



## **CARERS QUEENSLAND INC.**

### **QUALITY OF LIFE AUDIT 2014**

**Summary of Audit**

**September 2014**

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**Date:** September 2014  
**Author:** Sarah Walbank, Policy and Research Officer  
**Approved by:** Debra Cottrell, Chief Executive Officer  
Carers Queensland Inc.  
15 Abbott Street  
Camp Hill 4152 Queensland  
Phone: (07) 3900 8100  
ABN 20061257725  
Website: [www.carersqld.asn.au](http://www.carersqld.asn.au)  
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## FOREWORD

Many thanks to the carers who once again participated in our Quality of Life Audit. This year we also incorporated some questions on 'me-time', that is the opportunities carers have to enjoy some personal leisure pursuits. Like anyone, carers need regular breaks to sustain them. Those of us in paid employment get a break most weekends. Imagine the uproar if our employer expected us to work seven days a week, for more than 16 hours a day? Yet that is the reality for many carers.

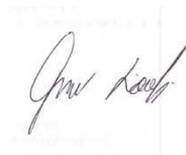
The context of being a carer in Australia is changing. As the population continues to age an increasing number of adults will be a carer or alternately giving and receiving care at the same time. This changing demographic landscape poses a challenge in our society; how best to deliver services that genuinely meet the needs of all concerned, preserving if not improving quality of life. This challenge, however, does not belong to the formal aged and disability sectors alone, it belongs to us all; because carers and the person they care for experience huge benefits from the support provided by family, friends and the community, not just formal services.

Our survey highlight the difficulty many carers encounter in accessing appropriate and good quality services at the right time and of managing the emotions surrounding seeking and using formal services, negatively impacting the health and wellbeing of many carers.

Our survey also bears out the results of the Australia Centre on Quality of Life research, which indicates that carers are more likely to be carrying an injury and often do not seek medical attention for themselves. This is impacted even more on rural and remote carers who incur long delays for an appointment to see a health professional and extensive and expensive travel costs.

It is a an extremely challenging environment at the moment, with complex reforms to the aged care sector and Queensland gearing up for the introduction of the National Disability Insurance Scheme (NDIS) roll out, commencing in July 2016.

Over the coming 18 months, Carers Queensland will be introducing health and wellbeing workshops for carers as well as our new program '*Full scheme ahead*' an NDIS readiness project initially targeted to older carers who have an adult son or daughter with a disability. Given that this survey shows that the number of carers who do not have any long term care arrangements in place rose by 3.1% to 65.1% in 2014, we think it is a timely response.



**Jim Toohey,**  
**President,**  
**Carers Queensland Board of Governance.**



**Debra Cottrell,**  
**Chief Executive Officer,**  
**Carers Queensland Inc.**

## INTRODUCTION

### About Carers Queensland Inc.

Carers Queensland represents the diverse needs and interests of family and friend carers in Queensland. A carer is a person who is providing or who has provided unpaid care and support to family members or friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged.

The Objects of the Association are:

- to improve the health, wellbeing, resilience and financial security of carers; and
- to promote the recognition of caring as a shared responsibility of family, community, business and government.

Carers Queensland's **Vision** is an Australia that values and supports family carers and its **Mission** is to improve the quality of life of all carers throughout Queensland.

### General facts about carers

In 2012 there were 2.7 million family and friend carers providing care and support to persons with a disability, mental illness, chronic medical condition or a frail older person in Australia.

- One third of these are the primary carer; that is they provide the majority of the informal care and support needed by the person (or persons) they care for.
- 56% of carers are female and one in five carers is aged between 55 and 64 years of age.
- 40% of carers report that they spent 40 hours or more per week providing care.
- Proportionately more men over 65 years of age than women are carers.
- For men, the likelihood of providing care increases steadily as they age.
- Women, on the other hand, are more likely to assume a caring role between the ages of 45 to 54 years and experience a greater likelihood of providing care up to the age of 65 years, when the incidence begins to fall.

Of the 2.7 million carers in Australia 484,400 carers reside in Queensland, approximately 10,000 less than in 2009. Carers are equally as likely to live in a major city (greater Brisbane conurbation) as regional Queensland. Only 0.5% of carers live in remote Queensland. 20% of all carers in Queensland are aged between 55 and 64 years. In Queensland there are 54,100 identified young carers aged between 15 and 24 years, 6,200 fewer than in 2009.

## QUALITY OF LIFE AND WELLBEING

Economic performance, demonstrated by indicators such as the gross domestic product (GDP) and the consumer price index (CPI), is frequently used by government as a proxy measure for the vitality of the nation and by extension its population. Whilst these measures are valuable for evaluating our position in a regional and global economic context they do not necessarily provide an accurate picture as to the wellbeing of the population or the spirit of our communities.

Quality of life indicators offer an alternative to the dry economic indicators used to measure and benchmark success. 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 – that is the emotional quality of a person's everyday experience, and life evaluation – that is 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 more often used to refer 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 includes 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 which 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.

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

The average wellbeing score for a carer in Australia is 58.4.

## 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 Carers Queensland Liveability Audit was introduced in 2011 as a means to promote 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.

#### Methodology

The 2011 Liveability Audit formed the benchmark estimate of the quality of life of carers in Queensland. The 2011 audit was issued as both a paper survey through the regional offices and electronically through the Carers Queensland website. The 2011 audit generated 575 responses; representing 0.1% of the 494,200 known carers in Queensland.

The 2012 Audit replicated the 2011 audit with only some very minor changes or additions to the 'personal demographic' questions and was launched on 1 September 2012, initially via email to 2,500 carers known to Carers Queensland and through the Carers Queensland's social media sites resulting in 480 responses.

In 2013 the Audit was launched on 1 August via email to 3814 carers known to Carers Queensland and promoted through Carers Queensland's social media sites resulting in 485 responses. Whilst the 2013 Audit replicated the quality of life and demographic questions of the 2012 survey six new questions relating to carers experiences of being *Prepared to Care* were included. These questions highlighted the issues confronting people when they move into their caring roles and responsibilities.

This year the Audit was launched on 1 August initially via email to the 4287 carers known to Carers Queensland and subsequently via our social media platforms. Of the initial email distribution 1640 or 40% of recipients opened the email and 184 emails bounced back as 'undeliverable'. Over the month 530 people completed the survey, of which eight did not reside in Queensland and two were not or had never been a carer. Of the remaining 520 completed surveys only 436 recipients completed the quality of life questions.

This year the Audit included one new quality of life question, *In the next year do you expect your Quality of Life to: get better... worsen... stay the same*, and six questions relating to *Taking a Break*; that is the opportunities carers create or snatch to enjoy personal leisure pursuits or just re-charge their batteries.

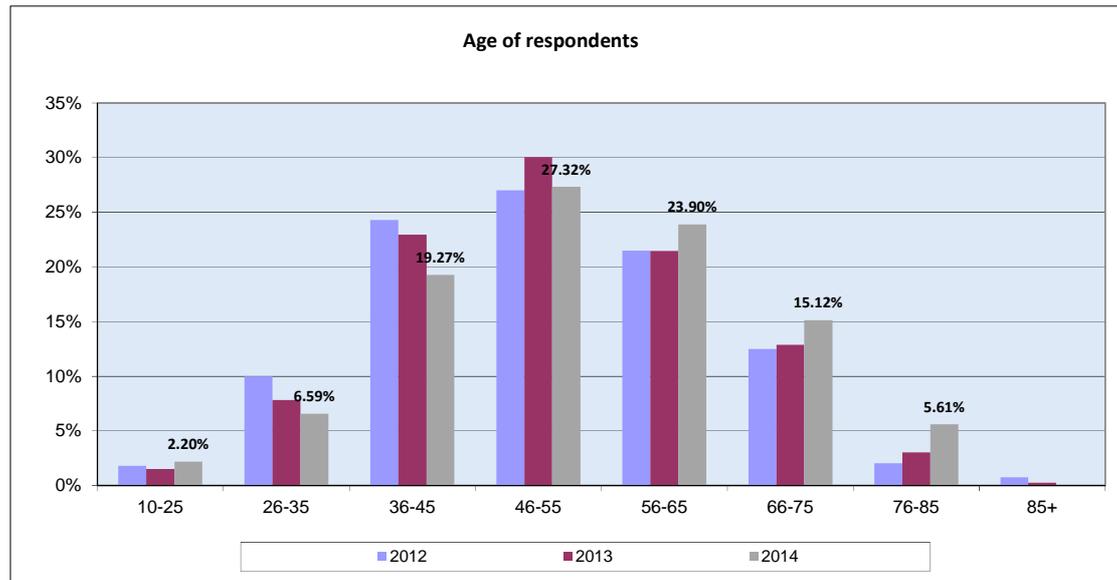
The geographic distribution of the responses reflects the ABS state data: 48% from the greater Brisbane, Gold Coast and Ipswich areas; 45% from regional Queensland, 5% from regional and 2% from remote Queensland.

**PART 1 PERSONAL DEMOGRAPHICS**

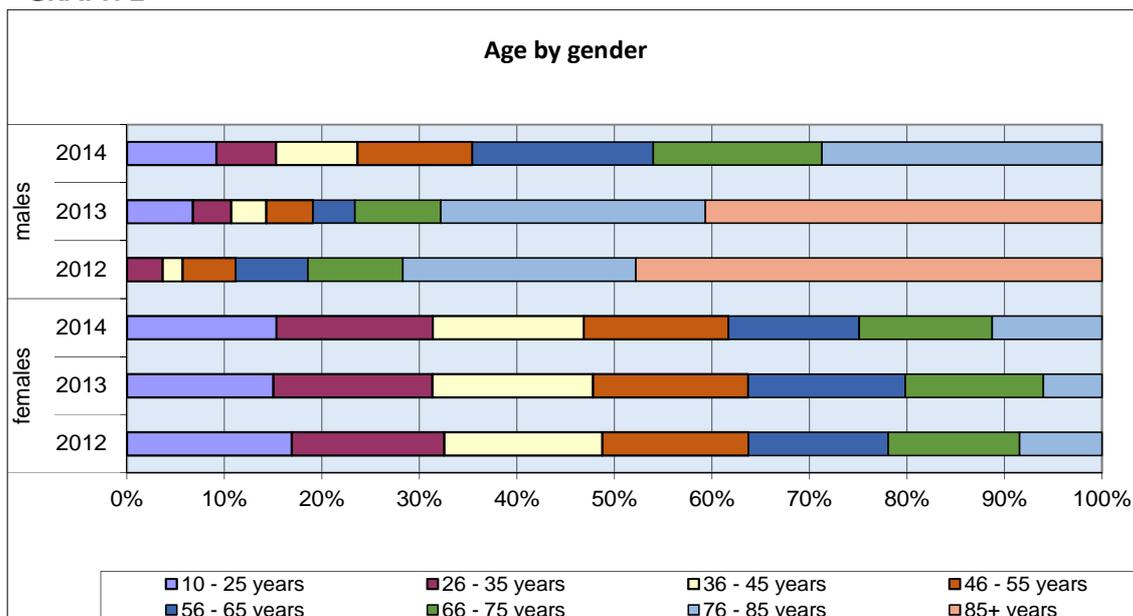
**1. Age and gender profile**

Of the survey respondents 97% are a current carer and 83% are female. The age and gender profile of the audit respondents closely reflects the national profile; that is more men than women assume the caring role in the older age ranges. However, for the first time the data is showing that there are more women caring in their older years (56 – 65 years of age) – evidence of the ageing (and diminishing) carer population.

**GRAPH 1**



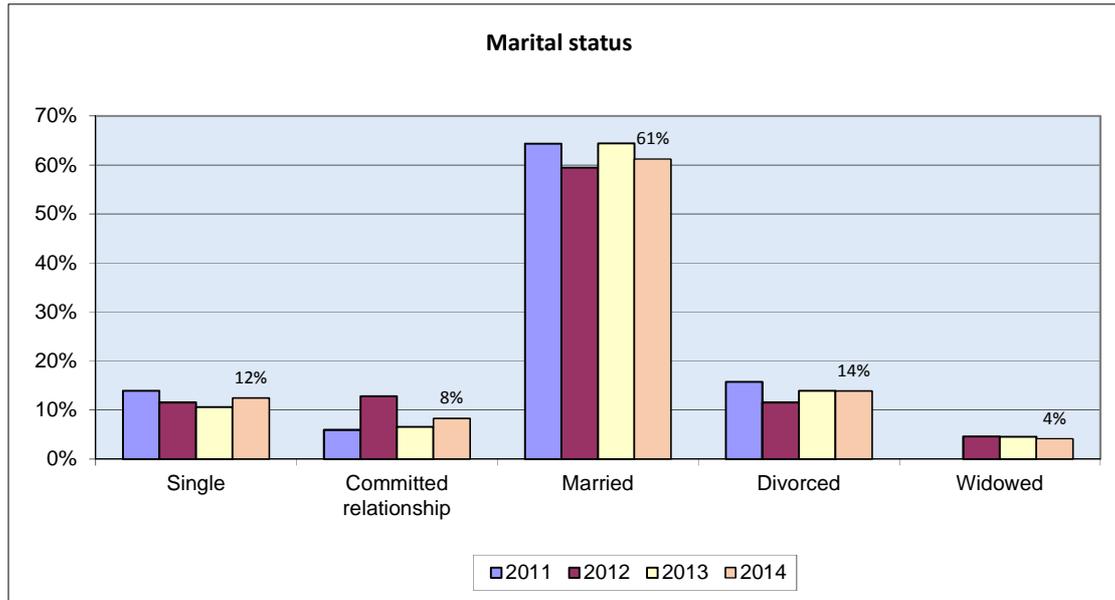
**GRAPH 2**



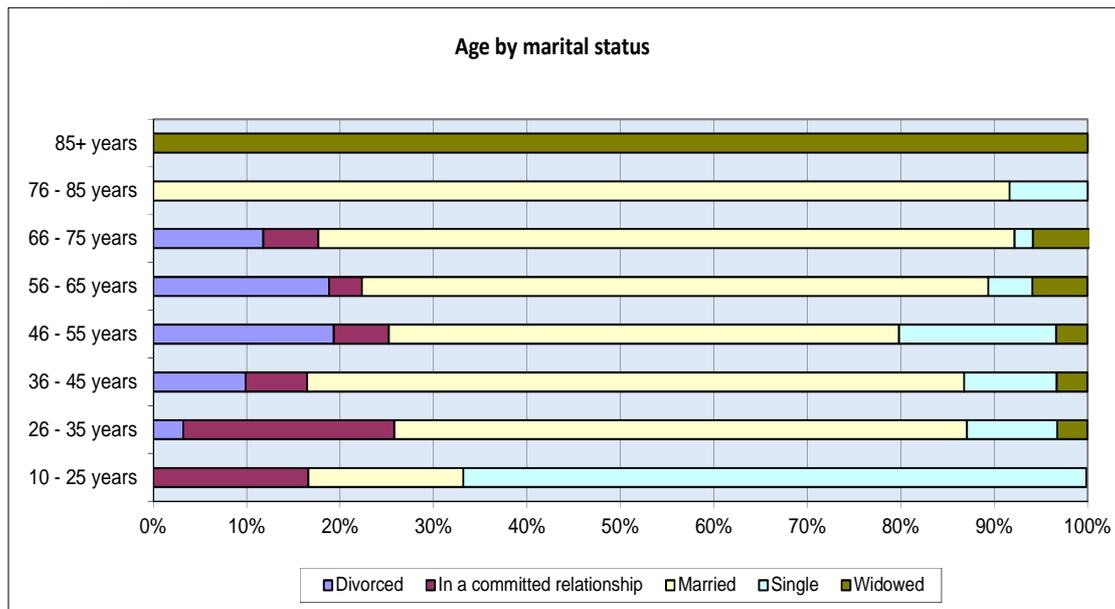
**2. Marital status**

Research indicates that within the carer community, people who are married or in a committed relationship are overrepresented against the general population. This is because the most common carer situation is where one spouse provides care and support to the other spouse. The underrepresentation of those who are single is similarly understandable since their probability of becoming a spousal carer is substantially reduced.

**GRAPH 3**



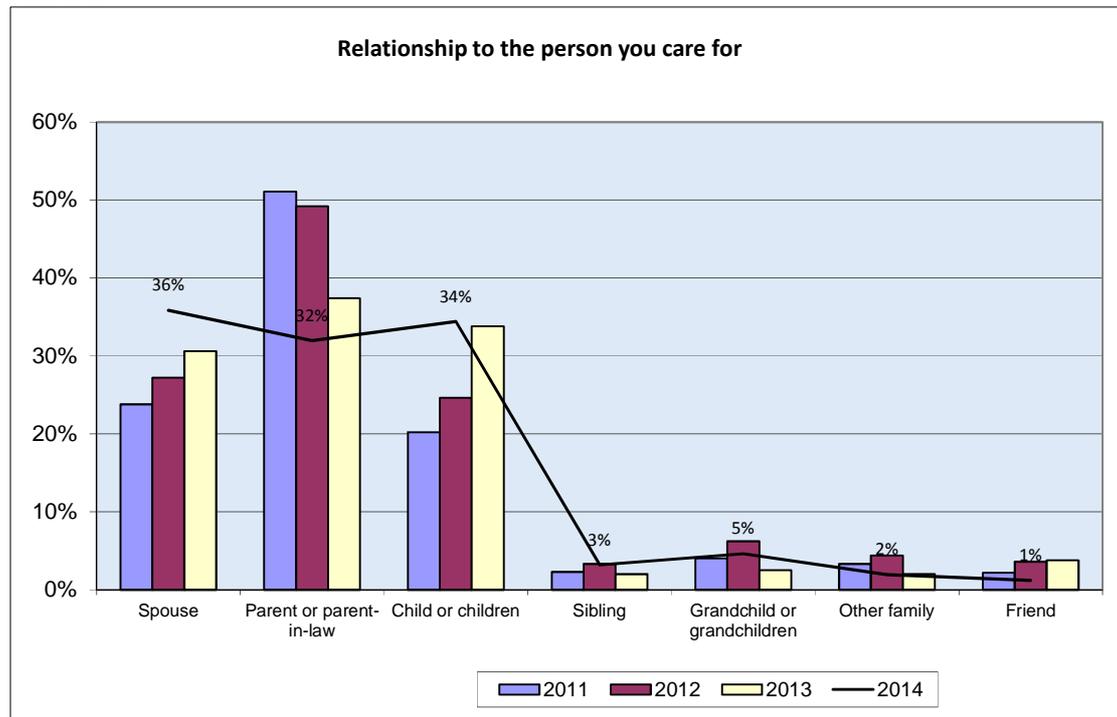
**GRAPH 4**



**3. Your relationship to the person you care for and support**

Australia, like other Western and industrialized countries is ageing. It is forecast that by 2050 approximately 22.6% of the population will be 65 years and older. The increase in the older population will be accompanied by a rise in chronic diseases including dementia, which has been estimated to increase four-fold from 245,400 in 2009 to 1.13 million by 2050. The rise in the number of older people and people living with chronic diseases will probably be accompanied by a rise in sandwich carers; those carers who care for more than one person across two or more generations. The 436 survey respondents provide care and support for 464 people.

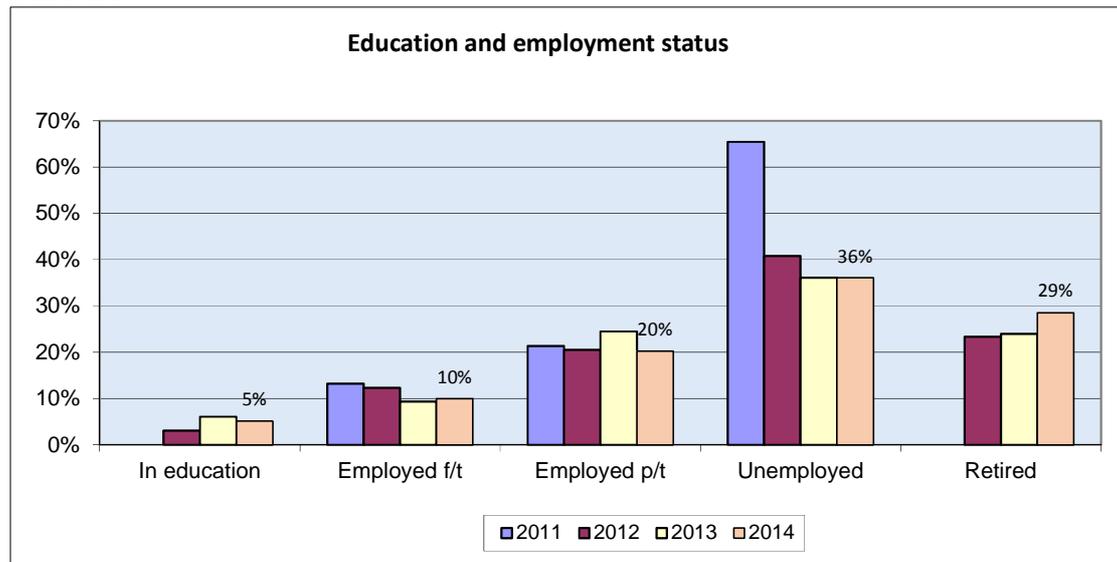
**GRAPH 6**



#### 4. Employment status

Research conducted by the Australian Centre on Quality of Life suggests that whilst most people don't live to work being employed 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. This is reflected in the comments of many carers who spoke of the difficulty of maintaining employment, securing suitable work and the fear of prolonged worklessness and impoverishment.

**GRAPH 7**

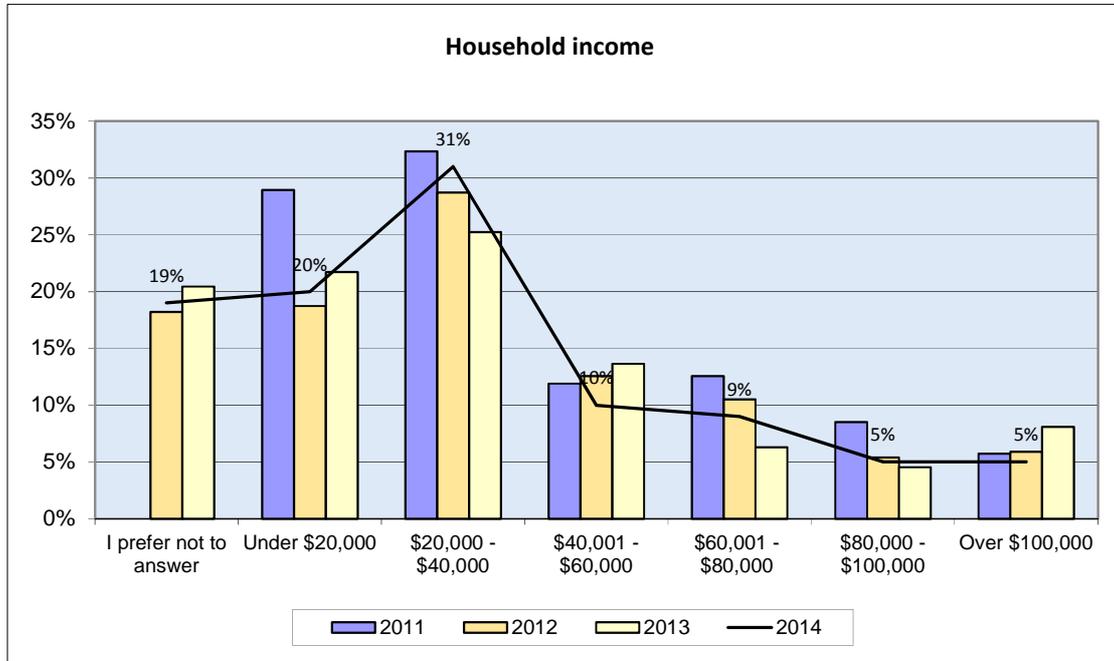


The 5% increase in the number of carers who moved into retirement offsets the 5% reduction in the number of carers in part-time work.

**5. Household income**

Overall, at the aggregate level, carers have 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.

**GRAPH 8**



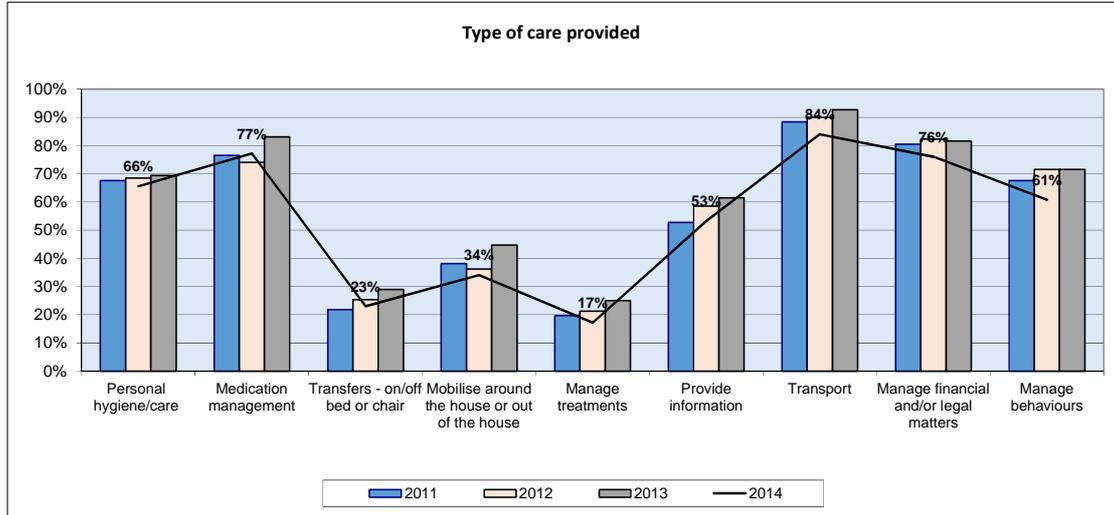
The full time adult average weekly ordinary earnings rose 2.3% in the 12 months to May 2014 to \$1453.90.

51% of survey respondents live on an annual income of less than \$40,000.

**6. Type of care provided**

The 2014 Quality of Life audit shows that the type of care and support provided by carers has been consistent across the last four years.

**GRAPH 9**

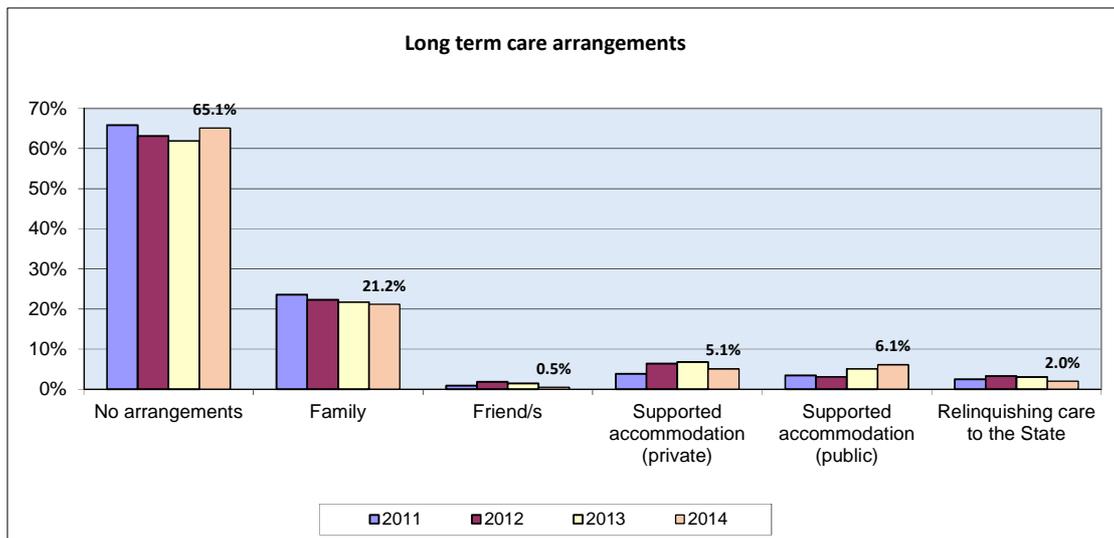


## 7. Long term care arrangements

The number of survey respondents who do not have any long term care arrangements in place rose by 3.1% to 65.1% in 2014. Conversely the number of survey respondents who believe that the State should provide necessary care and support dropped from 3% to 2% and similarly the number of people who have made arrangements for public care provision has also increased by 1% to 6.1%.

This data may reflect the changing demographics of the carer community (see Graph 6) – a rise in the number of parents caring for their children and older people caring for their spouse.

**GRAPH 10**



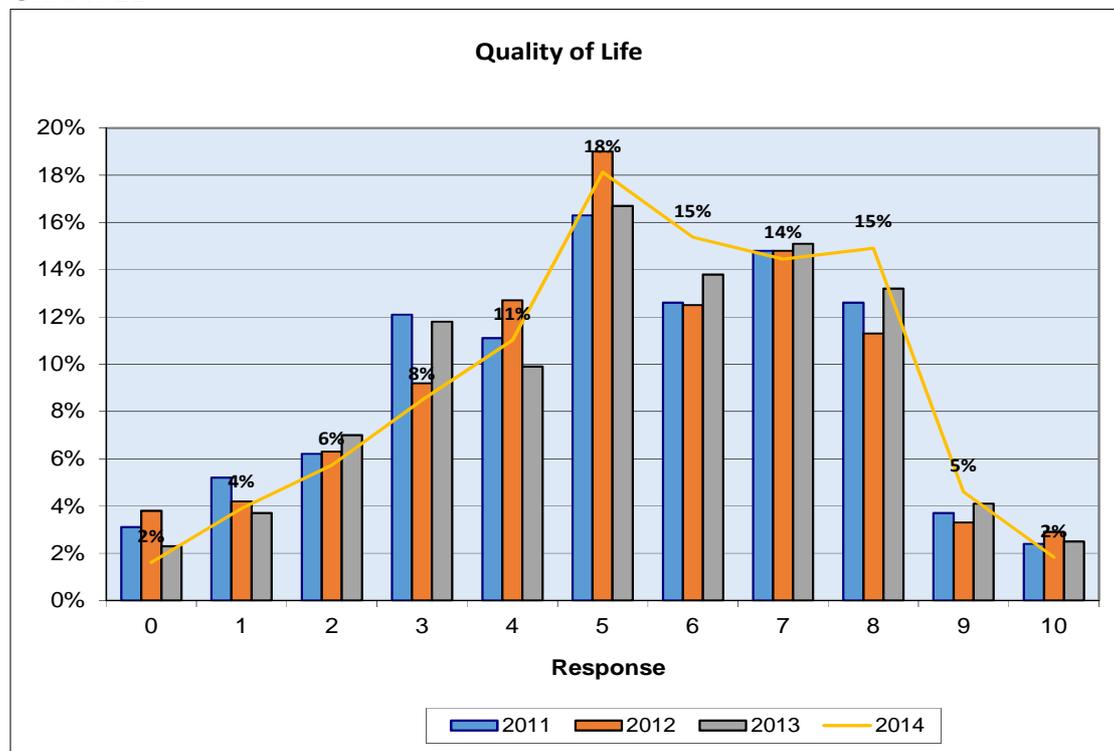
**PART 2 QUALITY OF LIFE INDICATORS**

**2.1 Quality of Life**

57% of the survey respondents indicated that overall they were satisfied with their quality of life, 6% higher than the 2013 audit. This may be a reflection of the number of older carers who have moved into retirement and in the process have gained greater financial security.

However, just over 40% of survey respondents indicated a lack of resources including time, money, physical and emotional energy as negatively impacting on their lives. In particular, many carers wrote of their frustration at the endless negotiations required to secure appropriate and timely formal support services for themselves and the person they care for and support whilst other wrote of their anxiety about the proposed changes to social welfare (the McClure Review).

**GRAPH 11**



***I look after 3 people. I feel very depressed and in a position where no one cares. I am constantly in a stressed out hopeless situation. I am trying to help myself by contacting beyond blue and I have had to go on anxiety pills but I feel used and abused and unheard.***

***My own hopes, dreams and goals have been completely pushed to the side due to my husband's needs coming first and being constant. Everything is expensive, time consuming and just plain HARD.***

***I have been caring for my mum for 11 years; 2 years ago she had a stroke and went in to a nursing and I am still assisting with her care 8 hours a day but I no longer get carers allowance. I am trying to support her, myself and my brother on \$400 a fortnight.***

***Due to caring for my child with a disability, I have lost my profession, many friends, my sense of self, any kind of inner balance. My health has suffered severely from sleep deprivation due to her sleep issues and stress. My personality has changed and I feel I live from one trauma to the next. The saving grace is that we have a dog. I feel stress, isolation and anxiety are what encapsulates my life now.***

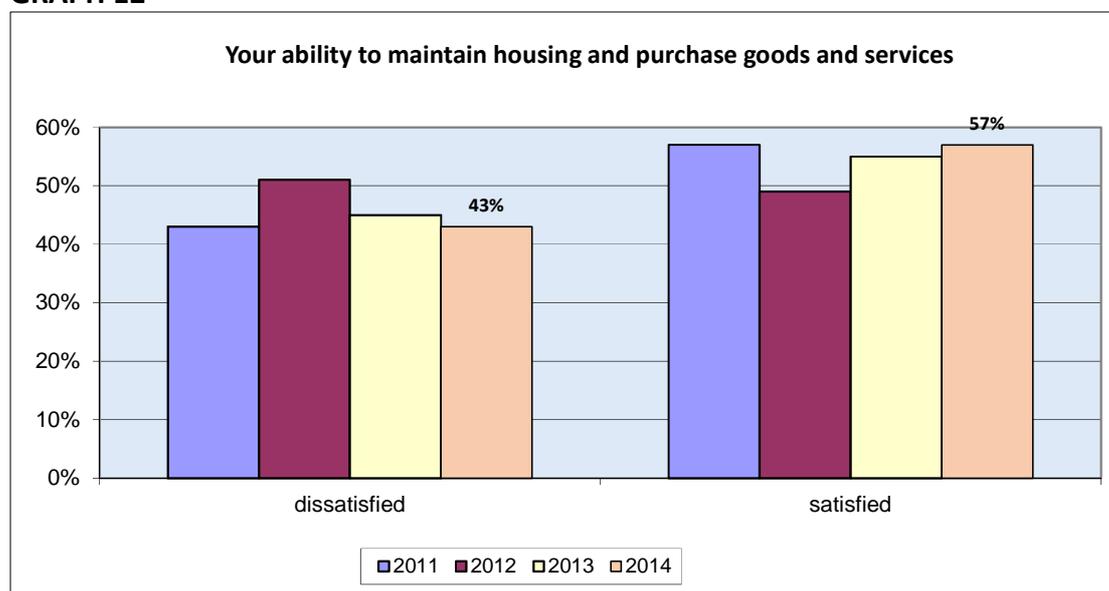
***My daughter requires 24 hour care but has funding for 42 hours of care a week. This means we are together every night and every week for 110 hours. I have no time off to socialise, no assets, no way back into the workforce.***

## 2.2 Housing and cost of living affordability

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.

As many survey respondents attest, living on income support involves living week to week with little room to accommodate an increase in utility costs or an emergency after the essentials such as food, electricity etc. are paid for.

**GRAPH 12**



*At present time we are feeling the crunch of high water bills because the person I care for experiences night time incontinence and refuses aids. The sum total is lots of washing on a daily basis.*

*I live in constant anxiety over thoughts about what will happen if we need to move from this rental house and find another or the biggest worry of all - how I will handle homelessness when the person I care for has to go into a home.*

*Our housing is too expensive in comparison to our income and unable to get cheaper housing. We are unable to pay for goods and services either. Don't have proper beds and can't afford to pay for essential services like the bus or doctor or pay for medication.*

*Cost of living keeps rising and pension does not. In regional areas we pay more for everyday basics and have not choice as to the provider hence more expensive services and utilities.*

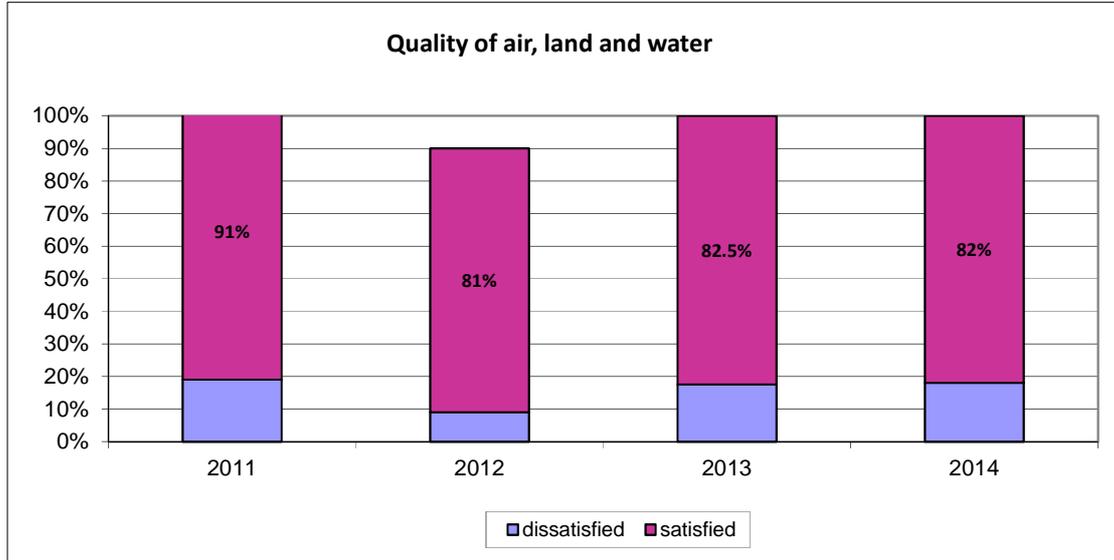
*Whilst we have private rental housing that is excellent for my disabled wife we struggle to make the week to week financial commitments for medical, medicines and school, food etc. We have little money left over for those 'rainy days' when things go wrong (i.e. Car, White Goods, TV, Computers etc.) What we currently have is barely adequate which is why I strongly object to the unannounced changes to Pensions by the current government. We have no 'wiggle room' left.*

*We certainly live on a very frugal budget, and it is only getting worse. Considering getting the home phone disconnected and cancelling out health insurance as they are the only two areas we can reduce/remove. We sold our second car. Utilities are getting very difficult to cover.*

**2.3 Quality of air, land and water**

Some respondents spoke of their dissatisfaction with environmental issues such as pollution and the impact of large-scale mineral mining including coal seam gas fracking.

**GRAPH 13**

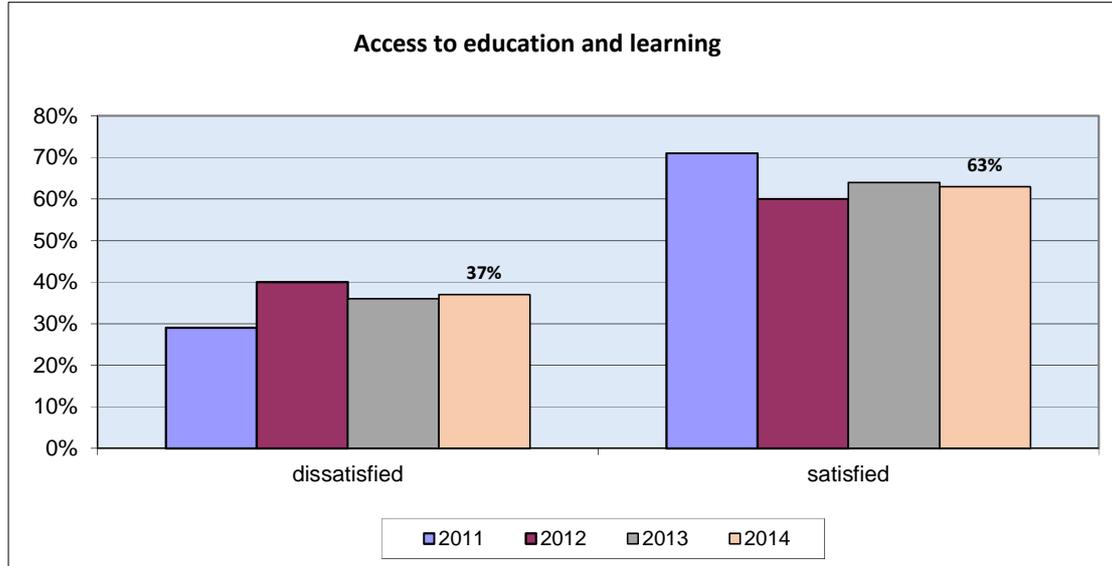


*We live in cluster housing in an industrial area next to a train yard and under a flight path. The person I care for is unable to leave the house as there is nowhere suitable to go, and her main condition is respiratory but the air quality here is absolutely disgusting. It is the dirtiest suburb I have ever lived and because of the avgas exhaust all the dust is black and sticky. The person I care for was almost at a point where she no longer required full time care when we moved in here, however the house and suburb are so bad that her condition has deteriorated to the worst it has ever been. The department doesn't view that as an adequate reason to move us into more suitable housing, and while she is sick like this I can't get training or a decent job to get the money to move us anywhere else. So I just get to watch her die here.*

**2.4 Access to education and learning**

Respondents of working age continue to express frustration at not being able to pursue educational and learning opportunities and lament potential employment or promotional opportunities foregone or out-of-reach.

**GRAPH 14**



*We live more than 80km from the nearest high school and the respite facilities.*

*We have no respite and can't access services.*

*I feel rising costs of education/learning is making this inaccessible for some. I have post graduate qualifications and whilst I would like to do a Masters at this point in my life I may not earn enough to pay off the bill. TAFE costs have risen substantially and if you hold qualifications greater than Certificate 3 you are unable to access government assistance for Certificate 3 subjects many of which are pre-requisite to higher study levels even if you are looking at a complete career change.*

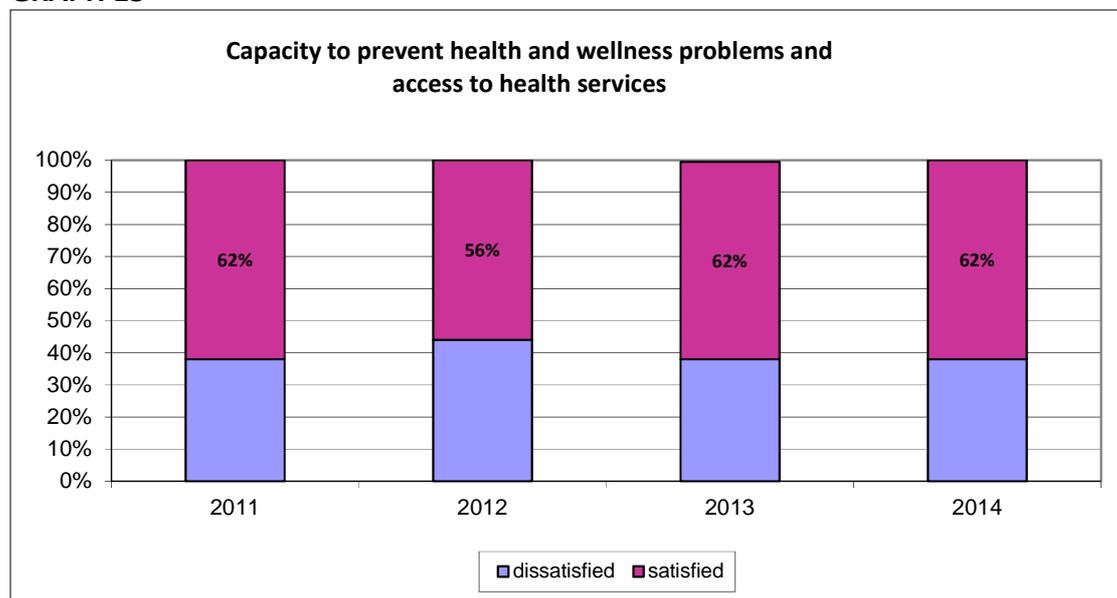
*I enrolled in an Open College course but was unable to proceed when the practical experience & training placement was required. Mum's condition deteriorated, which prevented any ability to commit to necessary practical work outside of our home. I am looking for non-work related education that I can complete at home and that I can afford to enrol in.*

**2.5 Access to health services**

The Australia Centre on Quality of Life research indicates that carers are more likely to be carrying an injury and often do not seek medical attention for themselves because they are energy/cash and/or time poor. The 2014 Quality of Life data, like data from previous years, indicates that many survey respondents place 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.

The respondents in rural and remote Queensland identify a ‘double whammy’ – long delays for an appointment to see a health professional and extensive and expensive travel costs. As a result many suffer poorer health and wellbeing.

**GRAPH 15**



*I have limited access to attend the oncology appointments scheduled for me due to the unreliable nature of support workers. Taking my high needs daughter is out of the question as the wait time can be in excess of 4 hours.*

*Because of the distance I live from the nearest mental health services - over an hour, I can't afford the petrol to travel to a psychologist on a regular basis to be treated for depression. It means my appointments have to be spaced so I can afford to continue. The isolation of being a carer of a daughter with schizophrenia has affected my mental health.*

*My time is exhausted ensuring health and wellness for the person I care for and almost never attend to preventative consultations.*

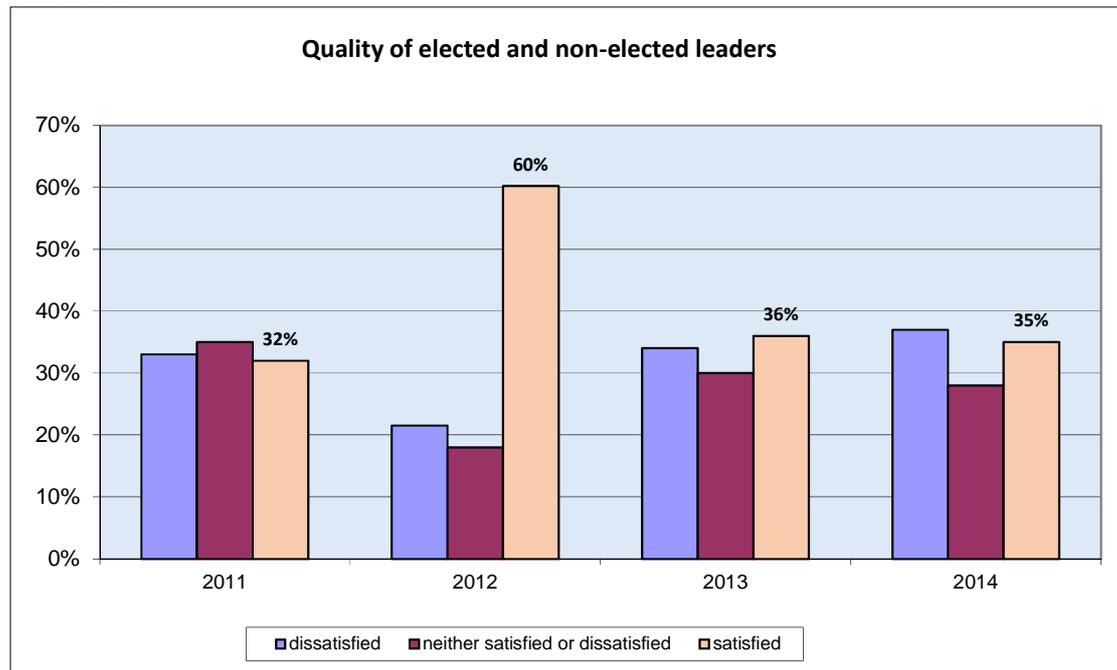
*The caring role impacts my ability to consider my own health needs, until I am forced to do so.*

**2.6 Satisfaction with the quality of elected and non-elected leaders**

Research conducted by the Australian Centre on Quality of Life 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 - such as the ‘hung’ parliaments or leadership challenges.

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 feel threatened by the proposed changes to Australia’s social welfare sector.

**GRAPH 16**

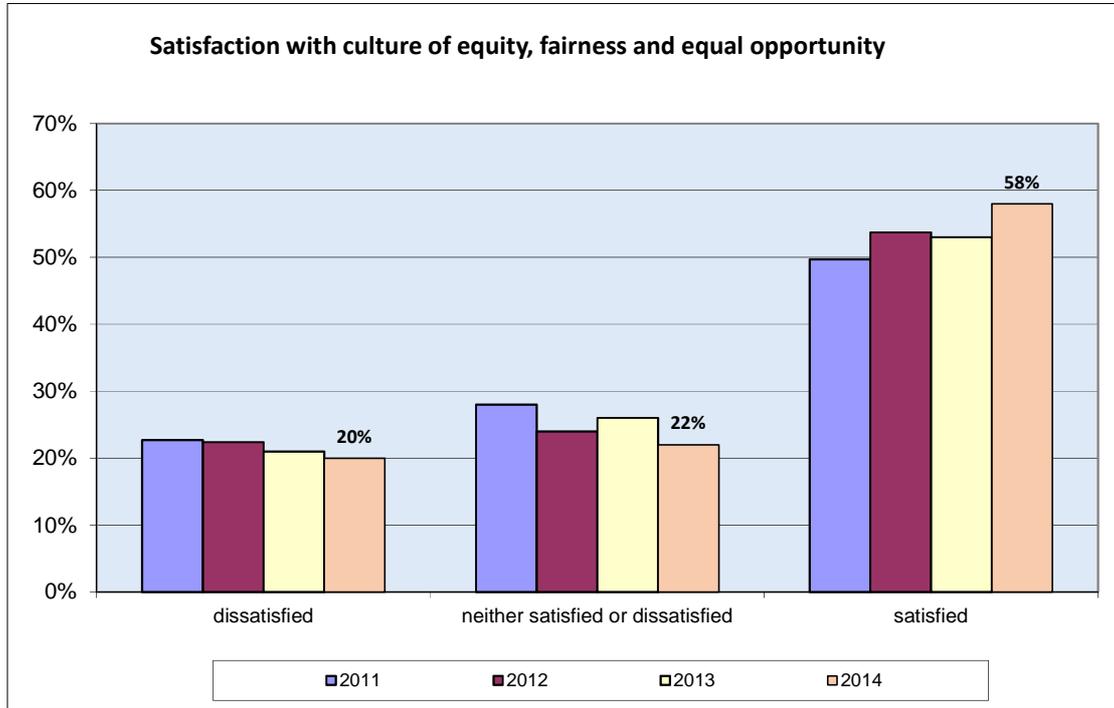


*In general, they are conspicuous by their absence throughout the community. It is my opinion that they are all self-serving and lack the ability to concern themselves with the real issues of their constituents, contrary to all their rhetorical claims.*

*Very unsatisfied as it seems that genuinely disabled families are targeted by the government as a burden that they need to lift off the taxpayers. My daughter tries desperately to obtain work and even with the help of employment services there are not enough equal opportunity employers out there.*

**2.7 Fairness, equity and equal opportunity**

**GRAPH 17**



*I live in a regional centre of around 55000 people and it is difficult to find work. I have post-graduate qualifications in business administration and gerontology, yet cannot even gain an interview on most occasions. Also, the centralising of jobs in capital cities when we have amazing technology that enables people to work virtually anywhere continues to be a very outdated way of getting the best people for the job; it excludes people living outside capital cities irrespective of their skills and experience. As a carer I couldn't move – my mother was dying in a nursing home and it was just not possible to chase work around Australia. After her death, the impact of over a decade of caring has taken a toll and I no longer have the desire or energy to resume what was once a challenging and hectic career.*

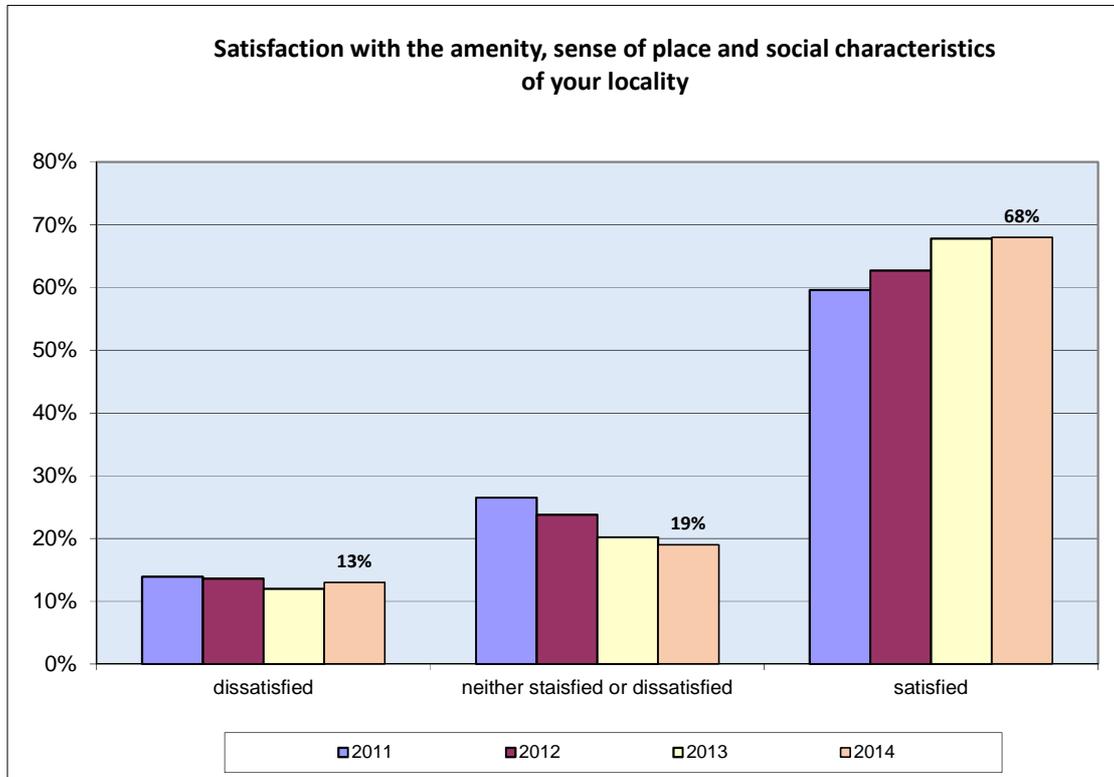
*It doesn't matter where you live, there are still stipulations on how you should live your life. Despite what longevity prospects you have genetically, they still want you to work to 70 and that you have to start working within 2 months of the death of the person you cared for. What about time to do up their house to sell it and getting it on the market and waiting for probate to get the money to do the place up? How can you look for a job and do that all on your own? If you have no other family you've had it. Also you're behind the game technology wise, policy wise etc., so no-one is going to want you.*

*.....I do feel that I am treated unfairly due to my caring responsibilities especially when being considered for career progression.*

**2.8 Amenity, sense of place and social characteristics**

The 2014 Quality of Life audit respondents indicate an overall increased sense of satisfaction with the amenity and social characteristics of their locality.

**GRAPH 18**



*No footpaths in my street or adjoining street. There is a lovely lake near us, however there is no access for wheelchairs to it even if we could get there on footpaths.*

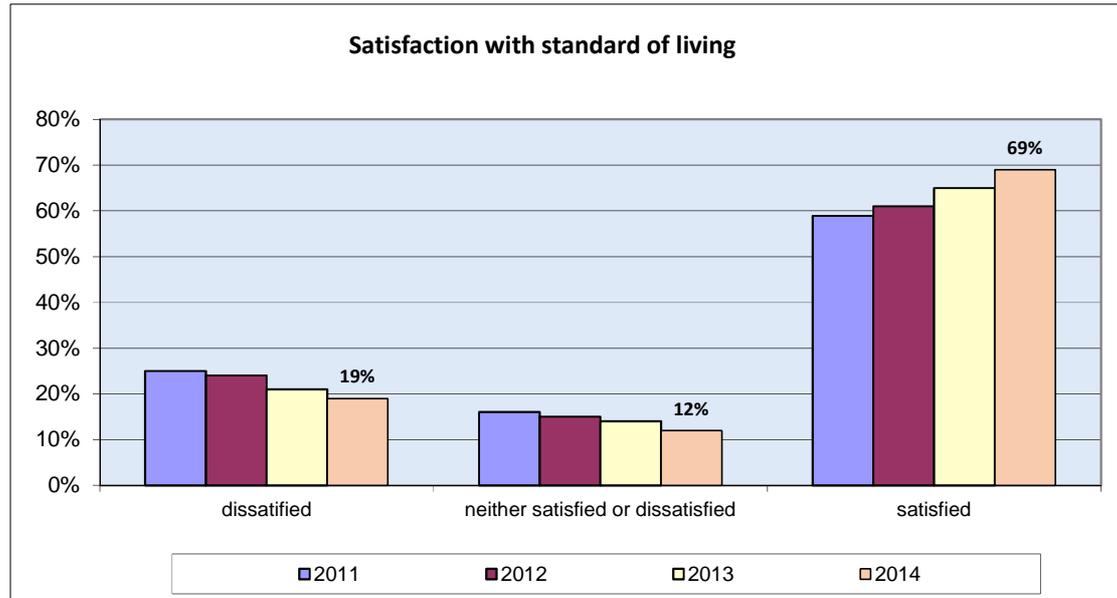
*Very disappointed that the local council is closing two local libraries that have been community meeting points and provide resources. Limited number of support groups.*

*No matter what area, our children can no longer play safely as certain groups tend to pick on and harass and destroy private and public property! Everyone is out for themselves and that's it, there is no such thing as community anymore!*

## 2.9 Satisfaction with current standard of living

Australian research has shown that carers dependent on statutory income support, particularly those who have been in receipt of income support for several years live in persistent poverty and financial stress. Within the carer community this is particularly so for co-resident and primary carers. Many carers pool household resources in order to cope.

**GRAPH 19**



*With two children with special needs, the monthly income only spreads so far and sometimes there is \$1 in the bank the day before pay day, but we make sacrifices and we survive.*

*This is only being maintained through sharing everyday living costs, reinforcing the importance of the family unit support.*

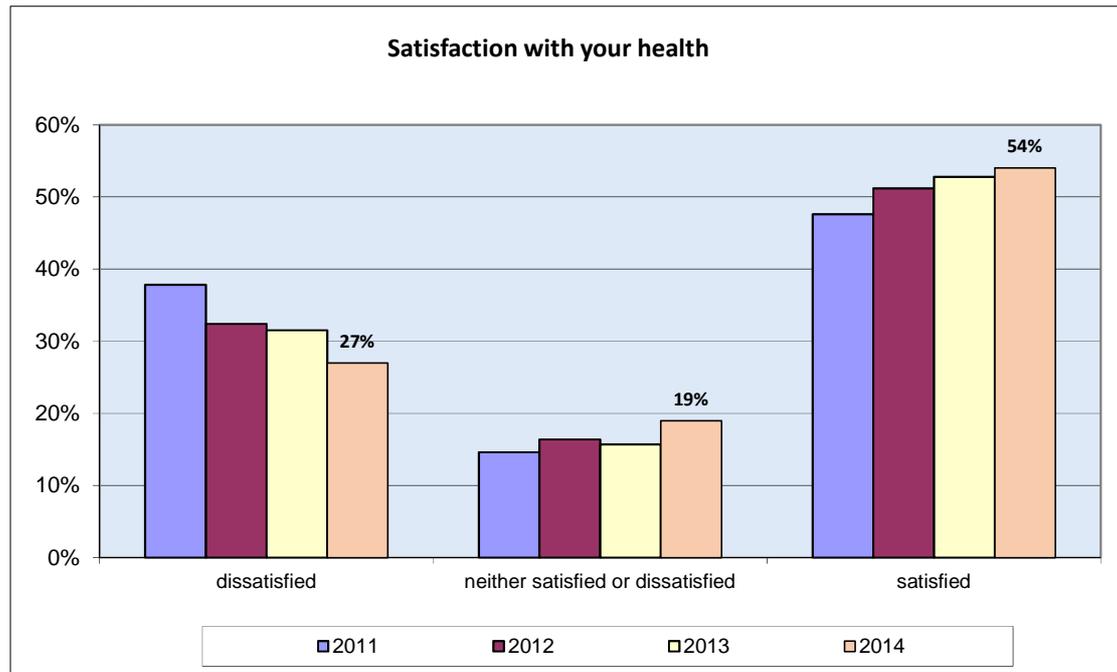
*Everything is a constant struggle as far as money, which restricts the ability to go places, and holidays do not exist. It would be lovely to be able to do this occasionally or to be able to treat my daughter and myself to the occasional treat like a day out etc.*

*Just existing.*

**2.10 Satisfaction with your standard of health**

Generally speaking, our satisfaction with our health decreases as we get older until we are about 55 years of age when subjective wellbeing increases for most, 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 20**



*My back is bad from lifting my mother. I had shoulder surgery a few years ago and it is painful again now too from the same thing. I also have nerve problems in my legs.*

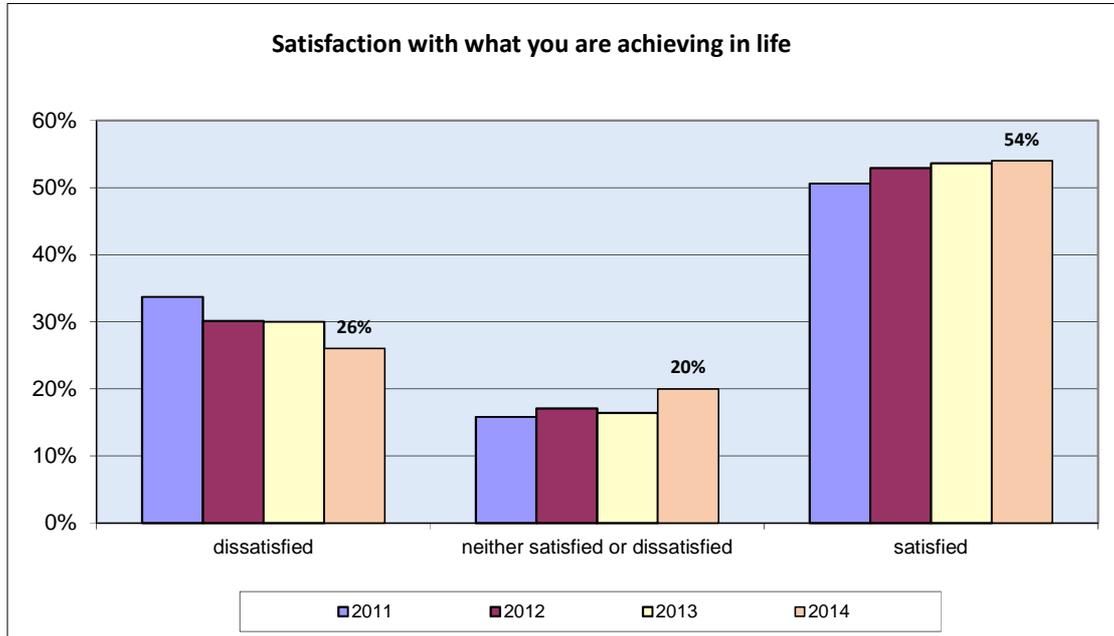
*Poor, due to poverty - have poverty related illnesses.*

*My own health is suffering because of the mental health and abusive behaviour of the person I care for. While I have access to health professions to assist me deal with the behaviour it is still affecting me and my health is deteriorating.*

*The physical and emotional toll from caring has impacted my health. Apart from high blood pressure, depression, lack of sleep, muscle & joint injury from lifting, I have 2 auto-immune conditions suspected to have come on due to stress.*

**2.11 Satisfaction with what you are achieving in life**

**GRAPH 23**



*I so wanted to be great at something, to master an art that was financially & emotionally fulfilling & to have finance to be better able to help others.*

*It is a matter of simply "survival" to enable the care of my daughter.*

*I feel trapped and unable to enjoy life.*

*I want to go back to work, [it would] give me self-satisfaction, like I am contributing to society. I miss having friends or fun work colleagues. I am lonely.*

*I had imagined I would have done many more things at this stage of my life and that I would have a more fulfilling career than the one I have.*

*I see my caring role as a worthwhile achievement and my main focus.*

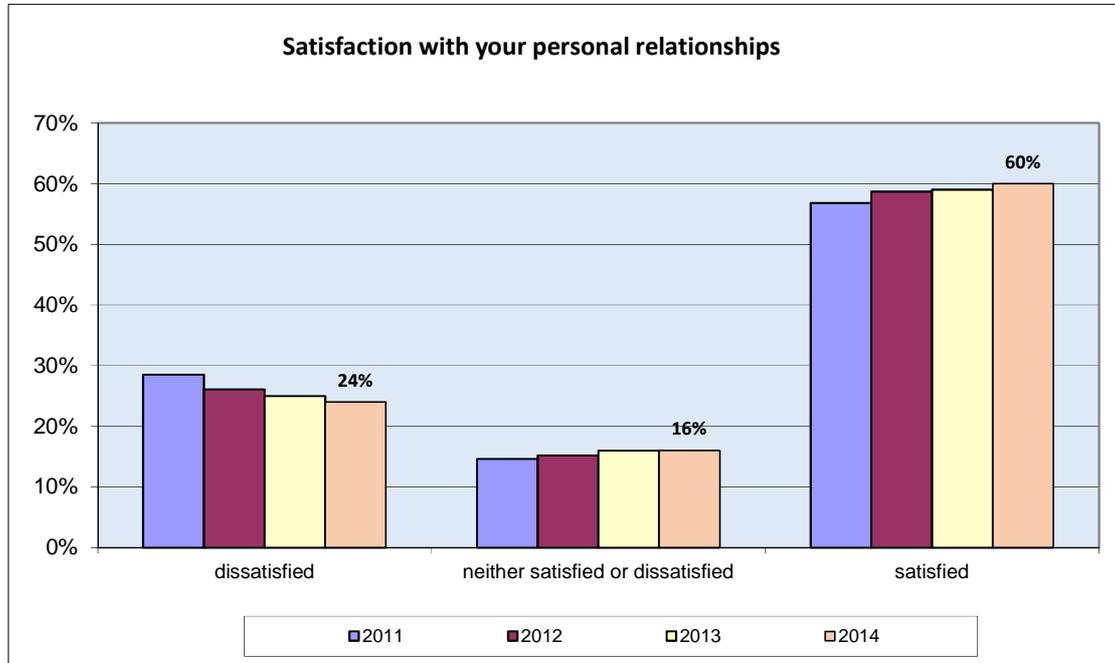
*I am achieving nothing. There are no opportunities and no help. When the person I am caring for dies, I will literally have absolutely nothing. No house, no job, nothing. I may as well die myself. What a waste of a life.*

*I cannot achieve anything I want in life due to caring for family members! But my biggest achievement is how well my son is doing and getting my disabled daughter to walk and highlights that a normal parent would take for granted!*

**2.12 Satisfaction with your personal relationships**

Many carers speak of isolation and loneliness both within their personal relationships and in the broader community as a result of their caring responsibilities.

**GRAPH 24**



*Have been coping with single parent status since 1984. I contend with my daughters challenging psychological/emotional behaviour on a daily basis, [but] this has precluded the pursuit of any personal relationships.*

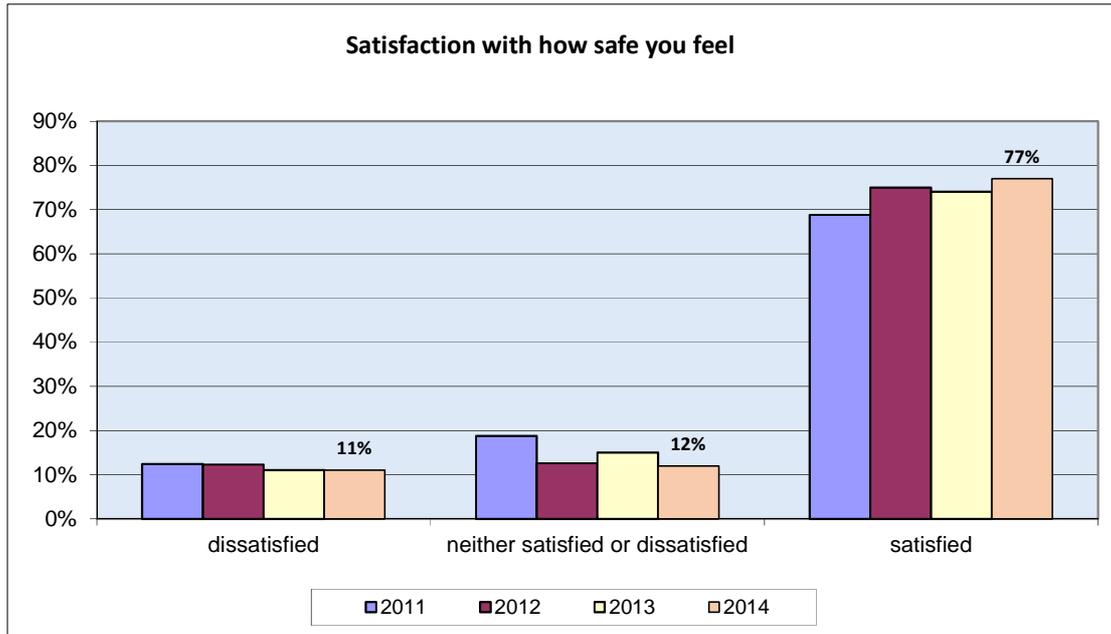
*Making friends and developing personal relationships requires time and resources to build. Due to my continued caring role, this time is not available. I have noticed recently even long term friendships are fading as I am not able to spend quality time with these people.*

*Have lots of good friends but rarely see family unless I take time out and go to them. If my husband (who I care for) comes it is a massively stressful time because I'm never sure what he's going to do or say. If I go alone, I pay for it with his anger and hostility for days afterwards. My students and their parents keep me sane.*

**2.13 Satisfaction with how safe you feel**

An individual’s perception of their safety, and conversely their vulnerability, is a subjective assessment of their circumstances and is relative to a specific point in time and relates to a number of variables, some of which are beyond the control of an individual. As noted in the anecdotal comments of respondents many carers feel vulnerable in relation to long term care options, housing, physical safety and financial security.

**GRAPH 27**



*I feel safe but I do worry about the future, I am lucky to have a supportive husband but I worry about my retirement and who will look after my son when I die. This makes me feel insecure.*

*I feel scared that things will never change. My situation is complex I fear I will be pushed over the edge.*

*I am often scared with the area we live in.*

*I feel insecure and vulnerable at times in public places with my special needs kids.*

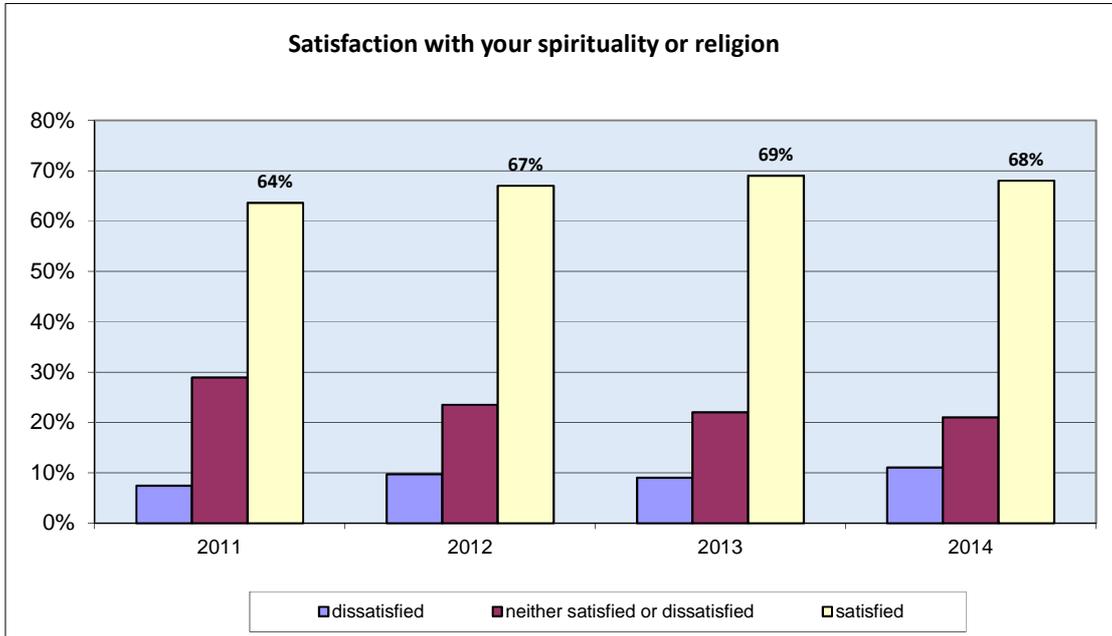
*I feel now that I am caring for my husband, I get scared as to what will happen to me if and when he leaves this world.*

*I have no safety, no security... I live in constant fear of ending up homeless and jobless because I didn't just leave my mother to die when I was 18.*

*Don't feel safe being on pensions, [with] the government threatening welfare cut backs, and expecting carers to go back to work. Fed up with our livelihoods being targeted.*

**2.14 Satisfaction with your spirituality or religion**

**GRAPH 28**



*I try to be a positivist and live by a philosophy that what will be will be and I have little control over outcomes. I lost faith a long time ago and spiritualism only enforces the notion that I somehow deserve the life I have as a carer.*

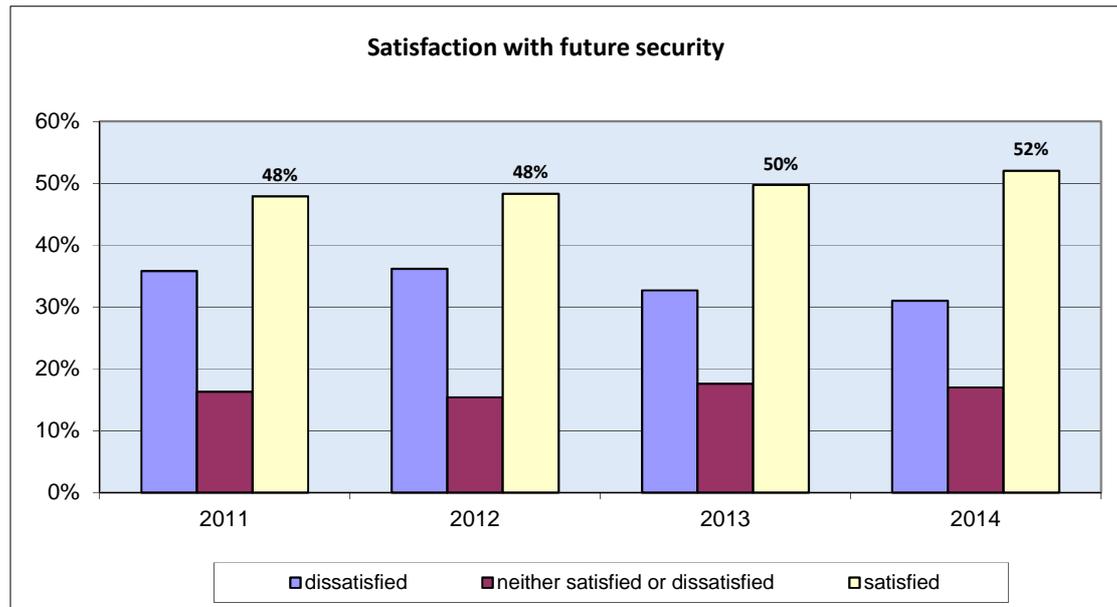
*I feel my spiritual alertness and own beliefs is what keeps me having hope.*

*I don't know what I would do without it.*

**2.15 Satisfaction with your future security**

As indicated by the 2014 audit data a carer’s satisfaction with their future security is very closely related to the security of their income, their current sense of safety, satisfaction with their personal relationships and friendships and their ability to direct and/or control the long term care options for the person they care for and support.

**GRAPH 29**



*The current government seems to be eroding the stability and financial security I have worked hard for. Talk of taking people off the disability pension, making the unemployed wait 6 months for benefits and looking for forty jobs a month to qualify for benefits, GP co contribution, funding cuts to support organisations and so on.*

*I worry about the future for my boys. Where will they live, who will support them? Can we continue to afford suitable housing for us all?*

*I am scared at where we and a lot of other families will be in the future as it feels as if we are all going to be living in poverty and on the streets! I am especially scared for my children and my special needs child as she will not have a place anywhere and no one to care for her if we pass!*

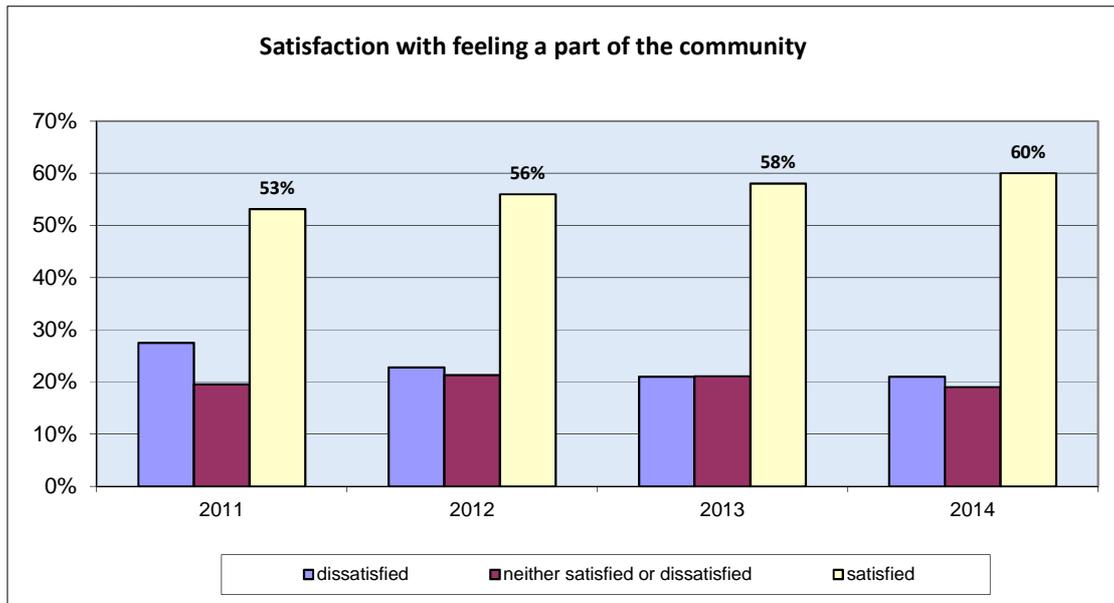
*Future security is the subject that keeps me up at night and constricts my chest. I have very little superannuation and no career. I have been a carer for 14 years and there is no end in sight. What will be my fate when I am aged?*

***There is no security for anyone in this current paradigm.***

**2.16 Satisfaction with feeling part of the community**

A carer’s satisfaction with feeling a part of the local community is very closely 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.

**GRAPH 30**



*I find it difficult taking my son to any public places. He looks normal but acts different, I don't like feeling like a bad mother not controlling his behaviour.*

*For me to join into community groups, my son also needs to be accepted.*

*I don't feel part of the community at all! I feel isolated and no-one is particularly interested.*

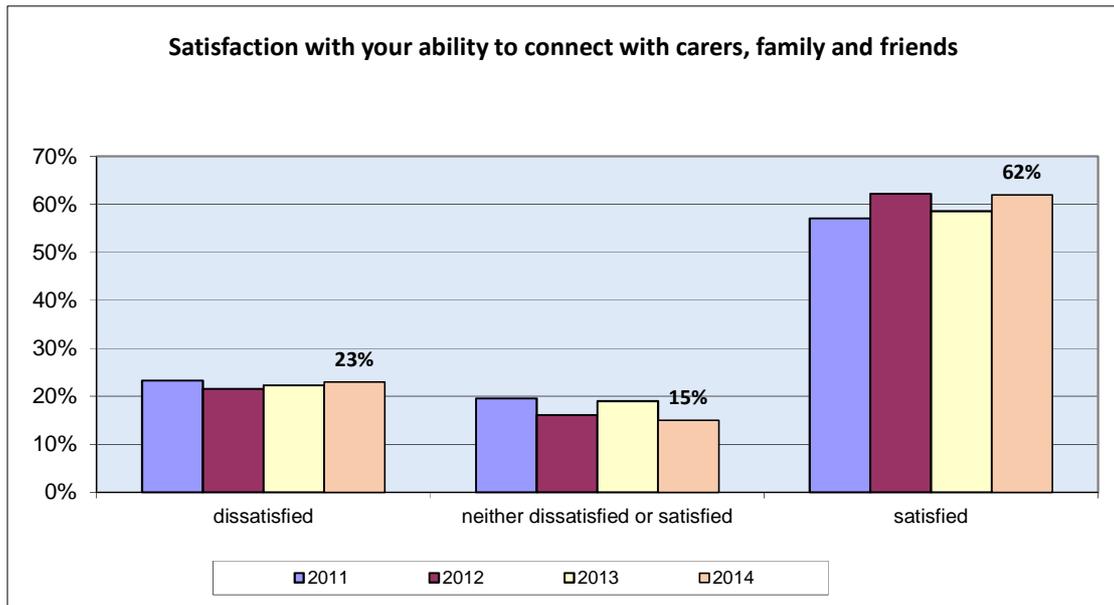
*There needs to be more adult change facilities; we can never go far from home because of it. It's all very well and good having the new inclusive playgrounds but without adult change facilities how can you expect our kids to use them? And why are disabled toilets always locked?*

*I feel like an island most days.*

**2.17 Satisfaction with your ability to communicate and connect with other carers, your family and friends**

The Australian Centre on Quality of Life research 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 judged (admired or belittled) is based on an individual’s perception or interpretation of the disability or illness of the care recipient.

**GRAPH 31**



*I often talk to my sister in a different state who gets me as she also has a child with disability. I do go to a MY TIME group to hear other parents talk so I don't feel alone in this but I haven't made any friends.*

*Discrimination when I'm with my husband who I care for. I do not have time to do anything on my own and not enough money to actively be involved in my community very often. It is embarrassing and very negative on my self-esteem.*

*I have wonderful friends and family, but am conscious of compassion fatigue as my husband has been ill for many years. I feel sometimes that people don't want to know so I don't always share truthfully.*

*I feel I am judged and feel out of place.*

## PART 3 TAKING A BREAK

### 3.1 Introduction

While some carers experience emotional and social wellbeing throughout their caring journey, many experience negative consequences including sleep deprivation, strained personal and family relationships, chronic physical injuries and reduced time and space for personal pursuits and employment, all of which have an impact on the health and wellbeing of the individual carer. Respite (short breaks) or me-time can, and does, go some way to alleviating these negative consequences, albeit temporarily. The need for a break or me-time is generally uncontested.

I suffer depression now... I eat a lot out of comfort so my weight has gained substantially... I have high blood pressure. I live in a constant state of anxiety. My doctor said I suffer from carer's stress!

Depending on the context of its use respite is a term that is used both as a noun and a verb. Respite has been variously defined as a 'desired outcome of an intervention' and the description of 'those alternative care arrangements that are funded and provided as one way to produce the desired outcomes for carers'. In more personal terms respite has been described as a gift of time to relieve stress, recharge one's batteries, to enjoy some non-caring time with other family and friends etc.

Carers possess the lowest subjective wellbeing of any sub-group yet surveyed in Australia.

Moreover, approximately 37% of carers report severe to extremely severe symptoms of depression and stress.

Me-time can involve both personal leisure activities and, for some, carer specific support activities such as counselling. Longitudinal research conducted by the Australian Centre on Quality of Life has shown that carers who participate in carer specific counselling can improve their overall quality of life.

Over a series of evaluations the research has shown that carers participating in the National Carer Counselling Program can improve their wellbeing score from approximately 58 points to 65 points, the most significant improvement occurring in the life domain of satisfaction with personal relationships.

While this is a significant personal improvement, the wellbeing value of participating carers remains below the normative range (73.6 to 76.3).

### 3.2 Survey results

Me-time means just that; time for a carer to enjoy personal activities or interests or just recharge the batteries either through personal pursuits or carer specific support activities.

Of the survey respondents:

- ✚ 79% have 10 hours or less of me-time per week
- ✚ 90% have 15 hours or less of me-time per week
- ✚ 71% find me-time to be either very (31%) or extremely (40%) valuable

Taking a break can be difficult, particularly if it involves securing and/or coordinating respite or alternative care arrangements. An onerous task in itself, organising respite can be more difficult if the carer is reliant on formal respite care which can often be either unavailable or heavily rationed.

In order to enjoy some me-time:

- ✚ 52% of survey respondents rely on formal (29%) or informal (23%) respite care arrangements
- ✚ 37% of survey respondents did not require alternative care arrangements
- ✚ 11% have other arrangements in place

For some carers valuable me-time includes carer specific activities, sharing time with other carers in a supportive environment, either face-to-face or on-line.

Of the survey respondents who participate in carer specific support activities:

- ✚ 22.6% attend a carer support group
- ✚ 6.0% attend carer retreats
- ✚ 13% reflect on personal concerns or issues with a professional counsellor

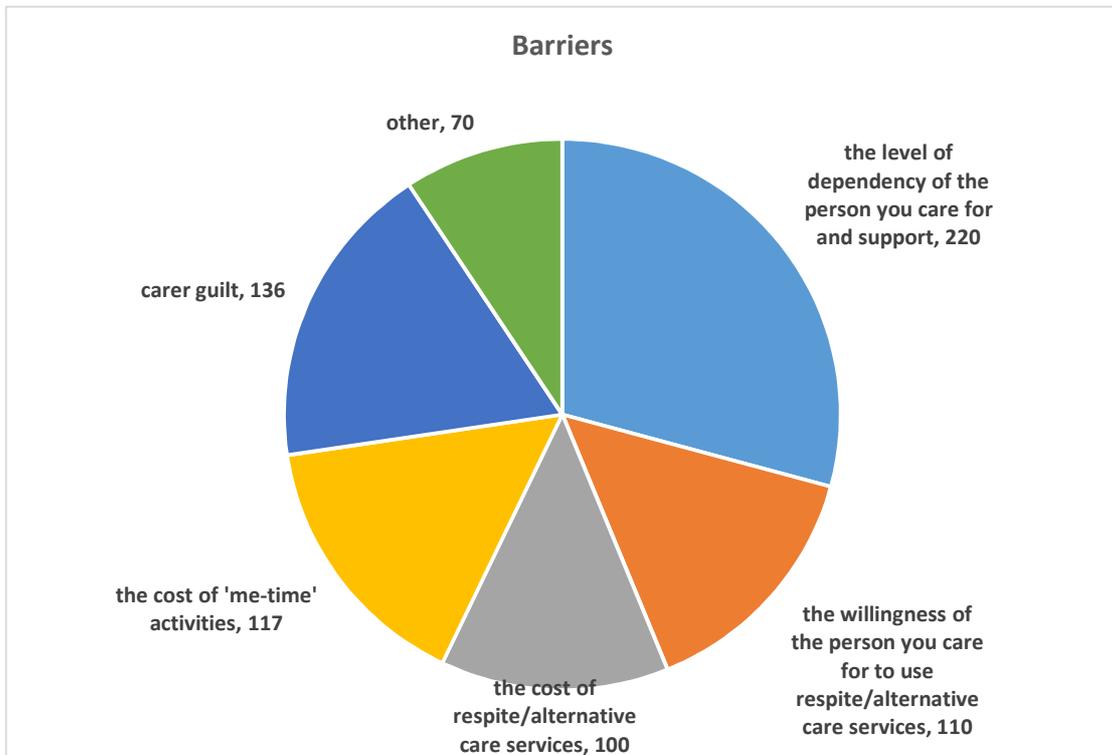
*I don't have any family support, but I feel okay about communicating with friends. Joining an on-line support group for carers has been a Godsend and has allowed me to meet other carers online and express some of my concerns in an atmosphere where people understand.*

**GRAPH 32**



Committing to or organising me-time can be easier said than done. A carers capacity to enjoy time can be mitigated by so many factors beyond the carers control and for many carers there can be more than one barrier to achieving me-time.

**GRAPH 33**



***I didn't really want "me" time; I just wanted "more" time. What would have helped me most when I was caring was to have someone come in for 3 hours per week and clean the house and do some ironing. This would have reduced a significant burden on me and allowed me to slow down a bit in all areas of my life.***

***If I ask someone else to look after my children I feel guilty. They also hate it unless it is a close family member.***

***Switching off from caring role is difficult at times so valuable quiet time is used thinking about our children instead of enjoying the break. I joke to myself that I need a personal stylist and makeup artist to help make me presentable for "me time" activities with my husband and/or others.***

***She likes to ruin it for me when I return by putting on a tantrum then next saying I can have time off whenever I want it.***

***Even though my son has been in respite this week there were issues that had to be dealt with - getting him to the doctor and organising medications.***

***There are no respite facilities that will take a tracheostomy patient.***

***My needs don't seem that important and all focus is on the person I care for.***

***I feel a burden asking others to look after my son especially when he 'acts out' as he is not happy to be away from me.***

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