



Who cares?

Older Australians do

May 2020

National Seniors
AUSTRALIA

Who cares? Older Australians do

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Publisher: National Seniors

ABN: 81 101 126 587 ISBN: 978-0-6483647-6-4

Suggested citation: Maccora, J., Ee, N., Hosking, D., McCallum, J. (2020) *Who Cares? Older Australians do*. Canberra: National Seniors

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Executive Summary

The care needs gap in Australia is being met with informal and unpaid care. Informal and unpaid carers provide support to those most in need within Australian society and provide a way forward for future generations. Older carers are leading contributors to the civic and social fabric of Australia, and yet their work often goes unrecognised, unacknowledged and unsupported. With increasing healthy life expectancy, there is a growing population of older adults who are able, willing and well-placed to provide care. This report seeks to illuminate the invaluable and continued contribution of older Australian carers, acknowledge their sacrifices and understand the challenges they currently face.

This report found the following:

- Older adults primarily care for partners, parents and adult children and many do so out of love.
- Marriage and duty were key drivers of caring for a partner, with older men and women equally fulfilling these roles.
- The role of caring for parents appears gendered, with more older women providing care to parents than older men.
- Older adults are providing care irrespective of their income status, though economic savings associated with unpaid care appears to be an incentive.
- Care is extensive and time consuming, with carers spending an average of 26 hours per week on caring.
- Over half of unpaid carers are providing high to medium level care and one sixth are providing high level care in the home.
- Caring involves great sacrifice and is associated with poorer mental and physical health.
- Most carers have not accessed care plans or government support.
- Older carers need accessible and effective practical, financial, social and psychological support.

In summary, older carers provide care, often at the expense of their own health and wellbeing, for a host of personal and pragmatic reasons. These centre around dignity and respect for their care partner, financial and practical reasons, and lack of feasible or acceptable alternatives. The state of caring can be improved to achieve more positive outcomes for older carers and support them on their care journey. To do so, proper consultation with older carers is required.

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1. Foreword

It is impossible to publish a report about care in Australia in the year 2020 without considering the context of the COVID-19 pandemic and its impact on Australian society, the full extent of which remains to be seen. One unexpected consequence of the health crisis is that it has forced a spotlight onto otherwise hidden structures which support the ways Australians live and work [1]. Structures such as grandparents picking up children from school to enable parents to work a full day; adult children driving older parents to medical appointments when they are unable to do so themselves; neighbours checking on each other to make sure that everything is OK; and older adults providing daily care to their partners when one of them is no longer able to care for themselves. The social distancing policies instigated to prevent the spread of the Coronavirus have caused the breakdown of some of these structures, and placed others under extreme pressure. This has resulted in yawning gaps that governments and individuals are scrambling to fill.

While we are still reeling from these changes and wondering where to go from here, it is an opportune moment to acknowledge the contributions of Australians over 50 to the health and wellbeing of the country through unpaid care. The time is ripe to reconsider the value we place on our older Australians and to recognise the vital role they play in our country's future.

2. Background

2.1. The state of informal care in Australia

Informal or unpaid care plays a critical role in fulfilling the care gap in society. In Australia, about 1 in 10 people act in long term informal care roles associated with supporting older persons, disability or long term health conditions [2], and many more engage in unpaid childcare arrangements. The cumulative Australian informal and unpaid care contribution is substantial:

- the majority of National Disability Insurance Scheme (NDIS) users have an informal carer [3];
- 420,000 Australians provide some form of care to older adults;
- a large proportion of childcare needs are met with a combination of formalised and unpaid care [4, 5]; and
- the annual informal disability and aged care contribution is estimated to be worth \$60.3 billion, forming 1.9 billion hours spent caring [6, 7].

This contribution is so great that no insurance scheme would be able to fund its replacement [8], as stated by the Productivity Commission in 2011. A further \$4.4 billion per year is estimated to represent the unpaid time spent by grandparents on childcare provision. The current report will focus on informal aged- and disability-related care. A companion report, *Australian Grandparents Care*, focuses specifically on the contribution of grandparent childcare in Australia.

Carers play an invaluable role in society and understanding who they are is critical to effectively supporting their needs. Informal carers are more likely to be females than males [2], in or approaching older adulthood, with 45% of carers aged between 45 and 64, and 24% aged 65 and older [3, 9]. Common challenges faced by informal carers include:

- poor mental health due to reasons such as feelings of social isolation;
- loss of privacy and personal control in providing care;
- having a disability or illness themselves;
- financial burden associated with caring, with 1 in 2 carers coming from low-income households; and
- lower participation in the active workforce due to caring responsibilities [2,5,10-12].

2.2. Caring for our carers

There is a range of government support for carers, dependent on meeting means test and qualification processes:

- the means-tested Carer Payment;
- Carer allowance;
- Child Disability Assistance Payment;
- Carer Adjustment Payment, and Carer supplement; and
- ancillary benefits such as bereavement payment concession, pharmaceutical allowances, rent assistance and a pensioner education supplement [13].

There are other forms of public carer support including: counselling, respite services and informational resources [14-16]. Fair Work, anti-discrimination and privacy laws also seek to protect carers [17, 18]. For example, informal carers are entitled to request flexible working hours and unpaid or compassionate leave to accommodate caring duties. This entitlement is not well-known and rarely exercised for practical reasons. Currently, only a small minority of all informal carers receive financial assistance from the government [3]. Many face delays or difficulties when accessing support payments, respite funding or services, and adherence to carer protection laws on an organisational level is variable [19].

The global care landscape provides some insight into successful and alternative frameworks for carer support. Amongst many we note:

- Canada's tax credit scheme aimed to minimise financial burden on carers and pension plans which provide income protection against periods of zero earnings due to providing care to a family member;
- legislation allowing early access to the full pension in France, and government provided non-contributory pension credits; home- or group- based carer skill training and legislation making carers eligible for up to two years of partial leave of absence for reasons of long-term home-based care [19].

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2.3. Research evidence about the ‘gift of older carers’

Older adults represent a significant proportion of the aged and disability care contribution. Older carers tend to be women, in part due to greater life expectancy for women and men tending to be older than their female partners in the older cohort [20, 21]. Most older male primary carers are providing care to their partners [22]. Importantly, older age is associated with higher risk of comorbidity, disability and frailty [23, 24]. Older carers are thus likely to be managing changing personal needs alongside their caring responsibilities. Indeed, higher rates of chronic disease and disability has been observed in older carers as compared to older non-carers [25, 26].

Care provision in older adulthood has also been associated with increased risk of depressive symptoms, malnutrition, and obesity [35]. Further, older carers are more likely than younger carers to become unemployed or give up employment due to caring duties [11, 27], and less likely than younger carers to be in receipt of financial support. Nevertheless, Australian older carers appear to better adapt than younger carer age groups. Data from the Australian Bureau of Statistics showed older carers were more likely than younger carers to provide care free of assistance [22], have their friendships and income unaffected by their caring role, and gain satisfaction from caring [28].

Despite the increasing number of older carers in our community and their significant role, a recent scoping review found that older carers are underexplored in qualitative research [29]. The majority of studies focusing on older carers investigate the social, economic and health impacts of caring, together with the demographic characteristics of older carers and care recipients. These studies are frequently based on administrative data or national survey data such as the Disability Ageing and Carers’ survey conducted every three years in Australia by the Australian Bureau of Statistics. Such quantitative data, however, do not capture the lived experience of carers, including their motivations, needs and choices, or lack thereof, in providing care.

In Australia, as in many other countries, aged care policy and budgets are built with the implicit assumption that spouses and families are available, willing, and equipped to care for older community members. Yet these policy settings create potential inequity for caregivers because consumer directed care focuses on the choices of older care recipients, seemingly at the expense of choice for their caregiver [30].

More research is required that prioritises the experiences of older carers so policy can equally support their needs and choices. A recent systematic review of informal caregivers’ preferences across 17 countries found four broad topics applied internationally:

1. informational needs;
2. support needs;
3. organisational needs; and
4. needs for societal recognition [31].

The authors highlight, however, that the experience of caregiving is geographically, demographically, and culturally defined. In the United Kingdom, there is an emerging

literature that addresses broad experiences of older caregivers [32-34], but in Australia, caregiving by older people is addressed primarily in the context of dementia care associated with exceptionally high caregiver burden [35].

Our study focuses on increasing the understanding of older community carers' demographic characteristics, social values and emotional experiences through a set of care-related questions that include options for describing caring activities, articulating motivations and reasons for caring, and reflecting on caring needs and perceptions.

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3. Data and Methods

3.1. The National Seniors Social Survey (NSSS-8)

Every year, National Seniors conducts an online survey of members' behaviours and views across a range of topics relevant to older peoples' lifestyle, health and wellbeing. The survey is open to members and non-members 50 years and over from all states and territories. A link to the survey was sent directly to all members who had provided an email address. The survey was made available on the National Seniors website and circulated via a member online newsletter and in the quarterly magazine. The NSSS-8 was approved by the Belberry Human Research Ethics Committee, reference HREC-2019-04-329. Questions were 'point and click' multiple choice format accompanied by free text boxes enabling participants to elaborate on their responses if they wished.

Data for this report were taken from participants' responses to a component of the Survey titled "The care you give". Questions asked about grandparenting care; care for adults including partners, parents, and adult children; and the types of care provided and required. The care questions from the Survey are provided as Appendix 1. Participants also provided socio-demographic information and their self-rated level of health.

Survey responses were collected online via the survey tool Survey Monkey®. 12 responses received via a paper copy of the survey were entered into Survey Monkey by a National Seniors Research Officer. A pre-defined data cleaning protocol was used to remove duplicate responses. Data were collated and graphed using Microsoft Excel and Stata (version 15.1).

Text comments were analysed using the thematic analysis framework described by Braun and Clarke [36]. Two National Seniors Research Officers separately read and coded the optional text comments which were provided as elaborations of participants' point and click responses to the 'care you give' section of the survey. Codes were discussed and agreed upon by the researchers and sorted into potential themes arrived at by consensus. Themes were identified primarily through inductive analysis i.e. data were coded without reference to an explicit pre-existing theoretical framework. The researchers acknowledge the influence of their pre-existing theoretical knowledge and understanding on the codes and themes identified from the data [36].

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There were 4139 responses to the question regarding whether participants provided care to anyone other than grandchildren, and of these, 22.2% were providing care to another adult.

4.1. How old are people who care?

The mean age of carers was 68.3, slightly younger than the mean age of other survey respondents of 70.8. The majority of carers were in the age bracket 60 to 79, with less than ten per cent of carers in the 80+ age group.

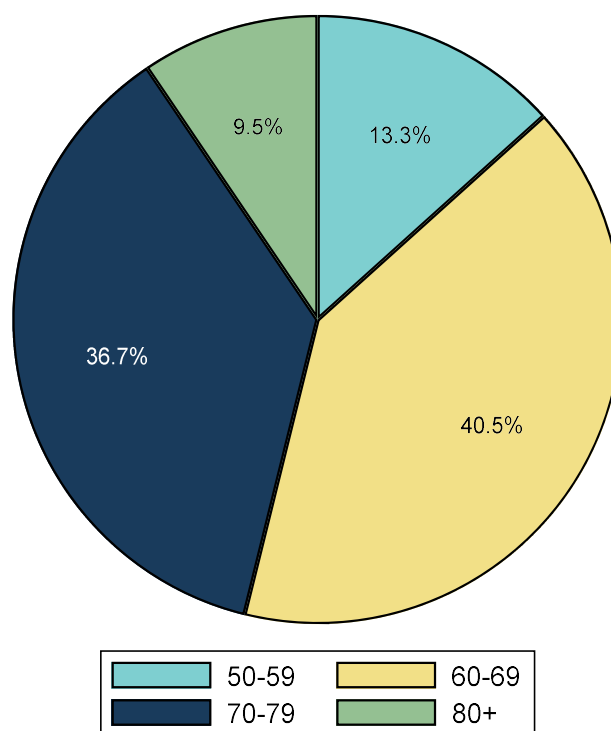


Figure 1: Age groups of those providing care

Looking at the proportions of carers by age group however, there were more people identifying as carers in the younger age groups than the older ones, with a gradual decline in proportions of carers as age increased. There are many possible explanations for this, for example, that the older people get, the less able they are to provide care. Interpreting responses reported here, it is also possible that older participants do not identify themselves as carers, even when performing what would be described as caring duties. Another explanation might be that older people requiring care might be more likely to have higher care needs that cannot be managed informally by their partners or friends. Further research is required to explore the plausibility of any of these hypotheses.

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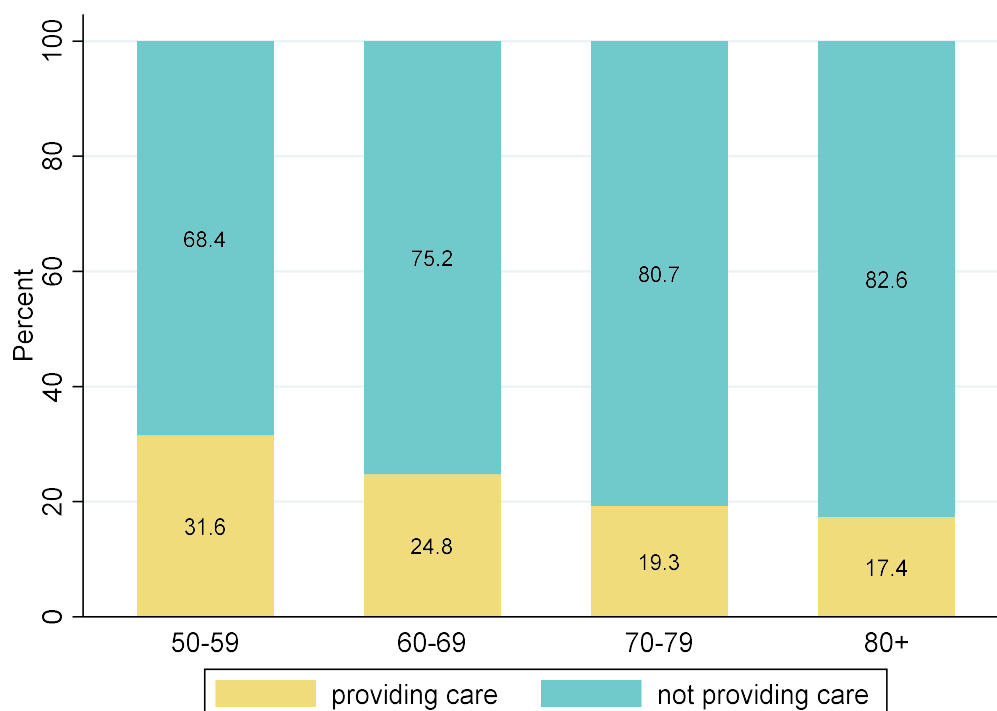


Figure 2: Proportions of participants providing care, by age group ($p < 0.001$)

4.2. Do more women provide care than men?

Although there is a statistical difference in the proportion of women caring compared to men (23.9% of women vs 20.1% of men), the actual difference is small and suggests that many men are providing care for others. This is contrary to both public perception and previous reports of the gendered role of caring [37, 38].

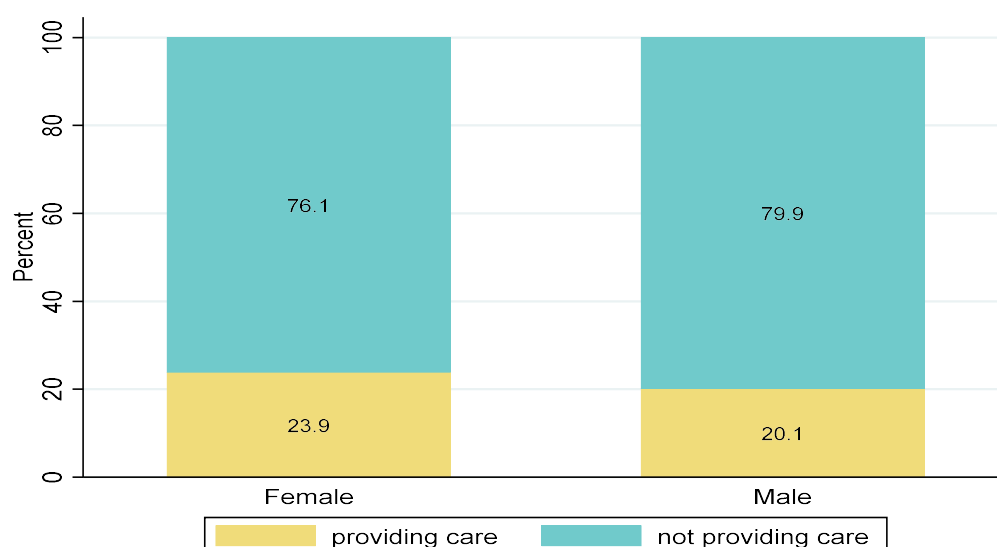


Figure 3: Proportions of participants providing care, by gender ($p = 0.004$)

It is likely that the high proportion of male carers are husbands caring for their wives, as discussed in the next section. The figure below shows that the balance of males and females among carers changes depending on whether carers have a partner or not, as is also demonstrated in Section 4.5 Who is caring for who?.

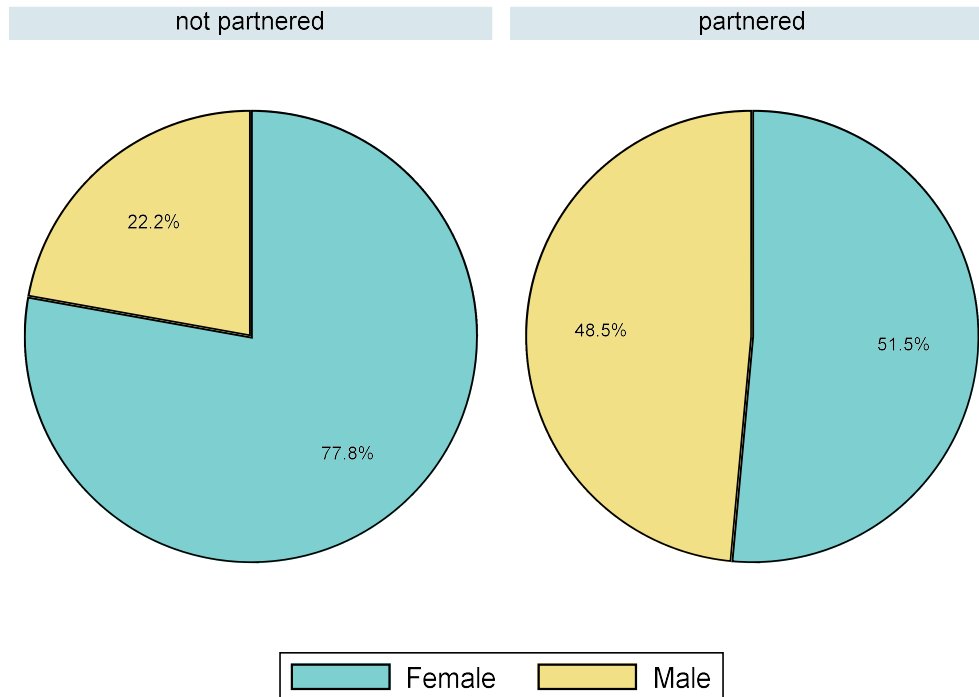


Figure 4: Carers by gender, differentiated by partnership status

In comments about caring, being married was strongly tied to respondents' sense of duty and commitment to care for their partners.

will be married 50 years this year and you have to take the worse as well as the better

I care for my husband because he is my husband and I care about his welfare. I don't expect any reward or thanks for that, especially not from the government.

I care for him because I love him, and because I know I can care for my husband better than anyone else can, and also because of my marriage vows....

The fact that he is still with me is a blessing, we have been married for 42 y[ea]rs, met 45 y[ea]rs ago...

We have been married over 54 years and both still care about the other [and] will continue to assist each other until we are unable to do so.

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We have been married for a long time [and] looking after my wife is what you do. If the roles were reversed, she would be looking after me no doubt.

I have no other option, in my generation you got married for better or worse and i will care for my wife as long as I am able. I would never want to put her in care for both social and financial reasons...

Although I am sad that my wife has an undiagnosed neurological problem that can't be fixed except with pain killers - after 42 years of marriage I am more than happy to care for my wife in the circumstances. In my mind it is part of my marriage commitment.

I believe that marriage is a life-long thing and thus, as she has been a great mother and companion, it is my duty - whilst I am able - to care for her...

The caring is something I do because this is my partner. I really have no choice. Thinking for my partner. Encouraging so that all abilities are not lost. Not showing impatience.

4.3. Is caring related to how much money you have?

Overall, the comments suggest that the economic impacts of caring on carers are significant. Caring appeared to reduce earning potential, causing respondents to step out of paid employment.

I don't get paid for anything but I have to take time off work and lose money.

That is 20 years of my life, earning power & superannuation that I have sacrificed, for a worthwhile (yet distressing & exhausting) cause...

I gave up work to care for my partner because I wanted to spend time with him in the few years he has left...

I work part time as well (reduced working hours as my mother wishes to remain at home so [I] have to co-ordinate support services, respite in aged care facility etc. All so time consuming....

The data, however, suggest that the proportion of carers is similar among participants no matter the value of their savings or whether their main source of income is the Age Pension.

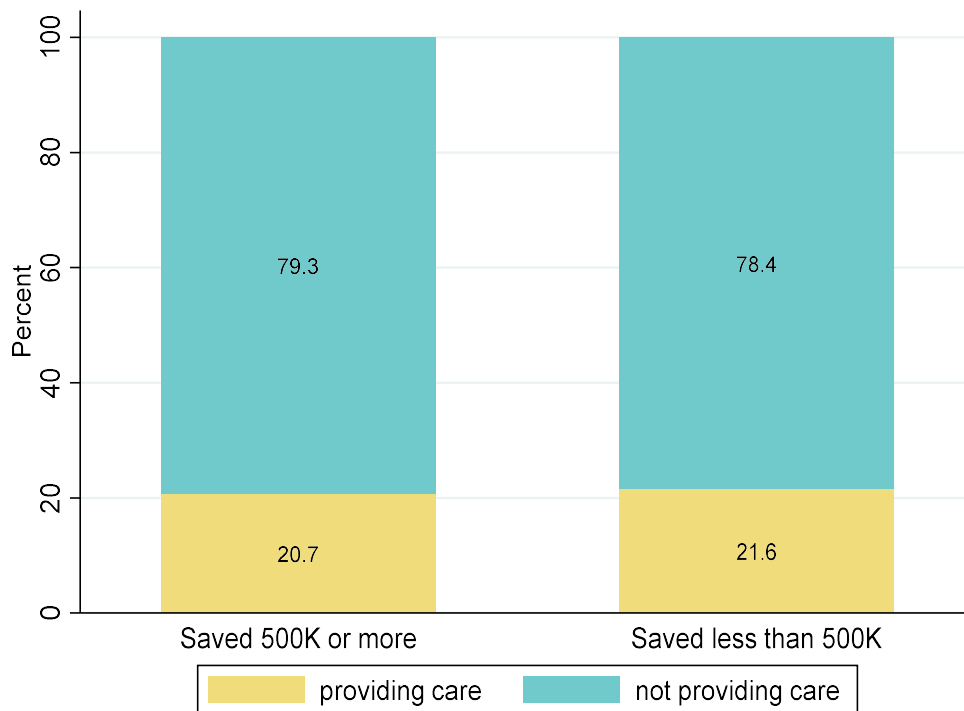


Figure 5: Proportions of participants providing care, by whether they have less than 500K saved or not ($p=0.540$)

One pragmatic driver to respondents providing care themselves related to the unaffordability of residential aged care or other care supports.

Option of nursing home is too expensive and not good enough.

Would love extra help however it costs. My mother is on the old age pension and I am on a low-income pension due to health issues. I fear we could not afford it. Low or free quality home care and assistance would be brilliant.

...I spend just about all daylight hours caring for my husband, there is very little time left to do general garden tidy ups and I also have mobility issues, help with the garden on a regular basis would be wonderful. Private businesses can be sourced but they all have a minimum 3hrs and are expensive also there would not be 3hrs work to do if it was done monthly.

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4.4. Do healthier people care more?

It is noteworthy that higher proportions of carers were found among participants who categorised their health as “fair” or “poor or very poor”.

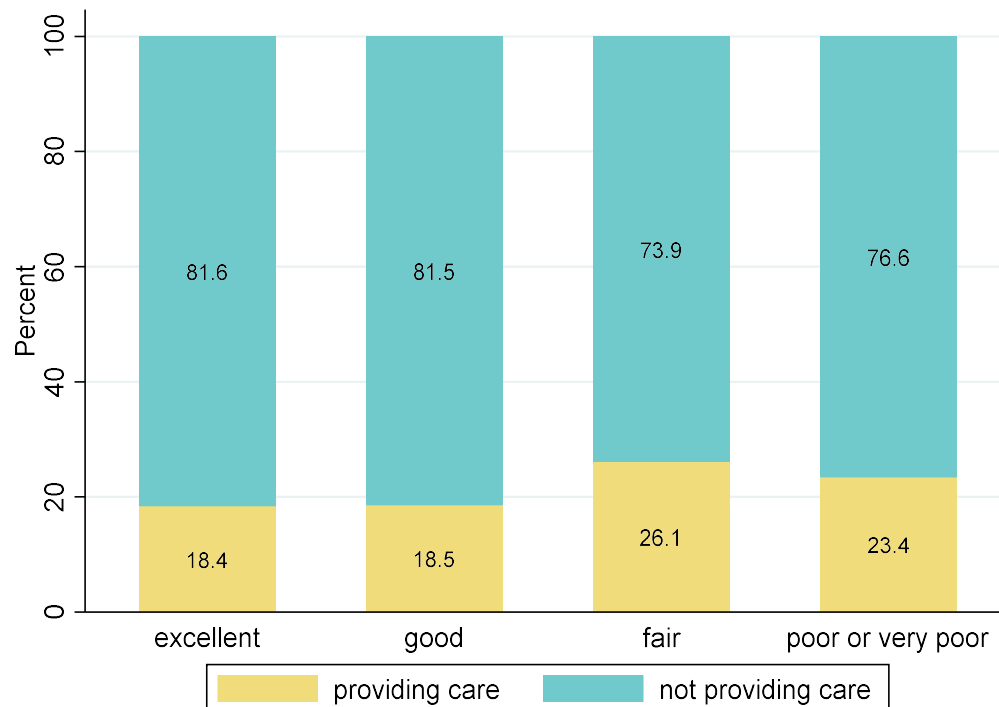
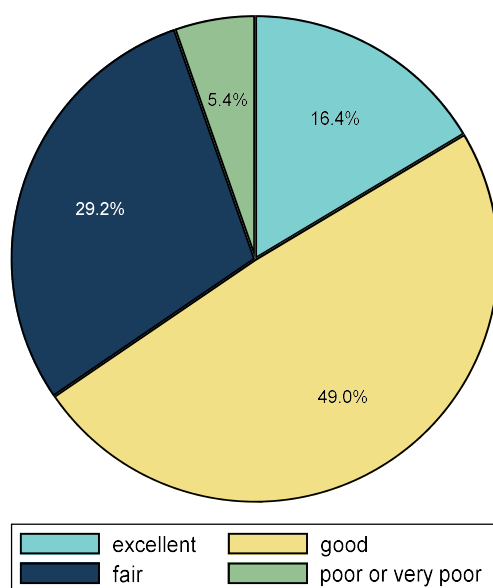
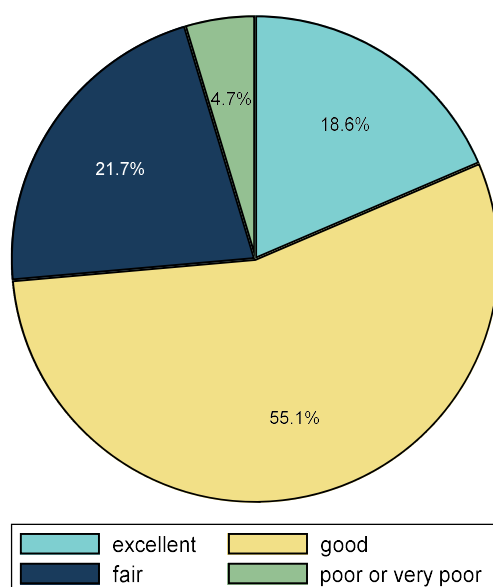


Figure 6: Proportions of participants providing care, by health status

The cross-sectional data of the survey does not allow inferences regarding causality. If we look at only the participants who identified as carers, the majority are in excellent or good health (65.5%), largely because the majority of survey participants are in excellent or good health (72.4%). It is when we compare the health status breakdown of carers with non-carers that a disparity emerges. The proportion of those in good or excellent health is lower in carers than non-carers, and 34.5% of all carers identify as not being in good health, compared to 25.4% of non-carers.



Health status of carers



Health status of non-carers

Figure 7: Carers by health status

Comments from participants indicated that in some circumstances, carers felt their health suffered as a consequence of their caring roles and responsibilities.

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4.4.1. Mentally and physically exhausting

Caring was described as emotionally and physically exhausting for many respondents, so it is unsurprising that this would take a toll on health.

Many of our age just provide care because it's the right thing to do, but it can be very exhausting sometimes and some days it drives up my own blood pressure

It's emotionally and physically draining caring for an elderly parent. I can't go on a holiday for more than a night or two. I have health problems too and I live alone so I really need to look after myself as well. It's a bit of an exhausting cycle.

But is it very draining on one self, particularly as I have a husband and family of my own and still work full time for financial reasons.

Stressful, tiring, draining.

The same conversations can be draining over and over again...

It's always extremely difficult when the caring roles between parents and children become reversed and I and others do things for my mum that would embarrass her if she was still cognitively able to be embarrassed. Seeing her like this, seeing her abandoned by other family members that she spent a lifetime caring for just breaks your heart, again and again and again. It's emotionally exhausting- but I'm lucky in that she has professionals to do most of the physical and personal care.

Our daughter is 43 and lives on her own, in accommodation we assist her with, as we could not cope with the stress of having her live with us.

My health has suffered from the effort to fit in everything.

... My health and mental state have deteriorated and I feel I can't manage his care adequately any more. Also of course I am aging. My husband is naturally distressed by this situation.

4.4.2. Care at the expense of self

A common theme was balancing care needs with personal needs. There was a sense that caring was provided at the expense of fulfilling respondents' own personal, social, emotional, financial and health needs.

...that is 20 years of my life, earning power & superannuation that I have sacrificed, for a worthwhile (yet distressing & exhausting) cause, but at significant health & wealth cost to myself...

Challenges include broken and insufficient sleep.

... when much of your time is taken up simply looking after yourself and your partner to the exclusion of most or any recreational activity (fun), life becomes tiresome and pointless.

...Sometimes I miss out on my own activities that may clash with appointments but he appreciates the effort I make and I regard this as my volunteer work.

4.5. Who is caring for who?

The most common response from people providing care was that they were caring for a partner, with well over a third of 866 carer respondents choosing this option. This was followed by caring for a parent, and then caring for an adult son or daughter.

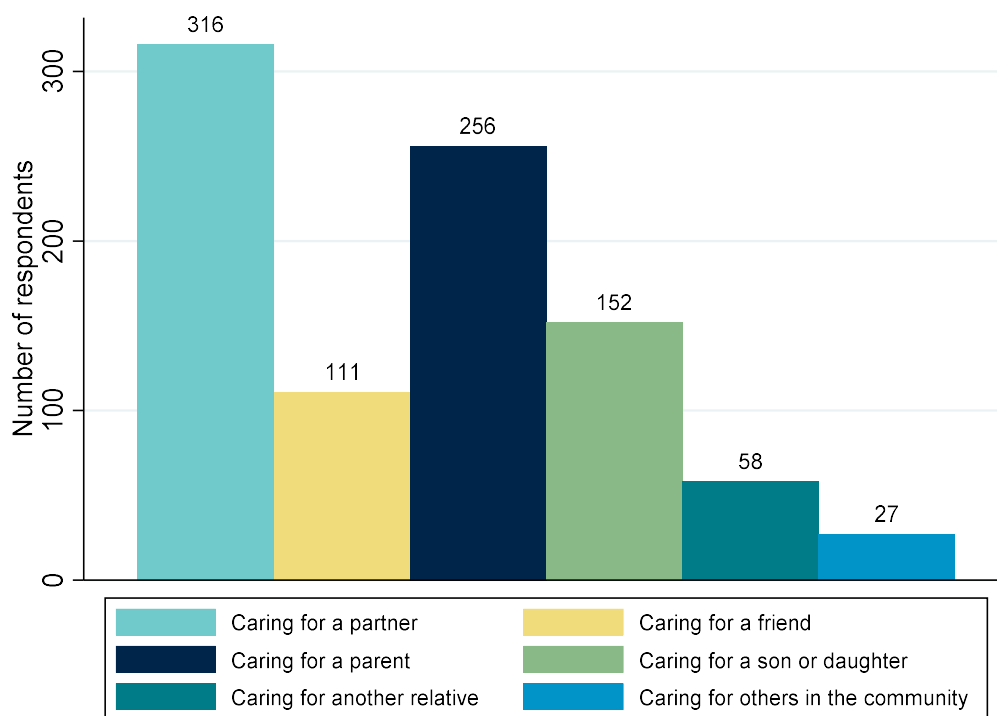


Figure 8: Counts of who participants are caring for

Profiles of carers were dependent on who they were caring for. The differences can be demonstrated comparing carers of partners with carers of parents.

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Carers of partners were evenly matched between genders, while carers of parents were much more likely to be women.

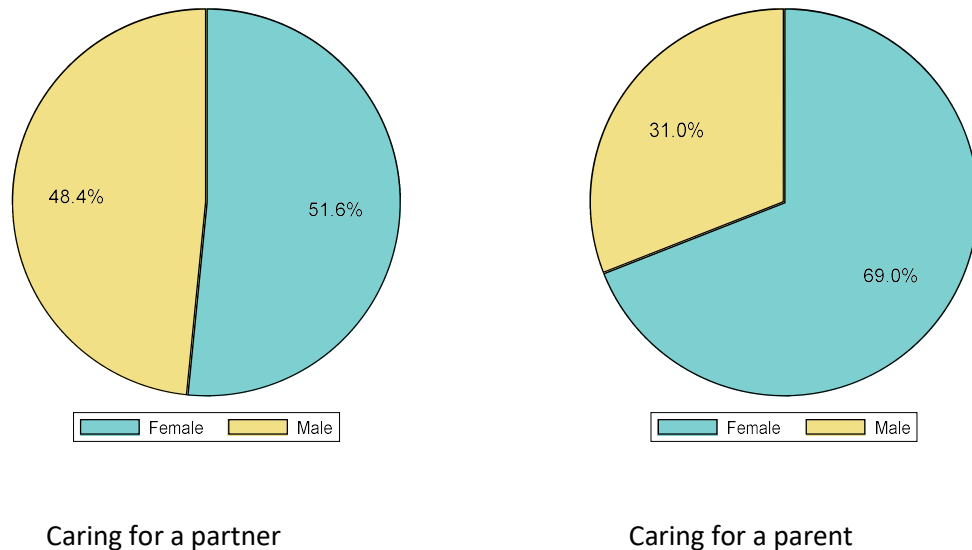


Figure 9: Carers by gender

Those caring for parents were, naturally, much more likely to be from younger age groups, whereas those caring for partners were from all age groups, with a high representation among those aged 80+ (15.9% of carers of partners are aged 80+ compared to 12.2% aged 80+ in the total participant population).

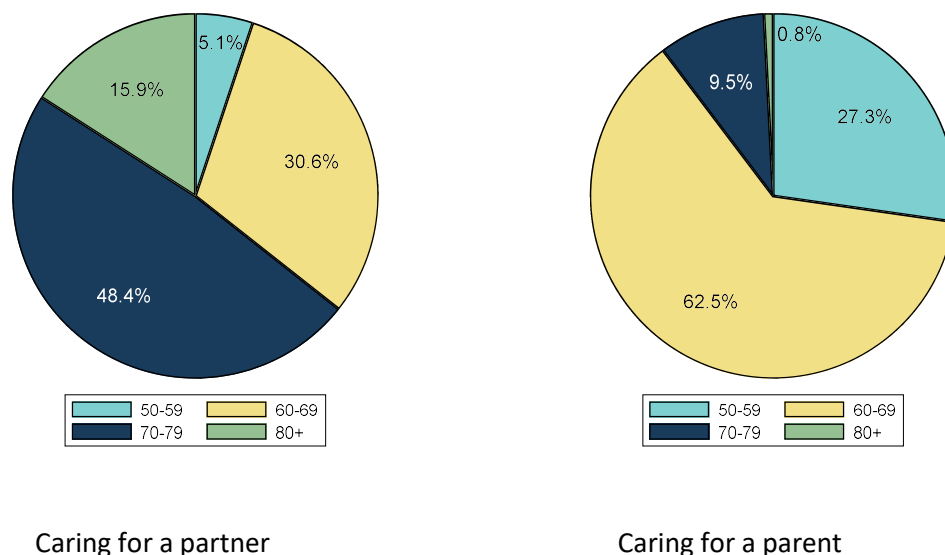
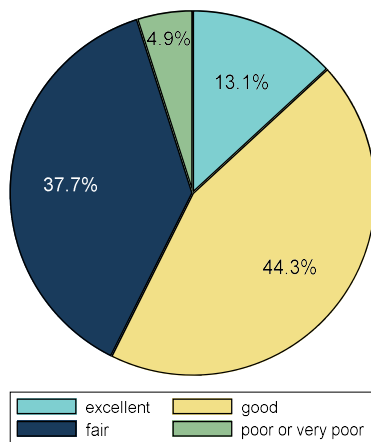
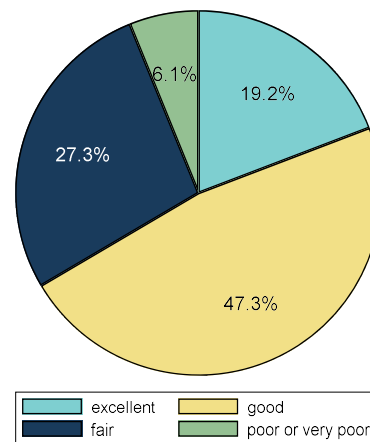


Figure 10: Carers by age group

Carers of partners were more likely to be in fair health than carers of parents, who were healthier overall, an unsurprising finding given age differences in these types of carers.

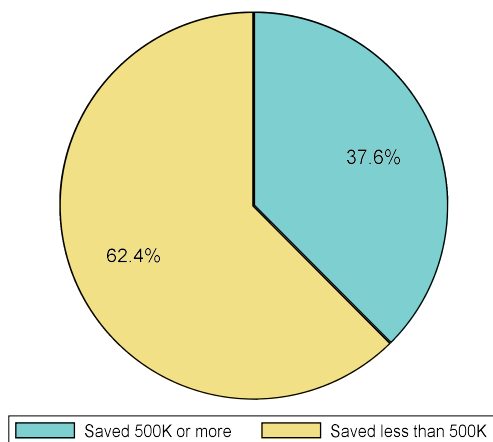


Caring for a partner

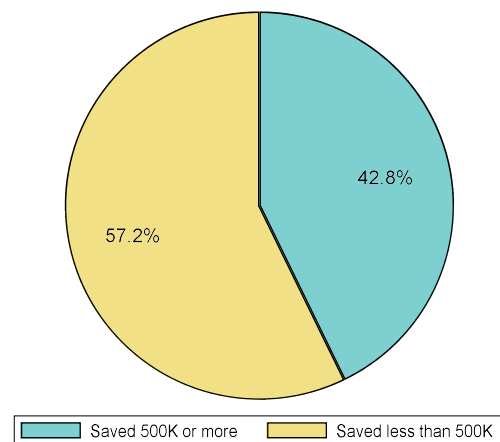


Caring for a parent

Figure 11: Carers by health status



Caring for a partner



Caring for a parent

Figure 12: Carers by financial status

4.6. How much time are people spending caring?

The numbers of hours spent caring ranged from one hour to full-time care, that is, 168 hours per week. The mean number of hours reported by participants was 26 hours, and the median was 12 hours (interquartile range five to 30 hours). What this, and the histogram below, demonstrate is that most carers are doing less than thirty hours a

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week, but around a quarter are doing more than this. The data suggest that ten percent of carers are giving more than 70 hours of care per week.

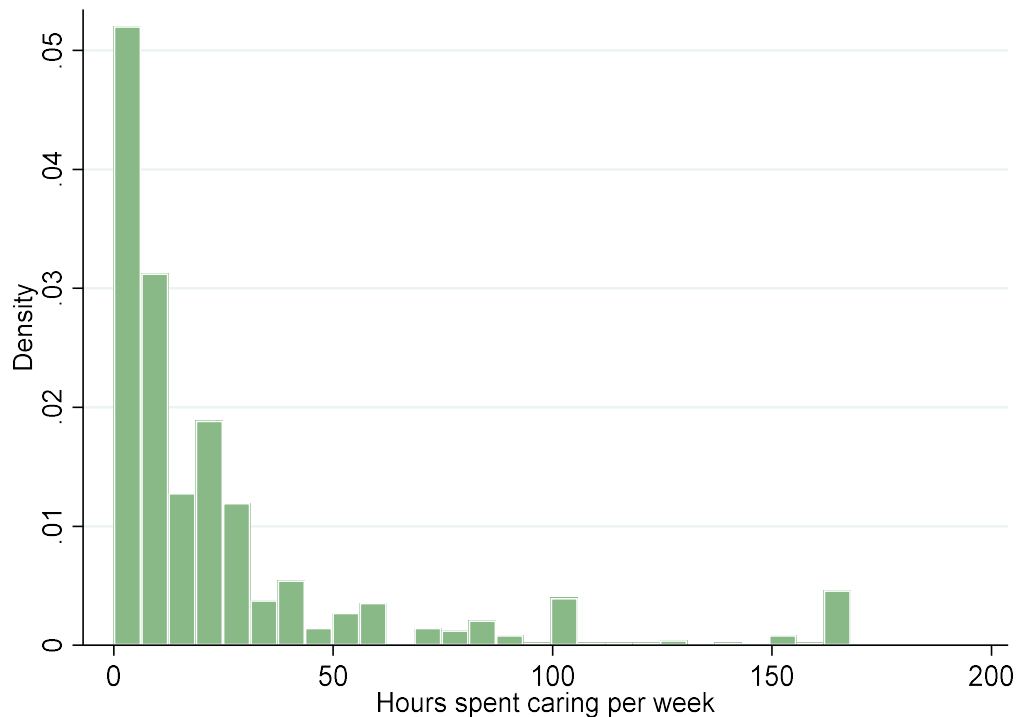


Figure 13: Histogram of hours spent caring per week

There was no statistical difference in the number of hours of care provided by women or men ($p=0.767$ from two-sided t-test).

4.6.1. Time strain

Participants wrote voluntarily about the time commitments of providing care, and how this made caring even more challenging.

Time can be a challenge, cost of petrol

The biggest challenge is me working 50+ hours a week in my daily place of employment and having to juggle attending appointments

...sometimes it can be time consuming though and to learn to have boundaries is hard.

However, as she gets older, taking care of her gets harder and takes up more time.

The biggest challenge for me is to always have the time available to assist.

The main challenges for me are associated with timing and time spent on the caring activities.

4.7. What sort of help is required?

Participants were asked what type of help the person they cared for needed: whether they had problems doing tasks in their daily life, whether they had problems with cognition or behaviour, or whether they had complex health needs, with the ability to choose more than one option. Help with daily life tasks was the most frequently required with 47.0% of carers choosing this option, followed by complex health needs for 28.3% of carers and then cognition or behaviour for 25.5% of carers.

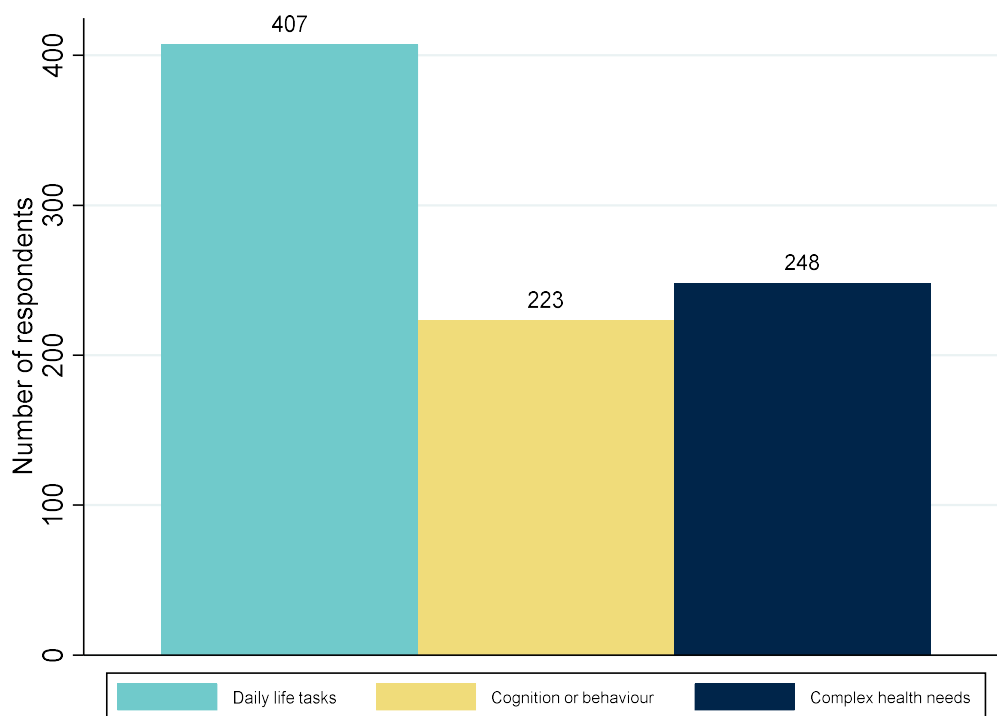


Figure 14: Frequency of responses to types of help required

Comments provided more insight into the type of help carers provided.

4.7.1. Pragmatic assistance

It was clear that carers were required to meet a wide and varied range of pragmatic needs including but not limited to transportation, personal care, domestic help, physical assistance, help with financial and administrative tasks and decision-making.

Anything they need

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All driving, financial and organising and planning. Make all major decisions. Cook, clean, laundry. Check meds. Organise all outside assistance, appointments medical and professional.

Transport, medical appointments, shopping, occasional personal care. Medicine assistance, meal assistance on occasion, phone and forms, assist [with] paying bills etc.

Admin/advocacy/phone calls/searching on-line/discussing health care/filling out forms [and] making claims, preparing documents for travel/investigating [and] sourcing/packing medications etc.

All household tasks - meal prep; gardening; shopping; transportation; washing. Personal - showering, medication, walking

All meal preparation, all house cleaning, shopping, laundry, transport to medical appointments, physio, podiatrist, hairdresser etc. Managing her financial affairs (I am her Plenary Administrator and Guardian). All the paperwork, accounts, phone arrangements, social plans, correspondence. Needs strict supervision taking numerous medications. Needs some help with personal hygiene and dressing.

4.7.2. Social and psychological supports

The provision of social, emotional and psychological support was also an important form of care need that respondents sought to meet.

Mostly emotional support now days which can be exhausting

social support, bureaucratic and emotional support...

It's mostly in the form of regular social, emotional support for 3 aged persons, two in their 90s.

She has mental health issues and mostly needs emotional support.

Patient has terminal disease but copes with daily tasks. Mostly needs emotional support due to depression and anxiety.

Emotional support... social reconnection...

advice, advocacy, pastoral support, spiritual support, emotional support

... attending events and social occasions as a companion...

everything.... including companionship...

Massage, social contact, sometimes art therapy

...listening, encouraging...

Company, caring, shared interests, shopping, social activities.

She is in a nursing home - family helps provide mental health benefits as opposed to physical health.

4.8. Are self-reported care needs low, moderate or high?

The majority of carers responded that the needs of the person they were caring for were either low or moderate, with only 17% reporting high care needs.

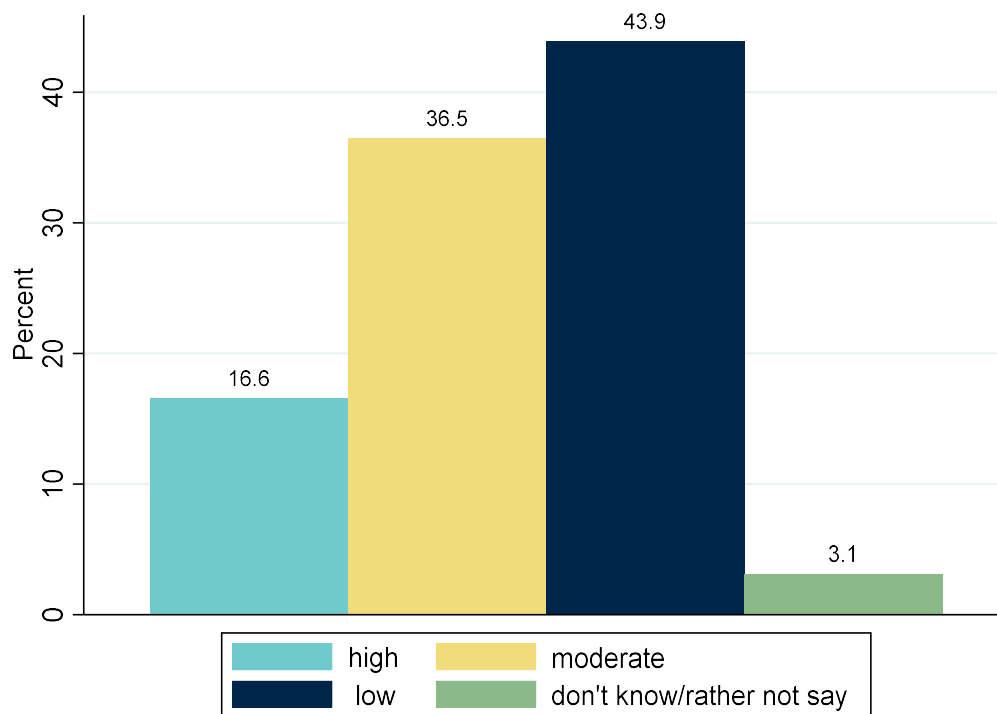


Figure 15: Intensity of care needs

Themes relating to extent and manageability of care needs, care provision contexts, and caregiver impacts and perspectives emerged from participants' additional text comments to this question.

4.8.1. Extensive needs

Many respondents described their care partner's needs as extensive and their caring role as demanding.

totally dependent

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You name it!

need[s] support often

Wife has had extensive surgery and required full-time high-level care after operations...

Moderate to high, could not live alone. Helped by nurse visit twice daily and still able to do many things for himself, but Dad now needs help for reducing stress and greater safety dressing and showering, needs most meals prepared, washing done, shopping, transport outside home etc.

Am caring at times for 4 different people (parents/in-laws) each with different issues/needs although they do still live mainly independently...

... High level of emotional support needed for father so am there most days except when really unwell myself. I've been their primary carer for last 13 years with mum with dementia

Husband has Vascular Dementia, Alzheimer's, is incontinent, can't walk, unable to feed [him]self, unable to bath or dress [him]self. Has osteoporosis and renal failure

I do Up to 40 Hours a Week caring for a 96-year-old Lady, this Lady is my Lady friends Mother and if I didn't Care for her she would have to go into a Nursing Home. She is on a Level 4 Care Package Under the Aged Care Home Care Package! I do not get Paid for this and whilst I have been Told I am Eligible for a Dept of Human Services Carers Payment I "Refuse" to Deal with the Centrelink Office as I regard it to be totally Inept and Untrustworthy in so many ways!!!

4.8.2. Rising demands

Many noticed that care needs were increasing over time, which sometimes led to an inability to cope or a need for external support.

Has Parkinsons and is getting worse.

Had home care plan for partner when still at home under direction of GP and Gerontologist but as things worsened and on medical advice, [we] placed [my] partner in a residential care. It became obvious that the I could not cope physically.

My wife has a worsening neurological hereditary illness and is becoming very frail.

My Wife has Dementia and is getting worse rapidly.

...We have seen a decline in her health over the last 6 years but we're all managing well enough with good back up support from her Care Service.

I am still able to manage at the present time but it is getting harder.

My wife has become increasingly disabled over the past 20 years. This affects her ability to walk unaided. This year she has been hospitalised for heart failure and also a tiny stroke.

At present my husband's mobility is fair, but deteriorating...

4.9. Are carers talking to people to make a care plan?

The majority of participants had not spoken to anyone about making a care plan.

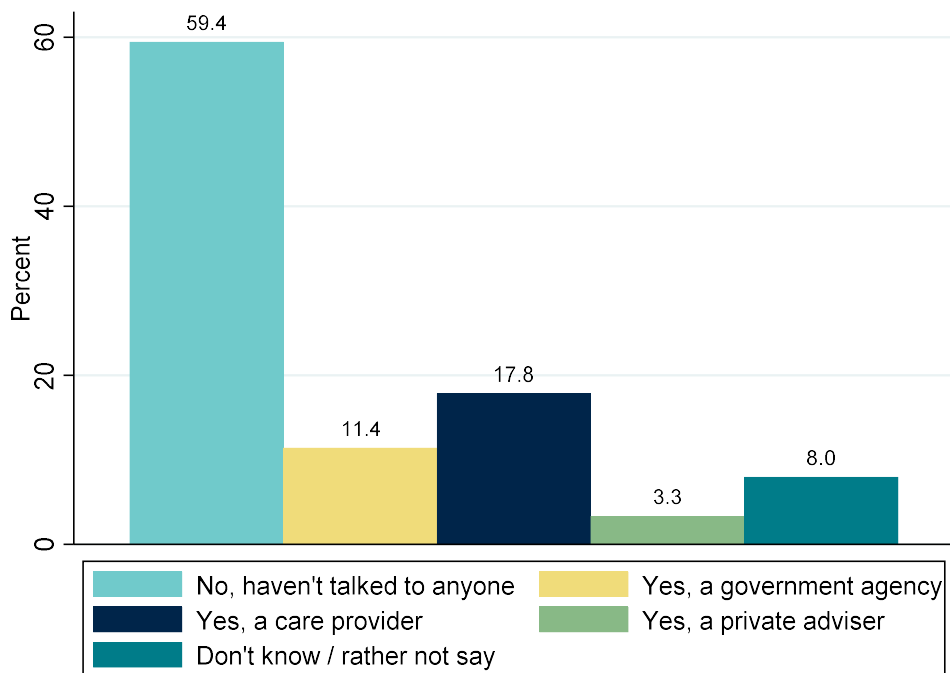


Figure 16: Percentage responses to question regarding making a care plan

Having an effective care plan was generally regarded as positive amongst respondents. However, there also appeared to be frustrations with respect to finding appropriate and clear information on accessing care plans, prolonged waiting periods, and challenges with gaining comprehensive or appropriate care.

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4.9.1. Helpful and needed

Care plans were generally described as helpful and necessary to facilitate ageing-in-place, and to manage and reduce carer burden. Respondents with existing care plans felt grateful for the help they were receiving, and others saw the potential positive benefits of a care plan for anticipated future needs.

A care plan allows my father more independence to remain in his home.

... Our Care Provider is [named], who has assigned us a Care Partner who works closely in seeing that our needs are looked after and that our Care Plan is working and kept up to date. Without this help I would not be able to continue to look after my husband in our family home

Paying for advice from aged care advisor was invaluable

Yes it is a big help to have some weekly home help but it is hard work getting the provider to be able to send the same workers!

We have a Level 4 MyAged Care plan and it has allowed me to have some independent time. On average 15 hours per week plus 2 hours domestic assistance with the house. I am very positive about this...

We already have Meals on Wheels and House Cleaning services and home maintenance care. We appreciate this very much

Very helpful in organising and planning.

... Would have NO way of coping without it

We do not need outside care at present although there are some tasks for which help would be useful now and may become necessary in the future, such as heavy lifting as in changing bedding.

4.9.2. Insufficient and not comprehensive

While care plans were helpful to some degree, gaps in care still existed. Many respondents reported still needing to fill gaps in care, and manage the assistance received.

They were pretty useless in helping. But better than nothing some of the time

my mother receives services via local gov[ernmen]t contracted out to home care provider - it is terrible - I have to spend time dealing with

them sorting out their poor service. She also privately employs home help - which I remotely supervise

I have personally arranged external services myself and with the assistance of My Aged Care processes

His Level 4 package is managed through a care agency. We have also employed a private provider organisation to fill in gaps.

Have worked out the care plan based on what is available and have divided the shortfall among immediate family members.

4.9.3. Issues with accessibility

Respondents reported that care plans were inaccessible due to lack of information and support, complex and exclusionary application and assessment procedures, and long waiting periods.

... I am not sure what a Care Plan actually involves, so would be interested in hearing more about it.

The whole care and support issue has been complex and not entirely clear to us.

Just got NDIS plan which is truly awful to understand...

Have rang 3 times my aged care still haven't heard from ACAT about a care plan and respite which is needed

General practitioner primary health support has been extremely helpful. Government agency has not provided follow up even when requested.

Have spoken with a care provider who, basically, believes there is NO care required. She would not listen to my questions and dismissed me.

With one of us still working, getting the required assistance is a labyrinth of forms and various agencies. Nothing is easy unless you are nearly dead.

I tried to obtain help with a care plan and the agency was dismissive. I rang the [named] Council to try to get a personal alarm for my mother because she lives alone and was told that until she has a fall, or is on 6 or more prescribed medications, this was not available.

I had to do all the work myself, the government proved useless. He was classed as Level 4 dementia and I still had to do all the work. He never reached the Level before he had to go into care.

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I've investigated care options but being both age pensioners we find none of these services are free or convenient.

Still waiting on Federal Governments caters assistance. 2 years of waiting for review.

Assessed for my age care in October 2018, I am accepted for level one but on the waiting list, husband accepted or level 3 but on a very long waiting list

assessed for level 3 care, on waiting list 14 months ??????

4.9.4. Issues with acceptability

A key barrier to care planning was a lack of agreement and acceptance of receiving external support amongst care recipients. Perceptions around care planning appeared to be negatively construed as an inability to cope or associated with restrictions of independence.

My friend has had an assessment for home services, however is reluctant to access these, as he feels that this restricts his independence and that it is an admission that he isn't coping.

Unless the person being cared for considers they need to be in the care system there is no point forcing them while I can fill the gap...

you can lead a horse to water but difficult to make it drink

So far no services have been supplied for many reasons. i.e. ... care recipient not agreeing to accepting services.

Person I care for doesn't like outside assistance

My mother doesn't want me to do this.

I think it would be helpful but would first require acceptance of the need for external help.

She was assessed twice by my aged care. But has refused all assistance except assisted shopping

would a care plan be of use to me, no I do not think so as there are so many restrictions on age, lifestyle, and financial

4.10. Would carers accept more support?

While many carers said they would accept more support, there was a large proportion who said they would not. Almost a quarter of respondents answered that they did not know if they would accept more support or would rather not say.

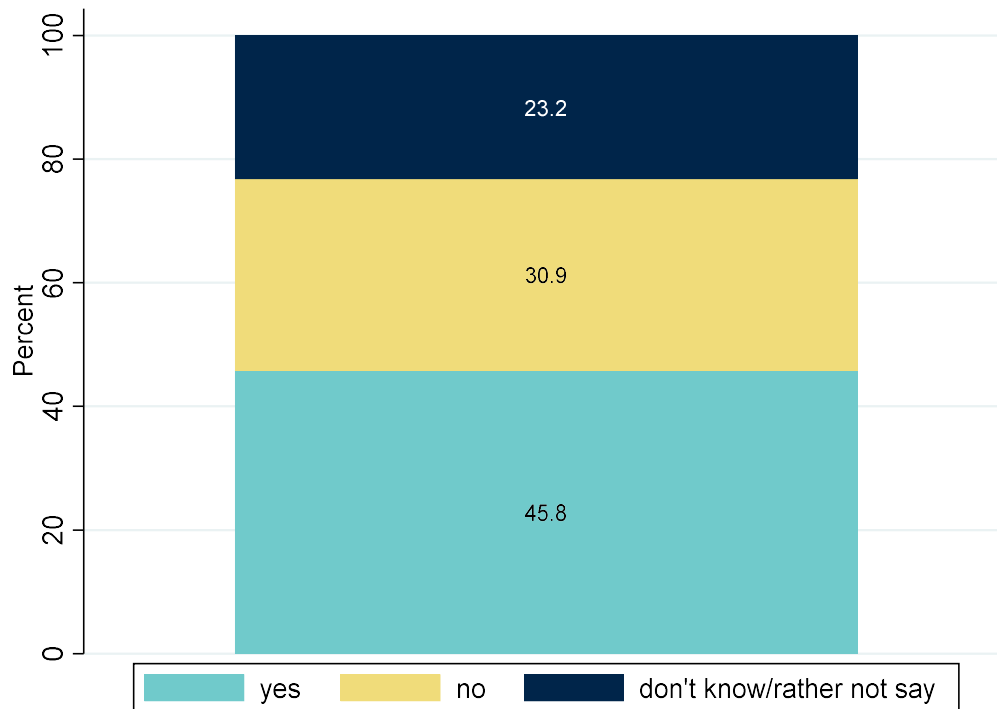


Figure 17: Percentage responses to question regarding receiving more support

4.11. What kind of support would be helpful?

Three distinct categories of support were articulated: the first related to assistance with pragmatic caring tasks; the second related to improving psychological or social outcomes for both carer and their care partner; and the third related to better government frameworks and policies to improve the care landscape.

4.11.1. Practical assistance

A wide range of practical support was desired, including help with personal care, domestic chores such as cooking and shopping, gardening, transport, interpretation, and assistance with financial matters. This request for pragmatic support appeared to serve two key functions – to allow for more meaningful time spent together, and to provide a possibility of relief or respite.

All the things I currently do

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Personal care for my parent. Where do I start

Household chores, i.e. Housework, which would help me to do more in my caring role

someone to keep my parent company at home during the day and in the evenings so I can get a break.

Someone to take over these smaller duties when we go on holidays.

Carer to stay with my husband while I go out to meet friends, hair dressing, personal shopping etc. all the current respite time goes on household tasks or routine maintenance.

...an interpreter for my parent when going to medical appointments

Transport. this is a very high cost and time consuming as well. transport to her daily care takes 2 hours in and 2 hours home for a 6 hour day. as she is sat in a car that goes all over the place.

Some-one to make sure he shaves each day, cleans his teeth properly, checks his nails etc. A once a week check is all that is needed. Someone to look after his bank card so he can't overspend.

Everything. Take over the entirety of jobs so that we can just have a parent-child relationship with our adult son and so that my wife and I could get time away together in our retirement as we both have terminal illnesses.

4.11.2. Wellbeing supports

Respondents also expressed desires for more respite care, and better social, emotional, and psychological support for themselves and those they were caring for. The wellbeing of both carers and care partners seemed to interdependent, whereby wellbeing aids for their care partners would also improve their wellbeing and respite prospects.

Respite. [I] haven't had a break in 4 years

Time off without worrying

... handling some of the emotion

More mental health information, groups, outings [and] brochures

Someone to talk to - who understands what you are going through. is very hard to access if you work as all [that is] available is during working hours, I work full time

Support to address social isolation experienced by my son. Currently respite is provided when I go on holidays.

Social support and someone to help in the care as family members are busy with their own lives and family.

My mother needs social support which I cannot provide, so a social group would be good for her.

Volunteers or social visit for communication due to loneliness

4.11.3. Government help and intervention

Accessibility and availability of government support for carers was a key issue raised in the comments. Some possible solutions included the provision of more financial assistance and subsidised carer services. Improving awareness, systems and policies around accessing carer supports and higher skill and training requirements for aged care workers were also suggested.

From the top by legislation - stop the health scam

Extra money in the care plans for additional care

Services that help more but don't cost the earth.

Mental health support with easy access and at no cost for carers e.g. Medicare benefit increased from the current eligibility and limitations under a Mental Health Plan - free face to face weekly and emergency access to psychologist on regular basis over long term. I am alone and not working and do hope to be able to apply an for aged care pension soon. Access and cost for these services are the major inhibitors to both my daughter's recovery and my mental health issues. Currently I cannot afford to pay for any mental health support.

Someone to talk to who has a good overview of the support services available and who could also help me navigate the health care system a bit more.

Leave provision. More work from home options

More Level 3 & 4 packages made available, and better training for Age Care Workers

Carers Allowance. More flexible, less time-consuming & convoluted

Quicker service implementation to determine if additional support is needed.

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Some financial. More skilled staff at aged care facilities...

An easier My Aged Care system

5. Why do people care?

The comments illuminated several key drivers to caring. These included love, marriage and commitment, facilitating dignity, as well as feeling like there is no other choice.

5.1. Love

Love was an overarching theme which underpinned respondents' willingness and commitment to provide care.

I love my husband and he is 88 years old, the benefits of caring at home far out way the alternative of residential care.

Spend a lot of time with and for my mother because I love her and choose to be with her.

Sometimes I am very tired. I do it because I love my Mum...

Rewards are the love of the people you are caring with.

I love him dearly, but I need some 'me' time & not sure how to achieve this.

It's called love...

I perform this care as this is the woman [that] I love.

I love my wife, so I would do anything to help her when help is required...

I do this care for my sister because there is no one else that is prepared to take the role and responsibility. I love my sister and I know how hard a struggle her life has been. It is hard on me now. I am disabled myself. I am tired. It is rewarding to see her healthy and happy and engaging in the world around her

Rewards at the hugs and love I can give my parents.

Caring for my wife of 40 odd years, the mother of our 4 children, Grandmother of 9, Great Grandmother of 2 plus 2 on the way, the woman I married because I loved her and still do. She was a wife, farm hand and a companion of the greatest kind. I will tend to her needs for as long as I possibly can

The caring I give freely, he is my life partner and our commitment is strong, I do try to hide my worries to alleviate his (although not always successfully), try to modify tasks or expectations to ensure he succeeds, share in his triumphs each day (and those goals achieved at night with sleep and pain management), try to find a balance between nudging a bit more to extend him and allowing him to dictate when enough is enough, having him be honest without feeling deflated or hopeless.

5.2. Giving back

Respondents also viewed caring as a privilege and opportunity to give back to their ageing parents.

It's an honour to be able to give back to my parents

I provide care for my mother as love her. She does not want to go into a nursing home and would like to live out her life as long as she can in her own home, and I respect this. This is the least I can do for my mother who raised me and cared for me as a child...

Care for this loved parent is an honour and positive obligation...

It's a privilege to care for elderly parents...

5.3. Dignity

Helping their loved ones maintain independence and dignity appeared to be an important driver for providing care.

Assistance for maintaining dignity and independence in communication

all normal daily living activities to ensure that my mother has a quality of life and her dignity. She is vision and hearing impaired, with complex medical issues, heart and mobility.

do most of the care as I wish to support my mother in her desire to remain independent in her ILU, and I live nearby.

Rewards - Giving my husband the most dignified existence possible in his ill health

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5.4. Rewards

The personal rewards of care generally were associated with feelings of fulfilment, closeness in family or community relationships, and their loved one's happiness, health and wellbeing.

The rewards are that I am with my mum for however much time God grants her on this earth and we have become a lot closer relationship wise.

the rewards are the feeling of still being useful.

[Rewards are that] my father has a good quality of life, knows what is available through aged care providers, keeps on top of medical issues and is socially active.

Rewards are her happiness and health.

The rewards, I have learnt to ask for help if needed, the generosity and love that our family and friends have given us, the little things that get done whenever I ask for assistance.

Satisfaction in helping.

...Rewards are knowing my partner of 50+ years is safe and happy in our own home

It is part and parcel of partnering to help each other and the reward is always the gratitude and well-being of the recipient.

Rewards are seeing her happy to see me.

5.5. Reciprocal & Community Care

Some respondents expressed being part of a wider system of care provision, either within the context of local community and interpersonal relationships, or within the context of residential aged care and professional teams.

This is my Neighbour, her family care for her but they need to work so we fill in the blanks for them and her.

The care needs are reliant upon the section of the home I am assisting in

Parent is in aged care but still I need to provide additional care

My Sister supplies regular care for our Mother - I go and stay with my Mother when my Sister takes Holidays.

Two days a week carers take my sister out for 5 hours. One weekend a month, she has a respite weekend. On alternate months, she lives with another sister and has a different carer for those months.

of the 4 siblings of which I am one, we try to take it in turns to take my father to his appointments or shopping.

Also has aged care come in daily in the mornings.

This applies to other family members as well when care is needed. they reciprocate in caring for me as needed.

5.6. Feeling there is no option

Finally, for some respondents, caring was not a choice but a responsibility or necessity.

No choice in the caring role...

It is not a choice is it a responsibility....

I feel that I have little choice at present but would like help to get better resolution of the situation in the next year or two, as it is hard work on my own.

I don't have any other option but to care for my parent who doesn't want to go to a nursing home.

I have no option. She's my mother. No-one will look after me when I'm her age & even if I had children that is no guarantee.

Because I want to and also because there is no other option...

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6. Discussion

Reflections on the findings

This research was undertaken to complement previous work on home care provided by commercial and not-for-profit businesses with government support, reported in the National Seniors' 2018 publication *Accentuating the positive: Consumer experiences of aged care at home*. The boundary between formal home care and unpaid care is blurred, with the latter a neglected, but essential, foundational piece of the aged care workforce. Formal and informal carers undertake similar tasks such as personal care, meal assistance, household chores, and care related to health maintenance. However, what differentiates formal from informal care systems is that the latter is unpaid, but still may need a variety of community and government supports to be maintained.

This report found that older adults primarily care for partners, parents, and adult children; predominantly out of love. Marriage and duty were key drivers of caring for a partner, with older men and women fulfilling these roles relatively equally. The role of caring for parents, however, is gendered, with more older women providing care to parents than older men. Older Australians are providing care irrespective of their income status, although the savings associated with unpaid care relative to the cost of formal care were reported by some as an incentive.

When formal care is provided it supports informal care rather than replacing it completely. Formal carers can provide regular or pragmatic support, which in turn allows informal carers to focus on emotional and social support. While residential care provides more comprehensive support and care structures, our previous research found home care is more positively regarded, where available [39]. Further, support from family and friends at home is also usually, but not always, preferred to formal home care. This suggests that informal care meets very specific and important needs that formal care does not. Given these care preferences, the nurturing and maintenance of informal home care should be a government priority and have the full attention of the Aged Care Royal Commission.

6.1. Improving the intersection between unpaid and commercial services

The intersection between aged care and hospital care has been seen as problematic and is under scrutiny by the Aged Care Royal Commission. Similar challenges exist with the intersection between formal and informal care delivered at home. For instance, when private carers require external support, they have poor access to information through complex systems and apps such as My Aged Care or Centrelink. The implementation of alternative support mechanisms like advocates or navigators are neither well known nor easily accessed. In some ways, they also indicate failures in the effectiveness of public communication and information systems. Ironically, informal care recipients who later require formal care may be inadvertently penalised as they end up lower on the waiting list than others who sought formal care from the outset. In some cases, they encounter

system barriers to hospital admission relative to those coming from a formal care environment with advocates for their needs. It is not prudent to penalise people who have managed care burdens privately, and measures of acuity should be applied more effectively.

The persistent complaint from informal home carers is difficulty with respite care access. There are multiple reasons why a need for respite might emerge – some are routine and can be planned for, but others are urgent and unexpected, and require immediate action. In order to maintain the care capability of informal carers, it is important that respite choices of suitable quality and proximity are available, both with short- and long-term notice. These respite care places must be an embedded part of the aged care system, and greater flexibility between formal and informal home care must be better supported, in order to maintain the health and motivations of people caring for older adults at home.

6.2. What COVID-19 is teaching us

The recent impacts of COVID-19 demonstrate the vulnerabilities of the care workforce and its 'invisible' work. During this crisis, concerns for people caring in the community were raised, but informal home carers were not prioritised in the same way as formal or paid care, with priorities appearing to be as follows: (1) Hospital; (2) General Practice; (3) Residential Care; (4) Home Care – and only then unpaid care at home. Informal home carers were never 'in the frame' for personal protective equipment (PPE), despite being both more exposed and more isolated than other groups, and it took some time to connect them with information and support services.

Informal home carers in aged care are the rural fire service equivalent in national fire protection, however their contribution during the April 2020 peak period of the COVID-19 pandemic is not equally revered or acknowledged. Numerically, informal carers are the biggest aged care workforce and deal with high level needs as well as basic care. While it is a traditional part of the culture and ecology of communities and families, without this informal care, the government would have to fund these services. Therefore, this workforce needs to be sustained by timely, publicly funded support and information.

The carers in the survey spend an average of 26 hours per week on caring for extended periods of time. Over a half are providing high or moderate levels of care and one sixth high levels of care but, unlike rural firefighting work, there are no low seasons through the year. Most carers did not have care plans or any government support. So, not surprisingly, being a carer is associated with poorer mental and physical health, particularly care by older partners. Older carers, then, need accessible and effective practical, financial, social and psychological support. Older carers, like the rural fire service workers, do not expect payment but similarly crave recognition and support.

6.3. What needs to be done?

Current research has found that only a small minority of all informal carers receive financial assistance from the government and many face delays or difficulties when

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accessing support payments, respite funding or services. Adherence to carer protection laws on an organisational level is also variable. The global landscape provides some insight into successful and alternative frameworks for carer support to assist in a dialogue for improvements. For example, Canada's tax credit scheme aims to minimise financial burden on carers and pension plans which provide income protection against periods of zero earnings due to providing care to a family member. In France legislation has allowed home- or group-based carer skill training and legislation making carers eligible for up to two years of partial leave of absence for reasons of long-term home-based care. However, there is no better source of ideas for improvement than those expressed by carers themselves which are documented in this research.

The respondents want to see improvements to carer support in Australia, in particular:

1. more practical assistance to allow them more meaningful time spent together with the person they're caring for, and to provide relief and respite;
2. better social, emotional, and psychological support for themselves and those they care for, because of the interdependence of both in wellbeing;
3. more accessible and available government support including more financial assistance, subsidised carer services based upon improved awareness and sensitivity to their needs;
4. more transparent systems and policies around accessing carer supports; and
5. higher skill and training requirements for aged care workers who interact with home carers.

These provide a good place to start since the ideas came from those at the 'caring coal face'.

Internationally four broad topics have been identified in a systematic review and provide a broader context for those that emerged from this work:

1. informational needs;
2. support needs;
3. organisational needs; and
4. needs for societal recognition.

It is a fact of life that residential care dominates aged care politics, media and public perceptions. Home care is making more progress but community care at home remains, more or less, invisible. In a reformed system, where care is more 'consumer-driven', a better understanding and support for the volunteer carers at home is an aged care reform imperative.

The broader context for change and improvement is, first, a national debt that has grown dramatically responding to COVID-19 impacts and continues to grow. Then, second, an Aged Care Royal Commission that has already signalled issues that require further government support, such as removing the waiting list for home care, with costly recommendations to come. So the future will be one where government will struggle to fund improvements in aged care. The third reality for the consumer and government is

that service providers will continue to increase fees and charges because of higher standards required and improved salaries for workers.

In this context the role of unpaid care at home will increase rather than diminish. This cost-effective voluntary service cannot be maintained, let alone expanded, without better support and recognition.

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7. Conclusion

This report, along with its companion *Australian Grandparents Care*, has brought to light the poorly recognised work of older Australians, demonstrating the vital role they play in fulfilling the care needs of the Australian population. Older Australians in grandparenting roles are also enabling a generation of parents to contribute to the economy in ways that would not be possible otherwise, given the prohibitive costs of childcare. Older Australians caring for each other, whether it be among partners or between adult children and parents, are essentially protecting the fragile aged care system in place in Australia. Contrary to the stereotypes of a ‘silver tsunami’ overwhelming the Australian population with their care needs, older Australians are in fact taking on that perceived “burden” – silently, among themselves, and with little to no recognition. It is time to redress this oversight and to not only value this vital contribution of older Australians, but to provide the support and infrastructure they need to continue in their invaluable roles.

8. Acknowledgements

We extend our heartfelt thanks to the participants of the National Seniors Social Survey, whose generosity in responding and especially in providing comments was overwhelming, and integral to our being able to put together this report.

We would also like to thank and acknowledge the work of Professor Julie Byles from the University of Newcastle for inspiration for the report title.

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National Seniors submissions to the Royal Commission into Aged Care Quality and Safety:

1. Witness Statement 31/1/19;
2. Review of recommendations of prior reviews that were not implemented 6/2/19;
3. The dementia journey legacy of trauma and what to do about it 9/5/19;
4. Response to the Interim Report of the Aged Care Royal Commission 22/11/19

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11. Appendix 1

11.1. Care questions from NSSS-8

17. Do you provide care for anyone else at the moment?

(This could be a partner, a parent, a friend, a son or daughter or anyone else you provide regular care for. It could be full-time or part-time or just a couple of hours a week.)

- ☐ Yes
- ☐ No (Please go to Question 28)

18. Do you get paid for this care?

- ☐ Yes
- ☐ No
- ☐ Some of it
- ☐ Other (please specify)

19. Who are you caring for?

(You can choose more than one option here)

- ☐ A partner
- ☐ A friend
- ☐ A parent
- ☐ A son or daughter
- ☐ Other (please specify)

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20. Thinking of the person you care for most, would you say their care needs are:

- ☐ High - this person needs help to do most things and doesn't do much alone
- ☐ Moderate - this person can do some things alone but often needs help
- ☐ Low - this person can do many things alone but needs help from time to time
- ☐ Don't know / rather not say

Other (please specify or feel free to leave a comment)

21. Again thinking of the person you care for most, what type of help do they need? In other words, why do you need to care for them?

You can choose more than one option.

- ☐ They have problems doing tasks in their daily life (e.g. they need help with things like meal preparation, personal hygiene, transport)
- ☐ They have problems with cognition or behaviour (e.g. they get confused, wander, have a mental health condition)
- ☐ They have complex health needs (e.g. they have one or more serious medical conditions and need help with medications etc)
- ☐ Don't know / rather not say

Other (please specify or feel free to leave a comment)

22. How many hours per week would you say you spend on caring duties?

23. What type of caring tasks do you do?

24. Has anyone helped you to plan the care you provide, as part of a broader care plan?

- ☐ No I haven't talked to anyone about a care plan
- ☐ Yes a government agency has helped me make a care plan
- ☐ Yes a care provider organisation has helped me make a care plan
- ☐ Yes a private adviser has helped me make a care plan
- ☐ Don't know / rather not say

Please feel free to add any comments or to let us know if you think having a care plan is (or might be) helpful for you.

25. Would you accept more support in your caring role if it were available?

- ☐ Yes
- ☐ No
- ☐ Don't know / rather not say

Please feel free to provide comments.

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