar number of people over 18 years of age reported high levels of distress. Anxiety in carers is more than double the national prevalence – estimated to between 23% and 56%.

*49% of survey respondents experience anxiety related to their situation*

*In Queensland in 2019:*

- *the median total personal income is \$34,320*
- *the median rent for a three bedroom house is \$360.00 per week*
- *the average weekly income is \$1,576*
- *the median total family income per week is \$1661*
- *\$1733 median monthly mortgage repayment*

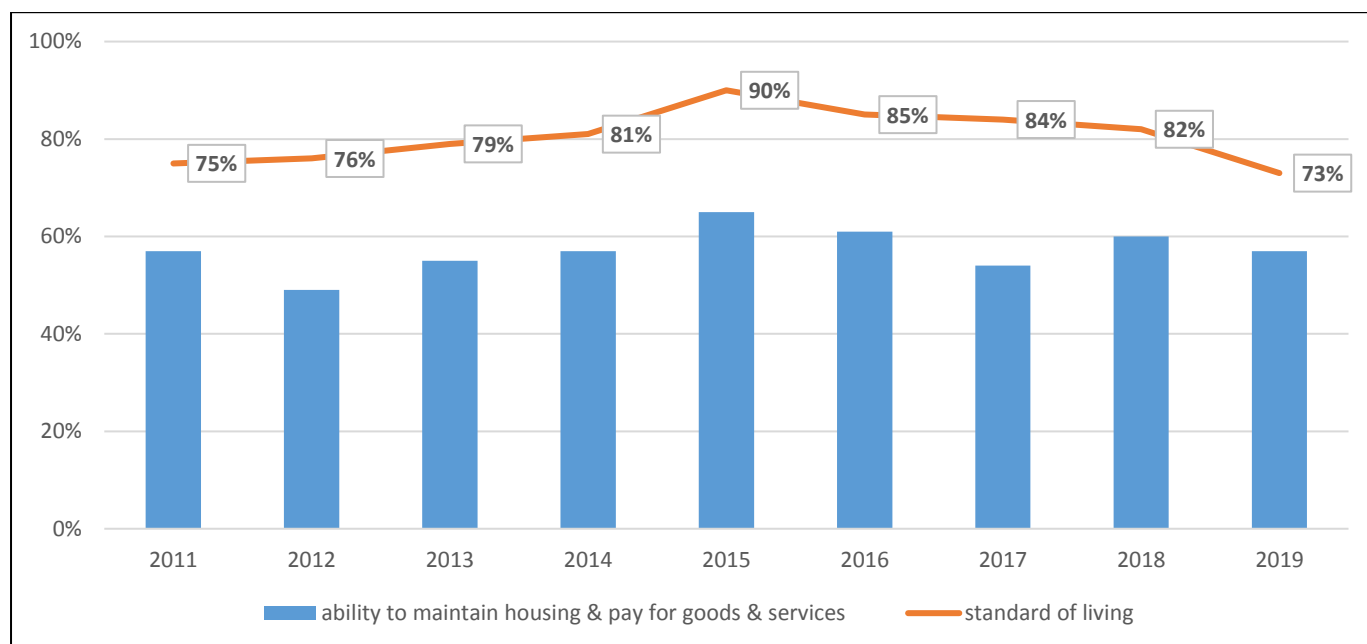
Since 2009, the median income has fallen, meaning that many Australians, including caring families, have wafer-thin financial resources and regularly juggle budgets to make a choice between heating or cooling the house and eating.

Food insecurity, as estimated by Foodbank Australia, affects 3.6 million Australians. Food costs should, ideally, represent about one-fifth to one-quarter of household income, but currently, some households need to spend 30-48% of the household income to enjoy healthy diets.

Analysis by the Queensland Council of Social Services, shows that low-income households are the most affected by the rising cost of essential goods and services and are most at risk of falling into a cycle of poverty and disadvantages because of cost of living pressures. For aged pensioners, the analysis demonstrated that housing and utility costs continue to have a significant impact on the capacity of an individual in receipt of the aged pension to afford a basic standard of living and that:

- a. rising housing costs are the single biggest financial burden; especially for those who rent in the private market
- b. single and couple households renting privately, are most likely to experience housing stress (with almost 50% of the gross income being spent on housing costs).

GRAPH 8 – Satisfaction with the current standard of living



Financial security is the key to many life opportunities. It primarily accrues from past income which contributes to future income. It can sustain people no longer working by generating investment returns. High levels of wealth inequality deepens and entrenches inequality. Income inequality is also on the rise in Australia.

*The average wealth of those in the highest 20% has risen by 53%, and the average wealth of those in the lowest 20% has declined by 9%.*

- I'm sick of living under the poverty line and being constantly in debt just to make ends meet when something needs to be replaced or fixed. With an 18-year-old car, I am always spending money just to try and keep it on the road. Forget about anything as extravagant as going out. I can't even remember the last time I went to the movies or out for a meal.
- I have no life of my own. I am living below the poverty line. I am constantly under extreme stress and suffer from anxiety and depression.
- Husband is employed full time but low income. My part carer's pension is small. Our combined income does not meet the average wage.
- Homelessness is a constant worry, very little money left for basics after rent is paid.

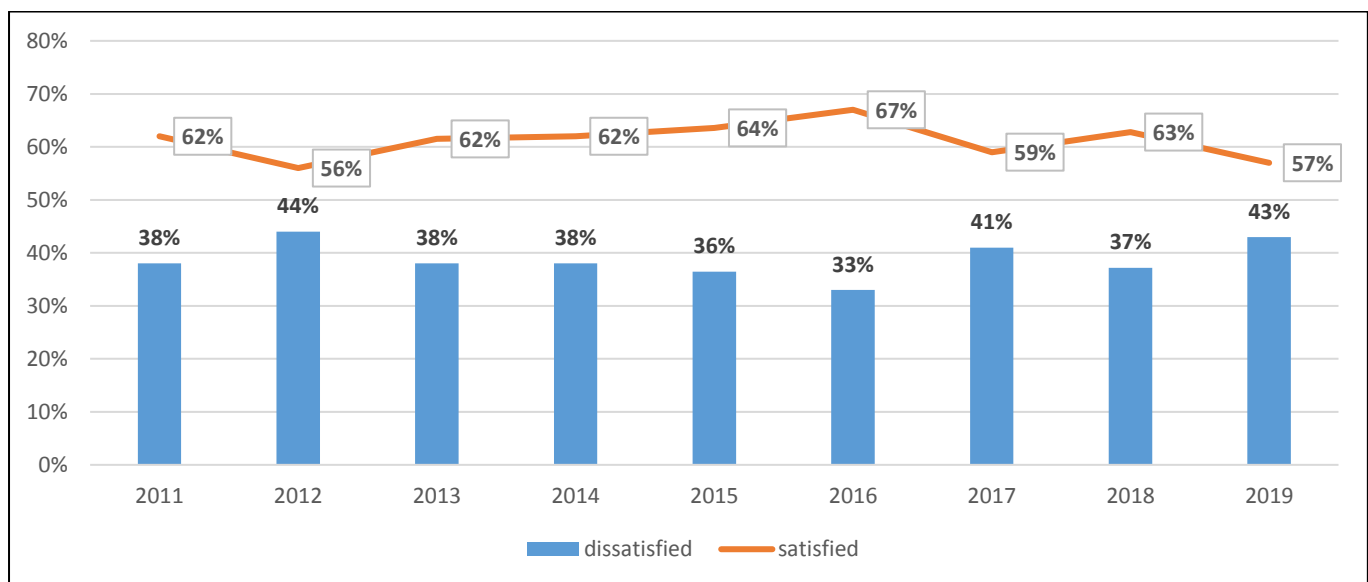


## 2.3 Health and wellbeing

People enjoying higher socioeconomic positions have a greater array of choices, more opportunities for a flourishing life and they better health outcomes. The two factors are linked: the more choices people enjoy, socially and economically, the better their health.

Health is more than an absence of disease or illness. It is a state of complete physical, mental and social wellbeing. Poorer Health outcomes are linked to sub-optimal socio-economic circumstances. Addressing health inequalities requires action across all the social determinants of health such as education, housing, income and wealth, and social inclusion, pre and post-natal care etc.

GRAPH 9 – Capacity to prevent health problems and the ability to access health services



It can be extremely difficult for carers to find the money, time or energy to look after their own health, activities such as preparing healthy meals, exercising, quality sleep or medical attention. In the short term, the consequences of such actions are limited, but over the longer term, carers who fail to address their own health needs will have poorer health and wellbeing.

Our satisfaction with our health decreases as we get older until we are about 55 years of age when subjective wellbeing increases for most people, with the exception of those who live with chronic and severe pain. Those living with chronic and severe pain are at risk of homeostatic defeat and their wellbeing will be negatively affected.

*Of survey respondents:*

*57% indicated that their mental health and physical health had worsened as a result of their caring responsibilities*

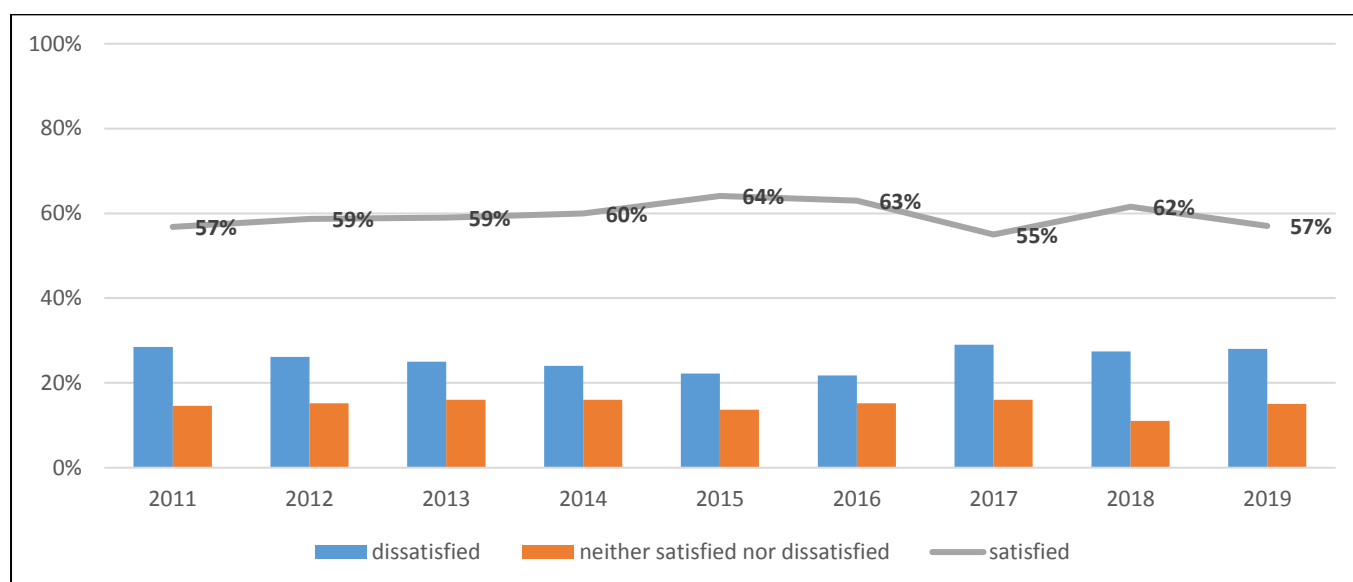
*50% had experienced an illness that had lasted at least 6 months, and of this group, 79% indicated that their caring responsibilities had impacted their recovery*

- My grief and anger are ongoing and, while I am very resilient, I still need regular counselling, psychology and psychiatrist visits to keep me stable, which are a drain on my resources and require a minimum 3 hours travel each time.
- Caring has adversely impacted my health. I have two autoimmune conditions, two bulging discs and high blood pressure, heart problems and depression.
- When am I going to get the time? I need to access the service between caring and working and sleeping. I'm treading water but accessing the services I have to stop treading, which could lead to sinking. It's hard.
- Everything gets on top of me. Nothing is where I would like it to be.

## 2.4 Connecting with others in the community and personal relationships

Emotional and social support is not always available with immediate and extended family. Caring, particularly over a long period of time, can affect personal relationships between partners, parents, children and other family members. These role changes are not static but evolve in response to changes in the health status of all parties, the level or frequency of formal support services and other support networks. For spousal carers, the caring role can be accompanied by a loss of communication, reduced intimacy, companionship and emotional support. Disability and ill-health change the sense of reciprocity between partners - that is the sharing of responsibilities and emotions - resulting in the carer assuming more responsibility for decision making, household tasks and planning.

GRAPH 10 – Satisfaction with personal relationships

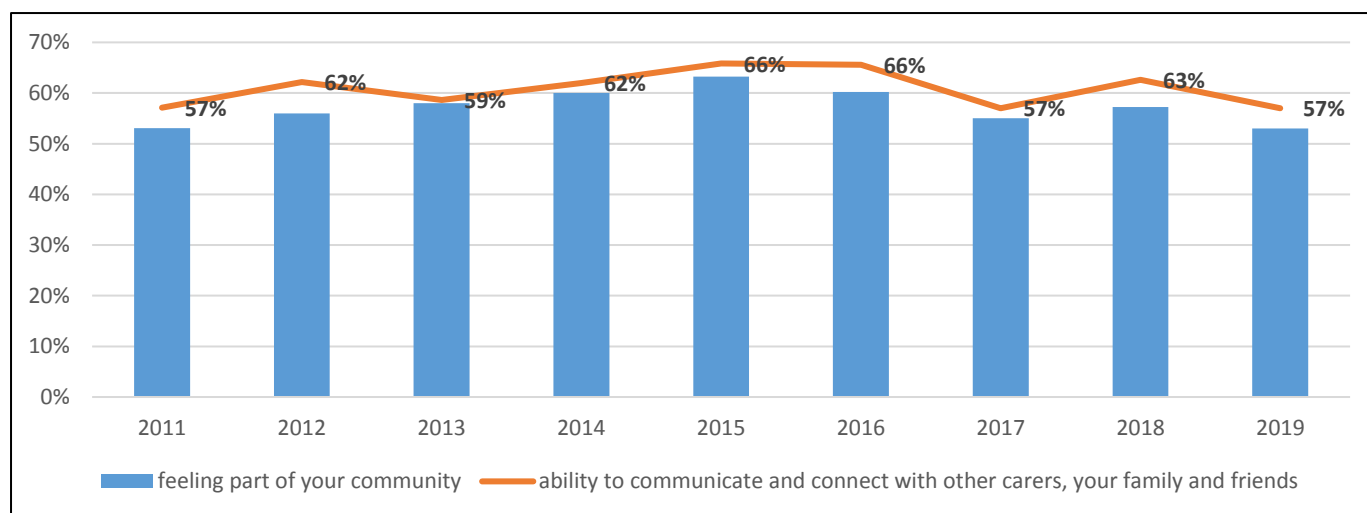


- I have no time to form deep personal relationships. If it was not for Carers Queensland and the retreats... my friendship network would not exist.
- My relationship with my spouse has declined to where I am just the servant and can't even get proper respite. My spouse is the one who gets NDIS so I have no control over support worker schedules. If my spouse thinks I am well, then no matter what I say, I get crumbs of respite. Other relationships? Over the years, I have got more and more isolated so I hardly ever see people.
- The majority of my time is spent with my two dependent sons. I feel quite isolated. The ONLY friendships I have in local area are people I have met at Carers Queensland support groups. I usually see them twice per month. I would like to have better personal relationships, spend time with extended family (who live interstate and overseas) and I would also like more of a social life.
- As long as I am not complaining and towing the line, things go well. I am very withdrawn and feel afraid to share my heart and how low I constantly feel because I am afraid of driving the few people I have in my life away completely ... I feel 'unknown, misunderstood and as though I have become an empty shell'.

Healthy communities are important for physical and mental wellbeing. Social wellbeing encompasses social acceptance, actualization, contribution and a sense of support and belonging and social integration.

The physical and social characteristics of communities and the degree to which they enable and promote healthy behaviours, make a contribution to inequalities in health outcomes. The built environment, social structures and organisations in the local community, deteriorating health, impaired mobility and a sense of fear and insecurity are contributory factors to social isolation and loneliness.

**GRAPH 11 – Satisfaction with feeling a part of the community and the ability to connect**



The world shrinks for many carers. The caring role takes over, the days and the weeks become structured around completing the myriad of tasks needed to ensure the happiness, safety, health and wellbeing of the family member or friend. Friendships may diminish or disappear, particularly if the carer has given up work. Invitations to social functions or to participate in group activities can fall away as others do not know how to respond to the concerns of carers or because the relationship is no longer reciprocal. Friendships may wither because of a fear of rejection.

Co-resident carers and long term caring can become socially isolated and lonely - seeing and a reduced social network beyond support staff. Lack of companionship and social connectedness contributes to loneliness.

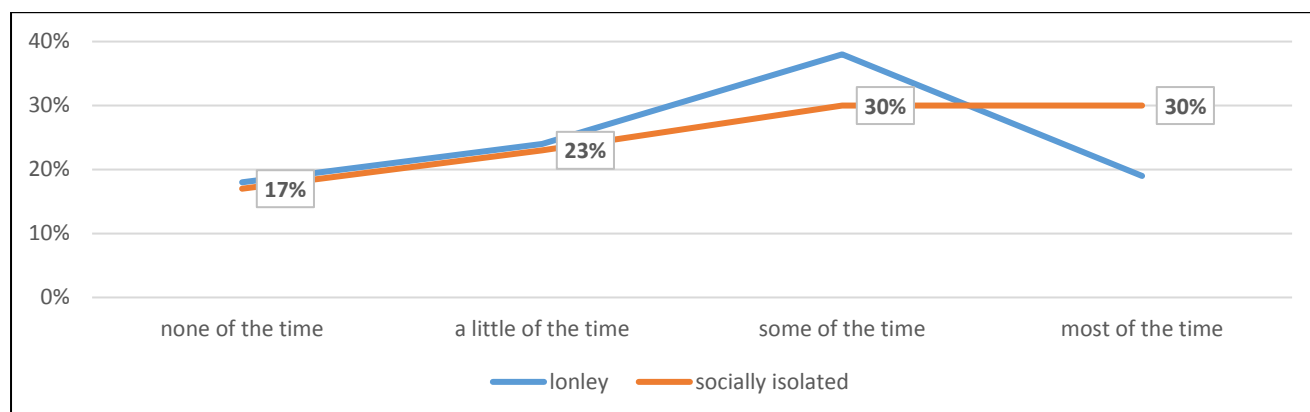
British research suggests that:

- 14% of the population feel lonely 'often or always.'
- 81% of carers have felt lonely or socially isolated because of the caring role
- more than a third of the elderly felt overwhelmed by loneliness
- Two hundred thousand people 2 over 75 years had not had a conversation with a relative or friend in over a month.

Australian Centre on Quality of Life research indicates that more than 30% of people in Australia are lonely.

Building social capital, the link that binds and connects people within and between communities helps to establish resilience, a buffer against the risks of poorer health. The extent to which an individual participates in their communities and the added control over their lives has the potential to contribute to their improved psychosocial wellbeing and health outcomes.

GRAPH 12 – Loneliness and social isolation



Making and sustain connections is not always easy. Research has shown that how a caring family is perceived by others is based on the individual's perception or interpretation of disability or illness. Caring families may fear and/or experience stigma – negative treatment from others, the embarrassment or shame associated with the negative treatment and the fear that they will experience stigma.

The assumption that caring is only a family responsibility renders carers and the impact of caring invisible within the broader community. With invisibility, carers lack appropriate support within the community that can address social isolation and other stressors associated with the role.

Recognition of the carer role varies with the age of the carer. 100% of young carer respondents perceive that their role is recognised some or most of the time, but this recognition is very much lower in the working-age group.

*Of the survey respondents*

*40% feel comfortable talking about caring*

*23% say their caring role is recognised and valued in their community*

*18% have enough time to participate in social activities*

- People don't understand dementia behaviour, so instead, they judge us - him and me. It can be embarrassing and isolating. It makes me feel anxious having to justify his behaviour all the time, to explain 'he has dementia' and apologise when he breaks social protocols.
- Friends have dropped by the wayside; family love a five-minute visit, often saying if you need me ring me, when rung they are too busy with life. Even neighbours have stopped invitations to social events.
- The friends I have are carers and all have great responsibilities themselves. The connection is the understanding and empathy we have for each other.
- We have only lived in this area for two years. I do not have a partner and I am unemployed with two dependent sons. I have no family in the area. The ONLY way I feel part of the community is via the Carers Queensland support groups that I attend twice per month.....and sometimes other Carers Queensland special events. I look forward to and enjoy these events immensely.

## 2.5 Educational opportunities, safety and future security

A carer's capacity to pursue further education or training, find and maintain employment, focus on improving health and wellbeing or keeping in contact with family and friends, is dependent on the intensity and duration of their caring role.

Carers' satisfaction with their life and their future security is intrinsically linked to their income, employment, housing security, sense of safety within the community and future care arrangements.

Like juggling work with care, juggling care with education can be just as problematic and stressful. Respondents of working-age continue to express frustration at not being able to pursue educational and learning opportunities, because of either time restrictions, training costs, or lack of formal support services such as respite care, and many feel trapped in poverty.

The Australian Centre on Quality of Life research suggests that whilst most people do not live to work, having employment is pivotal to how many people live; and that those people who want to work and who are unemployed incur reduced self-esteem and happiness.

Carers generally experience lower than average rates of employment.

In 2015, 47.83% of carers between 15 and 64 years of age in Queensland were employed; slightly less than the national figure. Primary carers experience higher rates of part-time employment than their average counterparts and a lower income level.

Similarly, many caring families feel unsafe in their community or fear the future – of insufficient financial resources to fund their retirement or the ability to continue to provide care and support.

- Besides the cost of education and learning opportunities being out of my scope, I do not have informal or formal supports in place to help with my three kids, so this makes any opportunities for me very difficult.
- Respite carer quit, so I was unable to complete TAFE course for requalifying in a job that would have fit in with my care obligations.
- I do not have enough time to take care of myself and make sure my mental illness is being looked after adequately. Also I have to take lesser roles in my work to be able to fulfil my caring role which means less money and a lower standard of living.
- I had to leave work several years ago due to our son's increasing support needs. I am grateful for the Carer's Payment but do find it difficult to budget for unexpected bills and there is little money left for anything beyond the essentials. I do worry about our financial future as I am nearing 60 and due to caring responsibilities I have very little chance of being able to return to work to save for retirement.

*Of the survey respondents:*

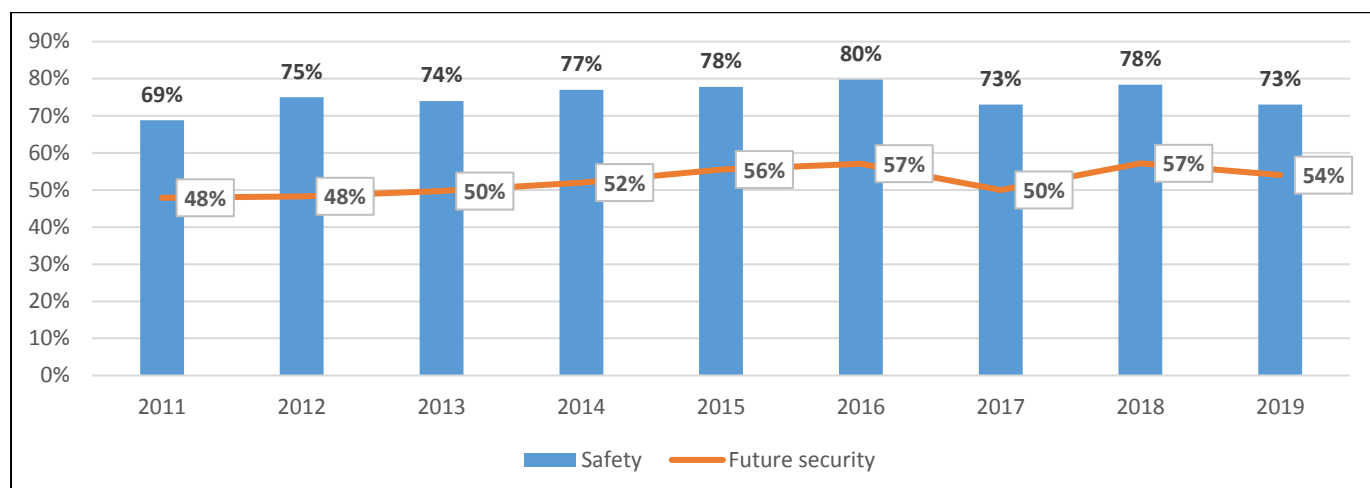
*18% provide 6 to 12 hours of care per day*

*49% provide 12 or more hours of care per day*

*26% are dissatisfied with their ability to access educational and learning opportunities*

*6% are unemployed and looking for work*

GRAPH 13 – Satisfaction with sense of safety and future security



- I live in a domestic violence situation with a three-year-old (3) as the perpetrator. I have suffered two fractured eye sockets, a broken nose, multiple cuts and abrasions, bruises and head butts in the last year. I have an 11year old who has major school refusal issues; I copped a hard-boiled egg to the head this morning over a change in the school schedule for the day.
- Safe enough unless my son (the person I care for) goes on a rampage, which he manages to do on a semi-regular basis.
- I no longer have my children living with me, so the stress of their violence towards me and one another is gone. I now concentrate on not allowing myself to ruminate too much and sink towards a more suicidal state of depression.
- Anxious about housing and money. I am always living in fear of losing housing and becoming homeless.
- I do not feel financially safe. I am left with \$200 per week to live on once I pay the rent and put some aside towards electricity and phone. I have been constantly having to dip into savings left over from the sale of my house in order to meet living expenses and live in a constant state of anxiety, fear and worry about how I am going to survive once my surplus funds have been used up.

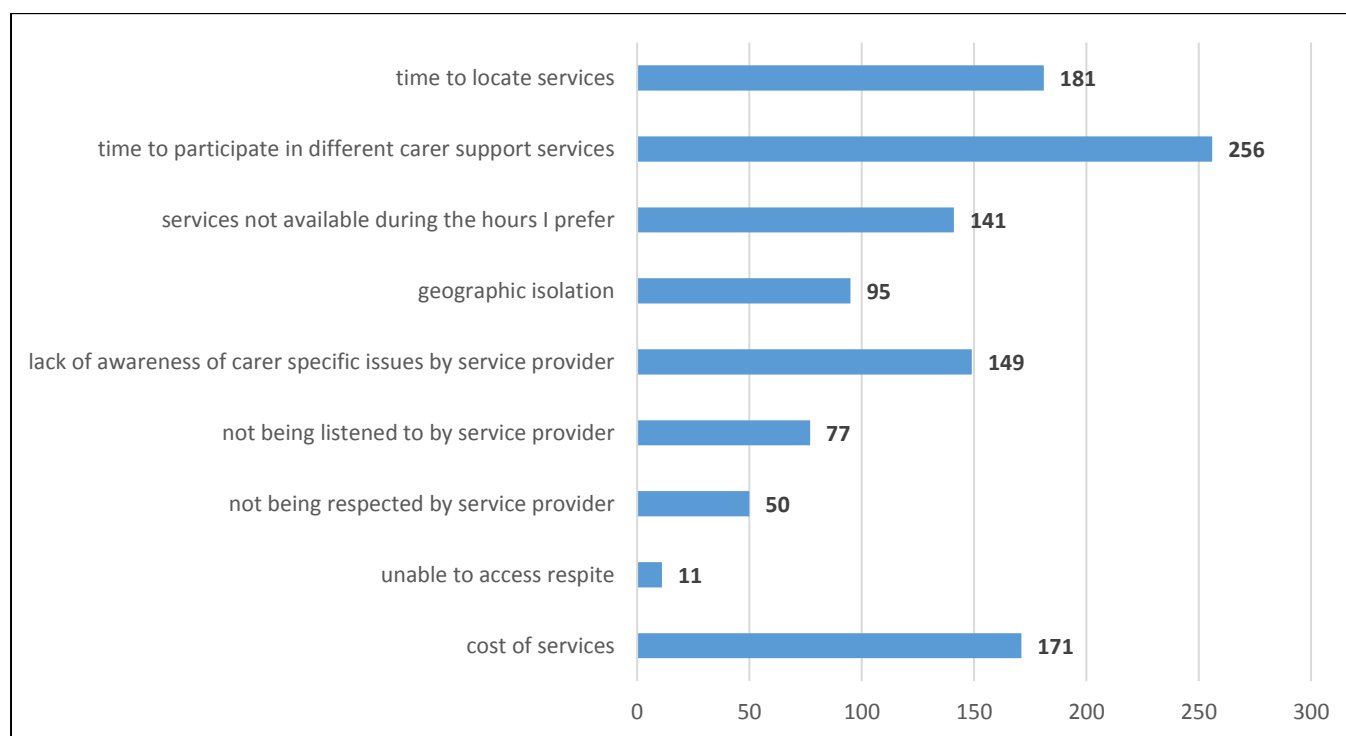
## PART 3. CARING CAN BE ISOLATING

Caring complicates relationships. Creating and maintaining connections with other people, who have an appreciation of the caring role and an empathy with the many consequences of providing care and support can be very difficult.

- Caring has cost me my health and my house, but my son needs me, he cannot cope without my support, and because I love him I continue to try and help him despite my own difficulties. No one is helping me, though because no one seems to recognise my suffering.
- It's tough working full time, doing all the mothering, the advocating, the fighting with the school, with well-meaning relatives, organizing therapists, attending appointments, and then trying to ensure I'm spending time with my other child.
- I feel undervalued and am considered unemployed by my family and society yet I work an average of 14 hours a day seven days a week and am still expected to do more.
- It is very hard having an elderly and ill husband (86 yrs.) and disabled son (52 yrs.) to care for although I have just found out about a lot of help I can access.

Accessing and utilising support services is not always easy for many carers and the people they care for and support for a multiplicity of factors including cost, availability, cultural fit, awareness and time.

GRAPH 14 – Barriers to accessing carer support services





Having the time and capacity to take time out of the day to make and maintain friendships is often dependent on accessing and securing respite and other support services. Carers who lack support, either through family and informal networks or via formal support services, become socially isolated and lonely. A significant commitment to improved access and affordability to quality respite services, would deliver a significant dividend to carers and the community.

*Of the survey respondents*

*53% use Carers Queensland's carer support services*

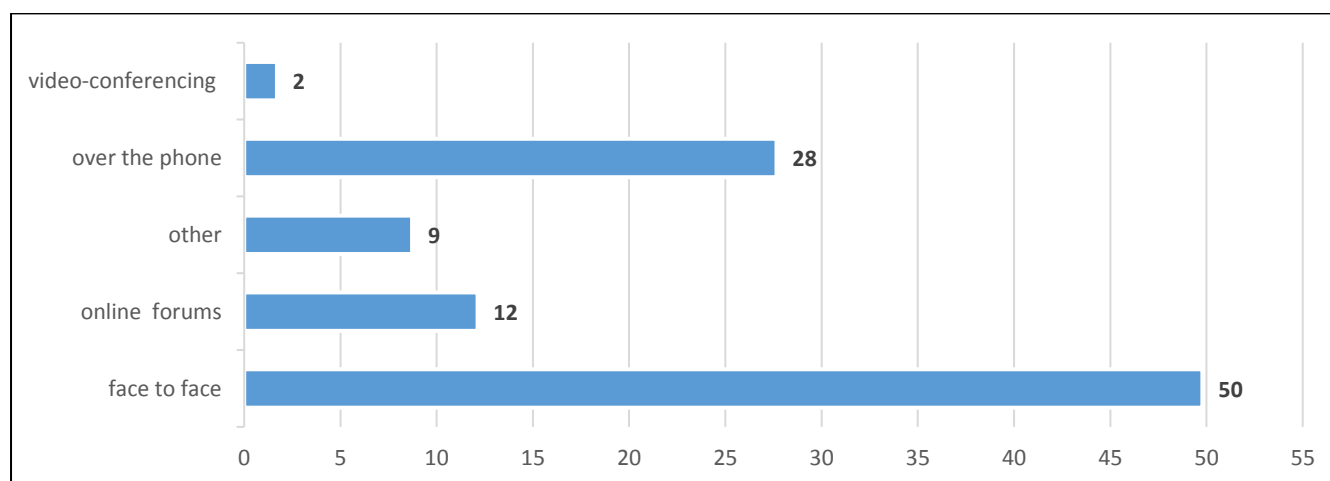
Understandably, carers look to other carers for connection and emotional support, often through carer support groups or online forums. Similarly, some carers seek out counselling to develop the skills to understand and interpret their circumstances and build resilience to manage the challenges of their caring responsibilities.

**TABLE 1 – Support service utilisation**

	once a week	more than once per week	once a month	a few times per year	less than once per year
young carer activities	0	1	3	9	13
carer retreats/group activities	1	0	17	43	74
online carer forums	28	33	21	46	31
respite services	34	61	19	35	58
counselling	10	1	48	92	139
information and/or referral	17	10	52	113	118

The unpredictability of the caring role often means that carers miss out on planned opportunities to engage in meaningful social relationships. Similarly, carers living in rural and remote Queensland may not have access to local carer support services and are dependent on digital technology to make contact with others.

**GRAPH 15 – Preferred communication methods**



## What we need!

- Emergency assistance back up. Services outside normal working hours and weekends. Reduced hurdles to affordable emergency, short term, regular and planned out of home respite. Including co accommodated, quality respite. Regular out of home respite in a quality facility. I care for four disabled young people, and they've never been able to be accommodated together.
- Respite that looks at the family as a whole not just the individual with a disability or frailty
- 24-hour counselling and over the phone support when feeling overwhelmed or not dealing with a caring issue and needing to talk to someone.
- Meet-ups at varying times so I can attend a few more and build up my social network. More activities to offer carers a break for a few hours
- Short breaks would be wonderful.
- Often simply a reassuring ear, with the understanding that there is genuine advice and helpful information available if needed.
- Somebody to listen and guide me when I feel out of my depth with legal issues and paperwork
- Time for self-care and leisure activities.
- Counselling
- Carer groups of different interests and hobbies and which may talk about confidence regarding employment.
- .
- Long-term counselling for myself to maintain my mental health while caring. Someone who listens with compassion rather than give me short term solutions.
- Future planning for when I am no longer able.
- A flying squad service which is available 24 hrs a day for when you just can't do it at that time. Like a 000 call for an ambulance, but for the carer, a service that comes to you, and cares for you AND the one you care for when in crisis.
- Re-entering the workforce programs - updating skills and linking to potential employers.

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