



YOUNG CARERS ROUNDTABLE RECORD OF MEETING

Prepared for Australian Government
Department of Social Services
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AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

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INTRODUCTION

Carers Australia is the national peak body representing Australia's unpaid carers, advocating on their behalf to influence policies and services at a national level. This includes facilitating efficient and effective discussion with the Australian Government. This roundtable is the first in a series to inform the National Carer Strategy being developed in 2024. It brings together a breadth of stakeholders including carers, support organisations, service providers, government representatives and advocacy groups.

The topics to be discussed are determined in collaboration with the Department of Social Services (DSS) based on identified need. Following each roundtable, a record of the meeting is to be provided to DSS, followed by a public brief made available on the Carers Australia website.

On 8 May 2024, the Young Carers Roundtable was held at Old Parliament House in Canberra. Young carers are children and young people under the age of 25 who currently provide unpaid care, assistance, or support to a family member with mental illness, chronic illness, disability, substance dependency or conditions related to aging.

It is estimated there are 246,000 young carers in Australia, with approximately 50,000 under the age of 15. These numbers are likely to be an underestimate due to the invisible nature of caring by young people and low rates of self-identification.

From a statistical perspective, the survey of disability and carers (SDAC) sampling method doesn't depend on carer self-identification. It is a large random sample, and the carers are identified by the older people and people with disability who are surveyed. This is one of the reasons carers and those they care for are sometimes referred to as invisible in the broader social services landscape.

25 young carers attended the roundtable event and were encouraged to discuss their experiences, challenges, frustrations and proposed solutions. Group discussions were facilitated by skilled youth workers from Little Dreamers. Detail of the questions asked can be found in Appendix 1.

The following report analyses the commentary from young carers under the four topic discussions: Your Caring Role; Education and Employment; Financials and Social Isolation and Support.



TOPIC 1: YOUR CARING ROLE

INTRODUCTION

In this topic, young carers were asked to discuss the Government supports they accessed; their level of inclusion in the planning of these supports; barriers to accessing them and how they identify and are recognised as a young carer.

Several key themes emerged:

- **Identification and Recognition:** Young people grapple with identifying themselves as a young carer due to varying levels of care provided and societal misconceptions about what constitutes caregiving and who a carer typically is.
- **Access to Support:** Challenges in accessing Government support like the NDIS and My Aged Care due to lack of awareness and difficulty navigating systems.
- **System Navigation:** Young carers rely on trial and error to navigate complex systems, highlighting the need for proactive educational campaigns and simplified processes.
- **Impostor Syndrome:** Some young carers struggle with feeling like impostors or not deserving of support, emphasising the importance of raising awareness and providing self-identification tools.
- **Importance of Recognition** from the broader community: Recognition of their role is important among young carers, but there were varied perceptions on its importance.

Young carers function on a 24/7 basis when it comes to their caring responsibilities. Without the existing Government support including both the Carer Payment and Carer Allowance this would be much more difficult. For two carers, one who lived in a home with domestic violence and another whose father was on the Disability Support Pension, both indicated their caring role was only possible with the support the Government provided including through the NDIS.

Additional priorities considered important for young carers included:

- Financial freedom
- Targeted support services
- Social events and respite
- Feeling safe
- Not identifying as carers

Feeling like nobody could understand a young carer's role but having a friend who could relate was considered paramount in terms of being able to live a semi-normal life. One teenager explained she only talked about being a carer with her very close friends and did not broadcast her caring role, especially to new people.

KEY CHALLENGES

IDENTIFICATION AND RECOGNITION

- There were varying levels of importance placed on public recognition of carers.
- Carer does not feel like a carer anymore after an acute phase of care responsibilities is complete.
- Those in fluctuating or episodic caring roles struggled with their self-perception as carers.
- Some find the term 'carer' limiting and grapple with its implications.
- Fear of being reported to child protection services if publicly identified as carers.
- Some emphasised the importance of identifying as a young carer to access support.
- Lack of general awareness and understanding of young carers' needs and experiences.
- Impostor syndrome experienced by young carers leading to not identifying as one or a reluctance to access services.
- Consistency of care not necessarily a good tool to measure or identify/self-identify.
- Many didn't publicly identify as carers.

NAVIGATING SUPPORT SYSTEMS

- Many young carers had accessed the Young Carer Bursary and found it helpful.
- Barriers around information – what services exist and how it can be accessed.
- A poor understanding of systems like NDIS, My Aged Care and Centrelink.
- Carers spoke about learning to navigate systems through trial and error because there is no place to go for support.
- Limited accessibility and poor usability of Government websites.
- Changing eligibility of supports available and inconsistencies in offerings was challenging.
- Lack of support and understanding from educational institutions like universities and schools.
- Time it takes to access support was often very long and time consuming.
- There was inconsistency in what supports could be accessed and the approvals required.

PROPOSED SOLUTIONS

- A broadening of the label of 'carer' and opening it up to alternatives like 'support' or 'support person', as well as recognition of what being a young carer entails.
- National education campaigns about what a carer is within relevant spaces like schools, child protection, hospitals, Centrelink, medical services, judicial systems, family court systems, general practitioners and universities.
 - This was reinforced in a quote from one carer "Government Systems such as Centrelink are very inflexible in terms of evidence, decision-making with no consideration for the nature of caring."
- Simplifying government system navigations to include simpler language and age-appropriate navigation tools.
- Improving awareness and support for young carers' needs within these systems.
- Training for frontline staff on young carers as consumers.

- A system tool or directory to signpost young carers to relevant supports.
- A knowledgeable person to guide young carers through the system.
 - Mentorship programs were highly regarded within the group.

BIOGRAPHIES OF YOUNG CARERS



An 18-year-old from urban Victoria cares for her brother who has an Acquired Brain Injury, vision impairment, ADHD, memory loss, cognitive disability and anxiety. She has been a carer since she was eight and currently provides 20-49 hours of care per week. She is in her first year of university and works casually one shift per week.



A 19-year-old from urban Victoria was 4 years old when she became a carer. She cares for her three brothers who are all neurodivergent, with mental health and medical conditions. She also cared for her mother through breast cancer. She doesn't live with her mother or brothers but spends up to 19 hours a week providing care while also studying for a bachelor's degree and working a casual job.



TOPIC 2: EDUCATION AND EMPLOYMENT

INTRODUCTION

Balancing caring duties with school commitments often leads to absenteeism, poor academic performance, and limited opportunities for higher education. Young carers who attended the roundtable reported very different levels of support from teachers, but a general theme emerged that identified poor support in primary years education, increased support – with some outstanding examples – at secondary level, before a return to limited support at tertiary and University level.

Online learning offers greater flexibility for carers, but some attendees were challenged by the lack of rapport you developed with teachers – which in turn made it harder to disclose their caring role.

Barriers to employment were also significant, with young carers citing low levels of understanding from employers about what it means to be a carer. The part-time, casual nature of employment sought by many young people also proved inflexible and challenging.

KEY CHALLENGES

EDUCATION

- Identification – for support to be offered, young people must identify as carers. Sometimes they do not wish to do this, or don't even know they're a young carer. Teachers don't know about young carers and therefore cannot help identifying them in educational settings.
- Lack of support and understanding from educational staff about what it means to be a young carer and the additional help you might need.
- Mandatory attendance requirements often impossible to fulfill when caring role is intense.
- Rigid medical certificate requirements, particularly within universities, placed undue financial pressure and stress on young carers to complete their studies.
- University policies recognise intersections such as disability or illness etc but not caring roles.

EMPLOYMENT

- Balancing caregiving responsibilities with employment is challenging, exacerbated by lack of understanding and support from employers.
- Transition into work life was hard because the caring role was still there. Majority of young carers found this hard due to lack of employer recognition of caring skills and experience that are transferrable to a workplace.
- Concerns about future career prospects due to caregiving responsibilities.
- Employer misunderstanding and stereotyping
- Employer making assumptions like availability, intensity of care and care responsibilities.

PROPOSED SOLUTIONS IN EDUCATION

- Increasing the bursary scheme to allow more young carers to access financial support.
- Better understanding from schools and peers about what being a carer involves. This includes talking to teachers about issues the young carer is facing.
- Formal training for teachers – in both recognition and support.
- Capacity building for teachers.
- A clearly defined position in school e.g. a wellbeing advisor / carer champion who is educated about and focuses on carers.
- Extensions for assignments and attendance support
- Legislate one form of caring proof required.
- Include an 'Are you a carer' tick box on enrolment forms to help schools identify young carers in their community.

PROPOSED SOLUTIONS IN EMPLOYMENT

- Awareness building among employers about how to identify a carer and supports they can offer.
- Mental health and first aid training.
- Ensure employers understand the impact of carer disclosures and the impact of their reactions and actions.
- Engagement with the Carer-Inclusive Workplace Initiative or Carers + Employers.
- Employment education for young people so they know what flexibility can be requested from an employer.



TOPIC 3: FINANCIALS



INTRODUCTION

Many young carers come from low-income households, exacerbating financial strain, and limiting access to resources and support. Young carers emerging into adulthood want to feel independent and not rely on support. Government financial support such as the Carer Allowance or Carer Payment goes a long way and pays for extras that wouldn't normally be possible, but it still doesn't address low levels of financial literacy within the cohort.

What does it mean to be financially well? Was a question the young carers attending the roundtable were asked. Essentially the response was not living pay cheque to pay cheque and having enough savings to cover emergencies.

Those living in low-income households spoke of the need for short term financial solutions during acute periods of financial risk or strain. Many carers linked financial wellbeing with mental health, i.e. they felt better about themselves when their finances were in check, and suffered anxiety and stress when their finances were strained.

KEY CHALLENGES

- Financial strain: Young carers experience financial stress due to caregiving responsibilities and limited access or difficulty accessing financial support like Carer Allowance and Carer Payment.
- Low levels of financial literacy: Young carers struggle with understanding financial systems and accessing appropriate support to improve skills in this area. This was particularly true for those caring for a parent – the traditional source of financial education in childhood.
- Need for flexible support: Flexible financial support that acknowledges the unique circumstances of young carers so there is more individual agency and choice.
- A fear of spending money due to uncertainty about future emergencies.
- Financial co-dependency within families – often relying on other members' social security payments to support them.
- Scepticism of frontline workers towards young carers seeking financial assistance programs.
- Young Carer scepticism of the effectiveness of assistance programs or supports.
- Perception of limited choices and agency in managing finances.
- Lack of discretionary ability to adjust to personal circumstances.
- Inadequate consideration of individual circumstances in financial support systems.
- Food insecurity and reliance on food banks.

PROPOSED SOLUTIONS

- More practical and tailored financial supports for young carers. Implementing a more nuanced and personalised approach to financial assistance, considering individual situations.
- Revising eligibility criteria for financial assistance programs to ensure inclusivity and flexibility for young carers.
- Fit for purpose programs that offer guidance and support for young carers transitioning into adulthood, including education, employment, financial literacy.
- Greater individual agency and choice in managing finances from assistance programs.
- National education campaign to improve awareness and accessibility of existing financial support services and benefits.
- Mentoring programs were highly regarded within the cohort to improve financial literacy as well as life skills.
- Fuel vouchers or discounts with mechanics.
- A carers discounts directory that lists all the discounts available to carers.
- Activity and meal vouchers to give instant financial relief and that can be used at a time convenient to the carer.

BIOGRAPHIES OF YOUNG CARERS (CONT'D)



20-year-old carer from Brisbane. She has gradually become a carer for her grandmother who has breast and lung cancer, this role has increased in responsibility since she left high school aged 17. She does not live with her grandmother and provides between 20 and 49 hours of care per week. She is studying for her Certificate III TAFE and has a part-time job.



20-year-old who lives in urban NSW. She became a carer for her elderly grandfather when she was 15. She helps with his hygiene, cooking meals, liaising with medical professionals, administering medications and many other responsibilities. She lives with her grandfather and provides between 20-49 hours of care a week. She is studying for a university degree and has a part-time job.



18-year-old from regional Queensland. She became a carer to her father when she was 11. He has a disability and mental illness. She also cares for her sister and lives with them both. On average she provides between 20-49 hours per week of care. She is studying for a university degree and has a casual job.

TOPIC 4: SOCIAL ISOLATION AND SUPPORT

INTRODUCTION

Young carers may feel isolated from their peers due to the stigma or lack of understanding surrounding their responsibilities, leading to feelings of loneliness and alienation. The intensity of caring can lead to some individuals dropping out of the systems which have in the past offered support and 'respite' – like sports and other hobbies.

In some cases, this isolation can be severe, with young carers worried about inviting friends to their homes for fear of how they will be judged. It can be very hard to maintain relationships. In some cases, young carers revealed their strongest relationships were with other carers, counsellors or psychologists.

Accessible ways for people to 'hang out' after school and university are needed, including youth centres and hobby clubs. "Such opportunities help enormously with social skills and lessens the feeling of isolation," said one young carer.

Family dynamics can also be affected, with some reporting disagreements over levels of support required and others disclosing a fuelling of domestic violence due to the stresses of unpaid care.

Coping with the demands of caregiving can take a toll on mental health, leading to anxiety, depression, and feelings of being overwhelmed. The number of hours of care provided had a direct correlation on the mental health of young carers, with those providing the highest number of hours having the worst mental health.

Making available mental health support to young carers is therefore critically important, along with recognising burnout.

KEY CHALLENGES

- Impact on Relationships: Caring responsibilities can strain relationships within a family and friends. It can lead to social withdrawal, highlighting the need for understanding and support from peers and partners and broader eco-system in which a young carer exists.
 - Some expressed difficulty discussing their caring roles with peers and others, fearing misunderstanding, pity or stigma.
- Accessing Support: Young carers benefit from tailored support programs and mentorship opportunities, but face barriers such as lack of awareness, availability, and administrative hurdles to uptake. These programs need to be co-designed and implemented with a young carer led approach. It was observed that some services try to fit young carers into a box of service they think they need rather than listening to what they need and are often not flexible in their service offerings.
- Life skill building: This was highly valued within the groups. A lot of this is missed during their younger years of development while growing up, particularly if one or two of the parents are the ones being cared for.

- Missing Supports: There is a need for additional support in areas such as respite care, system navigation mentorship, and transitioning in or out of the caregiving role.
- Felt either currently or in the past, growing up, embarrassed or ashamed to have friends over to their house due to family dynamics affected by disabilities, mental health condition and domestic violence. Some young carers shared that their places were not kept very clean by their parents who they cared for. This was an incredible source of shame or embarrassment which led to isolation or feeling the need to be out of their home to socialise or, for example, have birthday celebrations in parks or paid activities, not at home.
- Administrative hurdles such as long waiting times and bureaucratic processes deter individuals from seeking help or respite or social programs.
- Limited spots available within programs and/or respite opportunities

PROPOSED SOLUTIONS

- Plug the gaps in supports for young people.
- Vouchers so they can shout a friend at the cinema – helps with social connection.
- Mentoring programs for academic, life, financial, appropriate relationship skills.
- Accessible respite options.
- Support for transitioning out of or into caring roles.
- Support for secondary carers or siblings. They need help just as much as the primary carer.
- Positive experiences include support from organisations like Little Dreamers Programs and respite programs offered through the Carer Gateway Beneficial programs including life skills programs, Young Carer retreats.



QUOTES FROM YOUNG CARERS

A young carer from an urban area in Melbourne aged 18 had not told their friends about her caring role. Prefers not to involve someone in something that is so personal and having to explain things is frustrating. They worry she may not be able to open up to a partner in the future or be able to pursue a romantic relationship even though they would really want to.

A comment from a young carer in an urban area in Victoria explained that she missed out on “sex education” during her time at high school due to caring responsibilities. It is only now that she is a young adult navigating relationship for the first time that she realised what she lacked in knowledge.

Another carer said “I do not know what supports would be beneficial – I have lived like this (as a carer) for so long. I have never had financial support. Supports I do need (a new washing machine, a laptop) are not available to me. And it takes a long time to get support so it must be worth it to fight for it. By the time you realise what you need you’re in crisis and it’s often too late.”

Concerning Government services “There doesn’t seem to be uniformity – my experiences are very different each time I have received support packages. One year I received a full year of dance lessons, the next year it was just a term. It is confusing and confronting when it always changes.



SUMMATION AND NEXT STEPS

Young carers provide a vital service to Australia and this roundtable made it abundantly clear why. They are devoted young people who saw the roundtable as a vehicle to express themselves and be heard by relevant authorities to drive change within their communities and for other young carers around Australia. Young people should be able to experience life to the fullest and engage with appropriate and fit for purpose supports that allow this.

What was abundantly clear from the information emerging from this round table is that young carers miss opportunities to develop typical life skills that others do not, particularly around financial literacy, safe relationships and typical life and social skills. These young people face challenges very few adults could ever tackle let alone live with permanently at an incredibly young age. Facing adult responsibilities as a child impacts the development and mental health of young carers as they move through life and when faced with adulthood, this can be daunting, and they can feel unprepared.

Government support and early uptake of supports services is vital in this area as are having supportive relationships with friends, colleagues, teachers, councillors, and community who can relate to and support young carers experiences and needs.

This is not the end of the conversation. Rather the beginning. The results from this roundtable will go into the development of a National Carers Strategy with the recommendations being put to the Government for agreement and implementation.



APPENDIX 1: ROUNDTABLE AGENDA

Session name: National Carer Strategy - Young Adult Carer Roundtable (aged 18-25) 9.00am-4.00pm

Aim: To understand the views, experiences and perspectives of young carers aged 18-25 from around Australia, to influence the development of the National Carer Strategy.

Outcome: Key perspectives from young adult carers aged 18-25 from around Australia to inform the development of the new National Carer Strategy

Format: During the roundtable the group was split into working groups of around eight participants and through a guided discussion posed the following questions.

10.00am - Ice Breaker Exercise

- Continuum spectrum activity: Put yourself on the continuum based on how much you agree with a particular statement. Ask participants to explain why they have put themselves at a different point on the continuum.
- Do you prefer dogs or cats?
- Pineapple pizza yes or not?
- Which season do you prefer? – stand on the spectrum of summer, autumn, spring or winter
- How many people know about your caring role?
- How much care on average per week do you do? Use the continuum to articulate.
- How supported did/do you feel with your education?
- How would you rate your mental health?
- Do you believe your quality of life has been impacted by your caring role?

10.45am - Topic 1: Your Caring Role

- How would you describe your caring role in 1 minute?
- How involved in coordinating these supports? Do you wish it was more or less?
- What impact do you feel as a result of not being involved?
- What are the barriers to accessing support for your caring responsibilities?
- Do you identify as a young carer?
- How recognised do you feel in your role/responsibilities as a young carer? How important is recognition to you?

11.45am - Topic 2: Education and Employment

- Are you currently engaged in education and/or employment?
- For those engaged in education (or recently graduated) - Does/did your school know about your caring role? Do/did you feel supported? What was/is your attendance and engagement like?
- For those engaged in employment - Does your employer know about your caring role? Do you feel supported? Is your current employment impacted by your caring role?
- For those who are unemployed - is your employment status impacted by your caring role? And How?
- What is one thing you think schools/workplaces need to know to be more inclusive for young carers? What is one thing they should do differently?

1.15pm - Topic 3: Financials

- How would you rate your financial wellbeing?
- What does it look like to be financially well?
- What would you need to achieve that?
- Are you currently accessing financial support? If so, what support?
- Do you receive any financial support that allows you to focus on your own goals?
- Is your family currently accessing financial support? If so, what support?

2.00pm - Topic 4: Social Isolation and Support

- How has being a young carer impacted your ability to build and maintain social connections with people your age?
- In what ways have your friendships and relationships been influenced by your role as a young carer? How do you navigate disclosing your caring responsibilities to friends and what reactions have you encountered?
- Reflecting on your journey as a young carer, what have been the main challenges you've faced in accessing support? Have you encountered any barriers that made it difficult for you to find or receive support?
- Can you share examples of the support you've received as a young carer that have been most impactful or meaningful to you? How have these forms of support helped alleviate feelings of social isolation or provided practical assistance in your caring role?
- From your perspective, what are some key areas where support for young carers is lacking or insufficient? What do you think can be done to fill these gaps and better support young carers?

APPENDIX 2: PARKING LOT

On the day of the roundtable after the various discussions there were additional issues, questions, and comments that people had. Some of these topics or issues raised but which were too large or sensitive to cover in the roundtable were captured in a parking lot.

Parking lot questions and comments

- Complex relationship between caring role and tension in the household; young carers experiences of family and domestic violence, balancing personal safety and wellbeing with sense of obligation and desire to care.
- Carer transitions out of caring role.
- Age of consent.
- Young carers being restricted in their career options due to needing an accessible workplace.
- First responders should screen for young carers.

What does it mean to be a healthy adult?

- Do we, as young carers have an altered view or understanding of what it means to be a healthy adult?

What is your number one priority as young carer?

- Getting more young carers on board (width of advertising versus depth of support for existing young carers).

1) What is your number one priority as a young carer

- Targeted support services
- Financial freedom
- Access to financial literacy skills
- Awareness of my role
- Emotional regulation
- Disciplined
- Persistent
- Determined
- Healthy
- Work
- Education
- Resilience
- Being able to care for my mother financially.
- Putting my own health and wellbeing first.
- Advocacy – bringing awareness as to carers role and life in society
- To be seen and heard.
- Information about services available for young carers

- General support
- Understanding of available resources.
- Being able to care for my loved on.
- Be brave and resilient.
- Feeling like I won't be alone.
- Social events/respite care.
- Be the one that cares for my family so a stranger won't.
- Feeling safe.

2) What is the number one priority for young carers in Australia?

- Basic cost of living survival.
- Being financially stable enough to enjoy life.
- A break.
- Access and inclusion to education.
- Organising all funding into one place for easy access.
- Break down the stigma of the caring role.
- To make sure the person I'm caring for receives the care they need.
- Advocacy and education.
- Flexibility in accommodation from surrounding community/employers.
- Getting the support we need.
- Young cares to be supported throughout their entire caring journey.
- Financial aid.
- Financial stability.
- Awareness of the resources available.
- Kindness and wellbeing.
- Make sure young carers don't lose themselves.
- Social emotional, physical and financial.
- Getting out more.
- Understanding the options available for support more

APPENDIX 3: POST-EVENT SURVEY

What did you find most valuable about the discussions? (Open-ended response)	Feel free to share any additional comments or suggestions related to the roundtable discussion, including anything you didn't feel comfortable sharing on the day (Open-ended response)
The opportunity to recount our experience and express our honest opinions in a safe environment.	I would really love to see more awareness and action around young carers' experiences of family and domestic violence.
Having the opportunity to flesh out all of the varied and unique challenges young carers face in great detail was super valuable. It helped me to not only better understand my place in the conversation and broader role as a young carer in society, but think about how various social structures can be more accommodating to carers.	Having facilitators who were former/current carers was super comforting when sharing our stories!
That everyone was very passionate about making changes and could the need in making changes for the future	Something I forgot to mention, mostly because there was a lot being talked about, was <i>*service provider*</i> . <i>*Service Provider*</i> has so much funding but either doesn't do anything about or doesn't use it right. Another thing is the star review, it is a painful experience for us carers as we have to cons
Being able to share our lived experience with other young carers past and present, and have a facilitator to help navigate the discussions.	It was great to be included in the discussions as a past young carer. Sometimes not all the discussions were relevant to me however I look forward to seeing the new strategy being shaped. I believe there needs to be more flexible support for young carers throughout their role and after they transition caring for their loved one.
Being around carers my age who have the same passion for improving their circumstances as I do. Excellent group.	Please make details about payment (when and how) available upfront for every event.
Feeling as though our voices were truly heard, hearing others' stories	Michael was an awesome facilitator that dealt with a whole day's worth of emotional stories with a smile on his face, managed to keep people on track and change the topic naturally when needed. He tried to include everyone and would tactically ask questions to the people that zone out or check their phone. Very switched on and consistent facilitating.

Connecting with other Young Carers and not feeling so alone.	😊
Being open	
I'm not too sure honestly	
Meeting people who had the exact same struggles that I did and having the chance during the breaks to talk with them about the similarities we had.	
I loved hearing everyone's unique stories, particularly around their engagement with education and employment.	
Just seeing what other young carers were had trouble with. I felt heard during the discussions too which was really nice for me as well.	
Getting information about it services available where we can get help.	

APPENDIX 4: SURVEY RESPONSES REDACTED

Name	Age	From	Regional or urban	Age became carer?	Who do you care for, and why do you provide care? E.g. mental health, substance abuse, disability, chronic illness, degenerative illness etc.	Live with the person / people you care for?	Hours of care per week	In education? What level?	Currently employed? What type?
N	21	Vic	Urban	7	Siblings - ASD, ADHD, Mental Health Grandparents - Injury and illness	It's complicated	20-49	No	Casual
Ma	18	Tas	Urban	4	I care for my mother and sister. My sister has a disability and my mother has chronic illnesses	Yes	0-19	TAFE	Full time
L	22	WA	Urban	12	Mother - mental health	Yes	0-19	Uni	Full time
Ru	24	SA	Urban	9	Mother- mental illness, cancer. Brothers-neglect and mental illness/cognitive disability. Father- mental illness, cardiovascular illness.	No	0-19	Uni	Not employed
Je	22	Vic	Regional	14	I'm a passed carer to my mum who had dementia and chronic illness and a current carer for my dad with physical disability and mental health	Yes	20-49	TAFE	Not employed
Ky	22	NSW	Urban	2	My twin brother, M, is a person with Autism Spectrum Disorder (ASD) who was diagnosed at 18 months old. As M's twin sister, I have been a carer all my life. M was non-verbal until he was seven years old. Although he has started to develop speech, he often repeats phrases and struggles significantly with communication and adapting to new situations. His frustrations often lead to emotional outbursts and behaviours such as absconding, which require constant vigilance and support. I provide care to manage and support the daily challenges associated with ASD, balancing these responsibilities with my own academic and personal life challenges as a person with Attention Deficit Hyperactivity Disorder (ADHD). Additionally, I also care for my younger brother, B, who has Cystic Fibrosis. His condition, though mild, was particularly challenging during the bushfires in 2019 and the ongoing pandemic, affecting his education and health. My role involves managing their	Yes	20-49	Uni	Casual

Name	Age	From	Regional or urban	Age became carer?	Who do you care for, and why do you provide care? E.g. mental health, substance abuse, disability, chronic illness, degenerative illness etc.	Live with the person / people you care for?	Hours of care per week	In education? What level?	Currently employed? What type?
					daily needs and emergencies, supporting their education and development, and balancing this with my university studies, which have been notably demanding due to the disruptions caused by caring responsibilities.				
Ev	19	Qld	Urban	12	I care for my younger brother, L, who has Fragile X Syndrome, a genetic disorder associated with intellectual disabilities, autism, ADHD, anxiety, and social challenges.	Yes	20-49	Uni	Casual
Br	20	NSW	Urban	15	I care for my elderly grandfather after he had 2 strokes. I help maintain his hygiene, cook meals, liaise with medical professionals, administer medication among many other responsibilities.	Yes	20-49	Uni	Part time
Ma	21	Vic	Urban	18	Mother, Cancer	Yes	0-19	Uni	Part time
Sa	18	Vic	Regional	13	My Brother, Disability	Yes	50+	High school	Casual
EM	20	SA	Urban	14	I care for my mum who lives with complex mental health conditions including schizophrenia. Officially I became a carer at 14 but undertook caring roles prior to this time	Yes	50+	Uni	Casual
Lu	20	NSW	Regional	7	I care for my adult brother who is diagnosed with Autism and an intellectual disability (He was diagnosed when Aspergers and Autism were 2 separate entities so I am unable to clarify what stage he is without professional input. If I were to give an estimation, I would say stage 3) Though he is 22 years old, mentally speaking he is between the ages of 7-10 years old with an average IQ between 60 or 70. I also care for my mother who suffers from chronic migraines, chronic back pain. Mum also suffers from PTSD and Depression as a result of long-term domestic violence. An environment we were able to escape in 2016. As a result of this, she has days where she cannot get out of bed and is reliant on pain medication leaving me to run the	Yes	50+	TAFE	Full time

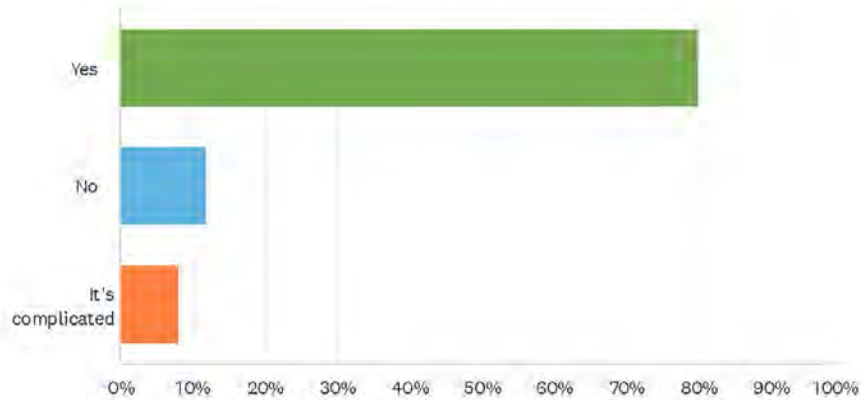
Name	Age	From	Regional or urban	Age became carer?	Who do you care for, and why do you provide care? E.g. mental health, substance abuse, disability, chronic illness, degenerative illness etc.	Live with the person / people you care for?	Hours of care per week	In education? What level?	Currently employed? What type?
					household, taking care of Jacob and multiple household pets including the therapy dog. The domestic violence I witnessed was severely detrimental to my mental and psychological wellbeing. I am now medicated for PTSD and severe Anxiety and see a domestic violence counsellor on a regular basis.				
Ai	18	Vic	Urban	8	Both my parents. Both of my parents have mental health and neurological disorders, as well as chronic pain. My dad has a genetic disorder, ABI and is in remission from cancer. My mum has rheumatoid arthritis.	It's complicated	0-19	Uni	Casual
Ca	23	NSW	Urban	5	I care for my mum currently, but I also cared for my father and uncle till their passing, my mum has rheumatoid arthritis, osteoporosis are the main things My father was post liver transplant, renal failure, diabetes, gout and a couple other issues My uncle had cancer and dementia	Yes	20-49	TAFE	Casual
So	18	Tas	Regional	16	Mother, Mental Health.	Yes	50+	High school	Not employed
Ri	20	Qld	Urban	17	I care for my grandmother who has breast cancer and lung cancer, as well as showing signs of cognitive decline. I don't really remember the age I became a carer, I gradually became a carer to my grandma from when I started high school, which has become more of a responsibility since I left high school at 17	No	20-49	TAFE	Part time
La	24	ACT	Urban	21	My partner - Mental Health & Health Conditions.	Yes	50+	No	other
Li	18	QLD	Urban	0	Dad, chronic illness and disability	Yes	20-49	High school	Casual
Bi	23	NSW	Regional	19	my father he has chronic illness that stops him from working.	Yes	20-49	Uni	Not employed
Sah	28	Vic	Urban	17	I cared for my dad who had a terminal illness, Motor Neurone Disease.	Yes	20-49	Uni	Casual
Jo	19	SA	Urban	16	Younger sister with level 2 ASD, OCD, GAD, disordered eating and agoraphobia. I provide care by simply	Yes	0-19	Uni	Casual

Name	Age	From	Regional or urban	Age became carer?	Who do you care for, and why do you provide care? E.g. mental health, substance abuse, disability, chronic illness, degenerative illness etc.	Live with the person / people you care for?	Hours of care per week	In education? What level?	Currently employed? What type?
					being with her and indirect care through helping the family.				
Lai	18	QLD	Regional	11	My father he is disabled mentally and physically, as well as my sister who I care for at my fathers	Yes	20-49	Uni	Casual
Fa	21	Tas	Urban	3	I care for my youngest brother, for his disability.	Yes	0-19	Uni post grad	Part time
Ja	19	Vic	Urban	4	Twin brother - neurodivergence, mental health conditions and medical conditions. Older brother - neurodivergence, mental health conditions and medical conditions. Mum - breast cancer. I have had my caring role since I was first able to provide care	No	0-19	Uni	Casual
Ma	18	Vic	Urban	8	For my brother F. He has an ABI, vision impairment, ADHD, memory loss, behavioural issues and cognitive issues (disability) and some mental health issues like anxiety	Yes	20-49	Uni	Casual

APPENDIX 5: DATA TRENDS (PRE-EVENT SURVEY)

Q7 Do you live with the person/people you care for?

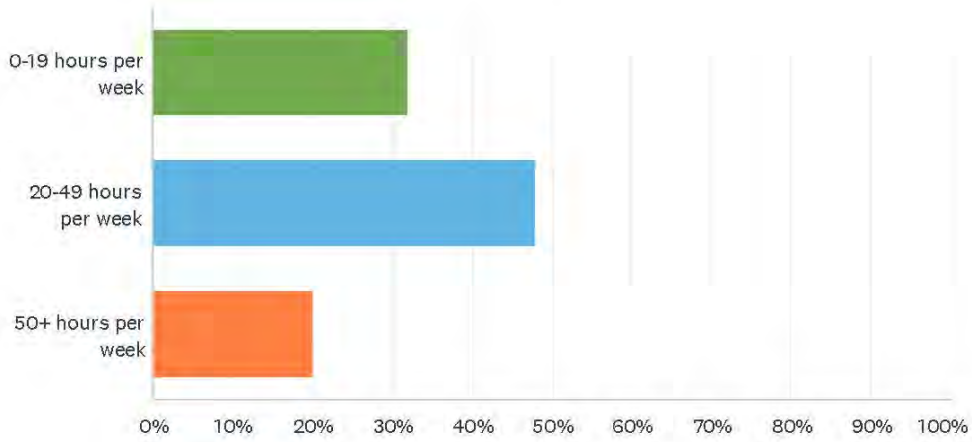
Answered: 25 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	80.00%	20
No	12.00%	3
It's complicated	8.00%	2
TOTAL		25

Q8 On average, how many hours per week do you provide care?

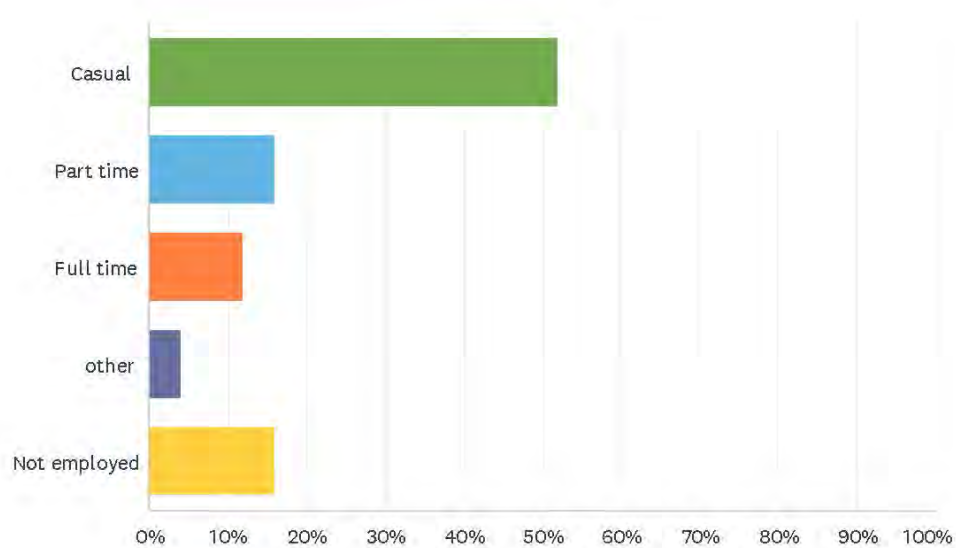
Answered: 25 Skipped: 0



ANSWER CHOICES	RESPONSES	
0-19 hours per week	32.00%	8
20-49 hours per week	48.00%	12
50+ hours per week	20.00%	5
TOTAL		25

Q10 Are you currently employed? If so, what type of employment? (e.g. Casual, Part-Time, Full-Time)

Answered: 25 Skipped: 0



ANSWER CHOICES	RESPONSES	
Casual	52.00%	13
Part time	16.00%	4
Full time	12.00%	3
other	4.00%	1
Not employed	16.00%	4
TOTAL		25



ABOUT US

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, alcohol or other drug related condition, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

For further information on this report, please contact policy@carersaustralia.com.au

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