



**CARERS QUEENSLAND LTD.**

**QUALITY OF LIFE AUDIT 2017**

**September 2017**

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## FOREWORD

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

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 a carer's health, wellbeing, relationships, employment and social and financial inclusion.

Longitudinal studies support 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 support, time and financial resources. The stresses carers experience in their caring role can and do affect their subjective emotions and moods throughout the day and across multiple activities and roles, including those outside the caring role.

How best to support carers 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 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 family and friend carers 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, carers adopting the role as budget manager, organiser and coordinator of services 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.

Research conducted by Carers Queensland in January highlighted that many in the lesbian, gay, bisexual, transgender and intersex (LGBTI) communities are reluctant to access services, or have accessed services only to be disappointed at best or discriminated against at worst, tacitly reinforcing their fear of marginalisation. Many LGBTI carers and the people they care for and support will consequently suffer poorer health outcomes. Recognising the need for better data on the quality of life of LGBTI carers, the Quality of Life Audit now incorporates new demographic fields. Over time, with more data, Carers Queensland will be able to build a comprehensive picture of LGBTI carers and use this information to inform strategic planning and service delivery.

This year's data sadly replicates the data of previous years, suggesting that, at the individual level, many carers operate in crisis mode – battling to balance work with caring, learning to manage individualised budgets, of having insufficient funds to purchase the basics. Sadly, 27% of survey respondents indicated that they believe that their quality of life will deteriorate over the next 12 months, an increase of 3% from the 2016 survey.

While many carers reflect on the rewarding and enriching aspects of providing care and support, many others share with us the harshness of 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 learning to renegotiate their relationships with family and friends, of asking for help and being rejected or being ignored.

Many carers described the difficulties of gaining respite from their caring role – either because of a lack of suitable options, cost or other barriers, including the care recipient not understanding their carer's need for the occasional break.

Carers Queensland remains committed to supporting all carers through robust advocacy to all levels of government and industry, seeking to secure carer-positive policy changes and system improvements, and additional funding for tailored programs that will improve the quality of life for all carers throughout Queensland.



Signature of Jim Toohey

**Jim Toohey**  
**Chair**  
**Carers Queensland Board of Governance**



Signature of Debra Cottrell

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

## INTRODUCTION

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. It also enables social scientists to identify those groups in the population, such as carers, who have lower quality of life and in turn how best to assist people with lower wellbeing.

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. The term "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 while 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 keep 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.

Those carers most at risk of lower wellbeing

- 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 you 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.
6. Keep healthy – staying healthy is all about balance.

## 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 carers and the people they care for and support. The survey acts as a barometer, measuring and reflecting the changing mood of Queensland's carers as they adapt to significant changes in the disability, mental health and aged care sectors and in social welfare policy.

### Methodology

The 2011 Liveability Audit formed the benchmark estimate of the quality of life of carers in Queensland. Issued as both a paper survey through the regional offices and electronically through the Carers Queensland website 575 carers completed the survey.

Launched on 1 September 2012, the Audit replicated the 2011 survey with only minor changes to the 'personal demographic' questions and resulted in 480 responses.

In 2013, we introduced a new component to the survey, six questions relating to a specific issue affecting carers. This year's questions related to carers experiences of being 'prepared to care'. 485 respondents completed the quality of life questions.

Launched on 1 August 2014 we introduced a new quality of life question; *in the next year do you expect your Quality of Life to: get better... worsen... stay the same*. 436 respondents completed the quality of life questions.

In 2015, the six thematic questions broached the very challenging subject of abuse and violence in the caring relationship. 571 respondents completed the quality of life questions.

In 2016, the thematic questions captured the extraordinary number of hours carers provide in supporting family and friends. 481 respondents completed the quality of life questions.

In 2017, promoted through our social media platforms and emailed to 6133 carers known to Carers Queensland, this year's thematic questions captured the extraordinary number of hours carers provide in supporting family and friends and the impact of caring on the individual's physical and mental health. 542 respondents completed the quality of life questions.

## PART 1 PERSONAL DEMOGRAPHICS

### 1.1 Respondent demographics

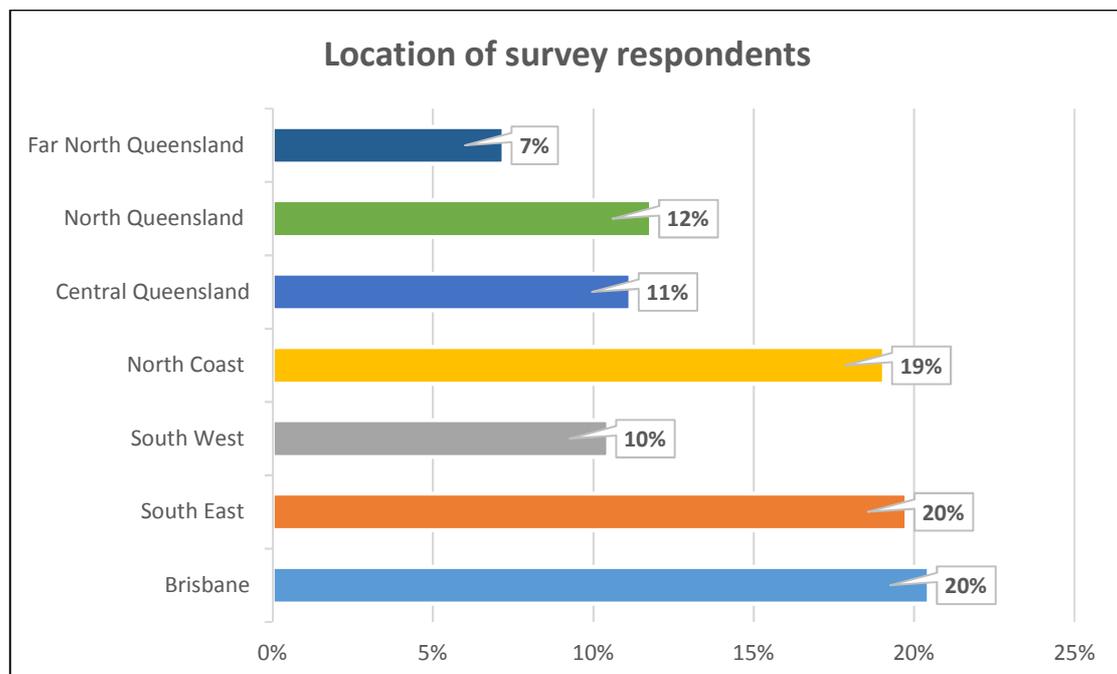
The 2017 responses closely reflect the 2016 survey responses across the personal demographic domains.

Of the respondents:

- 98% speak English as their first language
- 4.18% identify as Aboriginal and Torres Strait Islander
- 94% are the primary carer
- 92% are a current carer
- 84% are female
- 12% are single
- 2% are young or young adult carers
- 65% provide 12 or more hours of care and support per day
- 2% are attending school or other educational institution
- 35% are retired

The geographic distribution of survey respondents closely reflects the state profile. The 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.

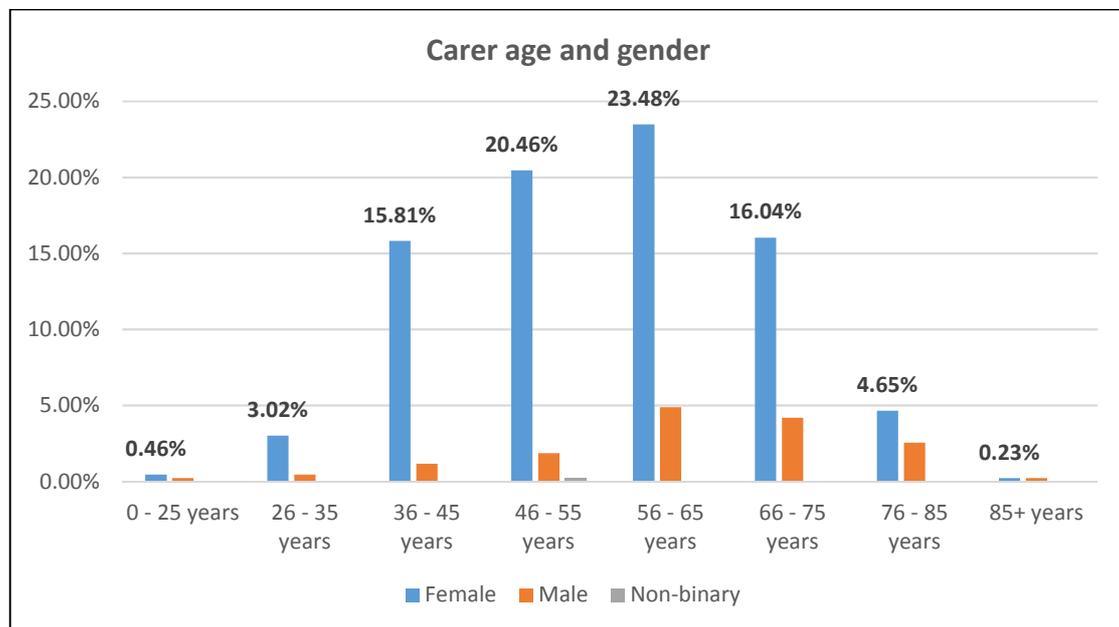
**GRAPH 1**



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

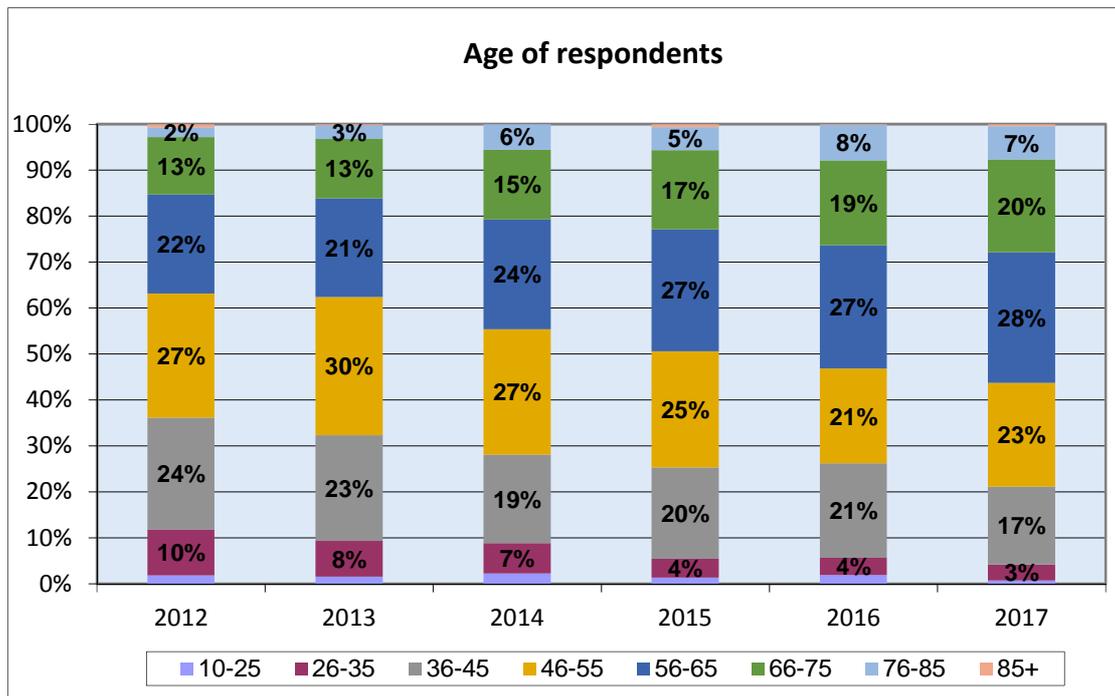
- Nationally, 68.1% of primary carers and 55.5% of all carers are women. Among people aged 55 to 64 years, the number of female primary carers is almost double the number of male primary carers. The number of male and female primary carers 75 years and over was similar.
- At the state level, 70.05% of primary carers and 56.4% of all carers are women.

**GRAPH 2**



Medical advances, changing lifestyles and new technologies mean that many older people will live with chronic and acute conditions that previously lead to an earlier demise in prior populations. Australia's ageing population means that many more people will be requiring care and support, and probably for longer.

**GRAPH 3**



**Data from the Survey of Disability, Ageing and Carers 2012 suggests that:**

- The need for assistance with cognitive and emotional tasks is four times greater for people aged 85 and over (28%) than those aged 65–84 (7%)
- Over half (59%) of people aged 85 years and over reported a need for assistance with health-care compared with one-fifth (20%) of people aged 65–84
- A higher proportion of women aged 85 and over (69%) reported the need for assistance with personal activities than men in the same age group (56%).

**Modelling suggests that by 2050:**

- approximately 22.6% of the population will be 65 years and older
- the number of people 65 to 84 years is expected to more than double and
- the very old (85 years and over) is expected to quadruple to 1.8 million.

In real terms, this means that a higher percentage of the population will require more assistance and care and over a longer period. In the next ten years, the demand for informal care will outstrip supply as the rate of people with severe and profound disability grows at a faster rate than the number of family and friend carers. Although the carer ratio is falling, there will be a rise in sandwich carers – a person who cares for two or more people in the generation either side of themselves.

**4 survey respondents are sandwich carers – caring for a parent or parent-in-law and a child/ren or grandchild/ren**

**68% of survey respondents are married or in a committed relationship**

An analysis the 'carer population' data highlights that people who are married or in a committed relationship are overrepresented against the general population. This reflects the most common carer situation; that is where one spouse provides care and support to the other spouse.

The 2011 ABS Census data suggests that the higher number of older male carers may be because life expectancy is shorter for men and because men are often older than their wife is. Men who survive in older age are more likely to be living with their spouse and providing care and support.

Recent research by Dr Teresa Cooney has explored the propensity of some people to provide care and support to former spouses or partners. Dr Cooney's research indicates that more than half of the people who care for an ex-spouse worked in the 'caring profession', suggesting that these people are predisposed to accept such a role despite formal separation. Others do it for their children; some do it so their children will not be responsible for all the caring; some do it with the blessing of their new partners and some do it because the lingering love is stronger than the hurt. It is anticipated that this phenomenon will rise as baby boomers reach older age.

**8 survey respondents provide care and support for an ex-spouse or ex-partner**

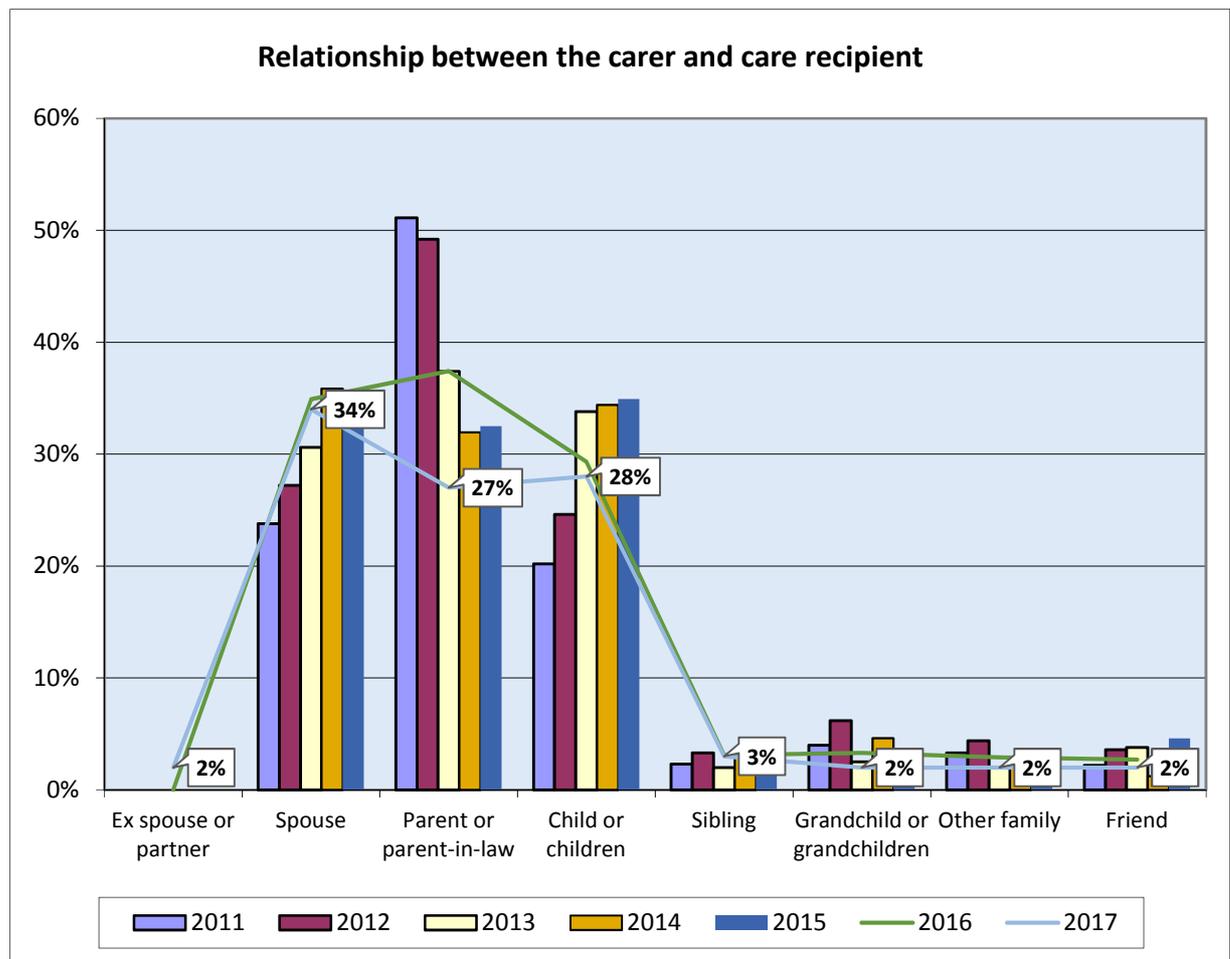
Whilst the idea of creating a familial long-term relationship that involves providing care and support with someone after the romance is over feels foreign to many divorced or separated heterosexual couples, in the lesbian, gay, bisexual, and queer communities there are many such stories.

The fear of discrimination, harassment, vilification and inappropriate questioning prompt many people in the LGBTI communities to provide care and support to family, and friends with little or no assistance from formal services.

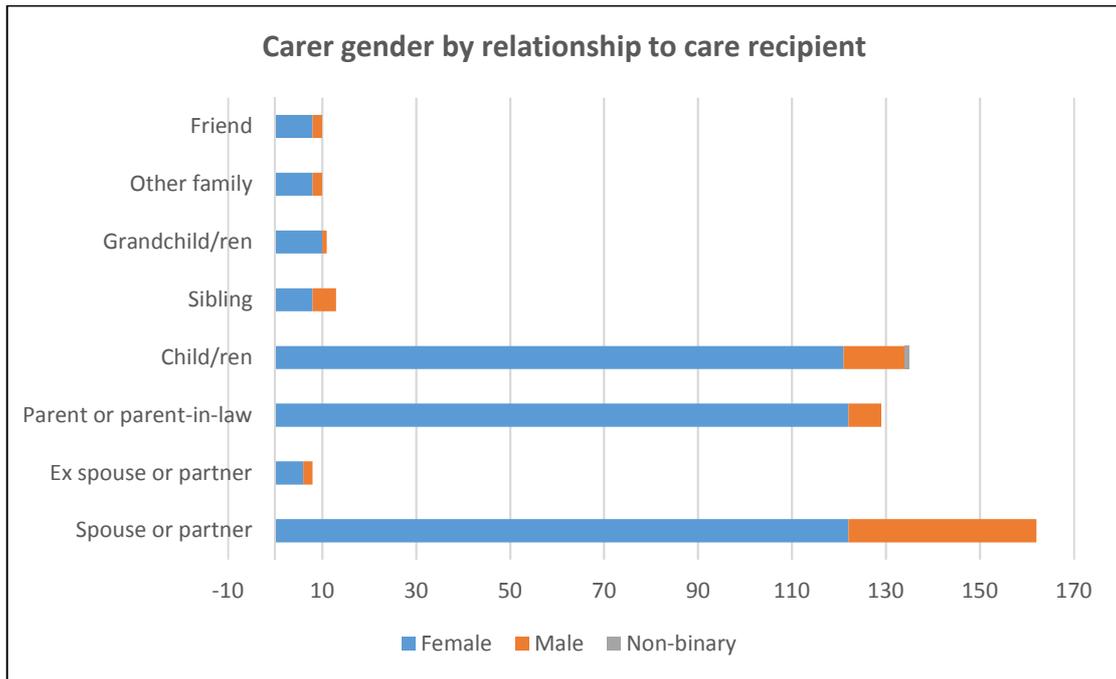
**In a survey conducted by Carers Queensland in January 2017 –**

- **80% of gender diverse and 39% of sexually diverse respondent expect to be discriminated against by service providers and**
- **48% have been or are carers and another 8% expect to assume the caring role in the very near future.**

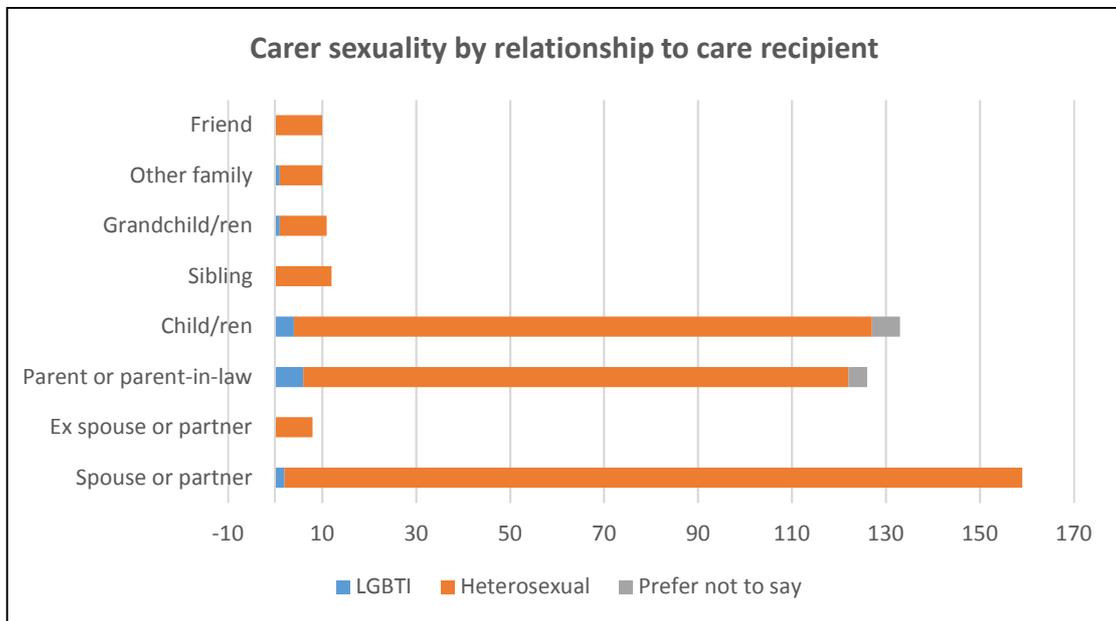
**GRAPH 4**



**GRAPH 5**



**GRAPH 6**



## PART 2 QUALITY OF LIFE INDICATORS

### 2.1 Quality of life

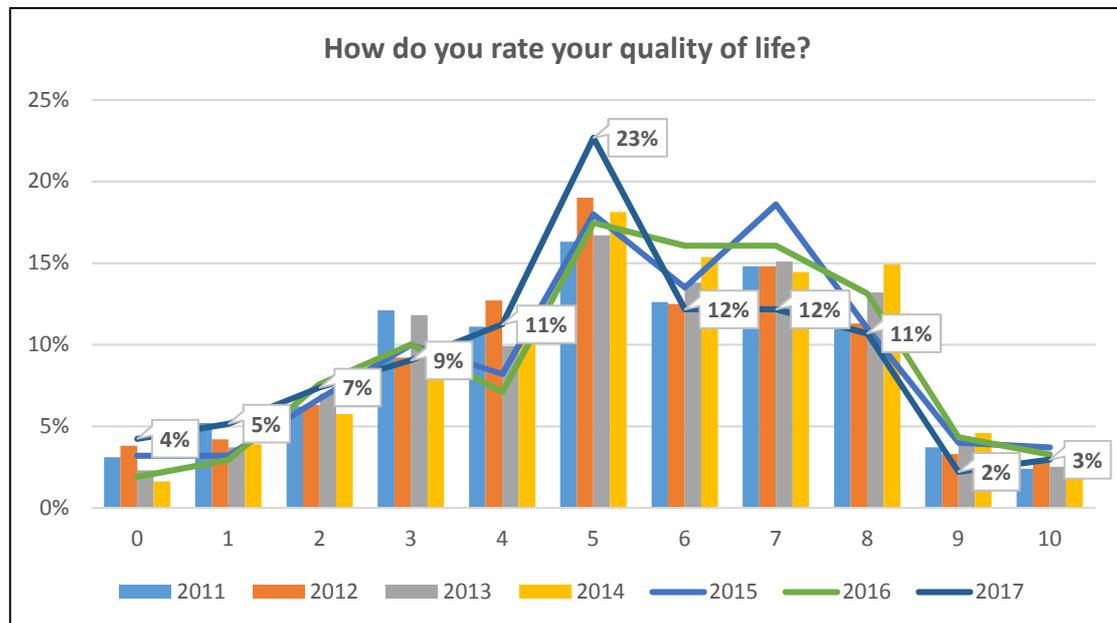
Australian Centre on Quality of Life research suggests that, while most people do not live to work, having employment is pivotal to how many people live; and that those people who want to work and who are unemployed incur lower self-esteem and happiness.

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, 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.

37% and 50% of survey respondents respectively indicated that they were dissatisfied with their quality of life and what they are achieving in life.

**27% of respondents expect their quality of life to worsen in the next year.**

**GRAPH 7**



**In the words of survey respondents:**

*After many years of stress and some dramas, our son now lives independently so it may be more accurate to describe us as support for him rather than carers. On a daily basis we are now able to live our lives to a large extent as we choose, although it does involve almost daily visits with our son. The main difficulty we currently face is that we are unable to have a holiday unless we take our son with us. The very mention of us having even one night away brings on a severe anxiety attack. Perhaps we're in a catch 22 situation – he is functioning well enough for some type of respite to be unsuitable but not well enough to feel comfortable coping without us for, say, two weeks.*

*Family relationships have disintegrated so far in the negative sense sometimes I think we stay married as a matter of convenience. The main topic of conversation focuses on the person with a disability whom we care for. It is always about that person and not ourselves or other family relationships. I have given up paid employment for the last four years to fulfil the caring role. Our health has suffered greatly and our mental wellness is poor. We are socially isolated. Extended family just do not get the complexity of the PWS syndrome and the impact on the family.*

*Sometimes I feel overwhelmed with the responsibility of helping to care for my mother, husband and grandchildren – not enough hours in the day.*

*Caring for three family members – two intellectually disabled sisters in their 50's, and an 80-year-old father with dementia – I have no quality of life. I am always 'on call' for their needs and on the rare occasion I make plans for myself they are usually interrupted.*

*My husband is becoming more aggravated and a little aggressive with the Alzheimer's he has. Not bad enough yet to get respite for him because, as he says to everybody, "I have H..... I don't need somebody to come and take me out or come in and sit with me." I know it will progressively get worse so just trying to get through this stage!*

*Having no support for the first three years of my child's life has led me to have PTSD and an addiction, we both now have the correct supports but it's been very difficult.*

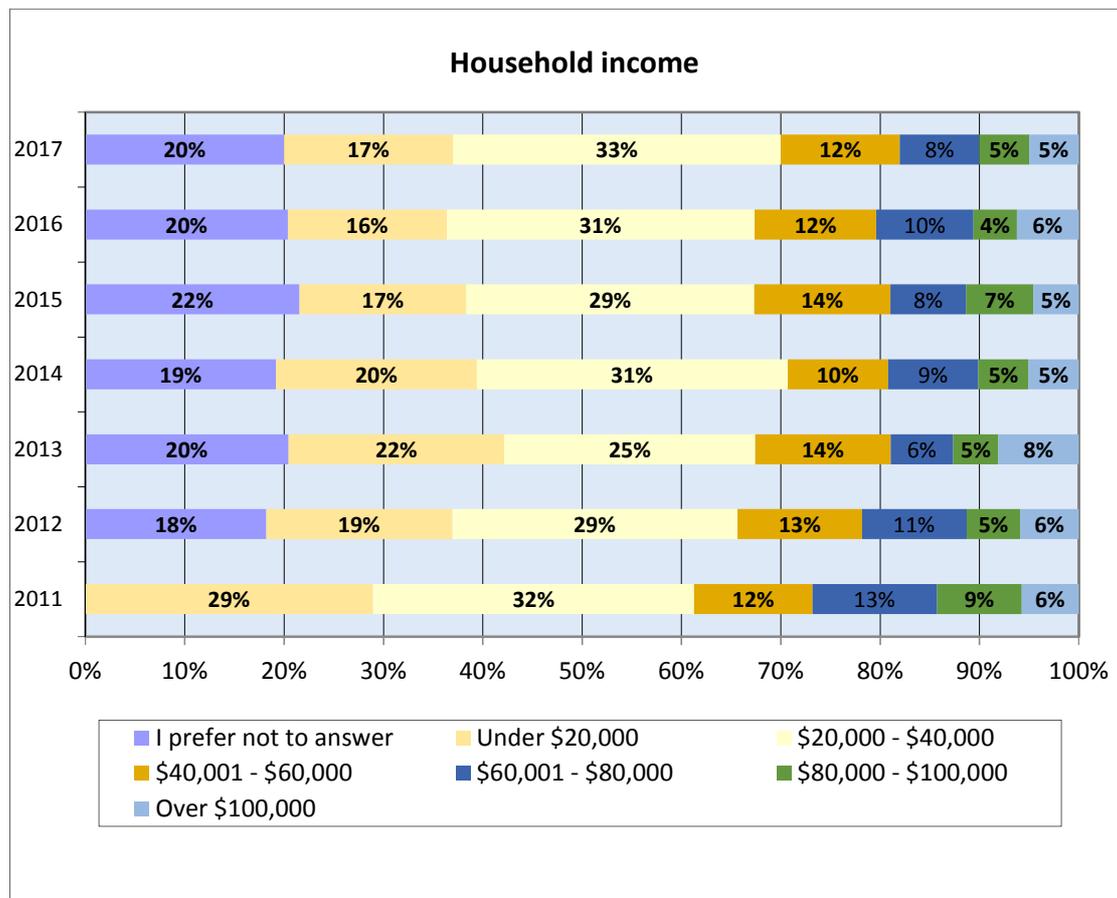
**2.2 Income, housing and cost of living affordability**

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. Many carers pool household resources in order to cope.

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).

**50% of respondents manage on less than \$40,000 income per year**

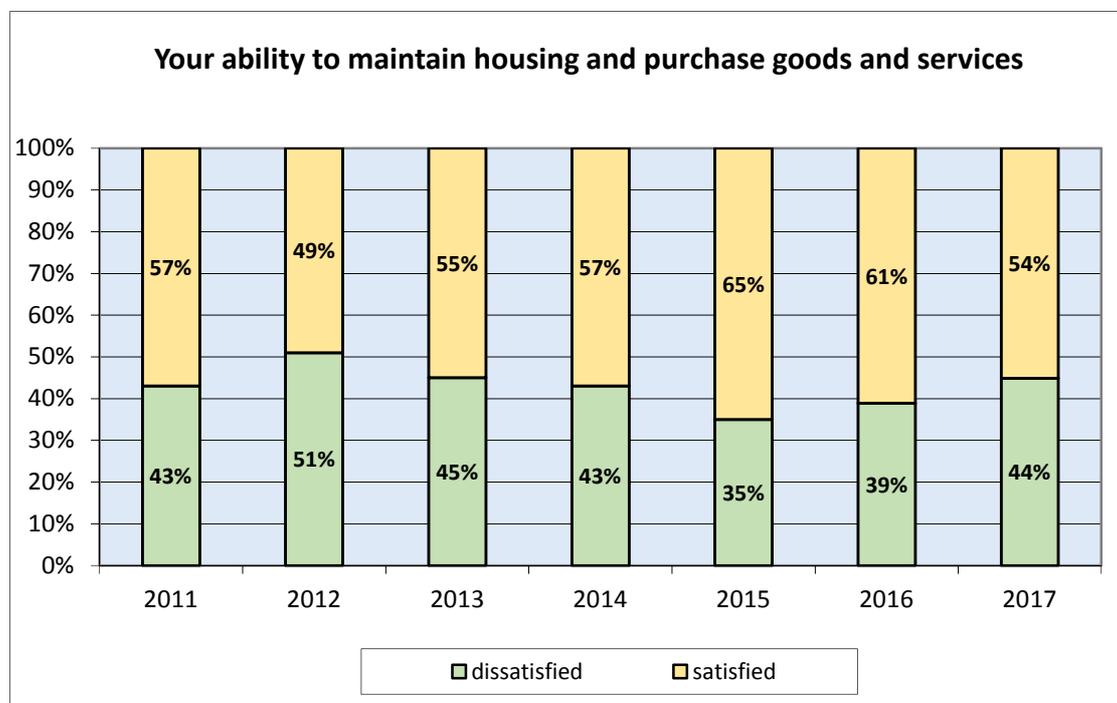
**GRAPH 8**



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:

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

**GRAPH 9**



An analysis of the Australian Unity Wellbeing Index 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.

**32% of survey respondents are dissatisfied with their standard of living, an increase of 7%**

**In the words of survey respondents:**

*Renting, disability related eviction. Homeless. Our rent is more than half of our weekly income.*

*Having given up work for the last four years to fulfil the caring role we went to a single income family. We have drawn down on our mortgage, which we were ahead on, to survive. We are now on interest-only repayments and wonder how long it will be before we could lose our family home. Our superannuation and savings for our own pension are minimal and we have concerns as to how we will navigate this next stage of our lives. Health declines make our current work professions, which are labour-intensive a problem to change careers at 60 years of age.*

*Have had to declare bankruptcy, move out of our house and into a rental. I can't work much due to being unreliable if I need to do extra caring duties and because I am worn out physically, mentally and emotionally.*

*I am currently caring for my mother in her own home, [which] when she passes I will not have a house to live in as her Will states it is to be sold to pay off mortgage. There will be no inheritance and I have no superannuation as I've been out of the workforce for 20 years as a single mum then carer for Dad (dec) and now Mum (90). I will struggle; I am 59 at the end of the month.*

*Our home is falling down around us and I have no money for repairs, maintenance or the modifications we desperately need.*

*Carers are paid well below the poverty level, so my standard of living is very low.*

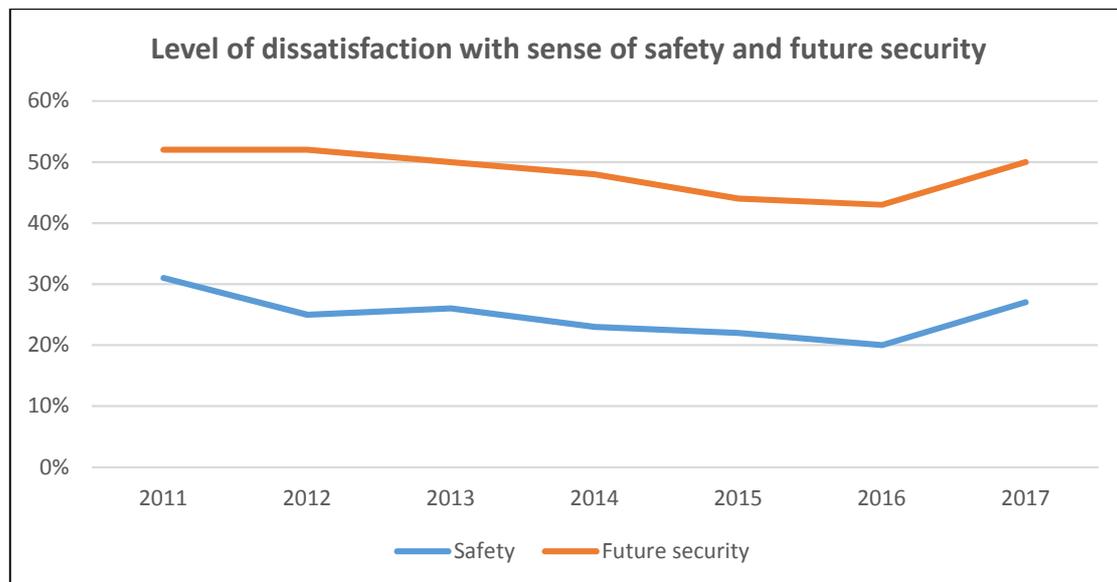
### 2.3 Future security and sense of safety

Carers' satisfaction with their life and future security is related to the security of their employment, income and home; their current sense of safety in their community; satisfaction with their personal relationships and friendships and their ability to plan and/or control the long-term care options for the person they care for and support.

**Of the survey respondents:**

- 2% are attending school or educational institution
- 7% in full time employment
- 17% in part time employment
- 7% are unemployed and looking for work
- 33% are unemployed and not looking for work
- 35% retired

**GRAPH 10**



For many carers the necessity to talk about, plan for and arrange for the future care of the care recipient is so daunting, it does not happen. Some carers expect to survive their care recipient; others expect that the extended family will 'step up to the mark,' whilst others fall asleep every night fearful of the future. Once again, the survey highlights the issue of future planning.

**Of the survey respondents – 64% have made no arrangements, 21% expect family and friends to assume the caring role, 2% will relinquish their caring responsibilities to the State and 13% of respondents have some formal future care arrangements in place.**

**In the words of survey respondents:**

*There seems to be a lot out there but for me – living in a rural area – it is difficult to access some of the courses due to the travel and too expensive as well.*

*Again, the financial burden of trying to re-educate/increase skills is frustrating. If only there were courses that fit with caring roles and our earnings, so when our caring role ceases, due to death or change in circumstances, we would have the skills for employment to support ourselves, and an outlet to keep our minds active in other areas.*

*I'm now 52... If I'm lucky she lives three more years. So at 55 will I have to retrain and get a job or will I just be left to rot on the dole?*

*My daughter has meltdowns and is too strong for me to restrain her on my own. I live with daily violence – threats from the person I care for. Takes forever for any services to reach me after I call. My son assaulted me and it took [the] police 40 minutes to arrive and when they came they did nothing to assist me.*

*I worry about the budget, paying bills and how screwed we'd be if my husband lost his job.*

*What happens to my adult child or me if my health deteriorates more and I am unable to give care?*

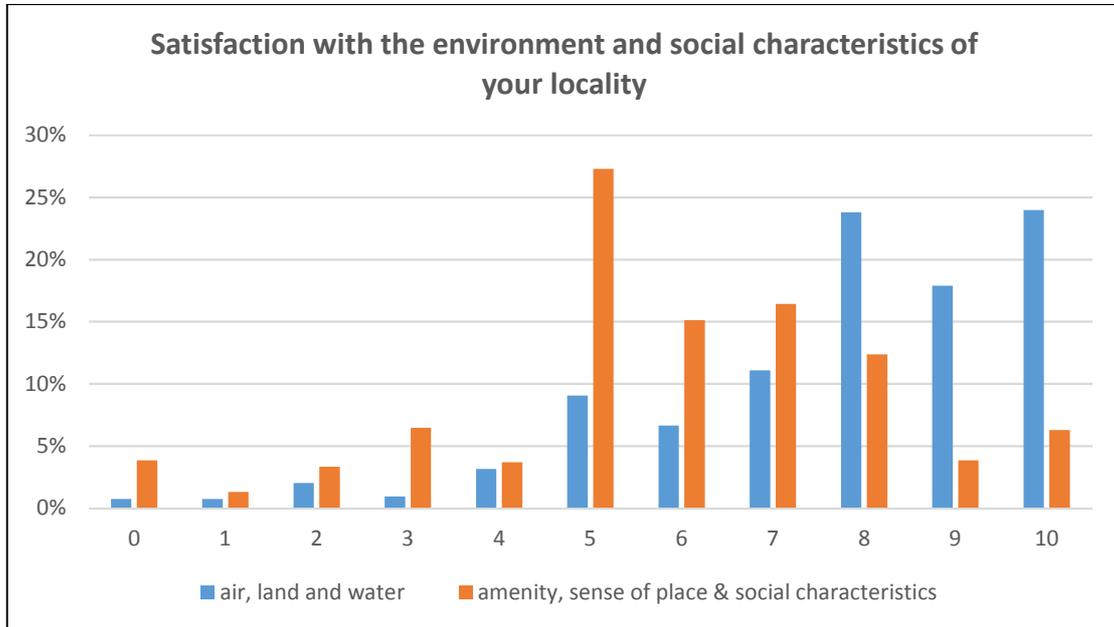
*I'm scared as a woman of 48 who thought she would be increasing her super and improving her retirement savings. Nearly 10 years out of the workforce as a carer and counting. I am scared about my old age.*

*I have no future security. I can't work to help build security in the future for myself. Should my husband pass away I have no house, no insurance, no job and will have to start again from scratch... I had a good career with a large telecommunications company, I was a manager; he had a good job as a tradesman, we had a house we were buying. We had money in the bank and super funds. We now are on a disability and carers pension, live in rented accommodation and have nothing in the bank. We live fortnight to fortnight. I have no idea what the future holds for us especially as rents are not cheap nor is the cost of living. It does worry me greatly.*

*Whilst I am well and functioning, I can care for and protect my daughter, our home and myself. But as I age, and/or become unwell I am very fearful for security as I have no family support and am not wealthy enough to see how I can put any plans in place to secure a more certain future. I worry about having a very poor, sad, and isolated end to my life and, as with many carers, I have grave concerns for my disabled daughter's long-term safety and wellbeing.*

2.4 Environment and its social characteristics

GRAPH 11



The continuing dry weather has negatively affected many carers living in regional and rural Queensland. Similarly, the relentless urban growth has negatively affected those carers who, until recently, have enjoyed the natural environment in their locality.

The number of survey respondents dissatisfied with the quality of air, land and water and the amenity, sense of place and social characteristics of their locality has increased 3% over the year

**In the words of survey respondents:**

*Sometimes we get too much water – flooding, but not for a few years now.*

*We live in an area where local government insist there is no water crisis and therefore put no money into it. In actual fact our dam is never above 21%. The water quality is appalling (undrinkable) – like a third world country and our rates are sky high. Not good enough. We have tank water and I can't always afford to keep it with enough water to bathe my kids daily.*

*Right next to industrial estate in Brisbane, very noisy and smelly/polluted.*

*There is a lot of construction and housing development happening in our area that aggravates my asthma.*

*[We are] close to the port and we get a lot of air, water and noise pollution from it.*

*We are currently being impacted by a huge residential development that will end up impacting on our lifestyle within 10m of where we now live, in a quiet suburb with a scrap of bush and wildlife nearby, on the Pumicestone Passage.*

*Carers are frowned upon as bludgers.*

*There is nothing fair or equal about ageing and the way the community treats [the] older generation. There is no equality in treatment you seek from professionals if you can't pay. Ageism is common in most locations Australia wide.*

*Small towns can suffer from small-minded commercially driven enterprises being too restricting.*

*I had my daughter with a service provider who was very unsatisfactory – I contacted the service provider, disability services for our region and politicians. I was completely ignored in the end. The only option was for me to bring her home. This gives me an unsatisfactory view of equity, fairness and equal opportunity.*

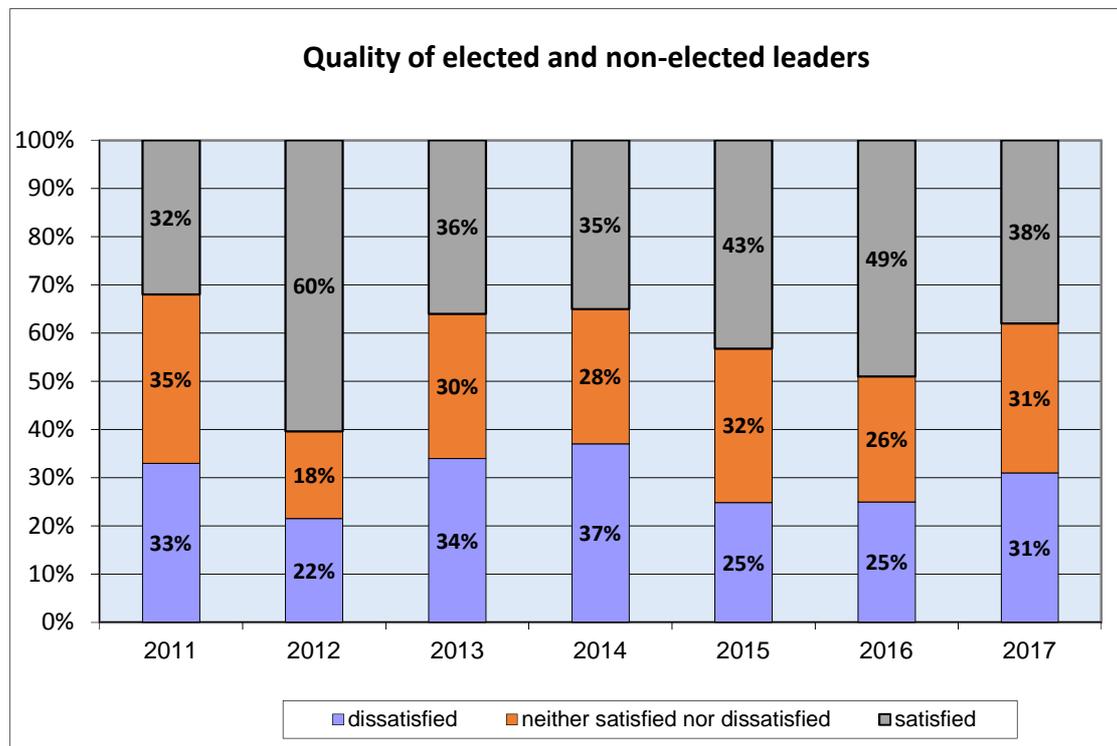
**2.5 Fairness, equity and equal opportunity**

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 that their elected and non-elected leaders fail to act on their concerns and issues from one election to the next. Understandably, some respondents feel threatened by the proposed 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 driven by government reform.

Social researcher, Hugh Mackay, suggests that the economic and social picture in Australia today is ‘somewhat gloomy’ and is reflected in the palpable decline of voter esteem for politics and politicians. This is reflected in the 62 % of survey respondents who are either dissatisfied or ambivalent about the quality of their elected and non-elected leaders, a rise of 11% over the year.

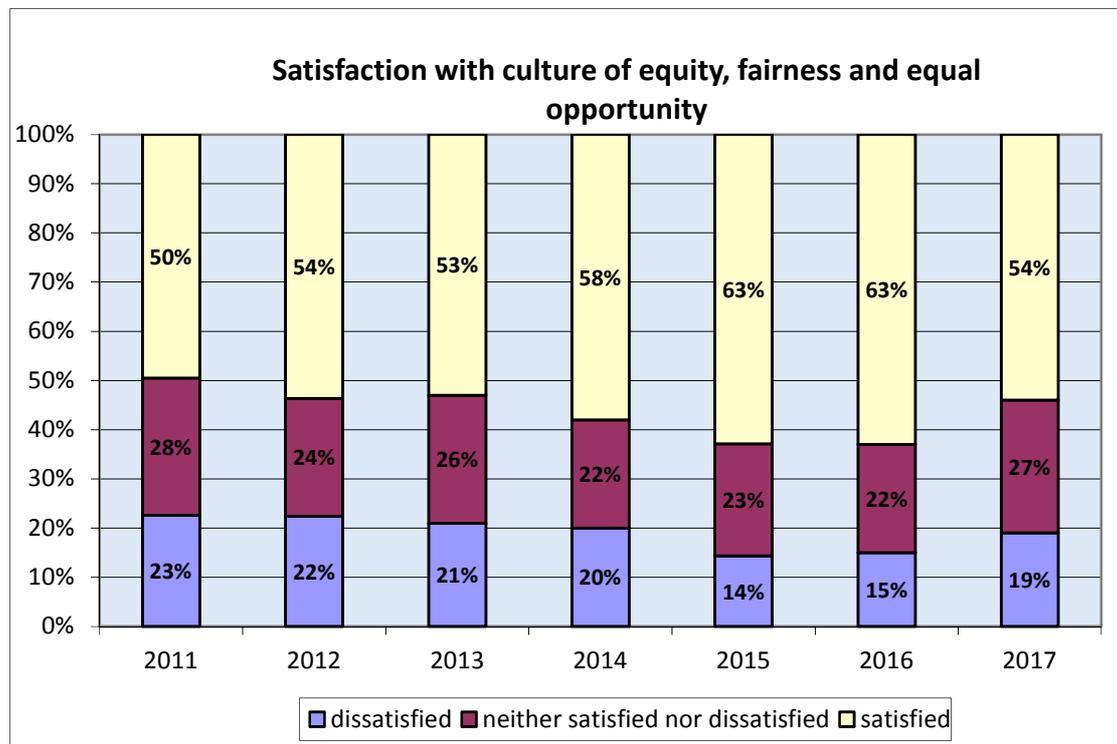
**GRAPH 12**



**41% of survey respondents were dissatisfied with their ability to access educational and learning opportunities. A rise of 6% over 2016.**

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.

**GRAPH 13**



Carers in Queensland, particularly those in rural and remote Queensland, face the added burden of geographical distance, making any opportunity to access education and other support, health and allied health services more difficult.

**In the words of survey respondents:**

*I live in a rural area, where we receive no mobile coverage. I can only connect to the internet through wireless. There is no public transport, if I wish to take up a course or a craft or even need transport to [go] into Mackay to seek medical help.*

*Usually vote for the person not the party the one who has best policies for disability.*

*The recent cuts to pensions and the increased difficulties in obtaining disability pensions and other support is ridiculous – the ones who most need support are given less but the politicians all received large pay rises, can access their pensions without the same reductions/restrictions faced by ordinary citizens and also get allowances etc. The local politicians are not seen to be opposing the generous handouts they receive at the expense of the ones who really need it.*

*I don't think they are very helpful. Where we live is not in one of the big cities, so I don't feel like they are that interested. I rang my local member re the delay in a care package and was told to ring another MP.*

*Disability is not on their horizon. Our ridiculous member for parliament is now advocating for our area to be on the cashless card. It is demeaning and makes me feel even more like a bludger on society.*

*We have offered our elected leaders to come and meet with our son, to have coffee with us and to discuss the lack of emergency respite in our area. We have also written about the lack of funded professional development for special education teachers. No takers!*

*Our state member is quite good although definite education is needed for these politicians about carers, disabilities and the NDIS. The state government department involved with guardianship is very autocratic...*

*Don't think they are particularly aware of the needs of carers or how many carers they have in their jurisdictions.*

*They are trying their best and I have seen many improvements in our area. However, there are way too many problems with different departments passing the buck and not taking action for what ultimately is a united problem.*

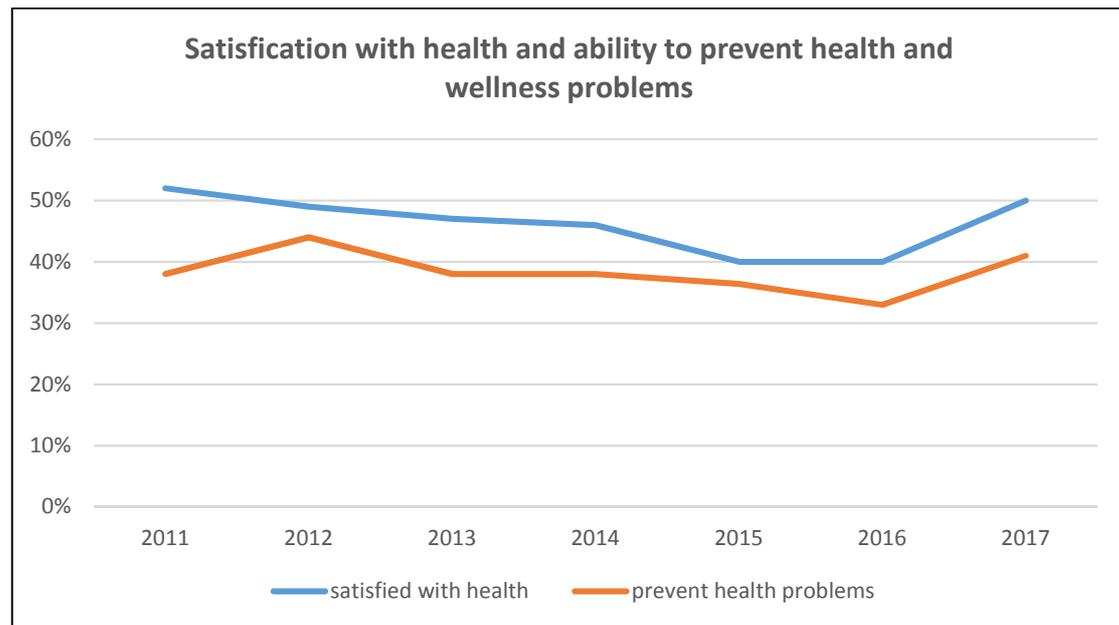
*We live in a "blue ribbon" electorate and it is all about the Haves. Our son is a Have-Not.*

*As a Carer, you are put in the "too hard basket". Nobody wants to recognise the role you provide, nor provide any incentives to maintain the role of carer.*

## 2.6 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.

**GRAPH 14**



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 is limited but over the longer term carers who fail to address their own health needs will have poorer health and wellbeing. Australian Bureau of Statistics data shows that 10% of Queenslanders delay or do not buy prescribed medications because of the cost and those who are most likely to delay or not fill a prescription are those who need it most. This behaviour is related to an increase in hospital admissions.

The 2017 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.

**In the words of survey respondents:**

*I often put my health issues off due to my husband's illnesses. My issues can and normally do wait until we are in a better place with him. Unless its urgent then it's seen too.*

*One doctor in the town, all specialists between one and four hours away.*

*So busy with the caring role, no time for me.*

*I am stressed and while I have and can access services to assist me with my mother I am not sure that it is enough to help me cope. I have for the past 15 months been concentrating on my mother, her care and health needs and been neglecting my own. I am no longer able to neglect my health care but unsure how to proceed.*

*Time is an issue due to caring commitments and therapy appointments, employment, supporting other family members etc. My personal medical appointments are either postponed or not addressed.*

*Very limited health services available in the Miles area. Needing to travel to access costs money and excess time off work.*

*Waiting lists are very long for services needed. I waited over 20 weeks to be granted the Carers Payment.*

*As I am a full time carer it is very difficult to care for my own health. My husband needs help mobilising, eating etc. We live in regional Queensland and it is costly to go to Brisbane where all the medical services are.*

*I am fatigued constantly, depression hangs around and I have fibromyalgia brought on from the stress of caring.*

*I am very stressed and unsure of my ability to cope much longer. I would like to think that things would improve. In addition, I have some physical health concerns that need to be addressed but it takes time and money – something that I don't have a lot of at the moment.*

*Been very unwell with asthma the last month and exhaustion from years of continual caring. Started to improve since recently enjoying 3 months away - just my little doggie and me. It has been a turning point of seeing a little hope at the end of the tunnel.*

*I am in pain most of the time unable to care properly for myself as I feel I live for another.*

## 2.7 Personal relationships and community

Research from the Australian Centre on Quality of Life indicates that more than 30% of people in Australia are lonely. Many of the comments of survey respondents highlight the isolating impact of societal attitudes towards disability and dependency, resulting in loneliness for the carer. Research from the United Kingdom has shown that how a carer is perceived by others is based on an individual's perception or interpretation of the disability or illness of the care recipient.

**27% of survey respondents feel dissatisfied with their sense of belonging in their local community**

**55% of survey respondents are dissatisfied with or ambivalent about their personal relationships**

**and**

**53% are dissatisfied with or ambivalent about with their ability to connect with carers, family and friends.**

A carer's satisfaction with feeling a part of the local community is related to their satisfaction with their personal relationships, the culture of equity, fairness and equal opportunity and the amenity, sense of place and social characteristics of their environment.

**13% of survey respondents are dissatisfied with, and another 18% are ambivalent about, their spirituality and religion.**

**In the words of survey respondents:**

*I don't have a husband or a mother, I have two sick people who rely totally on me for everything.*

*Except for family and they have distanced themselves greatly because of disability related issues, I don't have any personal relationships. I don't have the time or the ability to have time off to foster any.*

*Recently separated and single, difficult to develop meaningful relationship when caring for autistic child.*

*I don't have personal relationships. It is not possible to find someone who wants to exist like me.*

*We struggle to keep in contact with friends who are not in a caring role due to the challenges of taking our son out. We connect with other carers who are in the same boat, but it still makes for a lonely existence or a terrifying one if we try to take our son out to social situations.*

*Not part of the community, tried and got slapped down.*

*It's a two-way street – the community is not inclusive of carers and, as carers, it is hard to find time/motivation to create inclusive opportunities.*

*It is difficult to take our son out as he suffers anxiety in certain situations, is in a wheelchair and gets very distressed in certain circumstances. It is hard to get the courage to face the stares and the struggles by trying to integrate into community but we are working on it.*

*We mostly get to church and have some lovely friends and support within our church.*

*My faith is strong and is the only thing that keeps me going however I don't belong to or attend Church although I would like to.*

## **PART 3 THE CONTRIBUTION OF CARERS TO THE CARE ECONOMY**

### **3.1 Hours of care of support and me-time**

There is no doubting it – carers are unsung heroes in our community and the pillars of our health and community care sectors.

- Allen Consulting Group estimate that family and friend carers provide 74% of all the care and support provided in Australia, supplementing the stretched resources of our Commonwealth and State funded services.
- Deloitte Access Economics estimated the replacement national value of unpaid care in 2015 at \$60.3 billion per year; that is equivalent to 3.8% of the gross domestic product and 60% of the health and social care industry. The replacement value for Queensland was estimated at \$10.2 billion.

It is important that we quantify not only the number of hours carers provide in unpaid care and support but the impact of providing care on carers themselves to:

1. Highlight the incredible importance of caring and the pivotal contribution of carers to the humanity of our communities.
2. To inform the ongoing discussion around female workforce participation, gender equality and the division of labour.
3. To inform policy formation and investment decisions – to ensure that the needs of the unpaid economy, and the value it generates to society, is given appropriate weight in policy and investment decisions.

In this year's survey, we asked carers to identify how many hours of care and support they provided and the time available to them personally (me-time) in the 7 days prior to completing the survey.

#### **In the 7 days prior to completing the survey:**

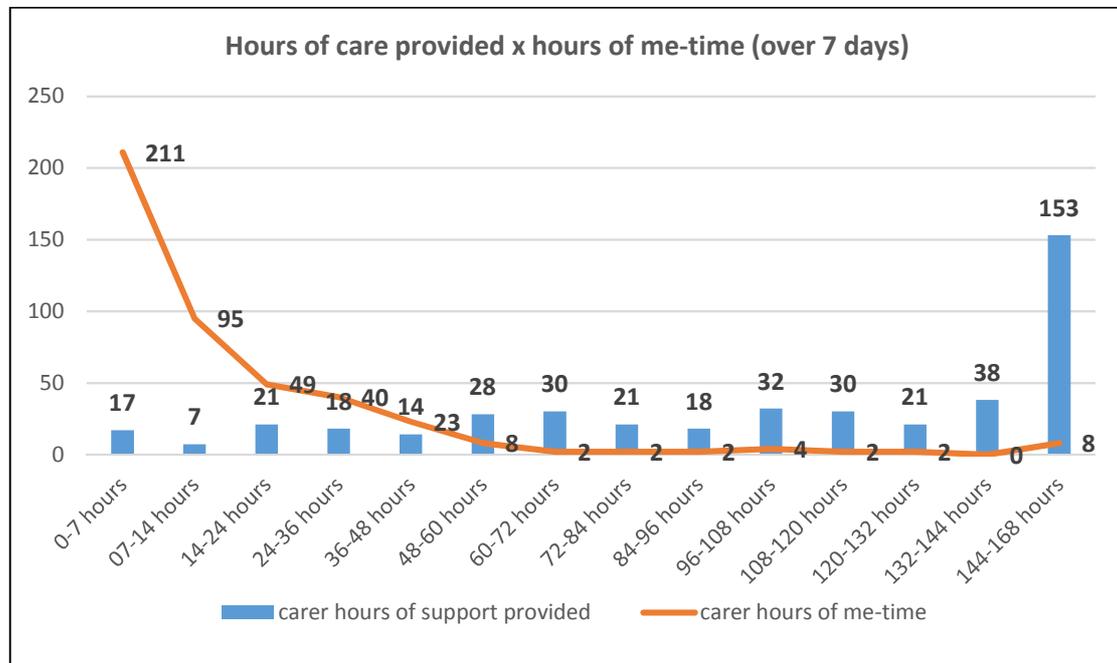
**The 448 respondents provided between 43,382 and 50,377 hours of care and support. That is between 97 and 112 hours of unpaid support per carer.**

**86% of respondents provided more than 36 hours of care and support per week. That is – between 42,590 and 48,336 hours of support in 1 week.**

**34% of respondents provided 24/7 care and support (144-168 hours) in the week.**

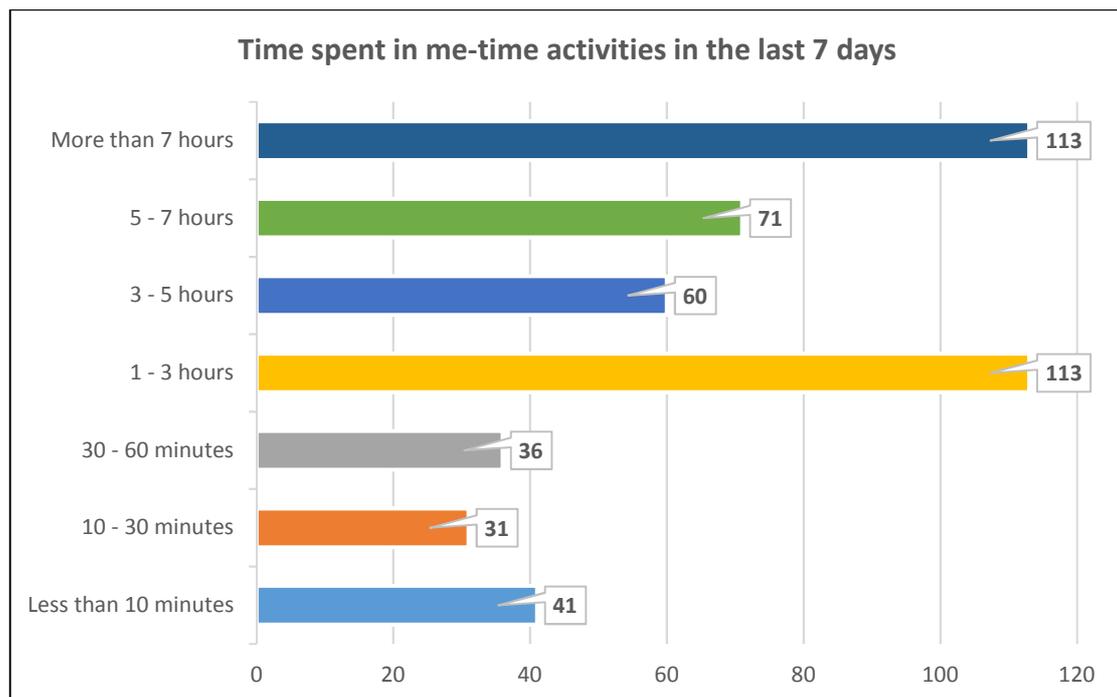
Obviously the more time an individual carer spends providing care and support, the less time there is available for me-time. The availability of me-time diminishes once a carer provides more than 36-48 hours of care and support per week.

**GRAPH 15**



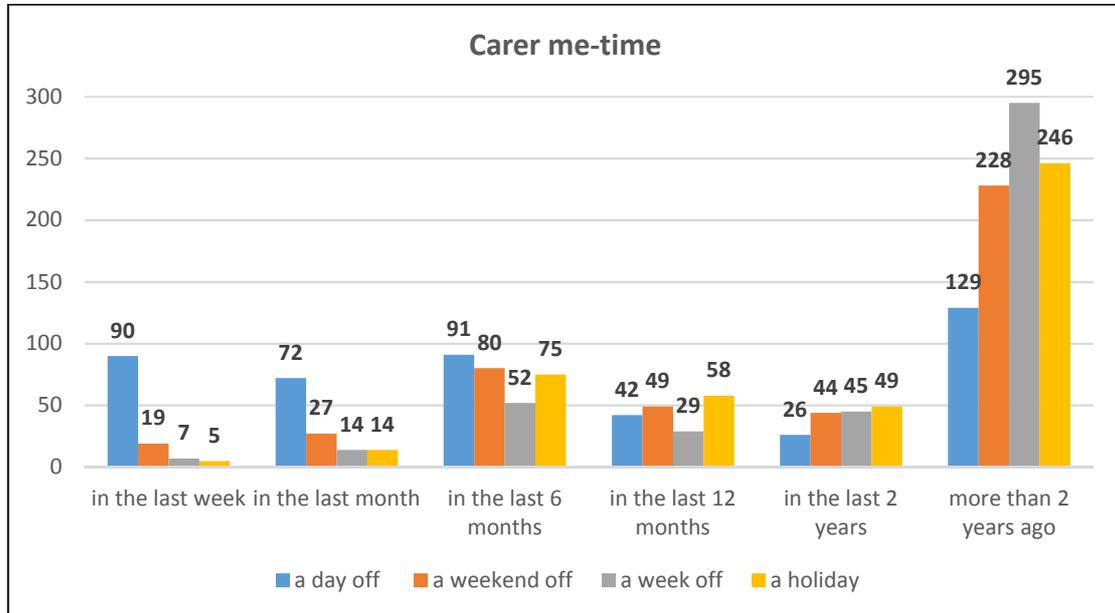
**23% of respondents had less than 60 minutes me-time and 90 enjoyed 1 day of me-time in the 7 days prior to completing the survey.**

**GRAPH 16**



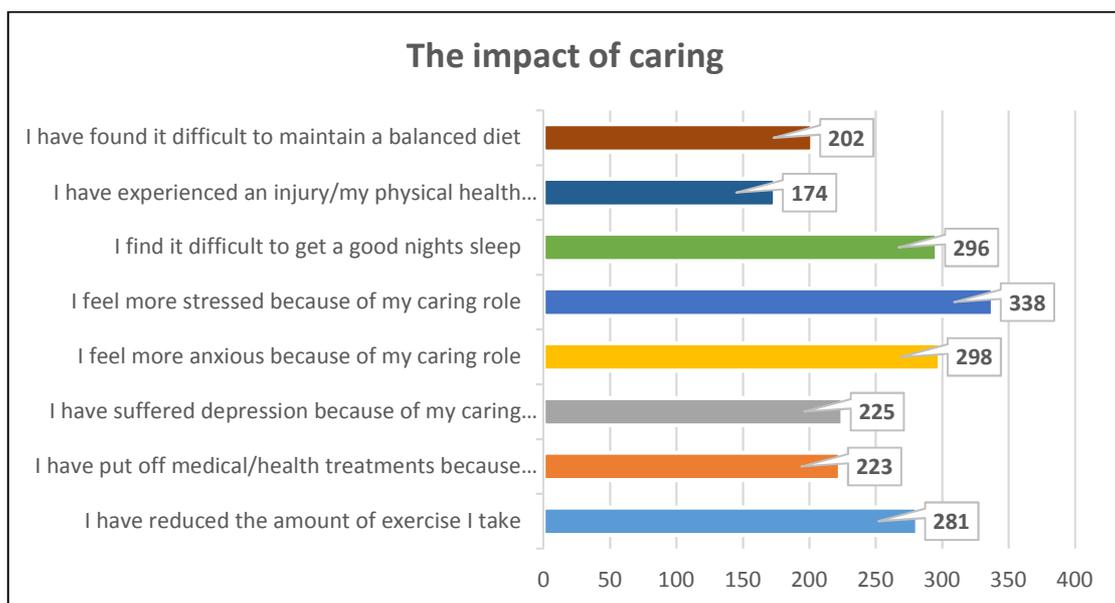
If grabbing an hour or two or me-time is difficult, organising and enjoying a weekend break or a holiday is nearly impossible for many carers who have 24/7 caring responsibilities.

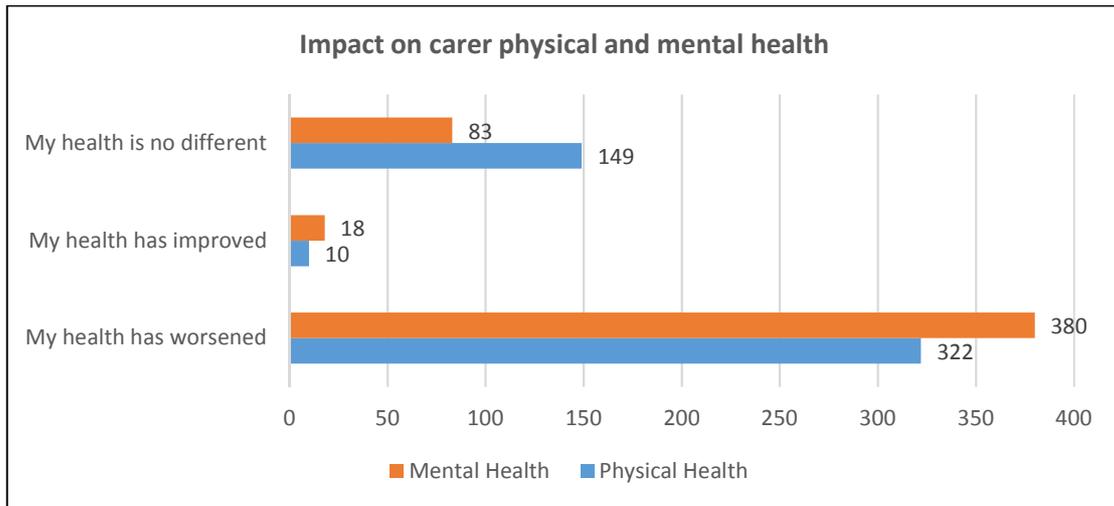
**GRAPH 17**



Caring comes at a cost. The cost of a good night’s sleep, of eating nutritious foods, of physical injuries brought on by frequent manual handling, of isolation and loneliness, social and economic exclusion, depression, anxiety, and poor physical health. Anxiety, hopelessness, depression and poor physical health are all risks factors for suicide in the general population.

**GRAPH 18**



**GRAPH 19**

Research has shown that the use of respite and other support services can and does support the carer and can delay or prevent the permanent admission of the person cared for in residential or other care facility. However, other research also shows that certain carer populations are low users of respite care or other services despite their needs.

The research has shown that carer access to support services is determined by four factors:

1. Pre-disposing factors (carer-care recipient relationship, ethnicity, health beliefs, perceptions about support service availability/convenience/quality and carers perception of their duty of care)
2. Enabling or impeding factors (resources such as transport to access services, information availability, and having the money to purchase the service/s)
3. Need factors (evaluated or assessed need for support and personal recognition for support need)
4. Care recipient behavioural problems (may present as a barrier to accessing some services).

The research provides some context as to the difficulties or impediments carers can experience in either wanting to (or not wanting to) access support services and the frequency of use of support services.

The information provided by Quality of Life respondents affirms the research findings:

- many carers lack the finances to purchase respite care
- for others the barriers are cultural
- for some the lack of available information on local service availability is a significant barrier
- and for many carers, the person being cared for does not desire care outside of the home or the immediate family or relationships.

**TABLE 1**

<b>The struggle to access a break from caring</b>	<b>No of responses</b>
Respite care is only available at the last minute	9
Respite care available is not with people of the same language or culture	11
The only options available are too far away to be reasonably accessed	39
The respite centre is fully booked well in advance	41
I don't know how to access respite care	44
The care needed by the person I support is not available in our area	49
I am not confident in the quality of respite care available	57
Respite care available is not with people of the same age	58
I haven't struggled to access a break from caring	99
Cost of paying for or contributing to the cost of a break	166
The person I care for will not accept care and support from others	169

There are two sides to every coin. Research conducted by the network of State and Territory Carer Associations into the availability of aged care respite services demonstrates that wanting and needing respite care is one thing, but being able to access or purchase the service is another!

The research clearly shows that there is a persistent under-supply of residential respite and other respite types are not always easily accessible. Completed by aged care providers and Commonwealth Respite and Carelink Centres (CRCC), the survey data supports the anecdotal evidence of carers – none of the survey respondents found emergency respite easy to access and only 3% were able to access planned respite very easily.

***Finding emergency respite is the most difficult as it is not always available immediately. At times there is no option but being admitted to hospital.***

The survey found that in-home respite was the easiest to access across the country except in Queensland where 44% of respondents said it was difficult or very difficult to obtain. Even more difficult is accessing respite care for people with dementia or other challenging behaviours – 64% of respondents said it was difficult or very difficult.

***In the words of one survey respondent: If the Commonwealth wants people to stay at home longer, then carer fatigue must be addressed, to meet the need for the carer to relinquish care temporarily without being consumed with guilt and anguish because of the conditions, environment and standard of care provided to the recipient when they are in the facility.***

***In the words of survey respondents:***

*We have had one long weekend away together on our own as husband and wife in 22 years. It is seldom we can take a break together, one is usually on standby while the other goes away. This will change under our plan for our son with the NDIS and we are looking forward to what this will mean for us.*

*I have not time for myself, have not had that for at least five years, no wonder I pray each night that if there is a God He/She ends it for [the] patient and carer!!!!*

*My best friend took me on a short P&O cruise in July, Is going to work really 'me' time? Without that I've spent approximately two hours a day on social media and four hours on two occasions catching up with my friend on my own.*

*Shopping, appointments, chemist for scripts, doctor. And I would not say I enjoyed it. Last year in October, I went on my first holiday ever.*

*Had a holiday away with my cousin. First time in over seven years.*

*I have never had a week away from caring and I have never had a holiday away from home on my own.*

*C has a 1000 sq. m property and a 75-year-old house. I do all of the repairs, renovations and upkeep etc. I am the tradesperson so in my spare time from C I am sanding, painting or something here. Then back up to check on her, up, down, up, down. Right now she is asleep so it is quiet time till 2pm. 😊 shhh!*

*I enjoyed a week off earlier in the year when my son was able to access respite. This was when we had a small 'My Life, My Choice' grant and we were able to pay the \$30 per night subsidy. Now we are required to pay the full amount of \$500+ per day and we have no funds to enable this to happen.*

*I haven't had one full day (24 hours) to myself since I became a carer. I get three hours per week to myself and I do pottery.*

*I have very little free time to myself. Usually six to nine hours per week. I am only able to have this by paying someone to look after my partner while I am away. There is no government funded in-home respite that I am aware of.*

*I have no life. I care for a 17-year-old intellectually impaired and autistic child and a three-year-old autistic child. I have no respite and never see anyone or go anywhere. Life is very hard.*

*Just making ends meet. Nothing left for me to have a break. No respite available where I am and I cannot afford to go away and have someone come in and give home care.*

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