



## Quality of Life Audit 2018

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## FOREWARD

In Queensland today 474,300 people will provide unpaid care and support to a family member or friend with a disability, mental health problem, terminal illness, chronic medical condition or frailty.

All of us will have our lives touched by caring - 1 in 11 of us will become a carer at some point in our life and many of us will need care and support in our lifetime. Caring can be rewarding and bring about life affirming experiences, but without the right support it can have significant negative effect on the health, wellbeing, relationships, employment and social and financial inclusion of caring families.

Research supports what we know to be true: that the health and wellbeing of a carer worsens over time, and this is especially true when a carer lacks recognition within their community.

**Regrettably, 37% of survey respondents believe their role is not recognised within the communities and 51% are lonely some or most of the time.**

The stresses carers experience in their caring role can and do affect their subjective emotions and moods throughout the day and across multiples activities and roles, including those outside the caring role. **71% of survey respondents indicated that their mental health had suffered as a consequence of their caring responsibilities and 30% feel worthless some or most of the time.**

How best to support caring families to ensure their health and wellbeing is not as simple as instituting bigger and better support programs. In reality, the care relationship is a dynamic, complex dependency between two or more people, constituted and reconstituted in response to personal, social and political changes over time, some of which we have little capacity to control or influence. There are three trends essential to understanding the contemporary crisis affecting carers in Australia.

First, the demand on caring families is increasing as the number of older people in the population grows, and as we live longer, often with chronic and/or debilitating diseases or significant disability.

The second trend is the declining availability of publicly provided and managed support services and the corresponding increase in individualised budgets, necessitating in some instances, caring families adopting the budget manager, organiser and service coordinator roles in addition to supplementing support provided by formal services.

The third trend involves conflicting public policies - such as policies encouraging women (who are the majority of working-age carers) to work and assume caring responsibilities without recourse to statutory safeguards to request flexible employment options or adequate community based services to provide the necessary support.

Accessing services is not always easy, and for some in our communities there are additional barriers to be negotiated. Many people in the lesbian, gay, bisexual, transgender and intersex (LGBTI) communities for example, are reluctant to access services, or have accessed services only to be disappointed at best or discriminated at worst, tacitly reinforcing their fear of marginalisation. **3% of survey respondents fear discrimination from service providers, either for themselves or the person they care for and support.**

There is a plethora of research about carers, exploring the consequences of caring on the individual and the family. Much of this research highlights the long term social, economic, physical and psychological costs of providing care and support. This year's survey supports existing data and suggests that at the individual level, many carers operate in crisis mode – battling to balance work with caring, or of having insufficient funds to purchase the basics. **38% of survey respondents struggle to maintain a healthy diet.**

Whilst many carers reflect on the rewarding and enriching aspects of providing care and support, many also share with us their reality. A reality of never having enough time or money, of the difficulties of trying to stay healthy when there is insufficient money and time, of learning to negotiate the health, disability, community care and education sectors, of asking for help and being rejected or being ignored.

Carers Queensland remains committed to supporting all carers through robust advocacy to all levels of 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 for all 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 grumpiness, 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 brain 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 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, housing 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 money you can access counts when things go wrong
3. get involved in 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 give you 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 and organisational policies and planning processes 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 through the regional offices and electronically through the Carers Queensland website.

Each year since 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 5,923 individuals known to Carers Queensland, promoted through our Facebook pages and newsletter, *Together* and was available in paper format at each office.

This year the thematic questions explored *why we care* and the related subjects of recognition and support, loneliness and social isolation. We received 467 responses of which 455 were from current and former carers who reside in Queensland.

## PART 1. PERSONAL DEMOGRAPHICS

### 1.1 Respondent Demographics

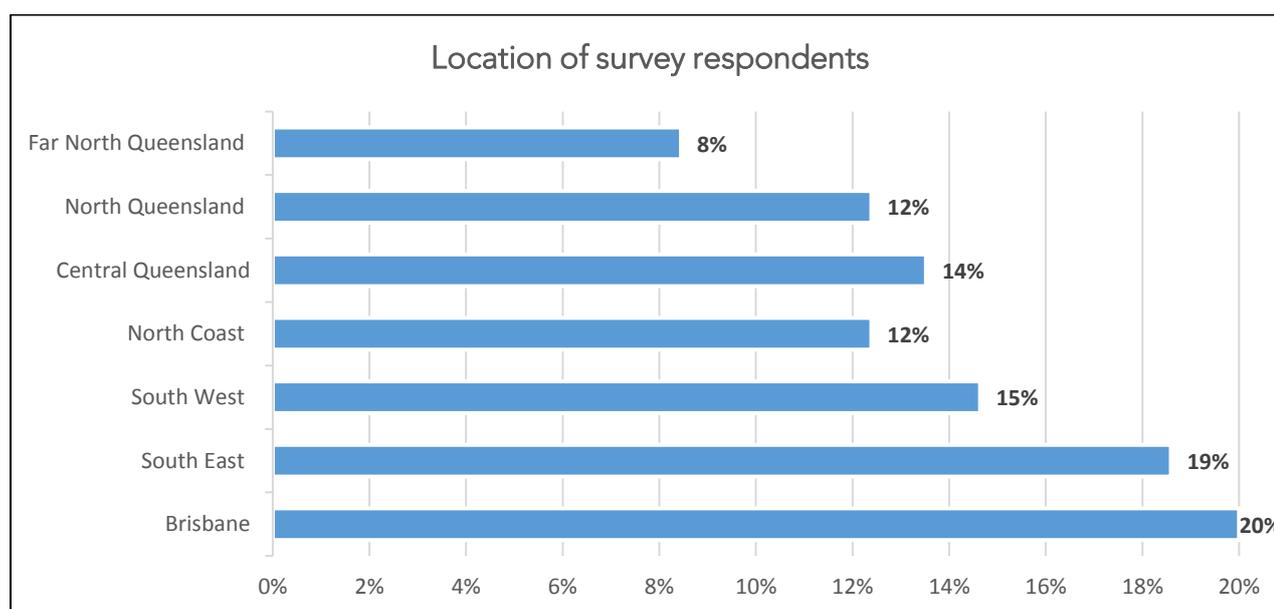
The 2018 responses closely reflect the 2017 survey responses across the personal demographic domains.

Of the respondents:

- 96% speak English as their first language
- 5% identify as Aboriginal and Torres Strait Islander
- 94% are the primary carer
- 91% are a current carer
- 83% are female
- 24% are single
- 1% are young or young adult carers
- 60% provide 12 or more hours of care and support per day
- 3% are attending school or other educational institution
- 32% are retired

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.

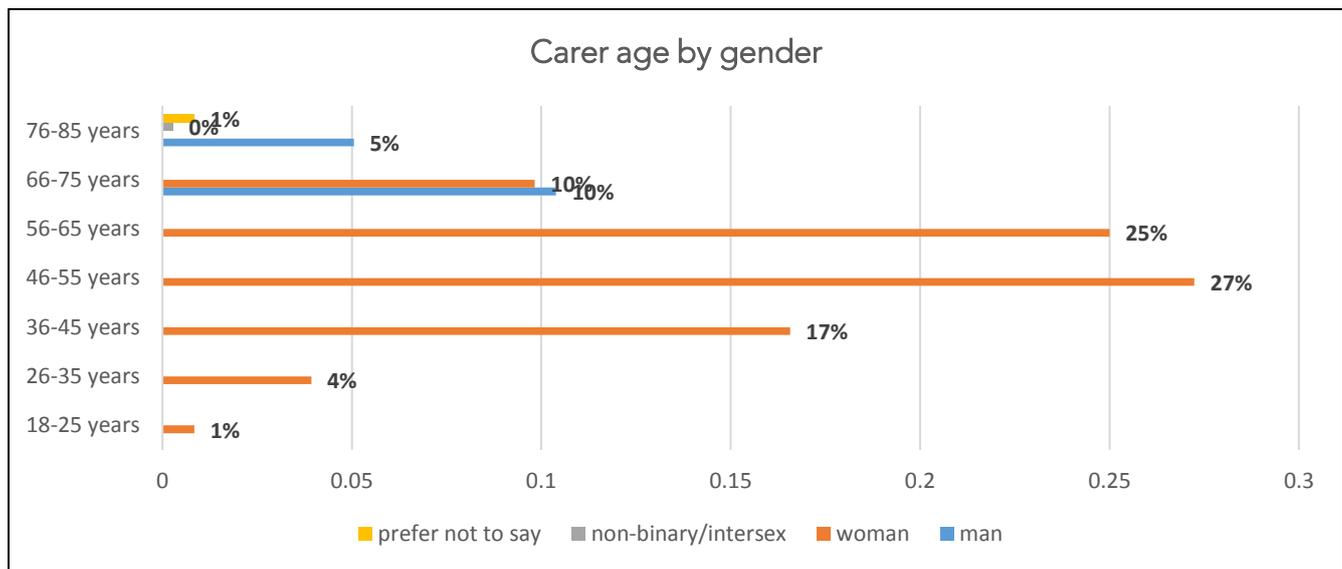
GRAPH 1



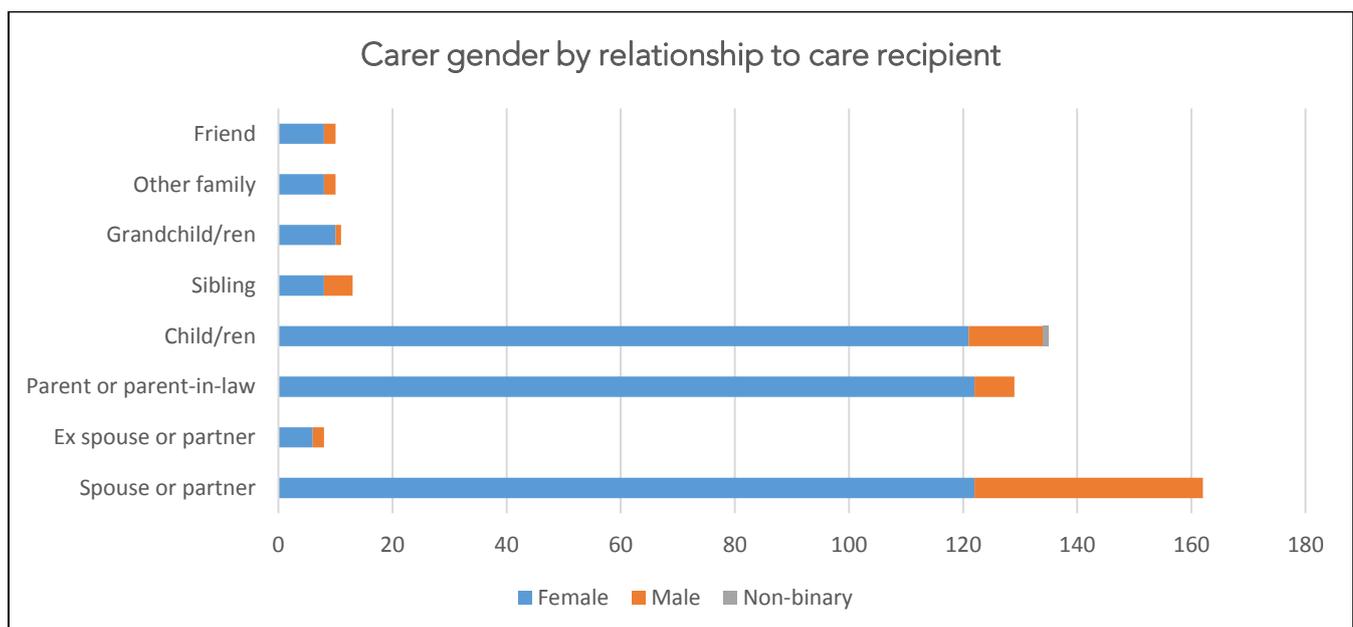
The age and gender profile of the survey respondents closely reflects the national and state profiles.

- 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



GRAPH 3



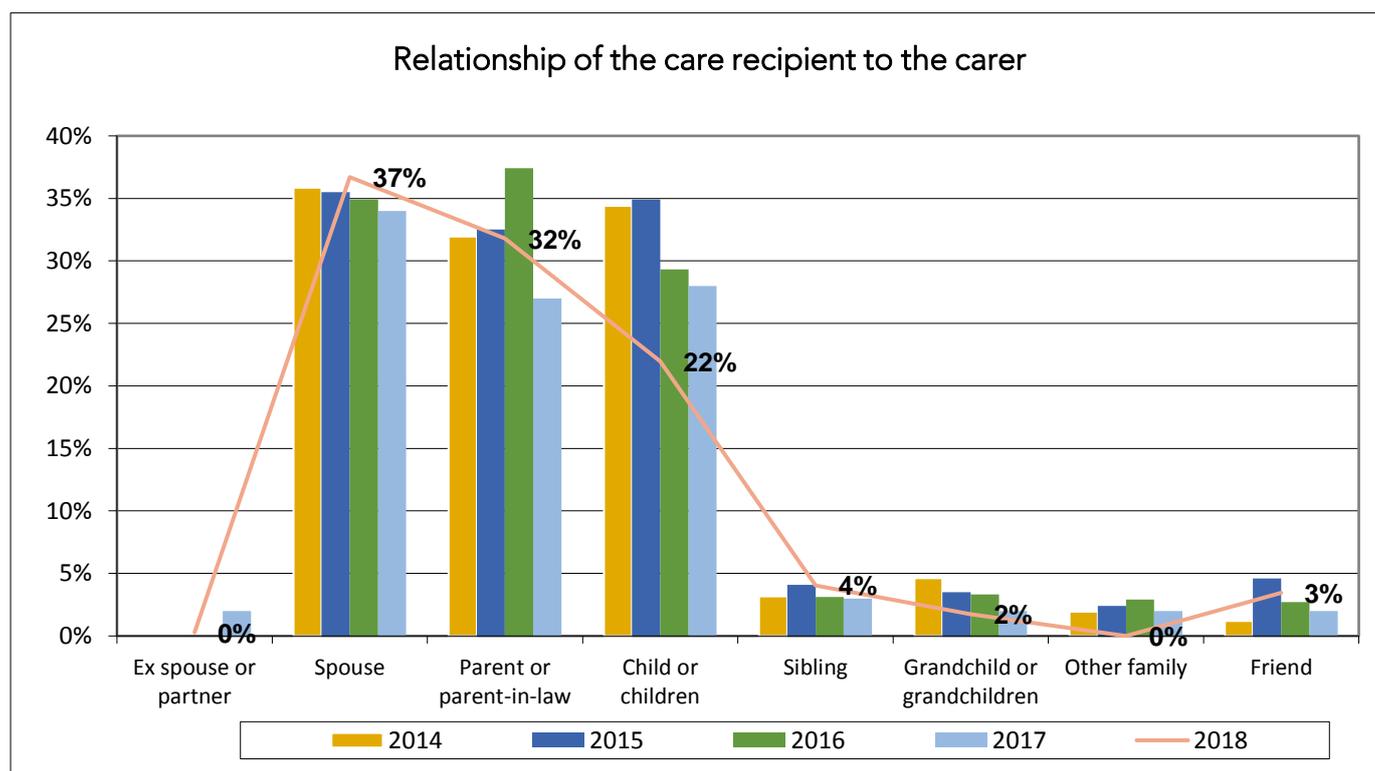
Analysis of the carer population highlights that people who are married or in a committed relationship are overrepresented against the general population. This reflects the most common carer relationship – that is where one spouse provides care and support to the other spouse.

*63% of survey respondents are married or in a committed relationship*

*14% LGBTI carers care for a spouse or partner*

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

GRAPH 4



## 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 support services 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 at the right time, carers suffer from physical and emotional exhaustion, anxiety, loneliness and exclusion.

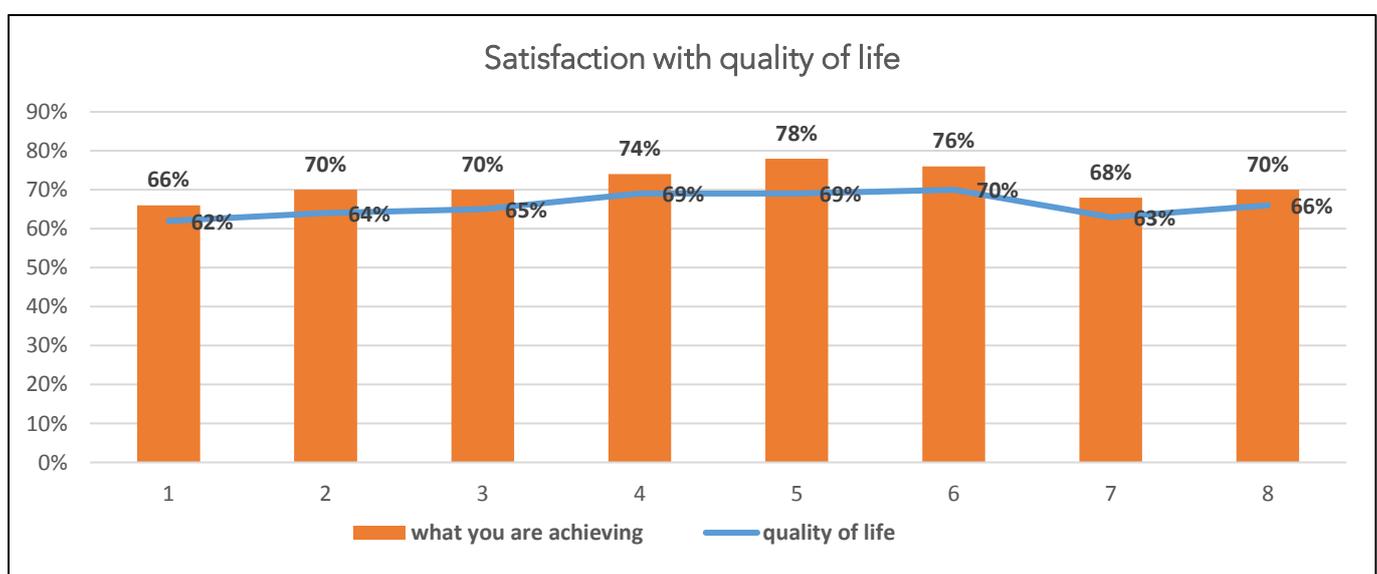
*Of the survey respondents:  
22% believe their quality of life will worsen and 54% expect it to stay the same over the next year.*

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 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 access to the appropriate support services at the right time, caring families will continue to experience lower quality of life than other population groups.

GRAPH 5



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*I love my son and am proud to be able to support him in his day to day activities. But I am heading nowhere. Every day is washing and cleaning and making beds and vacuuming and then it starts all over again ... oh and running my son to where he needs to go ... I'm heading nowhere.*

*I care for my husband who has a major illness and my father and his wife who live three houses up the street. Dad is frail-aged and cannot do anything for himself – even getting a drink of water. His wife has dementia. My time is taken up caring for them all, housework, shopping, doctor's appointments etc. No time for me. I am so tired I just want to sleep forever.*

*I have no life and no money to do anything with if I had a life. I constantly live by my diary...appointments, support workers, medication, reports, therapy.*

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## 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.

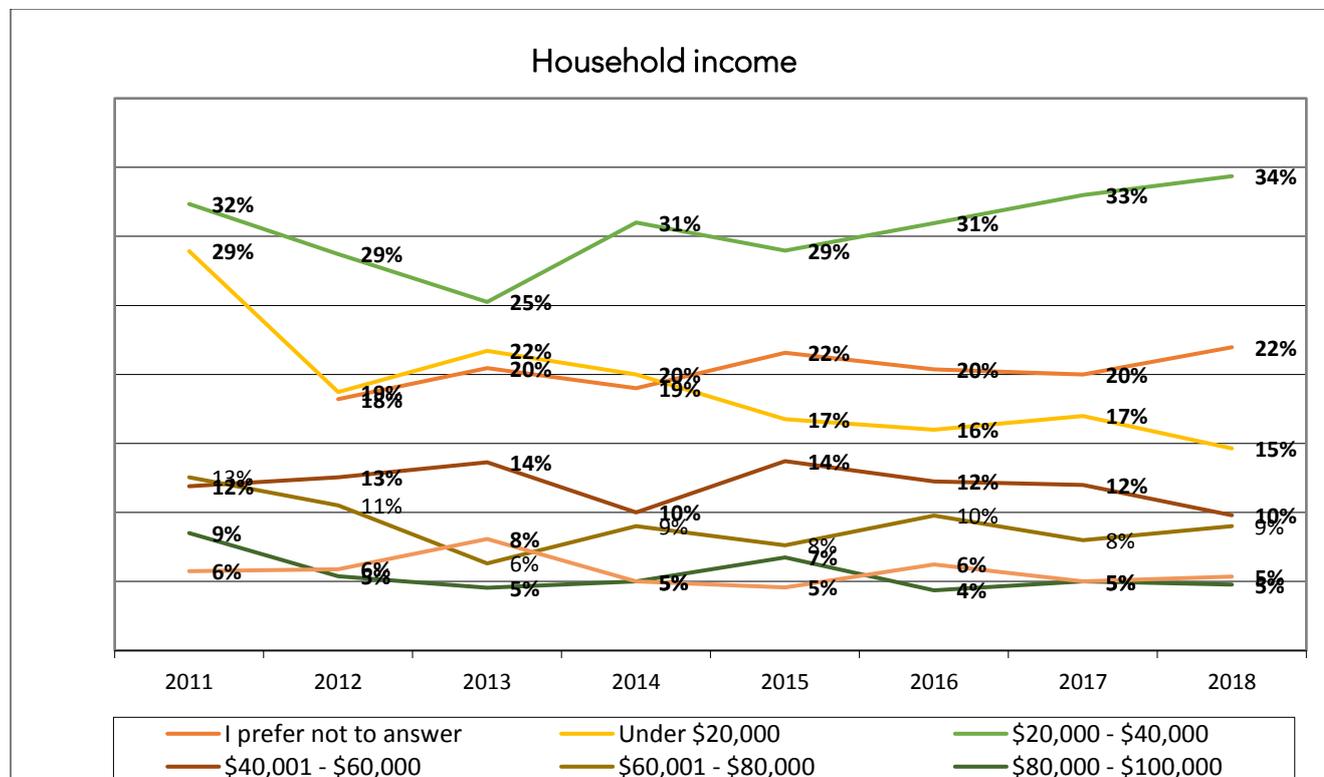
Excessive inequality is harmful. When people on low incomes and wealth are left behind, they struggle to reach socially acceptable living standards and participate in society. The nation's economic growth is diminished when people are too impoverished to participate effectively in the workforce or acquire the skills to do so.

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

*49% of survey respondents live in a household with a combined income of less than \$40,000 per year*

GRAPH 6



*73% of survey respondents experience stress or anxiety related to their situation*

Data analysis over seven years reveals that whilst the wellbeing of men is highly linked to earning money, the wellbeing of women is highly linked to the capacity to manage it. Further, the research indicates that carers are almost twice as likely as normal to worry that their income will not be sufficient to meet their expenses, the result of which is a lower 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.

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

Food insecurity, it is estimated by Foodbank Australia, affects 3.6 million Australians. Food costs should, ideally, take up about one-fifth to one-quarter of the household income, but with the recent welfare reforms and wage stagnation some households would need to spend 30-48% of the household income to buy nutritious food.

*Of the survey respondents:*

*60% are satisfied with the ability to maintain their housing and purchase goods and services*

*38% struggle to maintain a healthy diet*

*In Queensland:*

- *the median total personal income is \$34,320*
- *the median household income is \$86,372*
- *the median rent for a 3 bedroom house is \$350.00 per week*
- *the average weekly income is \$1,534*

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. Focussing on 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 7



Wealth is the key to many life opportunities. Wealth primarily accrues from past income and contributes to future income. It can boost income and sustain people no longer working by generating investment returns. High levels of wealth inequality can deepen and entrench overall inequality. Like income inequality, wealth 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%.*

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*The cost of everything goes up but the carer allowance is \$127.10 per fortnight 😞*

*I have some money left from the forced sale of my house and some from permanent disability insurance but once that is gone I am totally financially screwed. I have no superannuation to look forward to in my old age and the money I have now has to last me until I die. I am 55.*

*We were evicted the day before Christmas and were about to live in our car. A wealthy uncle stepped in unexpectedly and saved us from this disaster. I rang all available services at the time and none of them were able to help us. Frightening reality.*

*I worry that we will be homeless in a year or two.*

*Just scraping by does not give you quality in your standard of living. It's a marathon of hurdles. As you scramble over one, two more are in your face. It is exhausting, stressful and unrelenting.*

*We struggle but we live well enough. Our furniture is mostly second hand, we buy our clothes mainly from op shops but we have a roof over our head and food in our bellies. We have no savings but we have a car that goes and can meet our bills.*

*My current financial situation is not in a good way, therefore my family's quality of life is suffering!*

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## 2.3 Satisfaction with elected and non-elected leaders

Australian Centre on Quality of Life research reveals that our satisfaction with elected leaders fluctuates in response to external situations. Our satisfaction rises during times of national threat and diminishes when there is political instability.

Many respondents consider their elected and non-elected leaders have failed to act on their concerns and issues from one election to the next. Some respondents have been negatively impacted by the changes to Australia's social welfare policies or overwhelmed by the speed and complexity of change in the disability, aged care and mental health sectors.

In 2017, social researcher Hugh Mackay, suggested that the economic and social picture in Australia was 'somewhat gloomy' and reflected in the palpable decline of voter esteem for politics and politicians. Sadly, Mackay's assessment of this last 12 months is no different to the previous year. In his assessment, people are feeling actually worse off than they were a few years ago. Business confidence may have increased but consumer confidence is sluggish due to wage stagnation and inadequate and increasingly conditional welfare payments, resulting in rising inequality and a persistent sense of helplessness.

*Of the survey respondents 63% are either dissatisfied or ambivalent about the quality of the elected and non-elected leaders, a rise of 5% over the year.*

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*I think politicians could fight for those struggling on the fringes a little harder.  
Politicians seems to have lost its sense of social justice.*

*I want leadership that is committed to more social housing, support and opportunities for people with disabilities and mental health issues and the people who care for them.*

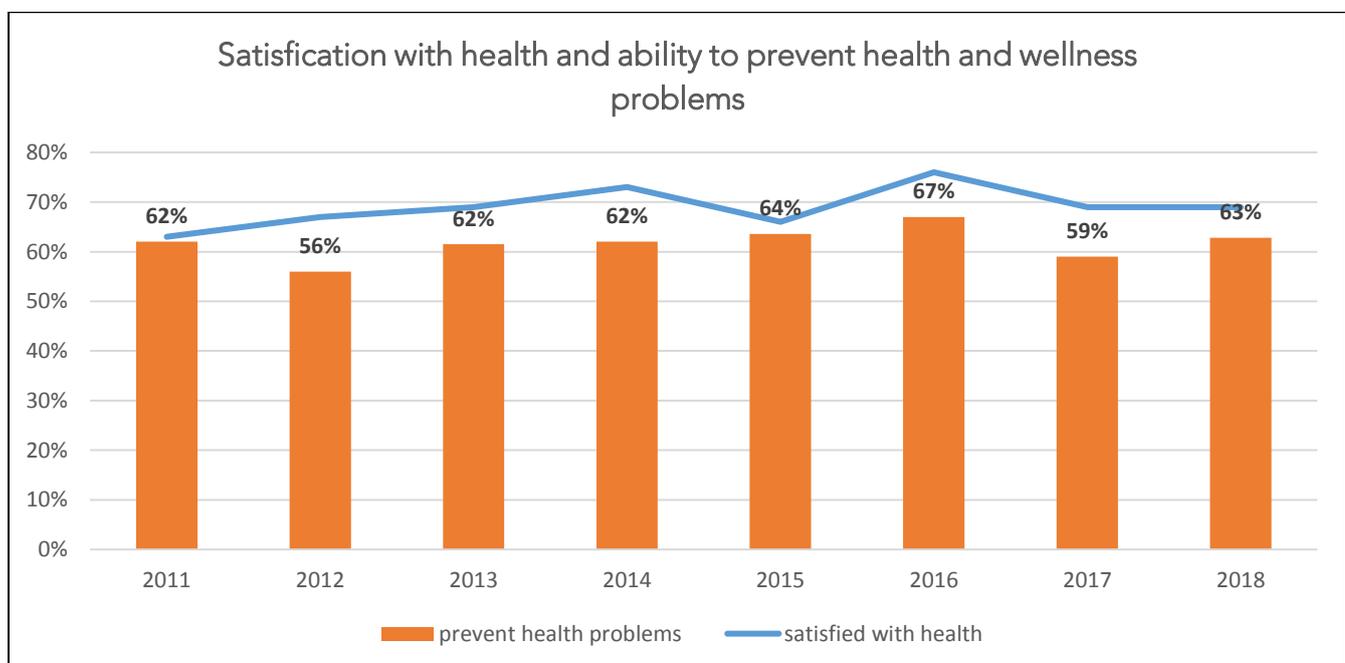
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## 2.4 Health and wellbeing

People with a higher socioeconomic position in society have a greater array of life chances, more opportunities for a flourishing life and they also have better health. That is because the two factors are linked: the more favoured people are, 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. Health inequalities result from social inequalities. Addressing health inequalities requires action across all the social determinants of health such as educational opportunities, housing, the environment, income and wealth, and social inclusion etc.

GRAPH 8



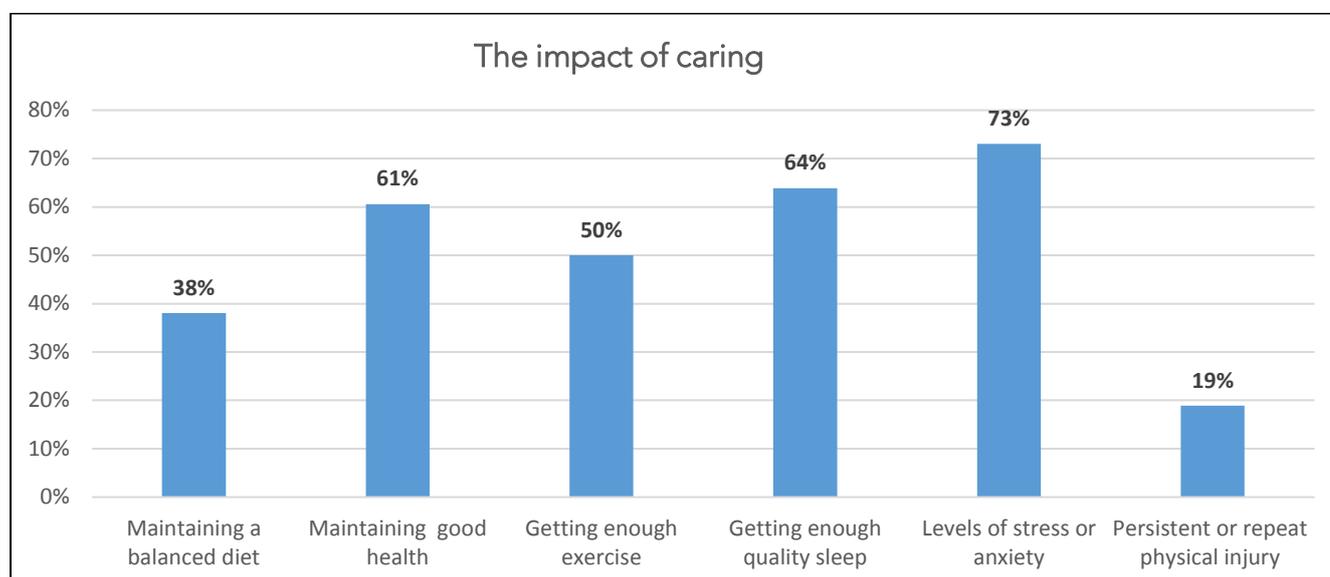
It can be extremely difficult for carers to find the money, time or the energy to look after their own health, activities such as preparing healthy meals, exercising, getting enough quality sleep or seeking medical attention. In the short term, the consequences of such actions are limited but over the 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:  
71% indicated that their mental health and 56% their physical health had suffered as a result of their caring responsibilities*

GRAPH 9



The 2018 Quality of Life data, like data from previous years, indicates that many survey respondents:

- prioritise the health care needs of the person they care for and support before their own, often at the expense of their own health and wellbeing.
- who live in rural and remote Queensland continued to identify a 'double whammy' – long delays for an appointment and expensive travel costs.
- are impacted by 'treatment burden' – that is trying to coordinate appointments with multiple health and allied health practitioners and/or complying with multiple treatment regimes, often at different places and requiring extra travel and parking costs.

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*Living regionally means health services are minimal and some services don't exist at all. I have to travel long distances to access my specialist. Other services I use are also a 1500km round trip. Travel is expensive and only a small portion is claimable, if at all.*

*As a full time carer my needs come last. I find it hard to prioritise my health needs and take the time and effort needed to look after my health. I'm run down, mentally and physically exhausted. I consider myself a person with great inner strength but it has been tested multiple times. It can get very lonely and hard.*

*As I age I get needier of rests. I physically manually handle my 21 year old son and I am getting tired. I would love to take two days away from manual handling but have to accept that this is not possible as we have never been apart. No extended family, no support from outside other than the day programs. As I move towards old age I hope he passes away before me.*

*I am completely housebound and burnout after being a carer for my mother, husband and daughter. My mother and husband have now passed away, but looking after all three at the same time has left me incapable of paid employment and with depression and anxiety.*

*I neglect myself to make sure my child has what she needs.*

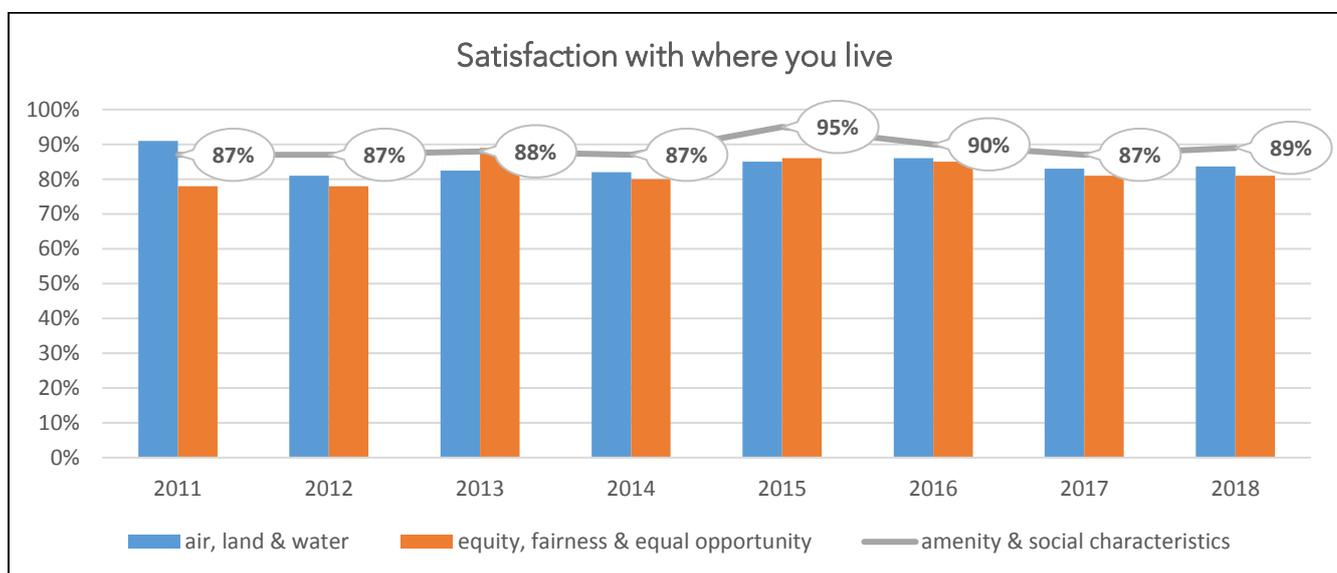
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## 2.5 Connecting with others in the community and personal relationships

Communities are important for physical and mental health and wellbeing. The physical and social characteristics of communities, and the degree to which they enable and promote healthy behaviours, make a contribution to the social inequalities in health.

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 10



The world shrinks for many carers. The caring role takes over, the days and the weeks become structured around completing the myriad of tasks that need to be done to ensure the happiness, safety, health and wellbeing of the family member or friend. Friendship may diminish or disappear particularly if the carer has given up work. Invitations to social functions or to participate in group activities can taper 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 those who have cared for a long time can become socially isolated and lonely - seeing and speaking with only a few people or seeing only 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
- 200,000 people over 75 years had not had a conversation with a relative or friend in over a month.

Of the survey respondents:

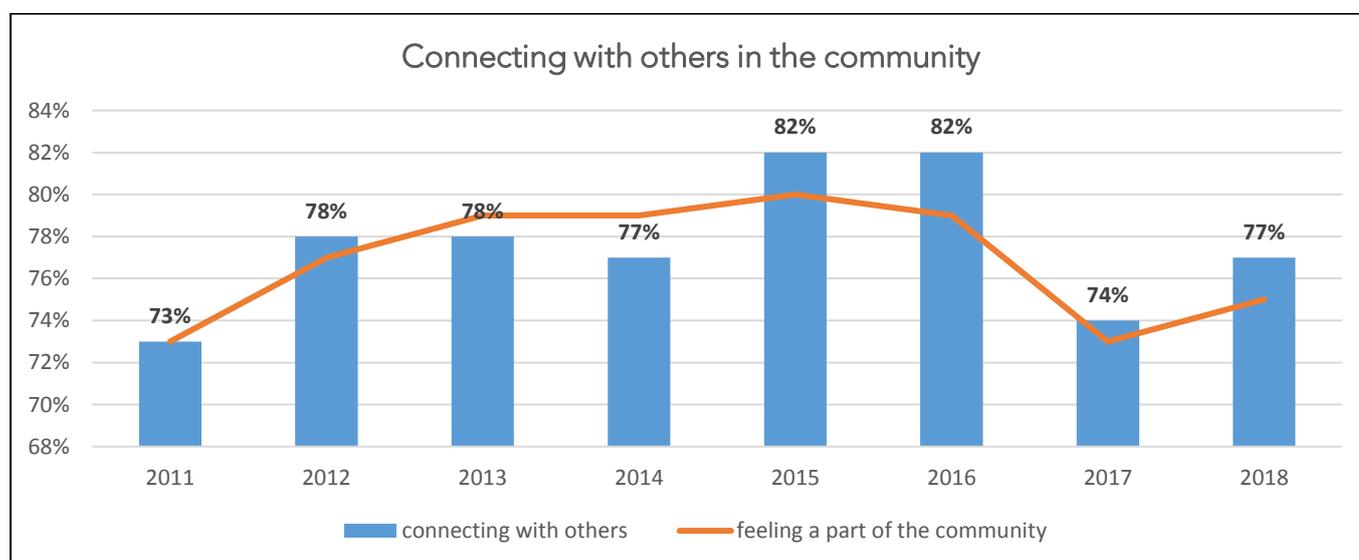
51% are lonely some or most of the time

54% are socially isolated some or most of the time

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 11



Making connections and staying connected 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 of that they will experience stigma. Young carers, for example, may feel ashamed to bring friends home or may want to protect their family from prying eyes by shielding the family from outsiders.

The assumption that caring is 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.

*Of the survey respondents only 30% say their caring role is recognised and valued in their community.*

Recognition of the carer role varies with the age of the carer. 33% of the young carer respondents perceive that their role is recognised some or most of the time. This recognition is very much lower in the working age group and increases to 42% in the 66-75 year cohort and 76% in carers over 75 years of age.

*Sources of Emotional Support -  
36% from immediate family  
24% from the GP or other health professional  
22% from counsellor or psychologist*

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 and 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 changes 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.

*38% of survey respondents are dissatisfied or ambivalent about their personal relationships*

The caring role is often accompanied by guilt. The guilt that arises from seeing family roles and relationships disrupted and from having insufficient time or energy to devote to family activities or the money and other resources to participate in other activities like holidays, further education or celebrating significant events etc.

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*There are times caring is extremely isolating. Exhaustion can make arranging respite just another tiring task to arrange, therefore you need to muster up the energy (from somewhere) to find out the options and make the arrangements and that doesn't happen because it's just another thing to be done and too hard. It can be difficult to put time aside for yourself.*

*It's really hard. I care for my husband, who has MS. I never know what he is going to be like from one day to the next. I always put his needs before my own, but that's my choice. However, I have given up a lot of things I use to do, just so I can give him the best care I possibly can. I also found out who my real friends were and unfortunately, I have lost a lot of friends because of becoming a carer.*

*I am unable to work and hence I get very little interaction with peers. I have become anxious and now lacking in confidence when engaging with others. I feel I have little value to society when my life has become defined as only a carer and even when I write these things I feel a strong sense of guilt. Financially I am very limited. My wife works (because she has the higher earning capacity) but I have had to cash in my superannuation so that we can maintain the home and fix things that were falling apart. I feel like I now have no future, that my life is spent and there is no hope of bettering anything and I get sad when I think of what will become of our son when we are too old to care for him ourselves.*

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## 2.6 Educational opportunities, safety and future security

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

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 lower self-esteem and happiness.

*Of the survey respondents:*

*26% have full or part time employment*

*7% are unemployed and looking for work*

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

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.

*Of the survey respondents:*

*60% provide 12 or more hours of care per day*

*19% provide 6 to 12 hours per day*

*Of the survey respondents:  
37% are dissatisfied with their ability to access educational and learning opportunities*

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.

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*I would love to study and further my career - but it is hard to juggle caring and Centrelink's 25 hour policy. I do worry about what will happen once my partner passes - I will be much older and not qualified and with no superannuation.*

*I live in the country and there is no local access to TAFE or university and no public transport either. Worse, I care for a disabled child and cannot get childcare so I cannot drive to the nearest regional town to study or get work placement.*

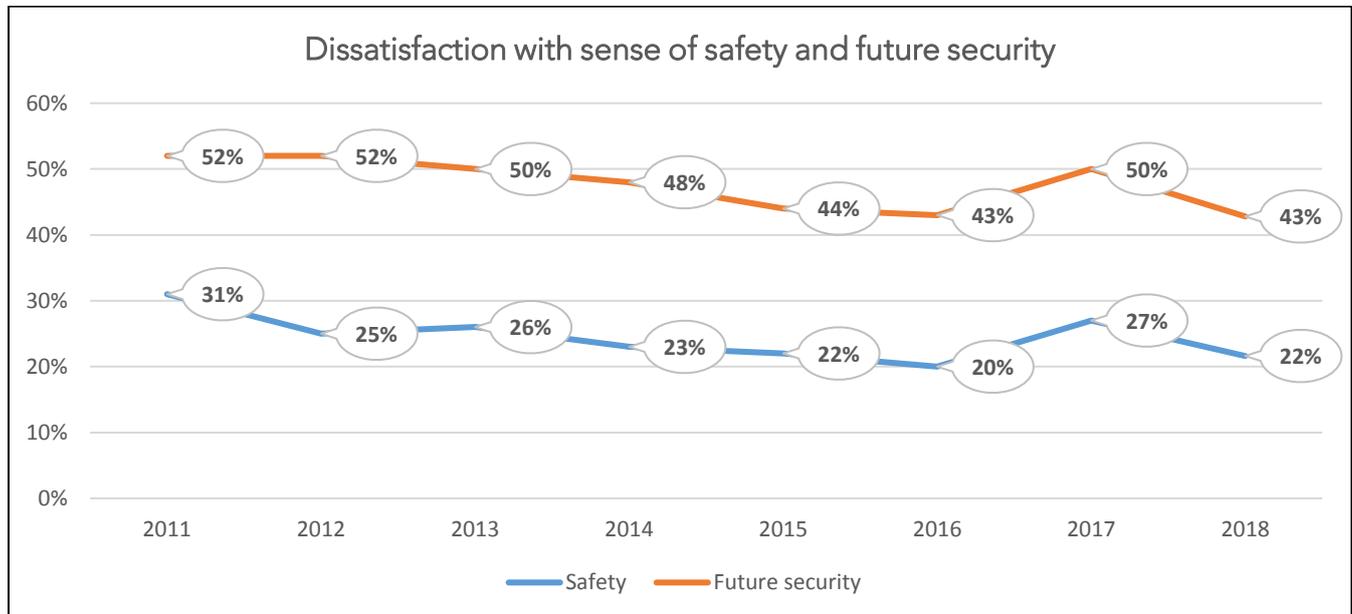
*My partner finds it hard to maintain employment and has lost six jobs this year due to having to take time off.*

*I cannot return to work even part time as I cannot get childcare. No-one will care for my grandson due to his complex needs. Finances are extremely low and I am a single grandparent carer, so my capacity to turn around my situation is almost non-existent.*

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Many caring families fear threats of violence or abuse within the caring relationship and outside the home on a regular if not daily basis. Research suggests that approximately 30% of carers will experience real or threatened abuse within the caring relationship.

GRAPH 12




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*Our daughter can viciously attack us at any moment. She's strong and often injures herself and us.*

*Constant criticism, verbal abuse and occasional threats to physically harm including a few instances of minor assault and sexual coercion. Living on eggshells.*

*My husband has dementia, which is affecting his logic and he gets verbally abusive at times which concerns me in case it becomes physical.*

*He is twelve now and has already tried hitting me and is regularly violent at school. I fear for the future.*

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Similarly, many caring families feel unsafe in their community or fear the future – of not having enough money to fund their retirement or the ability to continue to provide care and support.

For many caring families the necessity to talk about and plan for the future is so daunting it does not happen. Once again, the survey highlights the issue of future planning.

*70% of survey respondents have made no arrangements for the provision of ongoing care and support when they can no longer manage.*

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*Never feel safe from my mind. And terrified most nights to even leave my house for fear of my safety.*

*We live in a bad neighbourhood so I am always checking doors and hiding keys. I do get worried when I pop out to the shops and have to leave my partner at home – we have back-up plans for our back-up plans but I still worry that there might be a fire or something.*

*I haven't worked for years now and the DSP is not enough to live on let alone have a future security. I will have to rent a room in my old age or live in a caravan...unless I have a miracle. It is very depressing for a high income person who had huge retirement assets that were wiped out.....*

*I have no future security. My superannuation has gone into looking after the children. I hope to find a way to fund my old age or hope not to live long enough to be a burden on anyone.*

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## PART 3 WHY DO I CARE?

### 3.1 Why do I care?

It may happen as the result of an unexpected or traumatic event (accident or major health crisis) or it may evolve over a period of time. It is not uncommon for carers and caring families to feel that they didn't have a choice about whether or not to assume the caring role. They provide care and support because of cultural expectations, the lack or cost of formal services, geographical isolation or the fear of discrimination or retaliation. The motivation to adopt the caring role or to continue the caring role can change over time and is dependent on the health of all parties, the ability of formal service providers to provide culturally safe and inclusive services and the ability to pay.

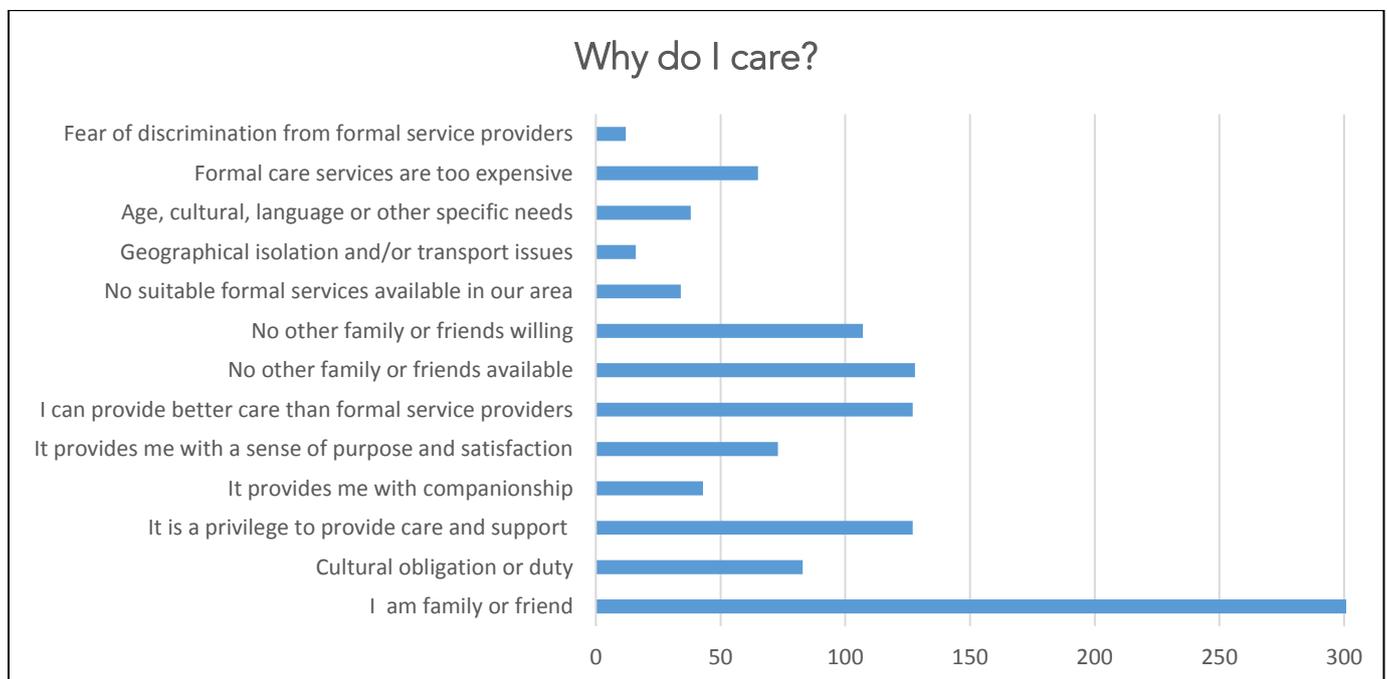
*Of survey respondents*

*83% provide care because they are family*

*3% fear of discrimination*

*18% cost of formal support services*

GRAPH 13



## Why do I care?

*According to Plato, Socrates explained that a life well lived was righteous, pious without deception (particularly of the self) and I agree. I want to know that I have done my personal best to support my family members to the utmost of my ability, to live my life without guilt or regret, to be fulfilled by the things that I do on a deeper level than one of personal comfort.*

*I am a carer because I have been one since I was 10 and from there the responsibilities just grew. And as a result of living with this for most of my life, my brain is conditioned to care for others; and can range from just being the listener in the friend group, to outright being a carer for my partner/best friend. The only way I find purpose in my life is my helping others but at the same time, I put so much of myself into caring for others that I lose myself into it and it majorly deteriorates my health and well-being. I care because if I don't then my suicidal best friend will die and my dysfunctional family will fall apart once again.*

*Before my partner was disabled, I ran a volunteer marine rescue unit in a very remote area. I found that saving lives was in a sense a form of redemption for harm I may have done to others in my life. I have always had a sense of empathy with people needing help so when faced with a caring role for my partner I was able to put aside my life to do the best I could for her to regain some quality of life. I was old enough and had lived enough life to accept the role. I fully understand how much harder this would be for younger people, I don't know if I could have made such a sacrifice when I was younger. Selfishness is a natural part of the nature of our species and is a part of our survival instincts. How much a person can overcome that instinct is not something you can quantify for it is dependent on so many factors of your existence and the makeup of your character. I care, simply because I am capable of caring.*

*I care for my children because they need support. I love them dearly and would do anything for them, even though this has meant putting their high needs before my own. My caring role would be easier with extra support, but until that eventuates, I will be there for them.*

*I grew into the caring role, not really knowing what I was getting myself into. It was normal to look after my wife. Then the challenges grew and with each one I'd think I can't do this or I can't do this anymore or my back's too bad for me to be doing this, but it wasn't in my nature to give up...and there was no one else here to do it.*

*I'm the one who walks in when the rest of the world walks out.*

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