



Draft National Carer Strategy

Improving the lives of Australia's unpaid carers

17/10/2024 – 03/11/2024

Response to the Consultation Survey Questions

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Section 1: Strategy Overview

In this section, we want to know if the Vision, Principles and Objectives for the National Carer Strategy (the Strategy) appropriately set the direction to implement improvements for carers.

Vision

The Vision defines where we aspire to be and what we want to accomplish with the strategy.

'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.'

Q1. Does the vision clearly articulate a desired end state that Government should be aiming for that reflects where carers want to be by the end of the Strategy?

Insert X into one option

YES

NO

UNSURE

If you selected 'no' or 'unsure', please explain why.

Please provide response below:

In Australia, it is estimated carers contribute over \$3.3 billion in informal care costs¹ for survivors of stroke; however, this support comes at a significant personal cost. Carers often shoulder a significant burden in supporting this navigation for those they care for, often at great personal cost and stress.

In consulting with our community, Stroke Foundation knows that caring responsibilities have a significant impact of all aspects of a carer's life, including work, relationships, psychological, physical and social wellbeing, as well as financial hardships.

Findings from a published survey of Australian survivors of stroke and their carers support this with evidence, showing that carers of survivors of stroke commonly experience a decline in their own physical and mental health and a reduced quality of life, with an estimated 30 to 68 percent experiencing anxiety or depression.²

¹ Kim J., Neville E., Dalli L., Zomer E., Birhanu M., Purvis T., Olaiya MT., Talic S., Kilkenny MF., Cadilhac DA. on behalf of the Stroke Foundation, Economic Impact of Stroke 2024. Stroke Foundation 2024. Melbourne Australia. Pages 1-115. DOI: 10.26180/27049219

² Monash University Stroke and Ageing Research Centre (STARC). 2013. Australian Stroke Survivor and Carer Needs Assessment Survey.

The parents of childhood survivors of stroke, in particular, have reported the significant impacts taking on a carer role can have on their physical, social and emotional wellbeing. Many are juggling work, personal relationships and their caring responsibilities, and often experience additional pressures because they do not qualify for a carers payment or other financial supports.

Therefore, we at Stroke Foundation would like to see the importance of carer's own physical and psychosocial wellbeing reflected in the vision statement, and suggest an amended version:

*'An Australian community in which all carers are recognised, valued, and empowered with the support they need to participate fully in society, **achieve own best health and wellbeing**, and fulfil their caring role.'*

Principles

The principles should guide the coordination and delivery of carer-related and carer-impacting policies, programs and initiatives across Australian Government agencies.

Principle 1: Carer-centred

What we will do:

Include carer lived experiences in the co-design and co-production of policies, supports and services for carers. Carers' lived experience will be included in evaluation processes.

How we will do it:

Continue to seek out, listen to and act on carers' perspectives.

Focus on what they tell us they need. Be flexible and responsive when circumstances change.

Principle 2: Evidence-informed

What we will do:

Ensure that carer policies, supports and services are informed by evidence and innovation, to address challenges experienced by carers.

How we will do it:

Focus on building and improving an evidence base to better support the development, implementation and monitoring of tailored and responsive supports and services.

Enable data sharing and evidence for use by governments and communities to evaluate interventions and resources.

Principle 3: Accessible, equitable and inclusive

What we will do:

Ensure carer policies, supports and services are inclusive and tailored to reflect the needs of all carers, at all stages of caring, recognising the diversity of carers, and the importance of cultural and psychological safety.

How we will do it:

Use evidence-based data and lived experience to co-design innovative, accessible, tailored and inclusive services. Recognise, respect and facilitate the vital role of non-government organisations in providing supports and services.

Principle 4: Supporting agency

What we will do:

The design of policies supports and services for carers will enable choices that suit them.

How we will do it:

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Acknowledge that carers know their needs and aspirations best. All have unique relationships, strengths, capabilities and resources, which may change over time.

Co-design policies, supports and services to empower and support carers to find and access the right supports at the right time and to ensure unintended consequences for carers are identified and remediated.

Principle 5: Transparent and accountable

What we will do:

Federal government departments will be transparent in their processes to better recognise and value carers and will report on their progress.

How we will do it:

Monitor, measure, evaluate and report on progress in delivering on the priority outcome areas and achieving the objectives set out in the Strategy.

Include carers in the continued development of actions and implementation plans to support realising the vision of the Strategy.

Q2. Is there anything the principles don't capture?

Insert X into one option

YES

NO

UNSURE

If yes, please tell us what is missing.

Please provide response below:

Although Stroke Foundation supports and endorses the proposed principles underpinning the draft National Carer Strategy 2024-2034, we would recommend including an acknowledgement of the need for a **whole-of-government approach** to support the design, implementation and monitoring of this National Strategy.

We would therefore recommend that the monitoring and evaluation framework for this National Strategy include representatives across government agencies, human services, primary and allied health, local government and other stakeholders; with meaningful and measurable objectives and outcomes co-designed with carers to ensure the delivered results are relevant and meaningful.

In 2023, over 45,000 Australians experienced a stroke, and there are now more than 440,000 survivors of stroke living in the community. Stroke affects people of all ages and backgrounds; and each survivor's recovery and carer support needs are unique, manifold and varied.

Currently, many survivors of stroke and carers describe navigating government supports and processes as complex, confusing and fragmented, requiring from them an understanding of a system with which they have had little or no previous contact, and which isn't set up to understand their needs well.

Depending on the circumstances, in their caring duties they may require interfacing with multiple government agencies and programs (e.g. NDIA/NDIS, My Aged Care, Services Australia,

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Department of Education, Department of Health and Aged Care, motor vehicle licensing authorities, and many others). The result is that many survivors of stroke and carers do not receive the services and supports they need to support their independence, which leads to poorer health outcomes, and reduced quality of life.

Objectives

Co-developed by carers, these objectives provide the overarching goals carers, and the Australian Government, want to see realised. Through monitoring improvements in these objectives, we will measure our progress toward achieving the Strategy vision.

Objective 1: Carers are identified, recognised, and valued

Carers are:

- able to identify they are in a caring role, and can access information of supports available to them
- acknowledged by others, and consulted, regarding the person/s for whom they are caring
- identified early and are offered information pathways to supports appropriate to their needs
- valued equally in their caring role.

Q3. Does Objective 1 support the Strategy's vision; is it realistic and measurable; and does the description under each objective reflect the core elements of that objective?

Insert X into one option

YES

NO

UNSURE

If you selected 'no' or 'unsure', please explain why.

Please provide response below:

Objective 1 calls for carers to be "identified, recognised and valued", and this statement of intent appears to align with and support the overarching vision statement for the Strategy.

Ensuring carers are able to access information about supports available to them is of paramount importance. In consulting with our community of carers of survivors of stroke, many carers reported not knowing what supports or government assistance they are entitled to; how and where to apply, and where resources are available. Carers have also reported that the Department of Social Services 'Carers Gateway' is not an easy platform to navigate, and needs to be made more user-friendly and accessible.

Stroke Foundation would also recommend the information on what government assistance is available for carers be made available to the community at many touchpoints in the community where carers can engage with it; such as GP and allied health clinics, community support groups, etc.

As the voice of stroke in Australia, Stroke Foundation maintains strong connections with the carer community, and would strongly support all initiatives to better value and support carers, and

ensure carers are offered information pathways to supports appropriate to their needs. Through our various programs (e.g. StrokeConnect Navigator; Living Well After Stroke) and platforms (e.g. EnableMe and YoungStroke, etc), we support and assist survivors of stroke, their families and carers to better navigate the complex systems and supports required for them to live well after stroke.

We note and support the fact that the draft National Carer Strategy Document (p. 20) refers to Objective 1 being "...grounded in the insights gathered from extensive consultations...", "supported by robust evidence" and that the key themes and challenges were "co-developed by carers ... to provide the overarching goals", and this approach gives us confidence as to the overall intent on Objective 1.

However, without detailed Action Plans, Theory of Change, Outcomes Framework, and a Monitoring and Evaluation Frameworks provided for review (as discussed under "Next Steps" on page 29 of the draft National Strategy document), we cannot comment on whether Objective 1 is measurable or achievable.

Furthermore, the draft Strategy (p. 29) states that "voices and perspectives of carers will inform and guide the Strategy implementation, monitoring and review to ensure outcomes are delivered", and we hope representatives from the stroke carer community will be consulted and engaged in co-designing that process.

Objective 2: Carers are empowered to fulfil their caring role, whilst still pursuing other aspects of their lives.

Carers have:

- access to resources and skills training that enhances safe and effective caregiving
- access to forms of respite that are most relevant to the circumstances of different carers and those they care for
- flexibility and adaptability with learning options and support to accommodate caring responsibilities from educational institutions to support personal and professional development goals
- carer-inclusive workplaces that welcome and accommodate their caring responsibilities to support employment goals and financial security.

Q4. Does Objective 2 support the Strategy’s vision; is it realistic and measurable; and does the description under each objective reflect the core elements of that objective?

Insert X into one option

YES

NO

UNSURE

If you selected 'no' or 'unsure', please explain why.

Please provide response below:

Stroke Foundation strongly supports the intent of Objective 2 in ensuring carers have access to resources and training to enhance safe and effective caregiving; respite and mental health supports; as well as carer-inclusive workplaces and educational institutions to support personal and professional development goals.

Evidence shows that caring responsibilities have a significant impact of all aspects of a carer’s life, including employment, physical and psychosocial wellbeing, relationships, and finances.

Findings from a published survey of Australian survivors of stroke and their carers³, provided strong evidence that there was a significant impact experienced by carers:

- Of those caregivers who were working prior to taking on a carer role, 40 percent reported a moderate to extreme reduction in the amount of work they were able to perform.
- Almost half (47 percent) of the carers who participated in leisure activities prior to taking on a carer role reported a moderate to severe reduction in the number or type of leisure activities in which they were able to participate.
- Almost a third (31 percent) of carers who were the partner or spouse of a person with stroke reported moderate to extreme changes in their relationship.
- A significant proportion of carers reported moderate to extreme changes in their relationships with other family members (20 percent), and with other people outside the family such as friends (32 percent).

As a consequence of these pressures, carers of survivors of stroke commonly experience a decline in their own physical and mental health and a reduced quality of life, with an estimated 30 to 68 percent experiencing anxiety or depression.

The parents of childhood survivors of stroke, and many partners and spouses who are informal carers juggle work and caring responsibilities, are often told they do not qualify for a carer's payment or other government assistance.

As the voice of stroke in Australia, Stroke Foundation would strongly support all initiatives to empower carers to better fulfill their caring role whilst still able to pursue other aspects of their lives, thrive and achieve self-fulfilment.

However, without detailed Action Plans, Theory of Change, Outcomes Framework, and a Monitoring and Evaluation Frameworks provided for review (as discussed under "Next Steps" on page 29 of the draft National Strategy document), we cannot comment on whether Objective 2 is measurable or achievable.

Furthermore, the draft Strategy (p. 29) states that "voices and perspectives of carers will inform and guide the Strategy implementation, monitoring and review to ensure outcomes are delivered", and we hope representatives from the stroke carer community will be consulted and engaged in co-designing that process.

³ Monash University Stroke and Ageing Research Centre (STARC). 2013. Australian Stroke Survivor and Carer Needs Assessment Survey.

Objective 3: Carers' health, safety, wellbeing and financial security are supported.

Carers can flexibly access the assistance they need to support their:

- physical well-being and safety
- psychological health
- social connection
- cultural and spiritual identity
- financial security

Q5. Does Objective 3 support the Strategy's vision; is it realistic and measurable; and does the description under each objective reflect the core elements of that objective?

Insert X into one option

YES

NO

UNSURE

If you selected 'no' or 'unsure', please explain why.

Please provide response below:

Stroke Foundation strongly supports the aims of Objective 3 to ensure carers' physical and psychological wellbeing and safety, social connectedness, financial security and cultural and spiritual identity are supported and prioritised.

As stated in previous responses, there is strong evidence that shows that caring responsibilities have a significant impact of all aspects of a carer's life.

Monash University Stroke and Ageing Research Centre (STARC) study⁴ surveyed Australian survivors of stroke and their carers, showed strong evidence that caring responsibilities affect carers across all aspects of life, including reduction in participation in enjoyed leisure activities (47 percent); moderate to extreme changes to inter-spouse relationships (31 percent) and other family members (20 percent) and friends (32 percent).

Carers of survivors of stroke commonly also frequently report experiencing a decline in their own physical and mental health and a reduced quality of life, with an estimated 30 to 68 percent experiencing anxiety or depression.

Ensuring better and earlier access to supports for carers is vital, and we argue must include a whole-of-government approach, to encompass review and changes to current arrangements for MBS Mental Health Treatment Care Plans; review of the Department of Social Services 'Carers Gateway', NDIS, My Aged Care, Disability Employment Services, Education and Early Childhood Early Intervention Support arrangements and many others.

⁴ Monash University Stroke and Ageing Research Centre (STARC). 2013. Australian Stroke Survivor and Carer Needs Assessment Survey.

Carers are as diverse as the people they care for. As acknowledged by the draft National Strategy (p. 30), some cohorts of carers experience intersectionality of additional challenges and barriers to accessing supports (e.g. Aboriginal and Torres Strait Islander carers, CALD, carers with a disability, carers from lower socioeconomic groups, LGBTQIA+, young carers, parents of children with a disability) are amongst some of the carer communities under recognised in data collections, service usage or carer needs assessments.

However, without Action Plans, Theory of Change, Outcomes Framework, and a Monitoring and Evaluation Frameworks (as discussed under "Next Steps" on page 29 of the draft National Strategy document), we cannot comment on whether Objective 3 is measurable or achievable.

Furthermore, the draft Strategy (p. 29) states that "voices and perspectives of carers will inform and guide the Strategy implementation, monitoring and review to ensure outcomes are delivered", and we hope representatives from the stroke carer community will be consulted and engaged in co-designing that process.

Section 2: Priority Outcome Areas

In this section we look at the priority outcome areas. The priority outcome areas encompass recognition and value, support and empowerment, and wellbeing. The priority outcome areas are where the Australian Government will direct efforts to achieve the above objectives and the Strategy's Vision.

Q6. Would action in these priority areas address the key challenges you face?

Insert X into one option below for each priority outcome area

	Priority Outcome Areas	Yes	No	Unsure
1	The community, government and those who provide paid care and support recognise and value carers' contributions and expertise and carers are supported to self-identify early.	X		
2	Carers can access supports, services and programs at the right time, right place and in the right way across the caring continuum.	X		
3	Ensure carers are able to develop the knowledge and skills they need to fulfill their caring role.	X		
4	Carers can access, pursue and maintain employment and education, including to improve financial well-being for themselves and those they care for.	X		
5	Carers have access to supports that safeguard their psychological, physical and social wellbeing.	X		
6	Build the evidence base on carers to better understand who carers are, what are their experiences, what works for them and why.			X

If you selected 'no' or 'unsure', please explain why.

Please provide response below:

As stated above, Stroke Foundation broadly supports the vision, principles objectives and priority outcome areas of the draft National Carer Strategy 2024-2034.

We acknowledge and salute the consultative process with which the draft strategy was developed, and the co-design process which was used to consult with carers' and their voice of lived experience to inform the vision, principles and objectives of the Strategy.

We, along with our community of carers for survivors of stroke, await the next phase of the consultation where the Action Plans, Outcomes Framework, and a Monitoring and Evaluation Framework will be outlined, as these will be critical for the implementation of the National Carer Strategy and its goals (again with carers empowered and engaged in planning and decision making).

As the voice of stroke in Australia, Stroke Foundation and our community of carers, is ready and willing to contribute to the next phase of this process.

Section 3: The National Carer Strategy

In this section we look at the National Carer Strategy overall. The Strategy sets out a national agenda to support Australia's unpaid carers to improve and maintain their wellbeing, to empower carers with the tools, skills and knowledge they need to reach their goals and aspirations, and to better balance their lives with their caring roles.

Q7. Are you satisfied that the National Carer Strategy will lead to a positive change in your caring experience and provide a foundation for the coordination of carer policies, programs and initiatives across Australian Government agencies?

Insert X into one option

YES

NO

UNSURE

If you selected 'no' or 'unsure', please explain why.

Please provide response below:

As stated above, Stroke Foundation broadly supports the vision, principles, objectives and priority outcome areas of the draft National Carer Strategy 2024-2034.

However, in order for real changes to carers lives and experience to be manifested, we would like to see a **whole-of-government approach** adopted, with representatives of governments of all levels, along with those from primary/allied care, disability, welfare, and other sectors represented alongside the carer community in joint, inclusive and empowered decision making and consultation process.

Robust and measurable targets and monitoring and evaluation frameworks will be required to achieve the worthwhile goals of the National Carer Strategy 2024-2034, and we look forward to engaging, contributing and participating in that process alongside representatives of the stroke carer community.

Section 4: Conclusion

We would like to thank you for participating in the National Carer Strategy survey. Your feedback and responses will assist in ensuring the Strategy makes a difference in improving the lives of carers across Australia.

Q8. Is there anything else you want to say about how the National Carer Strategy could be improved?

If yes, please tell us below:

Stroke Foundation is looking forward to the next phase of the National Carer Strategy Development where the "Next Steps" of the process are designed (e.g. Action Plans, Theory of Change, Outcomes Framework, and a Monitoring and Evaluation Frameworks).

Stroke Foundation is a national charity that partners with the community to prevent stroke, save lives and enhance recovery. We stand alongside survivors of stroke, their families, carers, healthcare professionals and researchers. We build community awareness and foster new thinking. We support survivors, their families and carers on their journey to live the best possible life after stroke.

THE END