



Older Australians' Experiences as Carers

2026

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Executive summary

National Seniors Australia (NSA) is a not-for-profit research and advocacy organisation representing Australians aged 50 and over.

Every year we survey thousands of older people on diverse topics relevant to lifestyle and wellbeing through our National Seniors Social Survey (NSSS).

This report is based on a module called 'Experiences as a carer' that was presented to thousands of older Australians in the 2026 iteration of the survey (NSSS-26).

This report highlights the experiences faced by older carers. These are people aged 50+ living in Australia who provide informal care to others – 'informal' meaning not in a professional capacity and usually unpaid.

In total, 791 people said they were carers at the time of the survey, and another 295 had recently ceased providing care at that time. Together these carers comprised around a quarter of the 2026 NSSS survey sample who answered the question about their carer status (1086 out of 4102 people).

Older carers' traits and the care they provide

Consistent with previous research into carers, the carers in this survey included significantly higher numbers of women. Carers averaged more chronic health conditions and felt tighter financially compared to non-carers.

These carers most commonly provided care to other people aged 70 and over, especially their spouses but also parents, friends, adult children and other relatives. A quarter cared for more than one person. Two-thirds lived with at least one person they cared for.

Three-fifths provided care nearly all the time or daily. Most of the people receiving care from NSSS participants needed 10 hours per week or less of care time (including travel for the carer), but over 10% needed 40-80 hours or more per week.

Just under half of current carers regularly completed life management tasks on behalf of the care recipient and the same proportion completed household tasks on their behalf. Just under a third engaged in minor medical or personal care tasks for the person. A huge 99% of carers said their role

entailed at least some amount of emotional support and nurturing.

One third of care recipients did not access care from anyone else other than the survey respondent – paid or unpaid. The survey respondent was the only carer they had at the time of the survey.

Even among those who did access care from elsewhere, three quarters of respondents reported a shortfall between what the person needed and what government services could provide. About half of them said they could make up most or all of that shortfall with the care they provided, but the other half said they could only make up some or little of it.

Comments showed that often the shortfall was because of tasks that needed to be done that are simply not supported by government-funded care. In other cases care recipients had been denied some kinds of government-funded support, or the support they did receive was poor quality.

Negative and positive impacts on the carers

Three-fifths of carers reported negative impacts on their life because of the caring role, and another tenth were unsure if they had experienced negative impacts.

Every kind of negative impact the survey asked about in a set-response question had been experienced by 10% or more of the carers. Three-fifths reported negative impacts on mental health, another three-fifths on travel and hobbies, and over two-fifths reported negative impacts on each of physical health, their relationship with the care recipient, and their relationships with others.

Those noting a care shortfall were 226% more likely to report negative impacts, and those who had used respite care were 463% more likely.

Free-text comments about negative impacts most often emphasised the immense stress and difficulty of caring, the physical and mental toll it can take, the shrinking of the carer's world and loss of their identity, the feeling of being trapped, and the heavy burden of duty, demands, and responsibility.

Some carers described their unrelentingly negative experience of caring succinctly, in comments like *"It is the absolute worse experience of my life with no end in sight"*, *"It is difficult and life draining being my mother's carer... I am in my late sixties and feel as if my life is being sacrificed for hers"*, *"I can't have a life because of caring"*, *"My job of caring for my husband for 12 years nearly broke me"*, and *"it left me a physical and mental wreck"*.

Some comments in response to a question asking about the positives and rewards of caring expressed similar sentiments, including, *"Nothing is positive about it... It is 24 hours a day of drudgery"* and *"There are no positives... It is a full time, thankless role... Long hours, no break, no respite."*

The lack of time to do anything else, the inability to ever be spontaneous, and the care recipient's refusal to let their carer have respite time off were among the negative effects described in comments that had not been included in the set-response question.

Some carers also expressed scepticism about the notion that carers can help others live independently and remain in their own homes, given the time and sacrifice carers must put in to make this possible.

Several older carers mentioned it was difficult to provide care when they themselves had disabilities, chronic pain, or other limitations due to the effects of ageing. Others felt grief about losing their retirement period to the carer role when they had hoped it would be finally time for them to relax and enjoy themselves.

A few carers drew attention to the sense of obligation many older Australians feel to provide care to their spouse or other relatives even when they can't or don't want to. This sense of obligation is often unspoken in our society. Care recipients may also make carers feel pressured to provide care to them even when there are alternatives such as paid support workers or respite opportunities.

Carers did also articulate positives of the role though, including spending time with the care recipient, knowing the person is receiving quality care, fulfilment of duty or a debt repaid, and, for some at least, genuine pleasure in service.

Experiences accessing carer supports

Most carers had not accessed respite care.

For many it was because they did not feel they needed it, but others faced resistance from the care recipient, a lack of knowledge of how to access respite, or problems getting it at the time they needed it or for sufficient duration. Some said there was simply none available to them. A few did not know what respite is.

When asked about other supports, two-fifths said they do not receive any emotional or practical supports from anywhere and three-quarters said they do not receive any financial support for the carer role.

When asked what they would need to continue supporting care recipients to live in their own homes, it was most common for carers to nominate cleaning and other housework or yard work, but they listed over 15 other types of support as well. It was not always clear if the required support was for them or the person they provide care to.

Some simply highlighted the long waits for government-funded home care or the fact that that care is insufficient for their needs (or the needs of the care recipient).

When asked to list any resources they were aware of through which they could access information about supports for carers, most carers did not answer the question as intended, often instead writing about supports for the people they provide care to.

Among those who did list resources that can help carers access supports, only 29 mentioned Carer Gateway. This is less than 10% of those who answered the question.

Recommendations

In general, this report has shown that big changes need to happen in this country to support older carers' wellbeing.

Many feel isolated and that their experiences are poorly understood, so we need a national conversation that shines a spotlight on what carers go through.

Unspoken societal assumptions about who is obliged to provide care must also be brought to light and openly discussed.

In immediate practical terms, this report makes two specific recommendations :

1. That the Federal Government implement the recommendations of the 2023 [Parliamentary Inquiry into the recognition of unpaid carers](#), and legislate carers' rights, following international examples such as the UK.
2. That the Federal Government intensify communications campaigns to promote existing carer supports including Carer Gateway, using language that recognises the enormity of what carers do and the real barriers they face to accessing help.

The Federal Government needs to prioritise investment in policies and programs that support the emotional and financial sustainability of carers who provide significant benefits to the community and economy through their caring activities.

Introduction

People who provide informal care and support to others – in other words, carers – provide immense benefit to Australia.

According to figures cited by [Carers Australia](#), there are currently 3 million unpaid carers in this country, and they provide 2.2 billion hours of care to their fellow Australians. The replacement value of this unpaid care is \$77.9 billion per year.

Among them are [1.2 million primary carers](#) – those who provide the most care to a person. Around [a quarter of primary carers](#) provide 40+ hours of care per week.

The [2022 Survey of Disability, Ageing and Carers](#) conducted by the Australian Bureau of Statistics showed the average age of a primary carer is 50 years old, and over two-thirds of primary carers are women.

The number of care hours provided also varies with age. Among women, the most care hours are provided by carers aged 45-74, and among men by carers aged 65+.

Yet despite their numbers and contribution, older carers' work and the impacts of caring on them often go unseen. This report is an attempt to redress some of this invisibility.

In Australia there is already an excellent annual barometer of carers' experiences: the [Carer Wellbeing Survey](#) produced by Carers Australia and the University of Canberra. This report is designed to complement it, by bringing a unique focus to the experiences of older carers.

The data for this report were collected through the 2026 iteration of NSA's annual National Seniors Social Survey (NSSS-26) in a module entitled 'Experiences as a carer'. That module was based on a survey originally drafted by NSA and Carers Australia, and incorporated suggestions by the NSSS's main funder, the Department of Health, Disability and Ageing.

The survey module

The NSSS was open to participants for just over 2 weeks in late January/early February 2026. Anyone aged 50 or older and living in Australia was welcome to participate, and around 4500 people did so.

The first question of the 'Experiences as a carer' module gave a definition of what was meant by a carer in this context, then asked respondents if they were a carer, had been until recently, or would like to provide care to someone but cannot:

In this survey, we define a carer as someone who provides personal care, support and assistance to another person who needs care because they have a disability, a medical condition, a mental illness, or are frail and aged.

Caring tasks we are interested in are:

- *Help with everyday tasks (e.g. housework, garden work, meal preparation, transport)*
- *Help with life management (e.g. banking, paperwork, making appointments)*
- *Help with minor health needs, medications, personal care or mobility.*

This definition of 'carer' doesn't include people who are employed to provide care or who provide care in the course of studying or doing voluntary work for charitable or community organisations. Are you currently a carer, according to this definition?

In total, 4102 people answered this first question, and 1086 said they are or were a carer by this definition (26.5%):

- Yes [I am a carer] (791)
- I was a carer until recently but not now (295).

The 791 current carers were presented with set-option or comment-based questions about their experiences of the carer role.

Topics addressed included:

- Personal characteristics of the person or people who the respondents provided cared to
- How often the respondents provided care to those people and the hours per week spent caring
- The tasks respondents performed in the carer role and the highest level of intensity of these
- Any care the person they care for receives from another individual or professional service and the shortfall the respondent must make up if any
- Positives and negatives of the carer role
- Experiences with respite care
- Any other supports the respondent received
- Supports the respondent would need in order to continue in the caring role

such that it would enable the person or people they care for to stay living in their own home (if applicable)

- Sources of information about carer supports that the respondent had encountered.

See Appendix 1 for full questioning route.

No question was compulsory.

Unless otherwise indicated, quantitative questions to current carers were answered by between 733 and 785 of the 791 total.

Those who were carers until recently were invited to comment on their experiences as a carer if there was anything they'd 'like to tell the government' about it, and 161 of the 295 did so. They were asked no other questions.

Comments from both past and current carers are reproduced throughout the report to illustrate themes, as relevant.

An additional 20 respondents said there was someone they would like to provide care to but they were unable to. They were only asked about the barriers that prevented them from providing care. Their responses are summarised in Appendix 2.

Characteristics of carers vs non-carers

The carers surveyed were more often 50-64 years old, female, and living with more chronic health conditions and tighter finances, compared to the non-carers surveyed.

Past or present carers comprised 27% of the 4102 participants who answered the 'are you a carer?' question (n=1086).

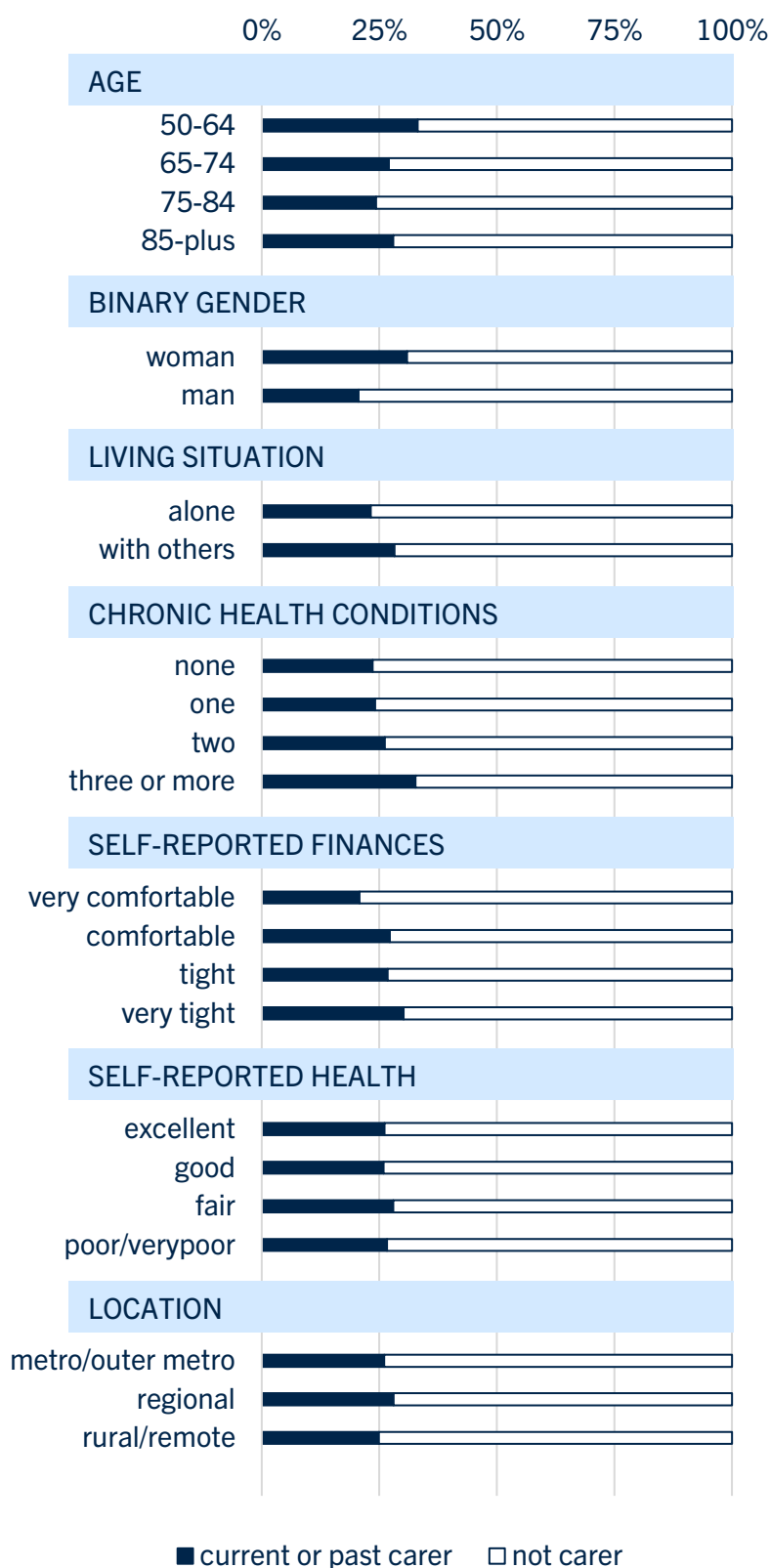
But when looking at specific socio-demographic traits, the proportion of carers varied, comprising between 21% and 33% of every trait examined.

For some traits there were statistically significant differences between the carers and non-carers surveyed. Compared to non-carers, higher proportions of carers were:

- 50-65 years old
- female not male
- living with others not alone
- living with more chronic health conditions
- feeling tighter financially.

There were no significant differences between the two groups in terms of self-reported health or location.

See the 'Sample' section at the end of this report for a full description of the socio-demographic traits of the 1086 carers surveyed.



The care older carers provide



Who do older carers provide care to?

More than half of the older carers surveyed provide care to their spouse, and most of the people receiving care from them are 70 or older.

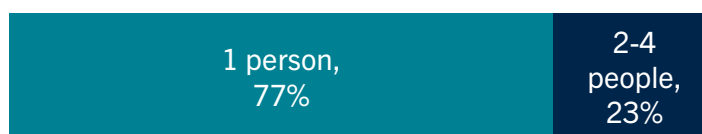
The graphs on this page show that older carers provide care to all kinds of people – of all ages, and with all different kinds of relationship to the carer.

Nevertheless, among this survey sample it was most common to provide care to other older people, especially those aged in their 70s and 80s or older, and most often the carer's spouse.

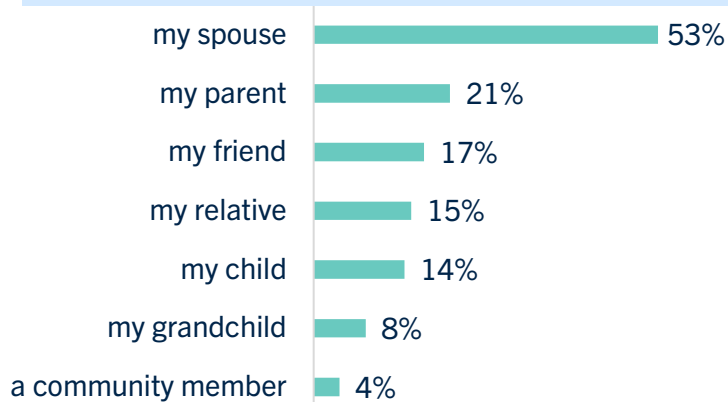
Around one quarter of older carers provided care to more than one person. This is why the percentages in each of the graphs add up to more than 100%.

Two-thirds of the carers live with someone they provide care to.

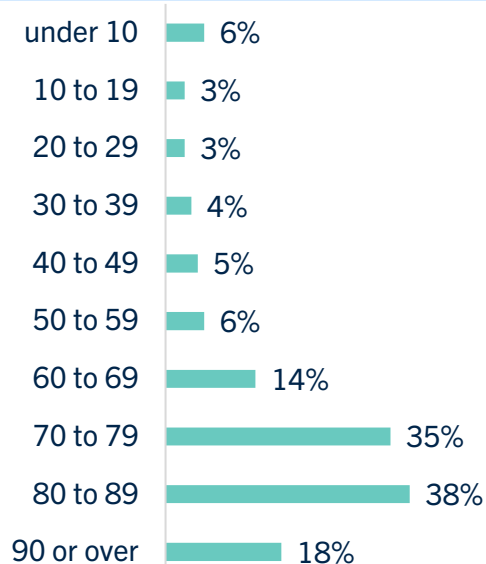
NUMBER OF PEOPLE THEY PROVIDE CARE TO



CARE RECIPIENT'S RELATIONSHIP TO CARER



CARE RECIPIENT'S AGE



DO THEY LIVE WITH CARE RECIPIENT?



How much time do they spend caring?

Three-fifths of carers provide care to someone 'nearly all the time' or daily.

Current carers were asked how often they provide care and how many hours per week they spend doing it.

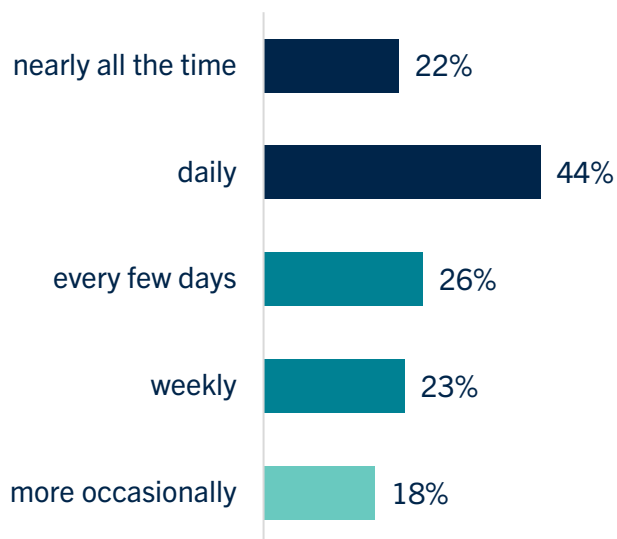
It was very common for them to provide care daily or more often.

However, the graphs indicate that caring more often does not necessarily go hand in hand with caring for more hours per week. It was most common for people to provide care on a daily basis but also most carers provided 10 hours of care per week or less.

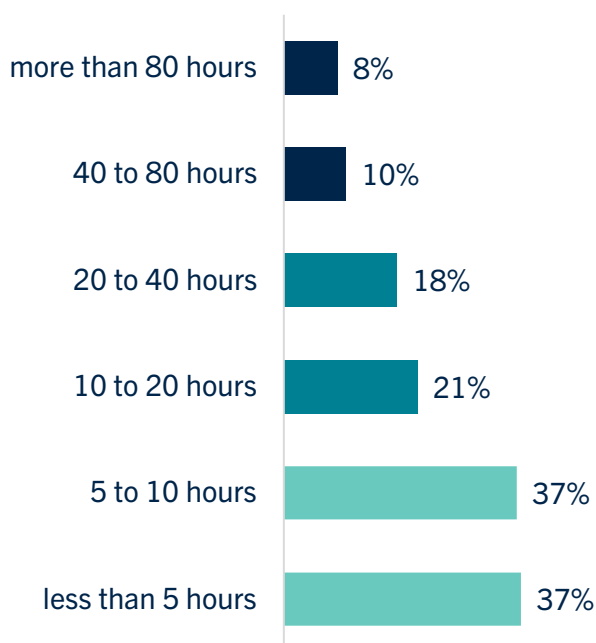
Note that the percentages for how often care was provided and the hours per week spent on care were totalled based on all care recipients, because some carers provide care to more than one recipient. This is why the figures in each graph add up to more than 100%.

This means that around a fifth to a quarter of carers are doing double, triple or quadruple duty within these graphs.

HOW OFTEN THEY PROVIDE CARE



HOURS PER WEEK THEY SPEND PROVIDING CARE INCLUDING ANY TRAVEL TIME



What does the care they provide involve?

It is common for older carers to complete administrative or household tasks on behalf of the people they provide care to, with around half doing so. Emotional support also plays a huge role in caring labour on top of practical tasks.

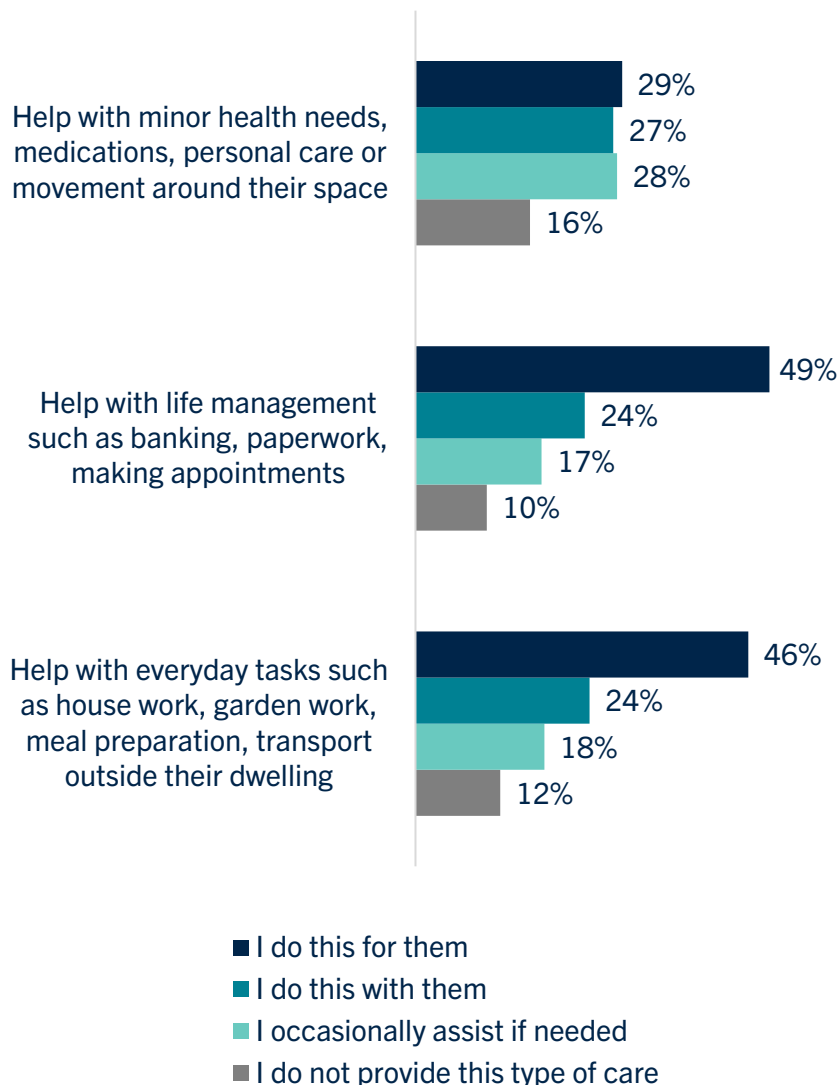
Carers were asked about three types of care task. For each, they were asked whether they provided it at all, and if so, the intensity of care provided for that type of task.

The question was intended to give an indication of whether older carers provide high, medium or low-level care for each of those three types of task.

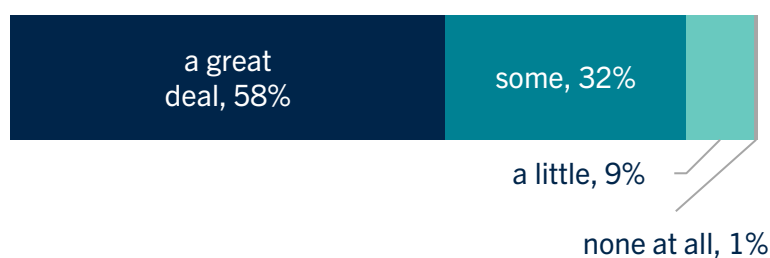
Providing high level care was very common, especially for life management and everyday tasks, and to a lesser extent for personal care and minor health needs.

Almost every carer provided some emotional support and nurturing to their care recipients, with over half of them providing a great deal of it.

TYPE OF CARE PROVIDED AND ITS INTENSITY



EMOTIONAL SUPPORT & NURTURING IN THE ROLE



Does the care recipient have other carers?

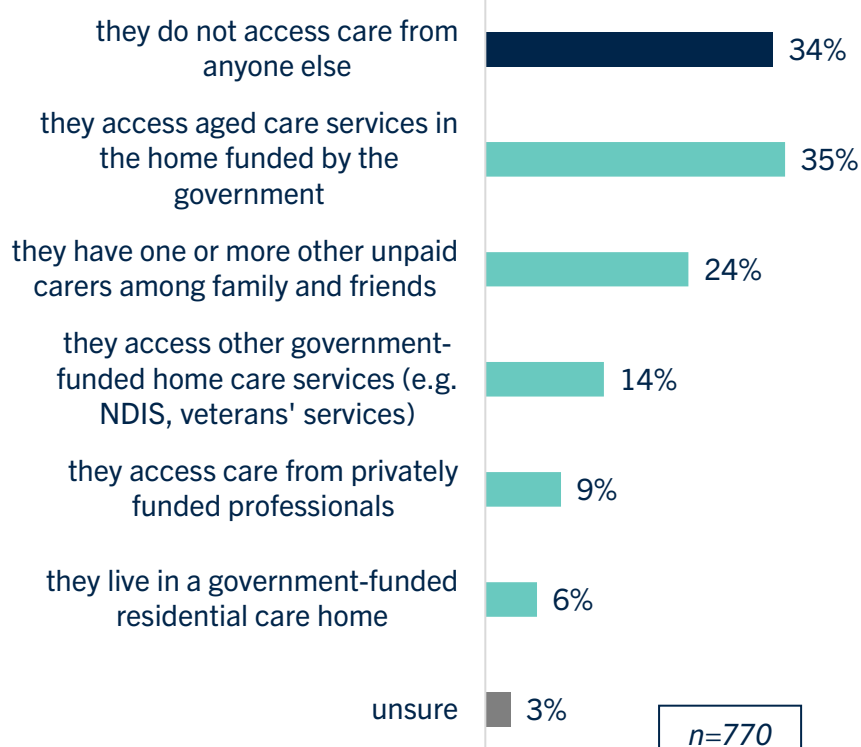
A third of the people the carers provide care to do not receive care from anyone else. The rest receive care from one or more additional sources, but there is often a shortfall.

In this survey section, respondents were first asked if the person they provide care to receives care from anyone else.

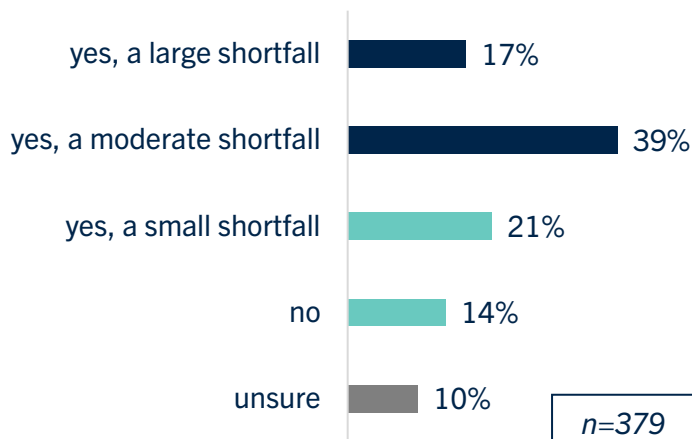
If they indicated the care recipient was accessing any kind of government-funded care, they were then asked if there was a shortfall between the service provided and what the person needs (n=379 respondents were asked this second question).

If there was a shortfall, they were asked how much of it they were able to make up for (n=327).

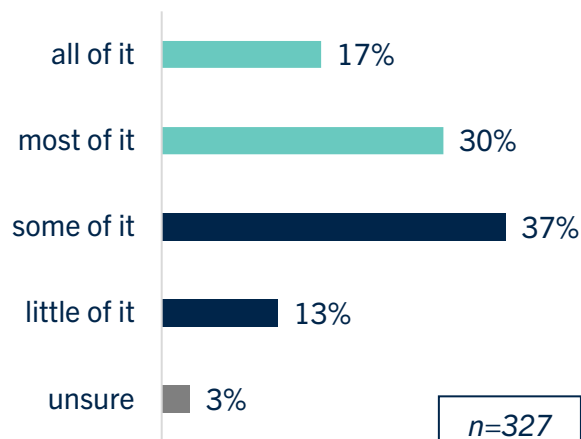
CARE THE PERSON RECEIVES FROM ANYONE OTHER THAN THE RESPONDENT



IS THERE A SHORTFALL BETWEEN WHAT THE RECIPIENT NEEDS AND THE CARE PROVIDED BY GOVERNMENT-FUNDED SERVICES?



HOW MUCH OF THE SHORTFALL IS THE RESPONDENT ABLE TO MAKE UP FOR WITH THE CARE THEY PROVIDE?



Comments on shortfalls in government-funded support

Carers who said there was a shortfall between government services and what the care recipient needs were given the opportunity to elaborate, and 84 people wrote informative comments.

- 33 people said the shortfall is outside the scope of available government support or funding level. Examples include:
 - yard services and gardening beyond basic mowing
 - home services that involve heights such as cleaning windows, fans, lights, guttering, or taking down curtains to be washed
 - home services that involve moving furniture, rugs, items to dust under
 - cleaning with Domestos
 - showering more often than 3 times per week
 - repairs or modifications to rental accommodation
 - clinical treatments beyond an allocated amount
 - life skills teaching
 - emotional or mental health support
 - administrative activities such as banking, appointments, technology help
 - trips to the vet for care recipients' pets
 - outings and social activities
 - transport for motor scooters or for extra tall clients
 - after hours or weekend care, because the cost increases
 - 24/7 care
 - short term personal care
 - funds to help the person move out of home and live independently
 - respite for the main carer, or enough respite to do an activity such as see a show.
- 23 people commented that the care recipient has insufficient access to government supports. This includes:
 - people not being eligible for a support program
 - people being granted a lower level home package than they need
 - processes for obtaining support are slow and hard
 - the necessary support does not exist
 - there is a higher-than-reasonable expectation placed on vulnerable people who are trying to access care, in terms of their capacity to navigate bureaucracies
 - government funding being withdrawn because a family member or friend is expected to do all the caring work
 - staffing and other issues render the service inadequate.

Efforts to have her come under the NDIS program have been totally denied

Mum has been on a level 2 package for a number of years and was reassessed last November (this took some months). She has been approved for an increase to level but this could take 12 months before it is applied. At 90 years old her needs far [outweigh] the funding she is currently receiving.

It takes so long to get NDIS approval for some things we just have to organise and pay for ourselves but NDIS should be providing. Three years is messing around for modifications for example

There is no day respite for people with young onset dementia

they are a couple. Both require considerable specialist health care. The system they operate under appears, to me at least, as confusing and convoluted. They both have poor memories and are easily confused. The need to access a dozen different service departments/people makes their life very difficult. In their condition they need one contact and perhaps a digital assistant for appointments.

Partner isn't very mobile. They were on list for assessment for aged care package but was removed because apparently I was still capable of doing all his care.

My friend is eligible for and receives government funded cleaners but there are serious staffing issues and it can be MONTHS between visits.

- 8 people said the person receives support through a home care package, residential care home, state trustees, or hospital, but the level of support is poor quality. Some of the carers surveyed attend residential homes for many hours duration to ensure the person they care for who is resident there gets everything they need.

Administrative support from State Trustees (Vic) to NDIS recipient, was exploitative and incompetent.

My experience has always been that if your relative or friend needs residential care, they need a person to oversee that their care needs are being properly taken care of and this is a constant concern. You feel guilty at times that you cannot take care of them full time anymore.

Not sure what you mean by this. I arrive at the aged care home daily at 9.30am. From then till I put my wife to bed and depart at approximately 7pm, I am fulltime carer for my wife. If I need assistance, I can call on staff from the home, but have to wait till they are available.

- The other commenters made a range of remarks on shortfalls:
 - 10 noted that the care recipient preferred the survey respondent to provide the care than for a stranger to do it, or they otherwise refused care
 - 8 people's responses suggest they were answering with respect to a financial shortfall not a care activity shortfall, especially for medical costs and outings
 - 5 people anticipated a shortfall in the near future, recognising they will not be able to cover it forever as the situation changes.

Many of the past carers who wrote a comment shared similar sentiments about the shortfalls and inadequacies of government-funded support in terms of aged care, disability care and the NDIS, hospital care, and Centrelink or Veterans Affairs assistance.

How did the carer come to be a carer?

All current carers were asked how they came to be the carer of the care recipient(s) and 476 wrote an interpretable comment in response.

However, respondents answered the question in different ways, making it difficult to draw generalisable conclusions.

Two approaches were the most common:

- 276 mentioned that the care recipient had become ill or incapacitated, and many described the cause or nature of the health or incapacity problem. Often this was the only explanation given, so was more informative about why the recipient needs care than how the carer came to be the person providing it. Within this group, people caring for spouses were over-represented, and people caring for friends under-represented, suggesting commitment or a sense of duty played a large role in them coming to provide care at the time of need.
- Further to that point, 86 people mentioned their relationship to the person (spouse, parent, and so on) without further explanation, as if the relationship spoke for itself, or wrote words like: *"They are our family, and live near by, so why wouldn't we help them"*, *"Love"*, *"63 years of marriage"*, *"Because I am married to them"*, *"I am their spouse so it falls to me"*, or *"He needs support in many ways and as a wife I feel the need to help him."* Many combined this response type with another.
- Some elaborated on this, explicitly writing about obligation as a motivation, with comments such as: *"Parent/child relationship obligations"*, and *"Society and the government expects spouses to do this. There is no option. I can hire someone to mow the lawn but I can't hire someone to do the worrying, make the phone calls, sit in the waiting room etc"*.

Less common response types were:

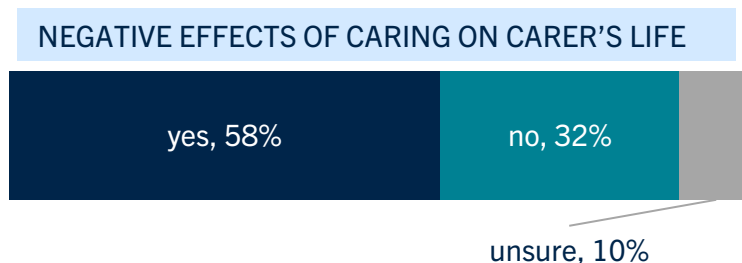
- 42 of those caring for friends, neighbours or other community members explained how they came to be doing this. Examples included: *"Long term friendships. Supporting Gay Elders"*, *"In my role as Secretary of an RSL Sub Branch I check on members who may require assistance"*, *"Through my Synagogue"*, *"Common interests"*, *"I assist Ex-ADF members, who are suffering PTSD and help them with living arrangements and support"*, and *"A neighbourly response to a struggling person without any family help"*.
- 39 said the person has no one else at all or no one else available or nearby to help.
- 20 mentioned the person's previous carer(s) had passed away or become incapacitated themselves.
- 15 adopted the carer role because of their own *"humanity"*, seeing a need and responding, they *"Just needed to be helpful"* or they were already caring for others – it is who they are or *"just something I do"*.
- 15 became a carer at the prompting of a GP, court order, or by being the person's appointed EPOA, guardian and/or administrator.
- 12 said their care helped the person remain independent or stay out of residential care.
- 10 were part of a shared caring arrangement with other family members, or they were caring to relieve others of the caring burden.
- 3 cared for people who had escaped situations of abuse or neglect.
- 5 gave other reasons such as repaying a debt of help, following through on a promise to care for someone, continuing to assist someone they previously supported professionally, or having more experience with necessary tasks.

The impacts of caring on older carers



Negative impacts of caring on older carers

Three-fifths of carers have experienced negative impacts on their life because of the caring role. Leisure activities and mental health were most commonly affected.



All current carers were asked if caring had affected their life negatively. Those that answered 'yes' were then presented with a list of life arenas that might be affected and invited to select all that applied to them.

Some demographic and caring-experience factors were associated with being more or less likely* to experience the negative impacts of care-giving:

- men were 55% less likely than women to be negatively impacted
- older age groups were 45% less likely than younger age groups to be negatively impacted
- those providing more frequent care were 63% more likely to be negatively impacted
- those experiencing a care shortfall were 226% more likely to be negatively impacted
- those who had used respite care were 463% more likely to be negatively impacted.



* Associations tested using multiple logistic regression models (details in Appendix 3).

Comments about negative impacts

The 425 carers who said caring had negatively affected their life were invited to elaborate in a comment and 183 people did so.

Some of the themes echoed those in the set-response question on this topic (see previous page) but not in order of prevalence. A larger proportion of commenters wrote about the impacts on their mental wellbeing, sense of self, sense of freedom, and relationships with other people. Themes that elicited at least 10 comments each are explored over the following pages.

Caring is hard and takes a physical and mental toll

The most prevalent theme was simply how hard caring is and the large toll it takes on carers, physically and mentally – whether because of exhaustion, stress, violence, or a combination of factors. Carers often have their own problems, health conditions or disabilities to manage as well as caring.

It is the absolute worst experience of my life with no end in sight.

From time to time they lash out verbally which can be confronting. They have no idea that they can be cruel. After a particularly bad outburst I distanced myself for a little while as unbeknownst to me it had affected my physical well being. It was only several months later that I realised the impact and I have been more careful to protect myself emotionally since.

The stress was [one] of the factors (not the only one) that put me in hospital for a few days.

Son can be physically and verbally aggressive. Have been bashed, personal belongings broken

It is very stressful dealing with 2 family members with serious mental health conditions, one with suicidal tendencies.

I get very tired managing the home and jobseeker volunteering.

It is very mentally and physically demanding particularly as I also have a disability (CFS).

At times the mental health issues I deal with can be extremely draining. Suicide is probably the worst.

Now on anti depressive medication

I am not as strong as I once was. Lifting a wheelchair in and out of my car is getting difficult

As a sole parent I had to work harder to keep a roof over my son's head. This damaged my spine at the neck trying to work unsuitable jobs. My spine is crappy now. If I had gone down so would he.

I don't know of any help I could get and just battle on day to day despite being in constant pain myself from arthritic knees and having difficulty walking easily.

Carers have no life, lose their identity, or must put others first

Another common theme was carers' sense of losing themselves, having no life, or feeling as though their world has shrunk. Some of this is due to demands placed upon carers by those they provide care to. Some could see no end to these feelings.

I start to see my world closing in. I have to try to overcome apathy, negativity and the loss of freedom to schedule my days. I am learning to structure my day so that essentials (like my exercise, my social activities) can be quietly fitted in, but I am around when needed.

When I ask to be allowed to pursue an individual activity a negative response is frequently observed.

Your world shrinks and my life is run by Carers schedules for my wife as she has reached a point where she can't be left alone

Living in fear of causing upset in her condition. Never feel happy or comfortable in my situation. Would like to discuss the whole situation with a medical professional in this field and how to help myself. Relieve depression.

My life is boring, tiring, disappointing my husband went into hospital for brain surgery & came out a different person. From independent & articulate to needy & forgetful

My whole life revolves around caring for my husband and his needs. I feel like a widow but still care for my husband who lives in his own time and space. There is no happy ending.

I don't even know where to start - I am so overwhelmed assisting my 91 yo mother, financially being the sole bread winner - husband doesn't work. I had hoped to retire by now but that won't happen for some time now.

I don't have time to do the things I am interested in, studying, or reading because I am always doing things for my husband

Because I spend half the week looking after elderly relatives etc, I haven't got time (or energy) to pursue a partner, or do all the things I'd like to do at my own home.

It has had a negative impact on my life as I feel as though I'm not free to do what I want

I am tired, feel different and isolated in many ways. Feel I don't fit in to life.

Our 16 year old Grand daughter said it is like I am losing all the joy and fun in my life since I have been looking after Nanna. And it feels like that too.

I have been reduced to a very domestic life. Trying to infuse our lives with joy is a bit of a challenge.

It is difficult and life draining being my mother's carer. I am in my late sixties and feel as if my life is being sacrificed for hers.

I cannot make decisions that relate to my life as I have to always consider my husband's needs first

I can't have a life because of caring

The 'me' before I started fulltime caring is perhaps gone forever.

Trapped by duty, demands, and the burden of being the back-up

Some carers commented on the dominance of their sense of obligation and duty, and the burden created by constant demands and always needing to be the back-up. Many felt trapped. Others felt unappreciated. Some felt a sense of unfairness about this expectation – whether it came from the care recipients, others in their life, or society in general.

when I cared for my mother fulltime in my house, I felt trapped.

Sometimes I feel obligated to provide support even while I'm not well or have other commitments. I feel guilty because if I don't assist, they won't get help.

I would love it to be the other way around. That my family did not need my support.

I often feel trapped in my life. It dominates my every day.

The expectation from my mother and also my brother that I will be around at any time for whatever [care] my mother needs is quite draining

I care for 2 people but only get paid for 1, it has affected me mentally its very hard to care for your loved ones I think too much is expected from us.

I feel pressured to phone support my friend and take her out

The nursing home staff could feed Mum, as they do breakfast and lunch, but mum prefers me.

I find it difficult to switch off from my care responsibilities and I worry about the future. I feel a lot of loss and grief.

It is hard to be 'on call' every waking moment. With [name's] vision loss he asks me to do things when I am already busy, not realising. At times I find it difficult to stay calm.

Managing her expectations so she doesn't treat us as staff.

it is time consuming, costly, mentally draining, unappreciated, never good enough, but when it is your Mum, what can you do.

There are 3 others who assist but not as regularly as I would like. I feel the burden falls on me.

All 4 people who do not know each other are getting more selfish & expect & state " I am old, I'm not going to be here much longer so I want. ..."

The stress is real. Person I care for had mental health issues and seeks continual attention

Lost relationships with others and feeling isolated

A sad reality for some was that caring led to isolation from friends, family members or the community due to time limitations or rejection.

The friends with whom we did these activities are now not inviting us.

Without respite, I am living a lonely life with no social interaction

Unable to catch up with friends or social groups

This is the first year ever we did not have our grandchildren stay over during the Christmas School Holidays because Mum is taking up all of my time.

I am now isolated from society. Have no friends etc

Missing out on travel, hobbies and interests

Missing out on leisure activities was also a caring-related loss, especially if their care recipient's needs were increasing.

I feel trapped and running out of the time when I'm still physically able to do things I love like travelling and hiking.

since 2023 Mum got much worse and I have ended up doing all the things for her as already mentioned. I have not been able to do a single thing I was so looking forward to doing in my retirement like writing books (which people have been telling me to do for years) exploring hobbies like drawing, painting and learning Finnish as well as travelling.

We are unable to travel. Have the funds, want to go but find travel difficult.

Losses to finances or work and career

The financial impact of caring was highlighted by commenters who wrote about lost work or career advancement opportunities, or the direct costs associated with providing care.

My husband and I provide around the clock care for a 99yr old who has no income which could support her due to government decisions. And who is unable to live on her own in her home. We provide her with a residence and full time care, taking care of her needs including food. This is in no way covered by the carers allowance.

I gave up my career and ability to have better income, had to find something that allowed me to work from home.

I work as a relief school teacher so that I can be available to care for my brother when he needs and sometimes this means I miss out on work.

I retired because my workplace would not let me help my mum

Financial costs are huge about average \$40,000 pa.

Inability to be spontaneous or leave care recipient for long periods

Carers also wrote about their inability to be spontaneous or to make plans in advance, either because they could not leave the person they care for alone, or because caring meant they were in no position to change plans without notice.

Not everybody understands that when you are responsible for someone, it means that you can't suddenly decide to go on holiday or to an activity that would overlap with times when you need to say give medication, prepare meals, etc.

I can't leave [name] for very long in case he falls and he gets upset if he can't find me.

I am continually anxious about leaving my spouse alone when leaving house to attend to my appointments.

The support provided to my husband is intermittent and therefore limits my ability to make commitments that can't be changed at the last minute.

Damaged relationship with care recipient

Some people expressed sadness or frustration that they can no longer even experience the relationship with the person they care for as the dynamic between them has changed, either due to the caring itself or the factors that make care necessary.

Loss of meaningful conversation with my husband

It is sometimes stressful dealing with my friend as he has delusions.

have to deal with some negativity from my partner when he feels unwell. He is normally a kind and generous man but his condition gets him down.

Early dementia means my spouse can get very angry with me

Disillusionment and frustration with support services

Carers' frustration with support services and government departments was evident, either because of difficulties accessing support or the perception that there is no support.

Ongoing mental strain with dealing with various bureaucratic organisations in arranging aspects of care for family member

I have developed a 'loss of faith' in a number of our institutions after prolonged proceedings in dealing with family member's situation

Feel that there is no support, only AI talkbots, which i find useless & dont like to use

Support at Home programmes do nothing for the Carer. They are totally focussed on their client. If the client goes into respite care they have nothing to do with the Carer, who is left to flounder.

What we receive does not translate to what Government talks

Health bureaucrats are wankers and contribute immensely to life's current frustrations.

Having no time for anything other than providing care

The huge time commitment of caring responsibilities, including travel time, was also highlighted.

The biggest negative impact is the time all of us have to spend looking after her and her affairs.

I declined counselling because I was too busy! I am thinking about contacting Carer Gateway again to see if it is still available.

Have to travel 2 and 1/2 hours back and forth to elderly parents.

Comments on negatives from past carers

Some comments from past carers also concerned negative impacts, echoing many of the concerns outlined above:

- **Exhaustion:** Some people mentioned the serious physical/mental/emotional health impact the caring experience had on them, and/or that caring is extremely hard (examples below).
- **Financial issues:** Topics mentioned included the direct expenses of caring (paying for special foods, petrol, services, etc), loss of income because the carer cannot work or can only work casually, difficulty finding work after a long term caring period, and the lack of payment or very low payment for the time spent being a carer. One person objected to the income/assets tests for carer's allowance/payment being based on the carer's spouse not the carer's own financial situation.
- **Loneliness:** Comments highlighted the loneliness of the caring role, and/or that caring is unacknowledged and under-valued.
- **Respite:** Using respite care was mentioned as being difficult due to feeling guilty about leaving the person being cared for or being pressured by them not to use it.
- **Other negative impacts:** These included lingering grief and trauma and unspoken societal assumptions about the capacity of family and friends to provide care irrespective of their own life circumstances.
- **More information:** A few people noted that they would have liked more information about what was available to help them.

Some past carers wrote movingly about the immense effect caring had on their wellbeing.

My job of caring for my husband for 12 years nearly broke me.

it left me a physical and mental wreck.

It was extremely taxing, particularly during Covid times. Dealing with government departments, hospitals and the entire system. By the time my husband passed away I was physically and emotionally exhausted. It adversely affected my health. I lost an enormous amount of weight, became depressed severely anaemic developed a heart condition, underwent many tests and procedures - Colonoscopy, Endoscopy, heart monitor, echocardiogram, ultrasounds etc, etc. Grief never leaves one, nor does the trauma of caring for a suffering loved one. I will never be the same person I was pre this period.

It is hard work. 24/7. Mentally and physically challenging. Very hard to 'take respite' thru the feeling of guilt as you know your loved one won't understand, due to their dementia, so you don't take it. THEY don't want to leave for a break either as they think they've been abandoned.

As the carer for my very elderly parents, with Alzheimer's and blindness, I had to resign from my job as a health care professional, and be their advocate as well as assisting with many tasks. We had 2-3 hrs of help from Aged care services, entirely insufficient. I lasted until it started to affect my mental and physical health, then the nightmare of arranging for residential aged care began. I will add that I have a Master's degree in Gerontology and 45yrs experience in the sector but I found it overwhelming and the one of the most challenging experiences of my life.

Others highlighted issues that may be of specific relevance to older carers.

Being elderly and trying to work out what to do and what help is out there, when physically and mentally exhausted

Being a carer is incredibly hard, specially if the person being looked after is your partner - and both are 'older'. It is emotionally & physically draining - and there is no respite. It is 24/7. Most carers don't 'use respite' or put their loved one into care until they can no longer physically manage the sheer weight of the person re personal care.

My husband died last March (Alzheimers). I experienced isolation, loneliness, depression, anxiety, stress, distress, mental health issues and FND became worse, Falls and broken bones. I found support from a psychologist. And found an assistance dog a wonderful support but I can no longer finance her accrediting.

Too many questionnaires etc that they can't complete so it is another responsibility that falls on the carer. LET PEOPLE AGE IN PEACE AND QUIETNESS. STOP DEMANDING INFORMATION FROM THEM. THEY CANT HANDLE IT, SO SOMEONE ELSE HAS TO DO IT FOR THEM SO YOU ARE JUST TRANSFERRING THE BURDEN TO ANOTHER PERSON

A few emphasised the necessity of caring even when the care recipient is in residential care.

Even when my mum was in residential aged care, I provided many hours of support every day. This ranged from advocating with medical and other carers, taking her to appointments, checking her invoices for care and pharmacy to stop her being overcharged, and crucial social and emotional support. The government does not recognise this for Carer Allowance even though it would restrict my ability to continue working

Ceased work age 51 to provide full-time care to mother who lived with us for 18 years until her recent passing. Also provided care to father for 2 years during this time, who also lived with us, with early onset dementia until he became too assist and entered aged care. Continued to visit twice daily at nursing home to feed him lunch and dinner as staffing there was stretched and we believed he was not receiving adequate one on one care.

Finally, some wrote scathingly about the notion that providing care helps a person live independently when it takes a huge amount of labour from their carers to achieve the semblance of this.

Encouraging seniors to remain in their own homes with Homecare support does not account for many hours also required by family to make this happen. Often due to lack of services or availability when required. Eg medical appointments, regular blood tests.

Awful. Supporting the person to be 'independent' when that can only happen when you pick up the slack.

Comments about positives and rewards

All current carers were given the opportunity to comment on the positive impacts and rewards of caring and 352 people wrote a comment in response to this prompt.

No positives

- A portion of this group (14%) said or implied there were no positives of caring.

Nothing is positive about it. It is 24 hours a day of drudgery.

Nothing positive been all negative and just feels like I am wasting my life to make my mother's better

There are no positives. It is a full time, thankless role. Long hours, no break, no respite.

Not many that I can think of, caring & my partner ill health have made my retirement very disappointing. No money left for extras like holidays after paying for ongoing medical expenses

Relationship rewards

- Caring for someone can be rewarding by enriching relationships between carers and care recipients. Comments mentioned the value of opportunities to stay together, spend more time in each other's company, to become closer, or to re-establish relationships. Some simply said "*friendship*" or similar as a reward.
- People described finding their care recipient interesting or fun, listening to their stories, and enjoying or appreciating them as a person. For others, the rewards were slightly loftier, such as "*Connection with the older generation*" or finding it "*stimulating and rewarding to help one of my fellow veterans*".

When we can sit down and have a laugh and joke about anything. I also get to spend one on one time with him as we enjoy the same type of shows and as he worked away a lot when we were little, it is nice to have that contact.

There are still good times that I treasure and that make me forget the bad times. Try to talk and laugh as much as possible.

A good life for the care recipient

- Carers felt rewarded when thanks to their care, the wellbeing, happiness, or quality of life improved for their care recipient.
- A tangible reward was enabling care recipients to continue living at home or in a familial environment. A few used phrases like "*live independently*".
- In some instances, carers felt they reduced serious risks for their care recipient including regular encounters with police or ambulance officers, or even imminent risk of death. Some people wrote about the relief of knowing their care recipient has backup care, e.g. when recipients live in residential care.
- Carers also found comfort in providing quality care or loving care, in a way consistent with their care recipients' wishes.

just knowing my friend has all the assistance she needs to live a comfortable, positive life is reward in itself.

Helping in deteriorating health both physical and mental during end of life period knowing the person is treated with love care and respect

Duty, repayment or love

- For some, caring fulfilled a sense of duty towards parents, partners or family, or a need to take care of people who have no one else to look after them. Several used phrases like it is *"just a necessary part of life"*, *"what one would expect to do"*, *"as it should be"*, *"what you do for your spouse"*, etc.
- Others said or implied they cared for the person because they loved them. For many, helping out a loved one or friend was its own reward. Some simply asserted statements of fact such as *"He is my friend"* as if that was explanation enough, or said things like, *"It's an expression of love"*, *"She's my mum I love her helping [is] not optional"*, or *"My spouse needs my help. I give it freely."*
- Receiving love or appreciation in return for caring was also noted as rewarding, as was having reciprocal or mutual care relationships where carer and care recipient look after each other and rely on each other through life.
- Some said they cared in order to give back or to repay their care recipient for all the caring that person had done in the past, whether for the respondent themselves or someone else in their life.

It's not that rewarding. It's actually a duty.

emotional rewards in being able to care for someone I love

The positive side for me it that I know my husband loves me and appreciates what I do for him, he feels guilty seeing me having to take on so much, because he is unable to.

We have cared for each other for our all of our life together.

A sense of meeting my familial responsibilities. Providing reciprocal support for all the love and care i received as a son.

A pleasure to serve

- Sentiments underpinning this group of comments were that caring is generally *"good"*, *"the right thing"* or *"what we were put on the earth for"*. Also, that caring for people in need is fulfilling and that the carer role gives purpose in life. In some cases, caring was an important part of the respondent's identity, e.g. *"Assisting is in keeping with my moral compass"* or *"I am a nurse – it comes naturally for me"*.
- Some respondents expressed gratitude or joy that they have the ability (are *"still able"*) to provide care, while others described feeling *"honoured"*, *"blessed"* or *"privileged"* to care for the care recipient(s), or that it is *"very special"*.

There are always lots of positives in caring for your loved ones or anyone else for that matter.

I like to think I have benefited greatly even though it has been a very difficult path at times. I think I have been a carer all my life

Other personal benefits from the carer role

- Some wrote about personal growth and development:
 - carers felt an *"achievement"*, *"satisfaction"* or *"pride"* in their own actions and attitudes.
 - the sense of becoming a better person or developing desirable qualities due to being a carer. For example, being non-judgemental, compassionate, patient, positive, strong, understanding, tolerant and kind.

Acquiring patience, understanding and strength. I'm learning to prioritise, to differentiate between essentials, wants, needs, and that there is often a quiet way to achieve a safe and satisfactory solution.

- some had gained knowledge or wisdom, for example about the carer experience, the needs of older people and society, medical matters, a different lifestyle, or just about what their care recipient needs.
- others gained skills, such as navigating legal or financial or bureaucratic processes, prioritising needs vs wants, problem solving, caring for someone with multiple health needs, or communicating with people with dementia.
- Rewarding relationships with people other than the care recipient were also mentioned. The examples given were:
 - other family members including those involved in caring for the same care recipient, or a general positive outcome of *"family harmony"*
 - other older people living alongside the carer for example in a residential care home, or residential care staff
 - the care recipient's primary carer(s), to whom the survey respondent provides respite or help
 - other people also engaged in caring, who the respondent has encountered.
- A few people commented on peace of mind or good mental health as a reward.
- Two people mentioned the material benefits of Carer's Allowance (noted to be *"welcome but hardly adequate"*), disability parking, and the Companion Card.

A pride in the way I have been able to act in his best interests and not judge him but accept that his cognitive planning is a bit awry and will worsen. It is what it is and I have to be sensible and make our lives work giving each of us contentment and interest in this part of our life.

Positive with mum - helping her manage dad. He has Vascular dementia and can be difficult to handle/live with.

by helping people I won't regret not helping them more, after they're gone.

Supports for older carers



Access to respite care

Most carers surveyed had not accessed respite care, but many said they do not need it. Among those who have accessed it, over two-thirds had difficulty gaining access when it was needed.

Respite care is an important avenue of support for carers, to enable them to take a break from caring knowing that the person they normally provide care to is being looked after.

Almost 90% of the carers surveyed had not accessed respite care.

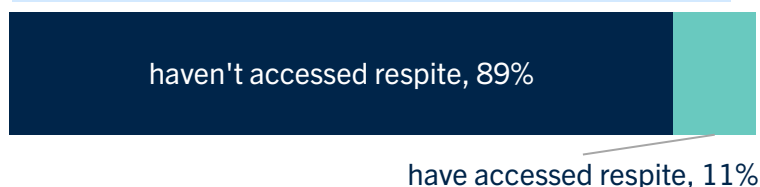
When asked why not, 62% of these said they didn't need it. But people providing care 'nearly all the time' or 40+ hours per week were under-represented in this response type.

Others faced different obstacles, including resistance from the person they care for – an obstacle for 22% of those who had never accessed it. People providing care 'nearly all the time' or daily comprised three-quarters of carers facing this – a heavy over-representation.

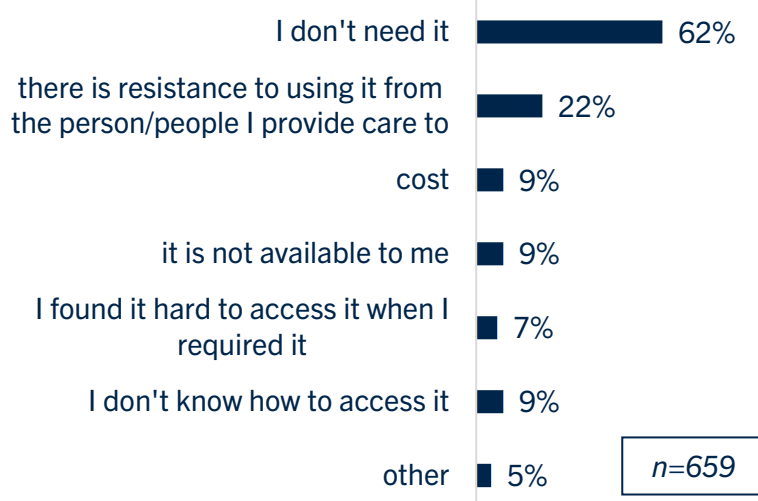
Among the 'other' reasons people wrote about for not accessing respite were the carer sharing the load with other family members; not having enough time to figure out the respite system; feeling respite was unsuitable for the individual they care for; getting respite via their own hospital stays when ill; and wanting to spend more time with the person.

Carers who had accessed respite were asked if they ever found it hard to access, and over two-thirds said 'yes' or 'sometimes'.

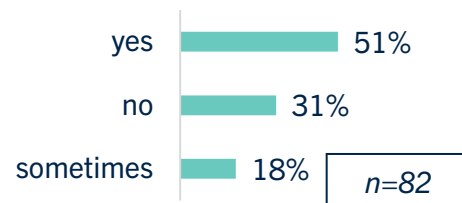
EXPERIENCE ACCESSING RESPITE CARE



REASONS FOR NOT ACCESSING RESPITE CARE



ANY DIFFICULTIES ACCESSING RESPITE



Comments about respite care

Carers were invited to write comments about respite care if they wanted to and 155 did so.

Some comments were positive about the idea of respite, with a few emphasising how much people value respite and would like it (or would have benefited from it in the past).

When my father was alive he lived with us and over the years his dementia increased. I would need to get [up?] 8 or 9 times a night, was unable to leave him on his own. Had 1 day of respite a week when he attended an aged centre but really needed one or two overnight respite opportunities, sometimes at very short notice when his episodes became manic and he needed to be physically restrained. This was not available. Eventually had to admit him to full time aged home living, something i swore to him i would never do and still feel so very guilty about this - 11 1/2 years later.

It would be nice if my son could have some respite from his father who has always been controlling but his dementia is making the situation worse. He has taken over our son's home.

I would love to have had access to this as my 4 ADHD children were in their teens with extremely challenging behaviour which ultimately led to divorce

I access short term respite care for my wife so that I can continue to do things with our son and daughter. It is always an issue particularly when the ACT Government doesn't want to continue it.

I cared for my mother full time in my home until she died, which was very difficult and draining on my health. I would have coped much better if I could have accessed regular weekend respite for her so I could have maintained my own social life and get some much needed rest/sleep.

Some described a positive or neutral experience of accessing respite, though these comments were sometimes mixed with negative aspects.

I use package for 3.5 hours (at once) weekly as 'respite' - ie i go out for personal appointments and 'me time'. Would like to increase to 4 hours/week but not enough funds and cost over time would be prohibitive.

Have to book ahead but most helpful the two times I have needed it when having medical treatment myself. My husband does not want to go into respite for me to have a rest only.

very pleased with the respite care

The person I care for accesses day respite once a week for approximately 3.75 hours per week. Can do more, but places are generally not available due to popularity of programme. I have previously tried to obtain longer respite (1- 2 week), however, a lot of aged care centres don't have short term placements available at short notice.

I went on a 3 day respite provided by carers ACT last year but this year went to a music festival for two days which served as my respite.

Resistance to accessing respite from the person receiving care is common as the numbers on the graph on page 30 showed. Some commenters described the challenge of using respite in these circumstances.

Unsure if she would agree. 3 animals would require care. Never tried.

My wife went to pieces when I talked to her about it. Visibly shaking and crying. So I did not seek any Respite services, and never will.

My husband is an unreasonable, cranky, uncooperative person who refuses to have anybody come to the house to provide any form of care for him. It is the subject of many heated conversations.

I work with my brother and sister to ensure we get breaks and holidays as needed. My Mum refuses to go into age or nursing care facilities, not even for a period of respite. She has been diagnosed with dementia that is going to get worse.

I have looked into respite care and been told repeatedly it is hard to get a placement. We will be going away in May and when I asked if I could have the list of possible places to visit and show Mum I was told that we can only apply for it within a three months period before you need it. Mum is very stubborn and getting her to agree is very hard.

Mum used respite/rehab when she broke her hip, however other than that, she is very stubborn and does not consider she needs respite. Unfortunately older people do not realise the impact on others for their stubbornness

Neither of them will go to respite care

My daughter and my husband are very private people and feel very uncomfortable with a stranger caring for them. Particularly my daughter as she is young and embarrassed that she needs help. The other issue is we are worried about our vulnerable family members being subjected to various forms of abuse by carers even though they have had screening. We have seen stories in the media that highlight these issues.

A few commenters described or alluded to negative past experiences with respite.

Will never use it again. No care and loved one will die.

I tried once when my brother went through a really bad period but all I could get was 2 hours a month to enable me to go shopping. It wasn't worth the hassle because I thought this bad period was temporary - he did recover enough for me to be able to leave him alone.

Not a problem for me but hearing a number of very poor experiences for a number of elderly people I know. And few good ones here in Hobart

Residential respite care isn't available in our area. Only offered at one place and booked out more than 12 months in advance. Home care package provides respite at home for a few hours each week to enable me to shop and go to my own medical appointments. Not really any respite for me.

We tried family support when I had some time away. It was not successful, but we manage for short breaks

The high needs of care recipients were also noted as a barrier to accessing respite, though some people emphasised other supports would still be very welcome.

My mother in law accessed cottage care for a period of time allowing us respite. However she is now unable to do so due to her incapacity.

Can't access respite care if the person has a feeding tube as deemed critical care.

Husband has dementia not easy to find anywhere to place him

Residential respite is not needed. However, I need a break from providing care and I doubt if the care package (when it is allocated) will be able to be sufficiently tailored to meet the rather unique needs.

Parkinson's sufferers become very non conforming and anxious so it's easier to keep going it would be easier if I could get the other services I need to support me

I cannot imagine anyone doing what I do for my family. Each member has personal needs, mental handicaps, and a sense of independence that restricts a stranger taking over.

Some of the comments indicated there is confusion or ambiguity among older Australian carers about who or what respite care is for. Several commenters seemed to think it was for the benefit of the care recipient, with no (or incidental) benefit to the carer, while others did not seem to know what it was at all.

All 4 people [who I care for] do not believe they need respite, they probably don't but the people picking up the load do.

Have only done it once - he was in rehab for a fortnight, but I think our GP thought it would help me too!!!

My Mum will need respite care when elevator engine will be replaced. So I will not need respite myself

I am not sure what you mean by definition respite care. I do have health issues, like I cannot lift my left arm over my head anymore not lift heavy items. I just grin and bear it. I live with chronic pain, sleep 5 hours or less.....

I do not want to be separated from my spouse, They need a break as much as I do.

My friend has dementia and now needs full time care in a secure unit and it is proving difficult to find a place.

My husband is self sufficient during day, long term diabetes etc would not leave alone overnight. I'm the one who needs respite.

These expressions of ambiguity or confusion suggest a public campaign to raise awareness about respite care may be warranted.

Emotional, practical & financial supports

Two-fifths of carers said they did not receive any emotional or practical support for themselves in their carer role, and three-quarters did not receive any financial support.

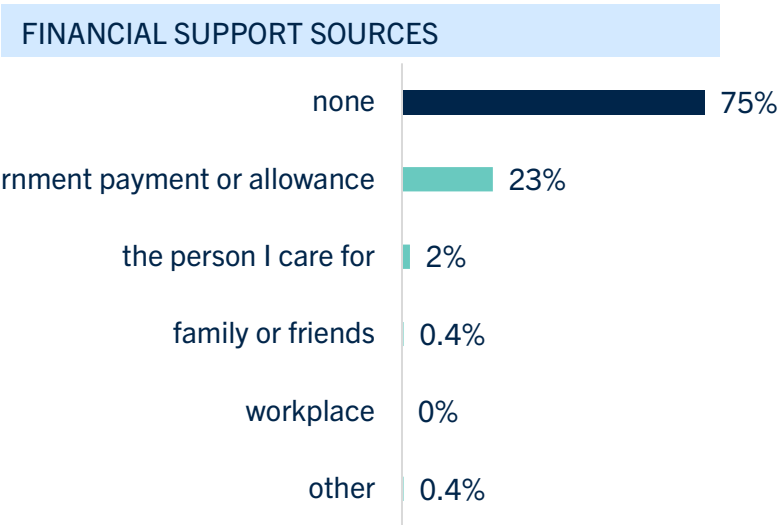
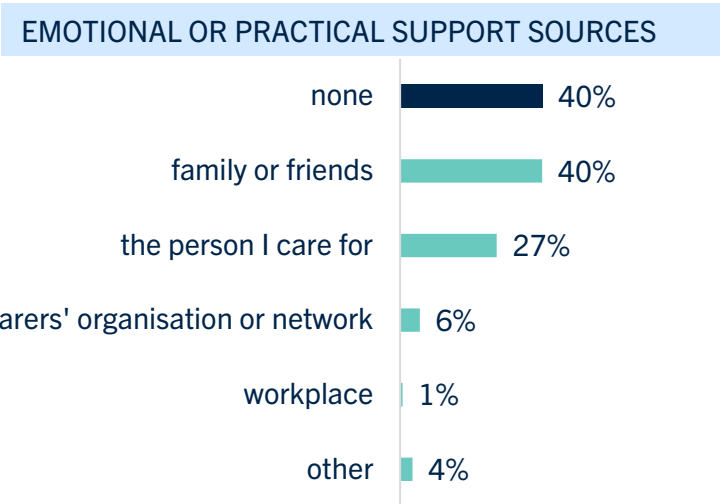
Current carers were asked two questions about other forms of support beyond respite care: one about sources of emotional or practical support and one about sources of financial support.

A large proportion did not receive these kinds of support from anyone or anywhere.

Both questions included the additional response option 'I receive some support, but it is not enough', and this was selected by 7% and 2% of carers respectively.

Some respondents who selected the 'other' emotional or practical supports option wrote a comment giving details. Among them, nine people said they receive professional mental health support. A further three detailed personal wellbeing practices that supported them:

"regular exercise and meditation"
"from pray to God and elders"
"And we can both 'let off steam' in the process and 'make up' afterwards..... eventually !!!"



What carers need to keep going

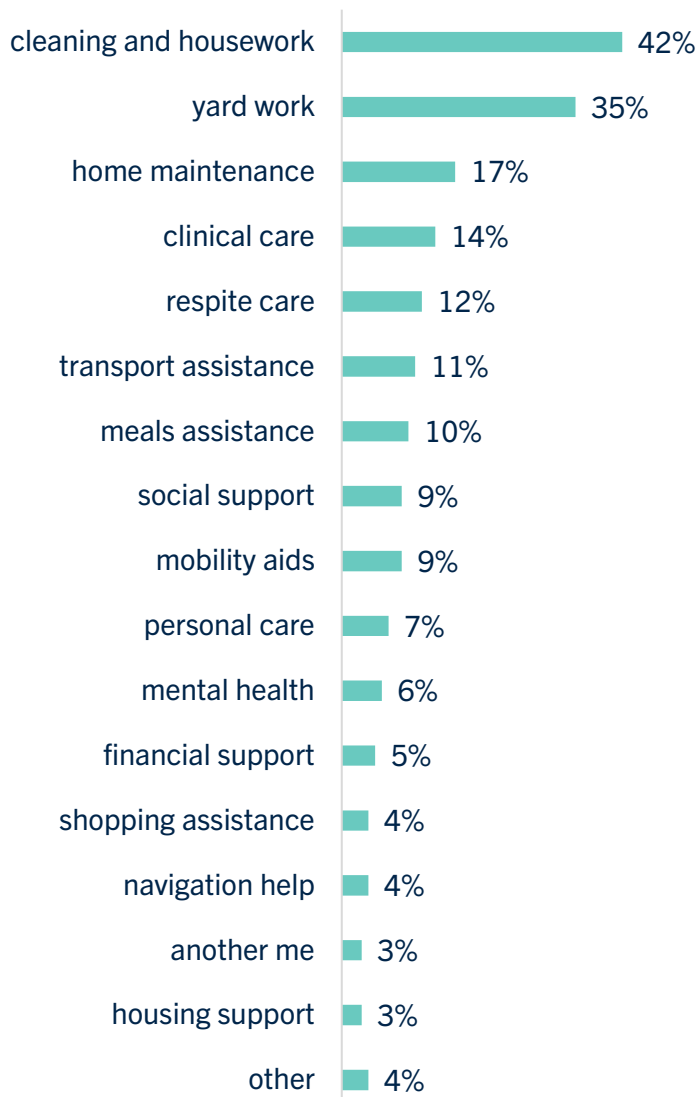
To continue providing care, many carers need assistance with the basics.

The final question of the survey module was addressed to current carers who provide care to a person who still lives in their own home. They were asked what kinds of carer supports would help them continue to provide that care so the person can stay in their own home.

In total, 234 people detailed the specific supports they need. These were analysed thematically and the number of comments per theme were counted (graph at right, details over the page).

Around 90 comments were excluded from further analysis because they were not very specific, but they stated that the carer or the care recipient was waiting for home care services to start or to be assessed, or that there are shortcomings in the current home care assistance they are eligible for or receive. The array of shortcomings they identified with the home care system remain critical to address too. These include long wait times, insufficient funding amounts, high care costs, insufficient care hours, poor service quality, inflexible service scheduling, insufficient staff to provide the work, inconsistency in the personnel provided, and being worse off after the recent home care policy changes.

NEEDS AMONG THE 234 COMMENTS ANALYSED (SEE OVER PAGE FOR DETAILS)



Details of supports carers said they need to continue

The 234 commenters who detailed the specific kinds of supports they need to continue providing care to someone who is living at home listed these items (graphed on previous page):

- 99 (42%) mentioned cleaning and other housework.
- 82 (35%) mentioned gardening and yard work, often commenting that they needed more than lawn mowing which is often the only gardening assistance provided.
- 39 (17%) mentioned home maintenance including handyperson jobs, odd jobs, and heavier cleaning jobs or cleaning that involves heights (e.g. windows, fans, curtains) given these are not usually supported with aged care system domestic assistance.
- 32 (14%) mentioned clinical care, whether in home care or out of it, from nurses, podiatrists, physiotherapists, GPs, psychiatrists, medication assistance and others.
- 28 (12%) mentioned respite care, whether regularly for a few hours or a day or two, or periodically for longer durations. Some specified their desire for 24/7 in-home respite.
- 25 (11%) mentioned transport, whether to medical appointments, leisure activities, social outings or simply when needed, and some specified the need for cheaper transport options.
- 23 (10%) specified food preparation, meals and cooking assistance.
- 22 (9%) wrote about social support including friendship, conversation and emotional support from a professional visitor or assistance to attend social gatherings and outings.
- 21 (9%) mentioned mobility aids, body support equipment, and modifications such as grab rails, ramps and bathroom renovations.
- 17 (7%) mentioned the need for some or more personal care for the care recipient, most often writing about showering assistance.
- 13 (6%) wrote about the need for mental health support and/or in a few cases physical health support such as yoga and exercise in the home, but it was not always clear if these were for the care recipient to access or the carer. Certainly both were in the mix as was clear from some comments.
- 11 (5%) said they need more financial support, including being granted Carer's Allowance or Payment, a more liveable income or increase in pension or allowance, the ability to work more without having government payments reduced, and more subsidies for appointments with specialists or allied health professionals.
- 10 (4%) wrote about needing assistance when shopping or wanting someone to do the shopping instead of them.
- 9 (4%) want more information to navigate the existing support systems and guide them as to what is available, or an advocate or translator to help with these processes.
- 8 people (3%) wrote about the need for another person just like them for when they are not available, e.g. to check in on the care recipient at night or when they are home alone, or to take over the caring responsibilities if and when the respondent ceases to be available, because of illness or death.
- 7 (3%) mentioned the need for more housing, including affordable and social housing for people with mental illness, trans people, and people currently dependent on their carer's housing because of the difficulties these groups have in the commercial rental market; plus more accessible single storey homes suitable for ageing in place, and retirement villages.
- 5 (2%) mentioned wanting support with financial management, technology training, and life administration for the care recipient.
- 4 (2%) listed other items: support with pet care; a disabled parking permit; a visiting hairdresser; and *"Sincere recognition of the valuable role that unpaid carers have in contributing to society"*.

Some of these commenters noted they were already receiving these supports, or that they weren't, but commentary on this was not consistent so it is not possible to say which needs are experiencing the biggest gaps. It was also often unclear if the supports were for them or for the person they provide care to, or both.

Note that some of the items mentioned echo the shortfalls in government services for care recipients that were described earlier in this report.

Comments from past carers also spoke to some useful supports:

"a dot point list of how to prepare to be a carer (before actually needing to be one) would be helpful.... it may already exist but I haven't seen one, perhaps a series of articles in National Seniors could cover this."

"Thank them [the government] that any problems I had with the person I was caring for, they always sent someone to visit us and handle the problem."

Carers' awareness of information sources about carer supports

Carers were also asked what sources of information about carer supports they had come across and their usefulness.

While 328 carers answered the question with a comment, many did not answer the question as asked, instead:

- writing about supports themselves not information sources
- giving only a broad indication of sources (e.g. "online" or "brochures")
- simply saying they know where to find information or don't need supports
- referencing sources of support for the people they are caring for (e.g. My Aged Care, NDIS, hospitals, etc), not supports for themselves in the carer role.

Among the much smaller number of comments that actually referenced sources of information about supports for carers:

- 29 mentioned Carer Gateway
- 24 mentioned Carers Australia, or one of its state/territory affiliates
- 14 mentioned Dementia Australia
- 17 mentioned other community organisations or NGOs including (described as written) NSA, COTA, OPAN, Continence Australia, Huntington's Australia, Parkinson's Australia, Leukemia Foundation, Cancer Council, Aspie Society, AIDS Council, Canteen, Vietnam Veterans Association, Veteran support
- 7 mentioned other carer-specific resources or groups: Carer's Pathway, Carer's Helpline, Australian Carers Guide, Time for Grandparents, Grandparents as Parents group, Partners of Veterans, Sibchat for siblings of disabled people
- 10 mentioned carers support groups without specifying any by name
- 4 mentioned expos (seniors, carers, dementia)
- 1 mentioned the University of Tasmania dementia course.



Conclusions and recommendations

Conclusions and recommendations

Informal care is a huge contributor to our society, economy and personal relationships

In Australia as in many other countries, informal carers play a crucial role in sustaining the viability of government-funded aged care and disability systems.

There is no question that both these systems depend on it. Without it, governments would otherwise be faced with making up a huge gap currently filled by the labour of informal carers.

As cited in the introduction, the replacement value of informal care is \$77.9 billion per year. To put this in perspective, it is almost equal to the combined government expenditure on the NDIS and aged care in recent years (approx. \$46 billion and \$40 billion respectively).

Because of this, the availability and contribution of carers is taken into consideration when identifying the service needs of care recipients. For example, two people with similar levels of disability *may be prioritised differently* for government funded care depending on whether they receive (or potentially could receive) care from a partner, family, friends or community members.

To be fair, many carers consider their care role to be fundamentally embedded in their relationship with the person they are caring for, and most people prefer to be – and may expect to be – cared for by people they know and love rather than professionals.

This was evident in NSSS-26 comments. For example, when asked how they came to be a carer, many participants simply wrote of their relationship as if it were the only

necessary explanation for them adopting the caring role, with comments like, “63 years of marriage”, or “I am their spouse so it falls to me”.

Other carers provide care because of their social conscience, out of compassion, or with a sense of duty. Example comments of these types included the statement that the carer “Just needed to be helpful” or the matter-of-fact “Parent/child relationship obligations”.

The positives of caring are *well documented*, including in *previous NSA research*. They include carers gaining personal fulfillment from carrying out caring roles, enriching their relationship with their care recipient, or developing new or deeper relationships with others.

NSSS-26 carers reported other benefits and rewards too, including relief at knowing the person has quality of life, and satisfaction at fulfilling a duty or repaying a debt of care.

For all these reasons, in an ideal world, informal caregiving is a win-win-win situation for those receiving care, those providing care, and society at large.

Informal care comes with significant costs

Of course, we do not live in an ideal world.

There is *substantial evidence* that informal caregivers experience relative disadvantage across multiple aspects of life including their physical and mental health, opportunities for social participation, their career trajectory, and financial security.

For NSSS-26 carers, negative effects of caring were more likely to be felt by those who had higher caring demands. These included caring more frequently or

experiencing shortfalls between the care needed and care provided by government-funded services.

Comments gave voice to feelings of despair about the caring role, the sense of being trapped or losing oneself, and in some cases the desire to walk away.

Some such comments are reproduced on pages 19-26. Their sentiments are perhaps summed up by the person who wrote, *"I can't have a life because of caring"*.

At the most extreme end, carers wrote comments like, *"It is the absolute worst experience of my life with no end in sight."*

Some past carers had a similar perspective, with one writing, *"My job of caring for my husband for 12 years nearly broke me."*

There are people for whom fulfilling an obligation provides satisfaction, but it is not the case for everyone. Some NSSS-26 participants felt somewhat (or entirely) forced into the carer role. Comments highlighting this include, *"It has had a negative impact on my life as I feel as though I'm not free to do what I want"* and *"Society and the government expects spouses to do this. There is no option."*

Heavy caregiving burden for carers contributes to the [projected 'carer gap'](#) between the increasing need for care in the population and the availability of informal carers who support the viability of the care economy.

Those who have intense care responsibilities without adequate support or respite frequently do not have time or resources to invest in looking after their own wellbeing.

Consequently, the physical and mental demands of providing care contribute to carers' [poor health and increased risk of developing multiple chronic diseases](#), including [dementia](#). Essentially, carers become unable to care for others and are more likely to need care themselves.

Again, some of the comments from NSSS-26 carers speak to this point. For example, some current carers wrote about needing anti-depressant medication, being hospitalised with stress, or being physically assaulted by the person they care for.

This past carer wrote at length about the health costs that caring had on them:

"It was extremely taxing, particularly during Covid times. Dealing with government departments, hospitals and the entire system. By the time my husband passed away I was physically and emotionally exhausted. It adversely affected my health. I lost an enormous amount of weight, became depressed severely anaemic developed a heart condition, underwent many tests and procedures - Colonoscopy, Endoscopy, heart monitor, echocardiogram, ultrasounds etc, etc. Grief never leaves one, nor does the trauma of caring for a suffering loved one. I will never be the same person I was pre this period."

The NSSS-26 results on this point were not unique. The fact that carers face a higher probability of negative health impacts is widely known, and these results merely reflect that.

But the results do highlight the point that many older carers experience age-related health problems, pain, or mobility limitations which, as comments show, hinder their ability to provide care and add to their burden of exhaustion.

In addition, negotiating complex bureaucracies can be especially difficult for older people, who are [less likely to feel confident using the digital technologies](#) that are essential tools in this space. This too adds to the burden older carers experience.

Recommendation 1: Australia should introduce more recognition for carers and legislate carers' rights

It is clear from all of this that the plight of carers demands greater recognition and many carers desperately need more support. Carers deserve better.

The Australian [Carers Recognition Act](#) legislated in 2010 has 10 principles that address the treatment of carers and how services should be delivered to them and the people they are caring for.

However, a 2023 [Parliamentary Inquiry into the recognition of unpaid carers](#) found the Act was essentially aspirational and did not empower carers with any legally enforceable rights, supports or protections.

The Inquiry made [22 recommendations](#) to ensure better implementation of the Act's principles so carers readily receive the recognition, support and services they need.

Unfortunately, recommendations relating to the establishment of carers' rights (Recommendation 4) and practical recognition of the financial impact of caring (Recommendation 21) [were not supported](#) in the government's response.

Most carers have little time, energy or expertise to advocate for their own rights. They need these protections.

For example, nearly 20% of NSSS carers provided upwards of 20 hours per week of care to their care recipient(s), and almost 50% of carers provided the highest level of care in the domains of household and life management tasks.

In addition, the survey results showed some carers who need respite or other supports were prevented from accessing them by the very people they care for, many of whom exert emotional pressure on their carer to be their sole care provider.

For instance, among the carers who had not accessed respite care, 22% said this was because the care recipient would not agree to it. Three-quarters of people in this situation were providing care on a daily basis or 'nearly all the time', so are surely in the highest category of need for respite.

Legislated protections would assist carers in such situations to access the supports they need. They may also help care recipients understand what their care providers are going through and that their need for respite is a standard part of the carer role.

Introducing protections of this kind would not be a radical move for the Australian government. Rather, it would bring this nation into line with what is happening overseas.

For example, in the UK, carers [have rights to support and protection from their local authority](#) and the right to a 'carer's assessment' through a GP referral to evaluate their ability to provide care at all.

This report therefore recommends the government adopt and implement all the recommendations of the Inquiry into the recognition of unpaid carers.

Recommendation 2: Available carer supports need wider and targeted promotion

Aside from legal protections, it is clear from this survey that older carers would benefit from more help to access carer supports.

An important resource for carers is the [Carer Gateway](#), a government program providing access to information, advice, online supports and local services including emergency and planned respite.

An [impact evaluation](#) prepared for the Department of Social Services found that the Carer Gateway is appropriate, effective and efficient, but at the time of evaluation

(2022) the Gateway was only being accessed by 5% of carers.

A [communication campaign](#) is ongoing but certainly amongst NSSS-26 respondents, there was very little evidence that carers were using the services on offer.

Only 11% of carers surveyed had accessed respite and 6% said they received emotional or practical support from a carers organisation or network. Less than 10% nominated the Carer Gateway when asked about supports they were aware of. Overall, 40% did not receive any practical or emotional support in their caring role.

A subset of comments revealed that some carers do not know what respite care is and many do not know that information hubs exist at all, that can help them find supports for themselves in the carer role.

This finding may be symptomatic of a general expectation – including sometimes among carers themselves – that carers will simply cope and serve others, and do not prioritise their own needs to be met.

Another issue, articulated in Recommendation 1 of the [Inquiry into the recognition of unpaid carers](#), is that there are some groups who may not readily self-identify as carers and therefore not seek out carers' services.

This may be especially the case for some older people who have very long-term and established pre-care relationships with partners, relatives or friends receiving their care (see discussions [here](#), [here](#) and [here](#)).

A government communication campaign that acknowledges the hours, days and years of work that carers give, the sacrifices that they make, and the impacts on their wellbeing – and the need for them to be supported, compensated and replenished – is warranted to increase uptake of the available supports.

This may also help carers have difficult conversations with the people they provide care to, if they feel they need respite or some other support but the person is resistant to the idea.

In addition, opening up the definition of 'carer' or using different language to describe the role may be needed to reach people who need support but who don't currently identify with the carer term.

Implications for the health and aged care systems

Clearly, the role of carers in limiting the cost of government healthcare and aged care is significant.

As an NSA recent report on the issue of [delayed discharge](#) from hospital has found, not having someone available to care for you is a risk factor in longer stays in hospital, which increases health and aged care system costs.

This raises a critical question for the health and aged care systems more broadly: who will care for people if a carer passes away or becomes unable to care?

If adequate aged care services do not exist, the burden will fall on younger generations of carers, many of whom who are still in the workforce or have not yet accumulated adequate savings to support their own retirement.

The [prevalence of younger carers](#) aged 50-65 highlights how this is already occurring, with women taking on the greater burden.

Supporting carers is critical to the financial sustainability of the health and aged care systems and to the wellbeing and financial independence of carers in later life.

Methods

The information in this report comes from the iteration of the National Seniors Social Survey (NSSS) conducted in January-February 2026.

Anyone aged 50 or older who resides in Australia is welcome to participate in the NSSS. The survey received ethics approval from Bellberry Ltd prior to implementation (approval 2025-11-1852).

The survey included a module about informal caring experience. For additional quantitative results from this module, see the NSSS-26 summary report to the Department of Health, Disability and Ageing.

The software package Stata v18 was used for quantitative analysis. Statistical tests took the form of chi-square tests and multiple logistic regression

analysis. The socio-demographic variables included in logistic regression models were selected via chi-square difference tests with p-values <.05 (see Appendix 3).

Comments were analysed for this report using the thematic analysis framework described by Braun and Clarke. We identified themes via inductive analysis guided by a critical realist approach that aimed for accuracy and objectivity in interpreting participants' views. The number of comments comprising any given theme was estimated to give a sense of its prominence. Data were not cross-coded so numbers should be treated as estimates.

Quotes from survey participants were selected to illustrate both the variety and prevalence of ideas expressed. Where possible, quotes were

reproduced verbatim, occasionally omitting or altering parts for clarity or anonymity (indicated with square brackets []). Minor typos were corrected for readability (no brackets). We retained all other phrasing idiosyncrasies.

When inviting people to participate in the NSSS, we strive for inclusivity and maximising participation, rather than numerical representativeness. This is especially relevant to open-ended questions because people's unique experiences are the focus with some groups being more likely than others to write a comment.

For this reason, we summarise key demographic traits of the sample below for readers' information.

Sample

These percentages characterise the sample of 1086 current or past carers. Unsure responses are not shown and no question was compulsory, so some rows do not add up to 100%. Data are unweighted.

Age group	50-64 years 11%	65-74 years 44%	75-84 years 37%	85+ years 7% (oldest 100)
Self-rated health	Excellent 13%	Good 56%	Fair 25%	Poor/very poor 5%
Savings including super	<\$200k 29%	\$200k-\$500k 15%	\$500k-\$750k 10%	>\$750k 25%
State or territory	ACT 4% SA 9%	NSW 23% TAS 2%	NT 1% VIC 19%	QLD 31% WA 10%
Not metro	Regional 28%	Rural 9%		Remote 7 people
Gender	Female 66%	Male 33%		Non-binary 1 person
Partner status	Single 11%	Live with partner 61%		Divorced/widowed 23%
Education	School up to Year 10 16%	Year 12 or cert/dip 38%		Degree or higher 45%
Diversity groups	First Nations 2% Living with disability 9%	CALD background 3% Veteran 3%		LGBTI 3%

Appendix 1

Questions in this NSSS module

The NSSS 'Experiences as a carer' module opened with the definition of a carer outlined on page 6 of this report then proceeded with the following questioning route.

1. Are you currently a carer, according to this definition?
 - Yes → Q4
 - No → exit module
 - Prefer not to say → exit module
 - There's someone I'd like to provide care to but I'm unable to → Q2
 - I was a carer until recently but not now → Q3

2. [Only for those who want to provide care but can't]
What are the reasons you can't provide care to the person? *Select all that apply.*
 - I work or have other time commitments
 - I live too far away from them
 - I don't have the necessary skills
 - I don't have the necessary physical strength or mobility
 - They don't want me to provide care to them
 - Other [free text comment option]

3. [Only for people who were carers until recently but not now]
Is there anything in particular you'd like to tell the government about your past experiences as a carer? [free text comment]

4. For each person that you provide care to under the definition, please provide the following details [option to respond for up to 4 care recipients]:
 - Their age group [10 year intervals ranging from 'under 10' to '90 and over']
 - Their relationship to you [my spouse, my parent, my child, my grandchild, my relative, my friend, a community member]
 - Do you live with them? [yes or no]
 - How often do you provide care? [nearly all the time, daily, every few days, weekly, more occasionally]
 - Hours per week spent on caring including any travel time [less than 5, 5-10, 10-20, 20-40, 40-80, more than 80]

5. How did you become their carer? [free text comment]

6. For each of the care types below, please indicate if you provide it regularly or not. If you do, specify the highest level of intensity at which you regularly provide that type of care [for all care types the response options were: I do not provide this type of care, I occasionally assist if needed, I do this with them, I do this for them, unsure or prefer not to say]:
- Help with everyday tasks such as house work, garden work, meal preparation, transport outside their dwelling
 - Help with life management such as banking, paperwork, making appointments
 - Help with minor health needs, medications, personal care or movement around their space
7. How much emotional support and nurturing features in your caring role?
[a great deal, some, a little, none at all, prefer not to say]
8. Does the person (or any of the people) you care for access care from anyone other than you? *Select all that apply.*
- Yes, they have one or more other unpaid carers among family and friends
 - Yes, they access aged care services in the home funded by the government
 - Yes, they access other government-funded home care services (e.g. NDIS, veterans' services)
 - Yes, they live in a government-funded residential care home
 - Yes, they access care from privately funded professionals
 - No, they do not access care from anyone else
 - Unsure
- If selected any of the three government-funded options → Q9
If did not select any government-funded option → Q13
9. [Only if care recipients were accessing support from a government-funded source]
In some cases, government-funded care services cannot provide all the care that a person needs. Thinking about the person or people you provide care to, is there a shortfall between the care they need and the care provided by government-funded services?
- Yes → Q10
 - No → Q13
 - Maybe → Q10
 - Prefer not to say → Q13
10. [Only for people who said there was or might be a shortfall]
How big is the shortfall between the care that they need and the care provided by government-funded services? [large, moderate, small, unsure]

11. [Only for people who said there was or might be a shortfall]
How much of this shortfall are you able to make up for with the care you provide? [all of it, most of it, some of it, little of it, unsure]
12. [Only for people who said there was or might be a shortfall]
Please tell us more about this if you would like to. [free text comment]
13. Have you ever accessed respite care?
- Yes → Q15
 - No → Q14
 - Unsure or prefer not to say → Q17
14. [Only for those who said they have not accessed respite care]
Why haven't you accessed respite care? *Select all that apply.*
- I don't need it
 - There is resistance to using it from the person/people I provide care to
 - Cost
 - It is not available to me
 - I found it hard to access it when I required it
 - I don't know how to access it
 - Other [free text comment option]
- all response options → Q16
15. [Only for those who said they have accessed respite care]
Have you found it difficult to access respite care when you need it?
[yes, no, sometimes, prefer not to say]
16. [For those who said they have or have not accessed respite care]
Please tell us more about access to respite care if you would like to. [free text comment]
17. In your experience, what have been the positive aspects or rewards of your carer role?
[free text comment]
18. Do you receive any emotional or practical support for yourself in your carer role? *Select all that apply.*
- No, I don't receive any support
 - Yes, from the person I care for
 - Yes, from family or friends
 - Yes, from my workplace
 - Yes, from a carers' support organisation or network
 - I receive some support, but it is not enough
 - Other [free text comment option]

19. Do you receive any financial support for your carer role? *Select all that apply.*

- No
- Yes, from the person I care for
- Yes, from family or friends
- Yes, from a government payment or allowance
- Yes, from my workplace
- I receive some support, but it is not enough
- Other [free text comment option]

20. Has your carer role negatively affected your life in any way?

- Yes → Q21
- No → Q23
- Unsure or prefer not to say → Q23

21. [Only for those who said caring had negatively affected their life]

Have any of the following aspects of your life been negatively affected by your carer role?
Select all that apply.

- My finances
- My ability to work or study
- Career opportunities
- My physical health
- My relationship with the person I care for
- My relationships with others
- The way the world sees me
- The way I feel about myself
- Pursuing hobbies and interests
- Travel opportunities
- Chance to live in a different location
- My mental health
- The way I see the world

22. [Only for those who said caring had negatively affected their life]

Please tell us more about any negative impacts or possible solutions if you would like to.
[free text comment]

23. What sources of information about carer support have you come across, if any? If you have come across any, please let us know how useful you found them. [free text comment]

24. Government policy seeks to enable people to live in their own homes for as long as possible. If the person (or people) you are caring for is living in their own home, what kinds of carer supports would help you continue caring for them at home? Feel free to include any supports you already access and find useful, and any you do not currently access. [free text comment]

Appendix 2

Reasons some people cannot provide care

Lack of physical strength or mobility is a major reason older people cannot care for someone who needs it.

The 20 respondents who indicated they would like to provide care to someone but cannot were asked about the barriers to doing so.

They were given set response options and were encouraged to choose as many as applied.

More than half said they did not have the physical capacity to provide care.

One fifth said they lived too far away from the person in need.

The three people who selected 'other' were given the opportunity to comment but the comments were not particularly informative.

The small number of NSSS participants in this situation suggests it would be incautious to generalise from these responses to the larger population of older Australians but the numbers are included for completion's sake.



Appendix 3

Logistic regression values

The table below presents output from a multiple logistic regression analysis testing the associations between socio-demographic variables and the probability of experiencing negative impacts from the carer role.

experienced negative impacts from the carer role	Odds ratio	Std. error	z	p-value	95% confidence interval	
binary gender	0.45	0.14	-2.63	0.008	0.25	0.82
age group	0.55	0.11	-3.13	0.002	0.37	0.80
health	1.27	0.25	1.21	0.227	0.86	1.87
financial comfort	1.68	0.56	1.57	0.118	0.88	3.21
care shortfall	2.26	0.67	2.76	0.006	1.27	4.04
accessed respite	4.63	2.69	2.64	0.008	1.48	14.45
live with care recipient	1.27	0.52	0.59	0.556	0.57	2.82
frequency of care provided	1.63	0.27	2.98	0.003	1.18	2.24
constant	0.98	0.81	-0.03	0.979	0.19	4.96

Outcome variable

Experienced negative impacts from the carer role: 0=experienced no negative impacts, 1=experienced negative impacts

Sociodemographic variables

Binary gender: 1=women, 2=men

Age group: 50-64=1, 65-74=2, 75-84=3, 85-plus=4

Self-reported health: excellent=1, good=2, fair=3, poor or very poor=4

Financial comfort: financially tight or very tight=1, financially comfortable or very comfortable=2

Shortfall in care provided by government funded services: no shortfall or maybe shortfall=1, shortfall=2

Accessed respite care: have not accessed respite=1, accessed respite=2

Live with care recipient: no=1, yes=2

Frequency of care provided: 1=occasionally, 2=weekly, 3=every few days, 4=daily, 5=nearly all the time

The head office of National Seniors Australia is located in Brisbane/Meanjin but we represent older people from across this great continent.

We acknowledge the traditional custodians of the land and waters in which we operate, the Turrbul People, and all other First Nations, Aboriginal, and Torres Strait Islander people.

We honour and value their continuing cultures, contributions, and connections to Country, and pay our respects to Elders, past and present.

We extend our warmest thanks to the thousands of people who participated in the 2026 National Seniors Social Survey, who so generously gave their time, thoughts, stories, and personal information. Without them this report would not be possible.

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Any correspondence may be addressed to research@nationalseniors.com.au.