

Discussion Paper NATIONAL CARER STRATEGY





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Acknowledgement of Country

The Australian Government acknowledges Aboriginal and Torres Strait Islander peoples throughout Australia and their continuing connection to land, water, culture and community. We pay our respects to the Elders both past and present.

The National Carer Strategy Advisory Committee

A National Carer Strategy Advisory Committee is guiding the development of the Strategy. The committee includes carers with lived experience from diverse backgrounds and sector representatives from across a range of portfolios. Members of the committee have been selected through an open expression of interest (EOI) process, and were appointed by the Minister for Social Services, the Hon Amanda Rishworth MP.

The committee will contribute to the development of the Strategy including scope, context, consultation approach and themes. Committee members will draw on their personal and professional experience to ensure the Strategy reflects the diversity of experiences and challenges faced by Australia's unpaid carers.

For more information, please see <u>National Carer Strategy Advisory Committee</u> | <u>Department of Social Services</u>, <u>Australian Government (dss.gov.au)</u>



Foreword

In April 2024, Minister Rishworth appointed a lived experience Carer Advisory Committee to guide and work alongside the Australian Government to oversee the development of the National Carer Strategy. This was to ensure the views, perspectives, collective experiences and aspirations of all carers were reflected in the final Strategy.

Our committee includes a diverse range of carers with lived experiences and representatives from carer organisations, including young carers, carers from First Peoples to newest arrivals, caring for children through to parents, from across the country. The nominated members of the Committee provide advice, representation and advocacy on the complexities, intersectionality, and unique barriers experienced by people in their caring roles across different communities across Australia.

This strategy is an opportunity to inform meaningful change, aiming to enhance the caring experience and improve the quality of life for both carers and those we care for. It also seeks to address the diverse challenges carers face, including impacts on the development, careers, education, financial, physical, mental, and cultural wellbeing, as well as our right to full participation in society.

Caring is a unique and essential responsibility in our society, often unseen, unacknowledged, and undervalued. The role is shaped by diverse individual relationships that translate to both challenging and rewarding caring experiences. Recognising, valuing, and supporting the vital role carers play and their profound contributions to the lives of those they care for is imperative. The recognition of the contribution and additional hours of unpaid care and support provided by carers is fundamental, as this support is necessary to complement and augment government-funded paid care and support services and reduces the demand that is placed on our health and social care systems.

As carers ourselves, we stand with you. We understand the unique complexities and the often-overwhelming nature of our shared journey. Caring is, a commitment that weaves through the fabric of our lives, often without fanfare and requiring resilience. It is a role that shapes our ability to participate in society, quietly underpinning the very essence of community.

There are three million unpaid carers in Australia, and we are keen to hear from you. We want your views, no matter where you are in your caring journey, even if you are just now recognising yourself in this role. Your stories, your challenges, and your needs will be the cornerstone of this strategy. This discussion paper and the consultation strategies that surround the development of the strategy is your platform to voice what is crucial to you, to shape the policies and programs that will support us all. It's an opportunity to ensure that every carer is recognised, valued, and supported to fully participate in society and in their caring roles.

We invite you to contribute to this conversation. Be open, be honest, and let's work together to create a future where every carer's role is acknowledged valued and supported.

Meredith Coote, Co-Chair

Andrew Whitecross, Co-Chair

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Statement on language

Throughout this document, we use the term 'carer' and the 'caring role' as umbrella terms for providing unpaid care, support and assistance for someone who has a disability, a medical condition, a mental illness or is frail due to age. We understand that caring and caring roles can take on many forms; you may be a friend, neighbour, extended family, spouse, child or parent.

The current definition of 'carer' in the <u>Carer Recognition Act 2010</u> (the Act) is someone who provides personal care, support and assistance to another person who needs it because that person has a disability, a medical condition (including a terminal or chronic illness), a mental illness, or is frail and aged. Formal care arrangements will not be discussed in this strategy and discussion paper. Formal carers are those that provide care, support and assistance as a paid service, as part of a volunteer arrangement or as part of training or education for paid care services.

Not everyone who provides help and support to someone thinks of themselves as a carer. This could be for many reasons: for example, it can be difficult for carers to see their caring role as separate from their relationship with the person for whom they care. These relationships and networks give people a sense of connectedness and belonging and can be an important part of people's identity and meaning. Becoming a carer can challenge the existing relationship for all parties. Some people may not recognise that the support they are provide is much greater than other people provide in their relationships. In recent consultations, some attendees shared that the term 'carer' can be uncomfortable. They felt it may be condescending to the care recipient and undermine their agency.

When providing care for someone, the title 'carer' may not be clear until the caring responsibilities impact on your ability to work, limits time with your own family and/or starts to impact on your own health and wellbeing.

In addition, we also understand the term carer may not be recognised, accepted or acknowledged by some people, including First Nations people and in culturally and linguistically diverse (CALD) communities.

For this discussion paper, when we refer to carers, we do <u>not</u> mean those who provide formal, paid care. A carer is anyone, whether a child or adult, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction who cannot cope without the carer's support. The care they give is unpaid. When we refer to carers in this document this is inclusive of both adult and young carers.

<u>Please note</u> that people undertaking normal day to day care of children, whether a parent or non-parent, kinship, grandparent or in foster care relationships (where the children do not have additional support needs due to disability, medical conditions or mental ill health) are not the focus for this discussion paper and the Strategy. Tailored support for this group of carers can be found by contacting the Grandparent, Foster and Kinship Carer Adviser at the Department of Social Services on 1800 245 965. Other relevant resources can be located on the <u>Department of Social Services website</u>.





We are interested to hear from all members of the community that may be supporting a loved one or friend, whether they choose to use the term 'carer' or not.

Do you use the term carer? Is there other language that you prefer to use??



You may also share this caring role with someone. Many carers are part of a circle of support, including but not limited to the role of primary carer. In Australia, the term 'primary carer' is used to refer to the person who provides the most unpaid care and assistance to a care recipient for day to day activities.

Is the idea of a primary carer helpful?

Consultation process

What is the purpose of this discussion paper?

This discussion paper forms part of the public consultation and engagement for a new National Carer Strategy (the Strategy), providing carers and stakeholders the opportunity to tell the government what is important to them.

We want to hear from all carers, including those from diverse backgrounds to ensure the Strategy is responsive to the needs of carers and provide outcomes that will better support all Australia's unpaid carers. This paper is intended to outline issues that the Department of Social Services is aware of as being important for carers. It is meant to prompt discussion not necessarily to identify all relevant issues or ways to address them.

Participating by responding to this discussion paper is an opportunity to work together, ensure carer experiences are represented, with carers sharing in the ownership of the new National Carer Strategy.

Providing a response to this discussion paper can be done via a written submission process with a range of questions in section 3 to guide your submission. The questions are provided as a guide only.

At the same time, we know carers can be short of time, and for that reason we have developed a short online questionnaire you may like to complete instead. You can answer all the questions, or just those most important or relevant to you. The questionnaire can be found at National Carer Strategy | engage.dss.gov.au.

This discussion paper is not government policy; however, it will shape the way the Commonwealth Government understands what the Australian community wants for carers and what the government should prioritise to drive better outcomes for all carers.

Closing date for submissions: 11:59pm AEST on 13 September 2024.



Lodge a written submission online, via DSS Engage:

- You can lodge a written submission online via DSS Engage at National Carer Strategy | engage.dss.gov.au.
- Please include headings with the relevant topics or questions you are addressing.
- You may wish to respond to all of the questions or choose to answer only the questions of most interest to you.
- If you are representing an organisation, we encourage you to provide case studies, data and evidence to support your views. Please be sure to de-identify such information, unless you have consent to share details that could identify individuals.
- The Government may choose to publish submissions to the National Carer Strategy consultations. When
 lodging a written submission, you will be asked to specify whether you would like your submission to be
 published as identified or anonymously on the department's website. For further information regarding your
 privacy, please refer to the privacy notice at Privacy Policy | Department of Social Services, Australian
 Government (dss.gov.au).

Email: NationalCarerStrategy@dss.gov.au

Mail: National Carer Strategy GPO Box 9820

Department of Social Services Canberra ACT 2601

Enquiries: All enquiries should be sent to <u>NationalCarerStrategy@dss.gov.au</u>

Subscribe: To stay informed throughout this consultation process please subscribe to engage.dss.gov.au

Help and support

Please be aware that this paper contains information that may be distressing to readers. It includes information about the experiences of Australia's carers and the challenges they face. If you need support to deal with difficult feelings after reading this paper, there are free services available to help you.

Carer Gateway

- Telephone 1800 422 737, Monday to Friday, 8am to 5pm for support and services.
- Website: Carer Gateway

Beyond Blue Support Service

- Telephone 1300 224 636, 24 hours, 7 days a week.
- Chat online 3pm to 12am AEST, 7 days a week.
- Email for free, short-term counselling, advice and referral services.
- Website: <u>Beyond Blue Support Service.</u>

Lifeline Crisis Support

- This confidential service provides support when you are feeling overwhelmed, having difficulty coping or thinking about suicide.
- Speak to a crisis support worker by telephone on 13 11 14, 24 hours, 7 days a week.



• Text 0477 13 11 14 for support, 24/7.

Chat online 24/7.

• Website: Lifeline Crisis Support.

1800RESPECT

- For support if you are affected by sexual assault or domestic and family violence or abuse.
- Telephone 1800 737 732, 24 hours a day, 7 days a week.
- Chat online 24 hours a day, 7 days a week.

• Website: 1800RESPECT

13YARN

- First Nations service providing culturally safe crisis support.
- Talk with an Aboriginal and Torres Strait Islander Crisis Supporter by telephone on 13 92 76, 24 hours a day, 7 days a week.

• Website: 13YARN

QLife

- QLife provides anonymous and free LGBTQ+ peer support and referral for people in Australia
- Call 1800 184 527, open 3pm to midnight, everyday or visit OLife Support and Referrals

Why national consultation?

The challenges carers face are diverse and often relate to their individual circumstances. We acknowledge that these experiences can lead to feelings of isolation, discrimination, and changes in family dynamics. These experiences can negatively impact carers quality of life, affecting their emotional wellbeing, physical health, autonomy and sense of identity.

The Strategy will be developed in consultation with carers across Australia. The department is undertaking nationwide consultations covering metropolitan, regional, rural and remote locations.

Consultations will include carers with lived experience, sector representatives and include diverse groups such as young carers, First Nations communities and CALD communities. Consultations will also include representatives from the diverse groups of people carers support such as, people with mental health challenges, older people, veterans and those with disability to better understand the unique needs of these different cohorts of carers.

Why is this a shared responsibility?

Commonwealth, state and territory governments continue to support a range of carer related needs through services and programs, with all levels of government having some degree of responsibility for funding, delivering and/or regulating these systems.

Through a broad range of recent consultation opportunities, such as royal commissions, inquiries, surveys and roundtables; carers have shared that accessing services can be difficult and time consuming due to difficult government processes. This feedback highlights the need for improved integration of services and coordination of policies across governments.



Carers also have shared their frustrations and insights into the challenges they experience in their caring role, their wellbeing and within their communities.

A National Carer Strategy will provide opportunities to acknowledge and understand the intersection of other reforms currently underway. This includes opportunities to identify points of collaboration to align a purpose, such as addressing increasing service demand or exploring improved economic participation of carers through increased flexible work participation.

Section 1: Introduction

The purpose of a National Carer Strategy

The Strategy will create an enduring vision for Australia's carers and their families. It will be a roadmap for the Commonwealth for the next five years, providing a vision of what Australia wants to achieve for carers.

It will focus on the diversity of carers by examining the carer landscape, including carers' unique circumstances and current supports. It aims to streamline and coordinate across commonwealth departments to support better collaboration and coordination functions, strengthening the Government's commitment to the wellbeing, education, health (including mental health) and safety of Australia's unpaid carers.

Why a new National Carer Strategy

The preceding National Carer Strategy was launched in 2011 and sat alongside the National Disability Strategy 2010-2020 and, in conjunction with the Carer Recognition Act 2010, formed part of the Australian Government's National Carer Recognition Framework.

That earlier Strategy was superseded in 2015 by the commencement of the Integrated Plan for Carer Support Services (known as Carer Gateway).

Since the release of the previous Strategy, there have been significant reforms to major service provisions for people with support needs including the implementation of the National Disability Insurance Scheme, Australia's Disability Strategy 2021-2031 and aged care reforms. The increasing focus on person-centred planning and service delivery is changing how formal support services interact with the people who use them, their families, friends and carers.



Demographic projections for the coming decades suggest the demand for informal carers is set to increase by 23% between 2020 and 2030. This is based on a projected change in the number of people with severe or profound disability living in the community (Deloitte, 2020). The number of older Australians is also increasing (ABS 2022-base---2071).



At the same time as demand for unpaid care is growing, labour force participation rates for women – who comprise just over two-thirds of all carers - have also increased (ABS, 2024). These factors will continue to impact carers' ability to combine informal care and paid work and will influence the economic participation of carers.

The new Strategy will provide a national framework for the coordination of carer policy across Commonwealth portfolios, facilitating improved support for carers, now and into the future.

Discussion paper

Developing a new National Carer Strategy is an opportunity to have a national conversation about how Australia supports carers. This discussion will look at the diverse circumstances of carers, including the individual needs of carers, the care recipients' needs, availability of supports in some geographical locations and how carers navigate the service systems providing those supports.

Figure 1: The diversity of Australia's carers

DIVERSITY OF AUSTRALIA'S CARERS

CARERS' CIRCUMSTANCES, EXPERIENCES AND SUPPORT VARY ON MANY DIMENSIONS, FOR EXAMPLE:

The National Carers Strategy will need to draw on and respond to the diversity of Australia's carers and care relationships



NEEDS OF CARE RECIPIENT



Physical needs Mental health needs Emotional needs End of life care Duration of caring relationship CARERS OWN
CHARACTERISTICS



Gender / Sexuality
Disability / health status
First Nations
Culturally and Linguistically Diverse
Caring for more than one person
Family structure

CARER – CARE RECIPIENT RELATIONSHIP



Parent – Child
Parent – Adult child
Child – Parent
Adult child – Parent
Partners
Siblings
Other relatives
Friends or peers

SERVICE SYSTEMS



Veterans Affairs Aged Care Disability Mental Health Health / Palliative Care GEOGRAPHICAL LOCATION



Urban Regional Remote Very Remote

Scope and key considerations

Data

Data is collected from a number of sources including via the national Census of Population and Housing in Australia as well as the Survey of Disability, Ageing and Carers (SDAC) conducted by the Australian Bureau of Statistics (ABS).



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According to the most recent SDAC data, of the 3.0 million unpaid carers in Australia, around 1.2 million (4.5% of all Australians) are considered primary carers (ABS, 2022). This is an increase from 3.5% or 861,600 people in 2018. Of these primary carers, 43.8 per cent identify as having a disability themselves. SDAC data indicates that 67.7% of primary carers in Australia are women.

Australian Institute of Health and Welfare analysis of the ABS Census of Population and Housing (2021) data noted 76,600 (15%) of Indigenous Australians aged 15 and over are carers.

The Carer Gateway is the Australian Government's national carer support system and data collected by service providers highlights the diversity of carers accessing services.

As at 30 June 2023, 163,403 or 6 per cent of Australia's carers had registered with Carer Gateway (Data Exchange data at 30 June 2023). Of the 163,403 total carers registered with Carer Gateway:

- 122,233 carers (or 75 per cent) were female
- 9,013 carers (or 6 per cent) were under 25 years old
- 6,733 carers (or 4 per cent) identified as First Nations People
- 9,583 carers (or 6 per cent) identify as culturally and linguistically diverse (CALD)

Respectful of diversity

The Strategy will recognise that carers across Australia are diverse in culture, religion, language, ability, location and family composition including our LGBTIQA+ community.

Young carers and older carers

We know carers can be any age, with children and young adults under 25 years referred to as 'young carers', and carers 65 years and over as 'older carers'.





As at 2022, of the 3.0 million unpaid carers in Australia, there were more than 392,900 young carers and over 758,000 older carers in Australia (ABS, 2022). This national conversation will ensure the Strategy better understands the needs and uniqueness of both our young carers and those who are older.

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First Nations carers



The ABS Census of Population and Housing 2021 found that First Nations people make up about 3.1% of the carer population, or 76,568 people. First Nations people often face additional challenges in identifying as a 'carer' and seeking support in their caring role (FPDN, 2023). We want to better understand these challenges.

Culturally and linguistically diverse carers

Based on Australian Bureau of Statistics (2021) census data, the proportion of carers for whom the 'main language at home is not English' is approximately 20.4% (cited by University of Canberra from 2021 Census) while 25%-30% are from CALD backgrounds.



What are the opportunities to improve your day-to-day life through this strategy?

Intersections across government

The National Carer Strategy Advisory Committee will provide guidance and advice throughout the development of the Strategy. This will ensure we consider a broad range of experiences and perspectives across the carer landscape, with public consultations to commence across Australia. These national conversations will inform how we should direct our efforts to achieve aspirations and develop appropriate policy outcomes that address gaps.

We are aware that carers frequently navigate a range of complex systems that requires them to interact with multiple agencies and service providers at the same time. Carers have told us this process can be time consuming and frustrating.

The Strategy will seek to improve carers' experiences across these important mechanisms of support. This could include better coordination of policy across Government portfolios, effective information sharing, greater communication across governments, better-aligned policies across Commonwealth agencies and/or eliminating unnecessary steps from systems where possible.



Meaningful change requires collaboration across Government to target systemic issues. The Strategy will be informed by learnings from a range of government initiatives such as Closing the Gap, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, the National Strategy to Achieve Gender Equality, the National Autism Strategy and work on the care and support economy led out of the Department of the Prime Minister and Cabinet.

The Strategy will look at systemic issues that affect carers across a range of Commonwealth portfolios including the National Disability Insurance Agency, the Department of Veterans Affairs and the Department of Health and Aged Care.



Have changes in service systems affected you as a carer?

What could make things easier for carers to get their needs met when interacting with provider services or with government processes?

Section 2: The case for a new National Carer Strategy

What we already know

Carers across the country have shared their thoughts into the challenges they experience in their caring role, their wellbeing and their communities through a broad range of recent consultation opportunities, such as royal commissions, inquiries, surveys and roundtables. We are seeking to build on what carers have already told us to drive improvements for carers, the people they care for, and their communities.

Carers and stakeholders have told us:

- There is a need for more emphasis on addressing the holistic needs of unpaid carers.
- There is a need to better integrate formal and informal caring to improve outcomes for care recipients for example, carers want to be recognised for the expertise they are able to contribute to better understanding the needs and preferences of their care recipient.
- The unique experiences and challenges of First Nations carers and other diverse communities requires culturally safe and tailored services and support. It is essential to include the perspectives and voices of First Nations people and other diverse communities in the development of policies, programs and supports so as to better understand and meet their unique needs.
- There is a need for localised care models and services, designed in collaboration with carer communities, including physical and mental health, financial wellbeing and access to respite care.
- Simplification and streamlining of administrative barriers would assist carers to better navigate the systems they are required to access to fulfil their roles.



Wellbeing

Evidence shows carers can experience a range of negative impacts on their wellbeing, often described as the "burden of caring". The time involved in providing care to another person limits the time available to the carer for employment, education, socialising and self-care (Carer Wellbeing Survey, 2022). Evidence suggests carers may prioritise the wellbeing of the people they care for over their own health and wellbeing. This can result in the carer neglecting self-care activities that are essential for maintaining good health, such as regular medical check-ups, exercise, a balanced diet, getting adequate sleep, social interaction, connection and support (Carers Wellbeing Survey, 2023).

The wellbeing and safety of Australia's carers remains front of mind for the Government. Many factors can contribute to carer stress and poor mental health. Regardless of the situation, if a carer or care recipient needs help, often there is a range of specialised support services available. To continue addressing the challenges carers face, we aim to improve both carers' and the community's understanding of what care is, who an unpaid carer may be and what is available to support and recognise the valuable contribution that unpaid carers provide. The efforts of unpaid carers in our community providing important assistance to individuals with disabilities, chronic illness and the elderly are often vital to enabling those individuals to remain in their homes and communities.

The lack of recognition of the caring role and its impact continues to be called out as structural factors that are neglected. Access to appropriate and timely services along with alternative care arrangements that allow for sufficient breaks from the caring role can be important factors in supporting the health and wellbeing for carers.

Access to services

The Carer Wellbeing Survey 2023 found that carers access a range of supports and services including education and training, social support groups and respite care. Research indicates several types of supports have a strong and consistent positive impact for carers including respite care, flexible working conditions, psychological therapy, training and education interventions and support groups. However, carers face barriers and challenges to accessing and navigating these services, including administrative processes. Research shows that barriers affect specific cohorts differently, including carers from regional and remote areas, carers of care recipients with complex needs and carers with transport, access and language barriers (Carers Wellbeing Survey, 2022).

In addition to this, recently the House of Representatives Standing Committee on Social Policy and Legal Affairs tabled the report on its Inquiry into the recognition of unpaid carers; <u>Recognising, valuing and supporting unpaid carers</u> (<u>aph.gov.au</u>) (2024). The Committee examined the challenges faced by unpaid carers and options for reform. The report contained 22 recommendations including a need for an increased focus of minority cohorts including but not limited to First Nations carers, culturally and linguistically diverse carers and young carers.

First Nations people

The Australian Institute of Health and Wellbeing undertook an analysis of the *ABS Census of Population and Housing 2021 (2023)*. The data shows that First Nations people aged 15 and above are significantly involved in unpaid caregiving, with 15% of Indigenous Australians involved. First Nations people are 1.3 times more likely to engage in unpaid caregiving compared to non-Indigenous Australians and take on caregiving at younger ages (AIHW, 2023). First Nations carers face unique challenges additional to declining wellbeing, financial stress and lower workforce participation rates (Carer Wellbeing Survey, 2023). For example, educational disparities for First Nations carers are particularly pronounced in remote and rural areas (LoGiudice et al., 2021), and there is higher prevalence of early onset health conditions and disabilities requiring support (Hill *et al.*, 2012).



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Culturally and linguistically diverse (CALD) carers

Through consultation activities, carers from culturally and linguistically diverse backgrounds have told us that better supporting CALD carers requires knowledge of how caring is understood in different communities and the additional barriers these carers face in performing their roles and accessing supports. A renewed focus on reducing these barriers by way of increased awareness and targeted supports could improve and aid in better mental health prevention care as well as better wellbeing and outcomes for CALD carers.

Young carers

Young carers play an important part in the carer community. Young carers report that they experience significant impacts on their wellbeing, education and workforce participation (Mohanty and Niyonsenga, 2021). It is important to recognise and better support young unpaid carers. This includes raising awareness about their role and contribution as carers within their community, providing training, improving education system awareness and improving the understanding of the role of a young carer.

LGBTQIA+ carers

There is a lack of consistent, national data on LGBTQIA+ people who provide care. Input to date indicates that LGBTQIA+ carers experience additional challenges in their caring role, including experiencing greater social isolation, discrimination (particularly in accessing supports, and services that may not be inclusive), a lack of recognition of identity or experience (Mental Health Carers NSW, 2024), and ongoing declines in wellbeing (Carer Wellbeing Survey, 2023). Barriers posed to LGBTQIA+ carers could be addressed through more targeted, peer led and culturally appropriate inclusive supports; and building greater awareness of the unique experience of LGBTQIA+ carers.

Section 3: Your views

Next steps

Through upcoming community and sector consultations, we are seeking to further understand the key challenges experienced by carers and to explore ideas for solutions that will improve the lives of carers and people they are supporting.

The following section invites you to respond to a range of questions. You are welcome to respond to some or all of the questions or provide any other feedback you think should be considered in the development of the Strategy. This will ensure the Strategy represents the views of as many people as possible.

This discussion paper is part of a national consultation process. Please visit the Department of Social Services website to find out how you can continue to be involved throughout the consultation process.

Proposed structure of the National Carer Strategy

The proposed structure of the Strategy includes guiding principles, a national vision, desired outcomes, policy priorities and indicators that will measure future success against the outcomes and priority reform areas.

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Vision statement

The vision statement for the new National Carer Strategy has been co-drafted by carers with lived experience from diverse backgrounds and locations across Australia. The vision statement sets the overarching aspirations and desired outcomes for the Strategy.

'Our vision is for an Australian community in which all carers are recognised, valued and empowered with the support they need to participate fully in society and fulfil their caring role.'

Principles of the Strategy

A set of principles will be developed to guide policy and proposed future implementation under the Strategy. Guiding principles could include things such as being carer focused, listening to the views of carers, and being inclusive of diverse carers. They could also consider the needs of carers across the service system and over time.

Through the consultation, stakeholders will have the opportunity to propose ideas for principles to guide the Strategy. These ideas may be raised in the context of a vision, an outcome or a priority area for the Strategy. These could be long-term or short-term areas for action.

Question:

1. What principles do you think should be in a National Carer Strategy?

What does your caring role look like?

Carers provide support and help with daily activities such as meal preparation, personal care, mobility assistance, transportation, support with decision making, assistance with medication, financial management, distress intolerance, mood management and crisis management. Some people provide care all the time, while others do so only occasionally. Some carers look after people who are mostly independent but might need some help with tasks such as banking, transport, shopping or housework. Every situation is different. Some people may require more practical support such as training and skill development to assist them in their caring role.

Questions:

- 2. What does your caring role involve or look like for you?
 - a. Are you a Primary Carer? And do you have secondary assistance, such as extended family also providing some care support?
- 3. What additional supports and/or skills do you need or would like to develop to assist or support you in your caring role?

Support for carers

The needs of unpaid carers are varied and often dependent on other factors. This may differ depending on the frequency or intensity of individual care arrangements, such as some carers may be providing care and also working. Some may not be the only person providing this care, or they may not be providing care every day. There are a range of supports and services available that are provided specifically for carers. In-person, online and over the phone services across Australia are available to anyone who is an unpaid carer. Practical supports and services can be delivered to you directly or through other organisations e.g. cleaning gardening, transport and respite care.



Questions:

- 4. Do you know what services are available to support you in your caring role?
 - a. Do you know how to find and access carer supports?
 - b. Have you used any carer supports or services in the past?
- 5. If you have accessed these services, what has worked for you or where have you experienced challenges?

Respite

'Respite' or 'respite care' is when someone else takes care of the person you care for, so you can have a break. A break can give you time to do everyday activities or to relax, deal with stress and look after yourself. Respite care can be given by family or friends or by a respite service. It can be for a short time or for a longer time, including overnight. You may even need to access emergency respite care at short notice if you find you are suddenly unable to provide care, for example if you become ill or injured. When you are a carer it's important to regularly take time for yourself to rest and recharge. Respite can support you to continue in your role as a carer.

The 2023 Carers Wellbeing Survey shows that respite care can reduce caregiver burnout, stress and fatigue, and provide time for essential self-care activities and social activities. Appropriate formal care may be crucial for some carers with unique or diverse needs, such as young carers who require time for education and social activities to support their development. We understand the term 'respite' may not be a preferred term for many people, and we are interested to learn more about this.

Questions:

- 6. We are aware that some carers feel they cannot leave their loved one with others due to the complexity of the care required. What has prevented you from accessing respite and what additional support might relieve your hesitancy to access respite in the future?
- 7. What do appropriate alternative care arrangements look like for you?

Employment and education

The demands of providing care to another person limits the time available to carers for employment, education, socialising and self-care (Carer Wellbeing Survey, 2022). Balancing caring responsibilities with education and employment can be challenging. Equally, the transition into work life can be difficult when co-existing with caring responsibilities.

The supports and services accessed across the caring lifespan can vary widely. At different times the requirements of care may change and impact a carer's ability to participate in work and or education.

Recent consultations have noted that balancing caring duties with school commitments for young carers often leads to absenteeism, poor academic performance and limited opportunities for higher education. More broadly, we also heard that flexible school and work arrangements can increase carers' capacity and support their economic and social participation. Equally, training and education interventions and supports increases participation.

The <u>Carer-Inclusive Workplace Initiative</u> was created to recognise the valuable contributions of carers and create a more inclusive, supportive workplace for those who provide unpaid care in the community. We want to identify and learn about supports and services in the workplace or school that have been beneficial for you.



Questions:

- 8. What carer-inclusive practices could benefit your workplace or education institution?
- 9. What types of assistance are available to you in your education setting, or in the workplace that you find helpful?
- 10. How can we best support carers to stay in or re-enter the workforce or education system?

Priorities

Being an unpaid carer can have a profound effect on relationships. The added responsibilities, changes in dynamics and the physical and emotional demands of being a carer can lead to stress, fatigue and even resentment. It can alter the nature of your relationships, especially where role reversal occurs, for example when a child provides care for a parent or a spouse provides care for their partner. No two caring roles are the same. We want to better understand what you as an individual feel is the most important priority in your caring role.

Questions:

- 11. What are the top three challenges you face as a carer?
- 12. What do you consider are the biggest opportunities to improve the lives of carers and the people they are supporting?

Peer support

Peer support groups can help provide the opportunity to talk to other carers about shared experiences. Peer-to-peer support can provide different types of support, from valuable information, to shared experiences and advice, to companionship and friendship.

Peer support can be practical support, assisting with things like ways to implement and maintain effective strategies to deal with specific situations e.g. strategies to manage medication, deal with mental health conditions etc. It might be emotional support and may help you to deal with the emotional complexity of the situation you're in. Many carers gain valuable knowledge and support to better navigate community and services.

Peer support might assist carers to make connections to new people, groups and services.

Questions:

13. Have you accessed peer supports? What did you find beneficial, or can you identify areas for improvement?

Reflecting on all carers

We know some groups or people can find it challenging to engage with government process or services and face additional barriers that other carers may not, such as language barriers, low digital literacy, cultural sensitivity, availability of tailored services or location.

These diverse groups include but are not limited to:

- First Nations people
- Carers from culturally and linguistically diverse communities including those from multicultural, immigrant and refugee backgrounds
- Carers in regional, rural and remote areas



- Carers who identify as, or care for people that identify as LGBTQIA+
- Young carers
- Older carers

Questions:

- 14. How would you like to see your experiences reflected in the Strategy.
- 15. If you belong to a diverse group, what opportunities do you see for the Strategy to improve access to supports and information in your community? (For example, have you identified a gap or challenge in receiving support and/or information for your particular diverse community and what could Government consider improving the issue).
- 16. What are some priorities that might assist or improve the experience of carers within your community?

Payments

The Australian Government provides payments through the social security system to support carers who are unable to support themselves through substantial paid employment due to the demands of their caring role.

Carer Payment and Carer Allowance are fortnightly social security payments to assist people who provide care in a private home to a person with disability, a medical condition or who is frail from age. Pensions, including Carer Payment, are generally paid at the highest legislated rate of income support payments in the Australian social security system. These payments are indexed in March and September each year in line with the Consumer Price Index to reflect increases in the cost of living.

In the 2024-25 Budget, the Australian Government is investing \$18.6 million over 5 years to give carers greater flexibility and choice to structure their work commitments around their caring role, by changing the 25 hour per week rule for recipients of Carer Payment to instead allow up to 100 hours over a 4-week settlement period. This measure promotes workforce participation by making the 25-hour participation rule more flexible and removing restrictions on study and voluntary activities. Around 31,000 Carer Payment recipients currently work and may benefit from the ability to work more flexibly (including around 25,000 women).

The Department of Social Services is currently reviewing to consider the modern suitability and appropriateness of assessment processes for carer payments in the social security system. This is involving engagement with stakeholders and a review of assessment tools, processes and requirements in the application process for a carer payment.

Questions:

- 17. Do you have any views on how the assessment process for carer payments in the social security system is working?
 - a. Are there any ways we could make it easier for carers to demonstrate they are eligible for a payment?
 - b. What barriers have you experienced in demonstrating your eligibility for a payment that we should be aware of?



Other services

Over recent years, Australia has experienced disaster events such as storms, floods, fires and earthquakes. Seeking support at these times can be challenging and the implementation of emergency responses can be varied, complex and fast depending on the emergency.

Questions:

- 18. Have you ever required emergency assistance or emergency support/s in your capacity as a carer?
 - a. Did you experience any barriers to accessing these emergency support/s due to your role as a carer?
 - b. Did the emergency support/s meet your and your care recipients' needs adequately (for example was there wheelchair access to emergency evacuation points; access quiet spaces for neurodiverse people?
 - c. Would you like to share your experience?

Share your experience:

19. Is there anything else you would like to tell us?



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References

ABS (Australian Bureau of Statistics) (2022) *Disability, Ageing and Carers*, ABS website, accessed 4 July 2024, https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2022

ABS (Australian Bureau of Statistics) (2018) *Disability, Ageing and Carers*, ABS website, accessed 12 July 2023. https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#carers

Australian Bureau of Statistics 2022-base---2071, *Population Projections, Australia*, ABS, viewed 4 April 2024, https://www.abs.gov.au/statistics/people/population/population-projections-australia/latest-release.

Australian Bureau of Statistics 2021, Population and Housing, ABS website, accessed 11 July 2023.

Australian Bureau of Statistics 2024, *Labour Force, Australia*, ABS, viewed 4 April 2024, https://www.abs.gov.au/statistics/labour/employment-and-unemployment/labour-force-australia/latest-release

AIHW (Australian Institute of Health and Welfare) and NIAA (National Indigenous Australians Agency) (2023) 'Health Status and Outcomes: 1.14 Disability', *Aboriginal and Torres Strait Islander Health Performance Framework,* AIHW and NIAA, Australian Government, accessed 11 July 2023.

Carers NSW (2023) 2022 National Carer Survey: Aboriginal and Torres Strait Islander Carers [PDF 138.82KB], fact sheet, accessed 11 July 2023.

Deloitte Access Economics (2020) The Value of Informal Care in 2020, Carers Australia, accessed 4 April 2024.

First Peoples Disability Network Australia (FPDN) (2023) *Disability Sector Strengthening Plan*, closingthegap.gov.au

Hill T, Cass B, Newton B and Valentine K (0212) Indigenous Carers, Department of Social Services

Standing Committee on Social Policy and Legal Affairs (27 March 2024) *Recognising, valuing and supporting unpaid carers*, Recognising, valuing and supporting unpaid carers – Parliament of Australia (aph.gov.au)

LoGiudice D, Josif CM, Malay R, Smith K, Hyde Z, Haswell M, Lindemann MA, Etherton-Beer C, Atkinson D, Bessarab D, Flicker L (2021) 'The Well-being of Carers of Older Aboriginal People Living in the Kimberley Region of Remote Western Australia: Empowerment, Depression, and Carer Burden', Journal of Applied Gerontology, 40(7), 693-702, doi: 10.1177/07334648198986.

Mohanty I, Niyongsenga, T 'Young Carers and their mental health', *The Lancet* Regional Health Western Pacific, Volume 16, 100304, DOI: https://doi.org/10.1016/j.lanwpc.2021.100304.

Schirmer, Mylek and Miranti (2022) Carer Wellbeing Survey: Full Data Report, Carers Australia, accessed 12 July 2023.

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