2025 National Policy Forum: Recognising Carers in Health Systems in Australia

OUTCOMES REPORT

CARERS AUSTRALIA
APRIL 2026

Foreword

Carers Australia is the national peak body representing over 3 million carers in Australia. Our vision is an Australia that values and supports all carers, where all carers have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment, and education.

Carers Australia's 2025 National Policy Forum, which was held in November 2025, was on the topic of recognising unpaid carers in Australia's health systems. While Carers Australia has long advocated for better recognition of family and friend carers, carers continue to tell us that they feel unrecognised, and even 'invisible' within our health care systems. Carers report that health professionals rarely seek their insights on the person they care for, or listen to what they have to say, and they are often excluded from health care processes, such as care planning and hospital discharges.

The Forum brought together government officials, policy makers, academics, representatives from peak health bodies and members of the National Carer Network to engage in discussions on the barriers preventing carer recognition in health systems. Participants, drawing on their list of identified barriers, voted on the two most urgent areas requiring attention. The two areas were: more proactive referral of carers to supports; and stronger carer identification, recognition and navigation support in health systems.

Strengthening health professionals' training and awareness of carers' roles will be critical to achieving changes in these two areas. Recognising carers in health care systems also has the potential to engage an unpaid and unacknowledged workforce of 3 million carers to support the delivery of health care.

This report provides summaries of the Forum presentations, the key issues raised in discussions, as well as the results of voting by participants on the blockers preventing carer recognition in health systems. It is intended to enable wider consideration of the Forum's valuable insights and guide future policy engagement and development in this important area.

I would like to thank everyone who participated in the Forum for their valuable contributions to this challenging policy issue of carer recognition and inclusion in health systems. Carers Australia will continue to work to improve the recognition of carers within our health care systems for better outcomes for carers, the people they care for, taxpayers and the Australian community.

Annabel Reid
CEO Carers Australia

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Executive summary

In 2024, the National Carer Network, which includes Carers Australia, agreed to focus on the systematic recognition of carers as one of three, most impactful areas for carers (the other two areas are remuneration and respite). Improving the identification and recognition of carers are also key themes of the *National Carer Strategy 2024–2034* and the *National Carer Strategy Action Plan 2024–2027*. The 2024 House of Representatives Inquiry into the Recognition of Unpaid Carers also recommended updating recognition laws and obligations for agencies.

Against this backdrop, the subject of Carers Australia 2025 National Policy Forum (the Forum), was systemic recognition of unpaid carers in health systems. The Forum was held in Canberra on 7 November 2025 and brought together key stakeholders to discuss the systematic barriers preventing carer recognition in Australia's health systems and to identify and prioritise two, key areas for action.

The Forum was facilitated by Phil Martin, Chair of the National Carer Strategy Advisory Committee Action Plan Working Group. Presentations informed the discussions:

- Kartika Medcraft-Smith (Director, National Carer Strategy – Carers and Early Childhood Branch, Department of Health, Disability and Ageing) – *Update on National Carer Strategy and Action Plan*
- Professor Trish Livingston (Acting Director, Institute of Health Transformation, Faculty of Health, Deakin University) – *Systemic barriers and enablers*
- Professor Jennifer Tieman (Director, Centre for Palliative Care, Death and Dying, Flinders University) and Dr Sara Javanparast (Senior Research Fellow, Centre for Palliative Care, Death and Dying, Flinders University) – *Defining Best Practice: What exemplary carer support looks like*.

There were four breakout groups and a plenary discussion where participants shared professional and lived experience perspectives, identified barriers to recognising unpaid carers in Australia's health systems, and prioritised areas requiring attention.

Forum themes

Themes from the forum included:

- Carers remain invisible in health systems. They are rarely identified, excluded from decisions, and overlooked in policy and design, resulting in fragmented care.
- System structures (medicalised, siloed systems) make it difficult for carers to access support for themselves.
- Carer recognition needs to be proactive and early. Health professionals — not carers — should initiate carer identification, supported by digital tools and streamlined pathways.
- Carers deliver critical value but are undervalued. Carers reduce system pressure and bridge service gaps, but their expertise is rarely acknowledged or integrated.

- Healthcare workforce training is not fit for purpose. Carers' roles are largely absent from medical and health education, resulting in missed opportunities for engagement.
- Cultural norms hide the carer role. Caring is seen as private 'family work', reinforcing invisibility and hindering system and cultural change.
- Carers face significant fatigue and wellbeing risks. Continuous caring, advocacy and system complexity create high stress, and wellbeing supports for carers are lacking.
- There are promising innovations, but they are not system wide. Effective programs and digital tools show impact, but adoption is fragmented and not at scale.
- Legislative frameworks need to be modernised and harmonised. Operational practice lags the policy in the National Carer Strategy.
- Systemic, coordinated reform is essential. Integrate carers into care teams, improve data and proactive supports, and co-design reforms across sectors.

A long list of barriers to carer recognition

Participants' list of barriers to carer recognition in health care systems included:

- time constraints – health professionals and providers are only remunerated for the care they provide patients
- carers are frequently left to navigate complex systems without a dedicated pathway to guide them through service and support options
- burdensome assessment processes
- carer fatigue due to the continuous nature of caring and the need to advocate, make appointments, attend appointments, clean, provide personal care and transport
- excessive bureaucracy in healthcare systems
- unclear service pathways create confusion and hinder access to support
- low public awareness of the National Carer Strategy
- cultural bias against carers with a need for a cultural shift to foster a more empathetic and inclusive system that values carers. Education can play a role reshaping societal perceptions helping carers to be recognised and supported.

The two most urgent areas for attention

The two most urgent areas for attention, as voted by participants, were:

1. Making health care systems more proactive at referring carers to supports; and
2. Stronger health care system carer identification, recognition and navigation.

While finding solutions was not an objective of the Forum, participants pointed to some practical solutions, including educating and training health care professionals about the role of informal carers, identifying carers on patient's records, and co-designing policies with carers.

Forum participants emphasised the need for systemic reform – changing existing health care systems so that they recognise carers and legislative backing – legislation in each jurisdiction that is up-to-date and coherent.

The Forum was an effective problem-identification process which resulted in consensus on areas for attention. It represents a significant starting point for action.

Introduction

Background

Australia has around 3 million unpaid, family and friend carers.[1] Carers are people who provide care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. Carers are an invisible workforce, delivering more than 2 billion hours of care each week. They enable more people to live at home, they improve the lives of those they care for, and they divert costs from formal health and care systems.

Carers often have little or no choice about becoming a carer. And caring can have a big negative impact on their health, wellbeing and financial outcomes. Despite their important contributions, carers remain under-recognised, including within health systems. Their roles are often overshadowed by the formal care sector. They are often left without adequate support for themselves and excluded from care planning and decision-making processes for the person they care for, and this can undermine their ability to provide care.

The need for family and friend carers is growing with our ageing population. Without stronger recognition and support for carers, our health and care systems will struggle to meet demand as they are heavily reliant on this hidden but essential workforce. Without support and recognition, carers' health and wellbeing will also deteriorate, resulting in carers needing increased support from formal systems.

In 2024, recognising the need to elevate the role of family and friend carers, the Australian Government, in partnership with organisations such as Carers Australia, developed a reform agenda which is detailed in the *National Carer Strategy 2024–2034* (the Strategy) and the *National Carer Strategy Action Plan 2024–2027* (the Action Plan). Both the Strategy and the Action Plan aim to embed carer recognition and support across all levels of the Australian community.

After the May 2025 Federal Election, Carers Australia and the National Carer Network jointly reviewed their policy advocacy strategy and agreed to focus on three core areas that are significantly impacting carers: recognition, remuneration (financial security), and respite care.

In the context of this reform agenda, the Carers Australia 2025 National Policy Forum, which was held in Canberra on 7 November 2025, focussed on systemic recognition of unpaid carers in health systems.

[1] Australian Bureau of Statistics (2022), *Disability, Ageing and Carers, Australia: Summary of Findings*, ABS Website, accessed 25 November 2025.

About the Forum

The Forum brought together a diverse group of stakeholders. 28 people participated in the Forum with representatives from the Department of Health, Disability and Ageing (DHDA), peak health bodies, researchers, health professionals, and members of the National Carer Network. Participants are listed in Appendix A.

The Forum's purpose was to discuss the systematic barriers and the enablers for effective carer recognition in health systems and to identify and prioritise two, key areas for action. The Forum's process included:

1. reviewing the role and value of carers
2. discussing the lack of carer recognition
3. identifying barriers to carer recognition and their underlying drivers
4. compiling a list of barriers
5. voting to rank the barriers and identify the two priority action areas.

These steps were aided by presentations on the current reform agenda, systemic barriers and enablers, and defining best practice.

Forum participants worked in four breakout groups and together in a plenary group. They shared professional insights and lived experiences, identified blockers to recognising unpaid carers in Australia's health systems, and having identified lists of blockers, voted on their first, second and third preferences.

The Forum was facilitated by Phil Martin, a leader in the not-for-profit sector with more than 35 years of experience, including in executive, as a CEO, and on boards. Phil Martin currently serves as Co-Chair of the National Carer Strategy Advisory Committee Action Plan Working Group and is a Ministerial appointee on the National Strategy Advisory Committee.

Forum presentations and discussions

Presentation 1 – The problem we're trying to solve

Phil Martin began the Forum speaking about the significant economic and social changes that are creating both challenges and opportunities, including the National Disability Insurance Scheme (NDIS) and aged care reforms. He noted that Australia's health care systems are adjusting to the lasting effects of the COVID-19 pandemic and severe shortages of health care professionals are predicted.[2]

In the context of these challenges and opportunities, there is a growing need to understand the needs of carers and the challenges they face and to drive systemic policy and program changes to improve the lives and recognition of unpaid carers in Australia.

DHDA has the task of delivering the National Carer Strategy and Action Plan. The Strategy, designed and created with carers, outlines the importance of identifying and recognising carers and valuing their expertise. including within health care systems, by health professionals, and by service providers. The Strategy also highlights the lack of carer recognition within the community more generally, including in education, training, and employment settings.

The House of Representatives Standing Committee on Social Policy and Legal Affairs (the Committee) Inquiry into the recognition of unpaid carers highlighted the unrecognised and undervalued role of carers, including First Nation carers, Culturally and Linguistically Diverse (CALD) Carers and young carers. The Committee's Report *Recognising, valuing and supporting unpaid carers* made recommendations to:

- modernise the *Carer (Recognition) Act 2010*
- strengthen legal rights and accountabilities
- expand and improve carer supports
- integrate carer wellbeing into health care systems, including training to identify carers
- address the financial and workforce barriers faced by carers
- improve measurement of carer contributions and report progress, including:
    - redesigning the *ABS Survey of Disability and Carers* to reflect revised carer definition and include diverse subgroups
    - revising the *Carer Wellbeing Survey* to be longitudinal and capture health, wellbeing, and suicide indicators
    - conducting public education campaigns to raise awareness, reduce stigma, and celebrate carer diversity.

DHDA has undergoing significant changes recently, and this presents both challenges and opportunities for improvement across four levels of change.

- *Individual Level*: at the individual level it is important to listen to carers and understand their needs. The Carer Gateway and carer networks have improved support for carers, but there is a need for ongoing refinement.

[2] National Health and Medical Research Council, National COVID-19 Health and Research Advisory Committee (2022). *Strengthening Australia's health system post COVID-19*. Canberra.

- *Program Level*: the training of health care workers and cultural awareness are essential. Carers must be seen as individuals, not just as carers.
- *Departmental Level*: there have been machinery of government changes and there are new ministers with responsibility for carers and the NDIS. The net effect is a degree of complexity. It is important to provide succinct advice to influence policy to support the Australian Government. We need to go beyond restating problems and identify solutions.
- *System Level*: legislative frameworks remain outdated and lack of systemic recognition limits progress despite strong recommendations in the National Carer Strategy.

It was noted that health care systems are not designed for carers and challenges remain.

Phil made the point that transformational change is possible. He provided the example of a hospital support program for children with cancer. Health care providers initially thought the program was failing because it overlooked hidden issues: financial stress, relationship breakdowns, and systemic barriers. However, adjustments were made, including flexible appointments, advocacy training, practical supports, and involving families and carers in the program, and outcomes improved significantly (over a decade a 90% morbidity rate had changed to a success rate of 90%).

Presentation 1 concluded with a call to action: Engage in creative, respectful discussions to identify barriers and prioritise two key areas for action. Focus on improving carer recognition and inclusion in health systems, aligning systemic and legislative frameworks, and laying foundations for future collaboration.[3]

[3] Phil Martin (Facilitator), Co-chair, National Carer Strategy Advisory Committee Action Plan Working Group.

Presentation 2 – National Carer Strategy and Action Plan - Update

Kartika Medcraft-Smith shared her lived-experience as a carer and the importance of recognising and supporting carers. Her personal carer journey spanned 18 years and included navigating health systems without being identified as a carer or being offered support. Kartika's experience informed her current role as the Director of the National Carer Strategy.

Kartika explained that the *National Carer Strategy 2024-34*, published in December 2024, was developed through extensive consultations with over 2,000 carers nationwide, including remote communities. Since the Strategy was released, there have been machinery of government changes. The Carers and Early Childhood Branch has moved from the Department of Social Security to the Department of Health, Disability and Ageing. This change has provided significant opportunities for integration.

The *National Carer Strategy Action Plan 2024-27* includes 22 actions across six commitment areas.[4] Kartika noted that the Department was consulting across several actions, including those under Commitment 1a (box 1).

- Action item 1.1 has been delivered. There are now an additional 10,000 phone counselling sessions available for carers via the Carer Gateway.
- Action item 1.2 – DHDA is working with service providers to extend the hours of Carer Gateway services.
- Action items 1.3, 1.4, and 1.7 are projects currently underway. They aim to better understand opportunities to improve respite, mental health supports, and to develop culturally safe and appropriate services for carers from diverse backgrounds. A survey was conducted in November 2025.

Consultation is also happening for Action item 1.8 – this Action item is about developing a cultural capability framework – or a blueprint on how service providers on the ground can be better empowered to serve the needs of vulnerable cohorts.[5]

DHDA is partnering with State and Territory government colleagues, as well as across government, to look at the issue of recognition. Under Commitment 2 in the Action Plan, there are several actions relevant across the states and territories.

Kartika spoke about governance arrangements for implementing the Strategy, including the Carer Advisory Committee, a working group, and six focus cohorts (including carers with disability CALD backgrounds, First Nations and young carers).

Kartika reported that uptake of services is improving, though some priority groups remain underrepresented.

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[4] Australian Government Department of Health, Disability and Ageing. (2024). *National Carer Strategy Action Plan 2024–2027*. https://www.health.gov.au/sites/default/files/2025-07/national-carer-strategy-action-plan-2024-2027_0.pdf

[5] Action item 1.8 comes under *Commitment 1b - Review and improve the accessibility and inclusivity of Carer Gateway to support the wellbeing of carers*

Box 1: National Carer Strategy Action Plan 2024-27 – Commitment 1a action items

Commitment 1a: Review and improve specific services offered through Carer Gateway to support the wellbeing of carers.

What we will do:

1.1 Increase access to phone counselling services for carers delivered through Carer Gateway by funding up to an additional 10,000 sessions per year.

1.2 Extend the hours supports and services are available through Carer Gateway and work with Carer Gateway providers to refine the offering that will be available to carers under extended business hours and after hours.

1.3 Work with the carer sector and other stakeholders to examine how to further improve the access, quality and range of counselling and mental health supports, including linkages and referrals to other mainstream and complementary services.

1.4 Work with carers, the carer sector and other stakeholders to identify strategies to improve access to respite arrangements in partnership with relevant policy and regulatory agencies including:

- improve access to respite arrangements both directly through Carer Gateway and in partnership with Aged Care and the NDIS.
- identifying current models of successful flexible and tailored respite models in service systems that could benefit carers.
- identify options to ensure respite arrangements are tailored and personalised and address the needs of both the carer and the care recipient.

1.5 Expand the current peer support arrangements under Carer Gateway and the connection to complementary peer support systems, including through alternative commissioning or partnership arrangements with organisations that have specific expertise and experience dealing with particular populations, to ensure carers can connect with people in similar circumstances in a safe environment, in a way that meets their specific needs.

1.6 Identify appropriate and culturally safe in-person and online training that will be provided via Carer Gateway to support unpaid carers build the knowledge and skills they need to fulfil their caring role including:

- manual handling
- first aid
- medication management and wound care
- financial literacy
- mental health first aid and suicide intervention training modules.

1.7 Work with relevant stakeholders and the carer sector to research and co-design improved supports for First Nations carers, CALD carers, LGBTQIA+ carers, carers with disability, carers of veterans and young carers that address their unique needs and improve service outcome.

Source: *National Carer Strategy 2024-2034 – Action Plan 2024-2027, p.10.*

Discussion 1: The role and value of carers

Breakout groups in this discussion considered the role of carers, their value to the community, their interactions with health care systems and other services. Participants were asked to consider awareness of the *National Carer Strategy 2024-2034* and the *National Carer Strategy Action Plan 2024–2027* among carers, health care providers and aged care providers.

In summary, Forum participants discussed:

- Carers as an invisible, but vital, component to Australia's health care systems – health care systems would collapse without them (although often carers do not realise they are carers). Carers reduce significant pressures on health systems, act as an early warning mechanism for patients, and bridge service gaps between formal systems.
- Carers' roles include navigating, information/record keeping, and advocating for the person they care for. Often, carers are not recognised as part of the care team but are given caring tasks. Addressing systemic problems is challenging.
- Carers interact with health care systems, the NDIS, education, and community systems but their knowledge and contributions are undervalued and rarely acknowledged financially. For example, in aged care, providers often think someone in residential aged care or receiving support at home does not need a carer, but carers remain essential for the wellbeing of those they care for. In education systems, carers can be young and completely unrecognised.
- The experience of carers interacting with health care systems between Australia's states and territories varies, but in general health care systems do not recognise the significant role of carers as part of the care team. It was noted that New South Wales has taken steps to ensure patient records record the name of their carer.[6]

The National Carer Strategy is a means to improve carer recognition, but Forum participants agreed there is very low awareness (some suggested less than 1% awareness) of the Strategy by health care professionals and carers.

Linked to the Strategy is the Inquiry into the recognition of unpaid carers by the House of Representatives Standing Committee on Social Policy and Legal Affairs. Participants noted that the Government was still to respond to the recommendations of the Committee's 2024 Report, *Recognising, valuing and supporting unpaid carers*. The Australian Government has now responded to the inquiry.[7]

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[6] In NSW, patient records are recorded in a Cerner PAS (Patient Administration System), which is a system for managing patient information, including registration, appointments, and medical records. Recording carers is part of the "care documentation" process, where information about patient care activities is logged to facilitate communication and ensure comprehensive care. This documentation can include the patient's personal details, who they are registered to, and information about the services they receive. The NSW Government is working to introduce the NSW Single Patient Digital Record. For more information: *Single Digital Patient Record | eHealth NSW*

[7] Australia. Government. *Australian Government response to the House of Representatives Standing Committee inquiry into the recognition of unpaid carers*. Tabled in the House of Representatives on 12 March 2026. *Government Response to the House Standing Committee on Social Policy and Legal Affairs for the Inquiry into the recognition of unpaid carers*

Discussion 2: Identifying blockers

Breakout groups had three tasks for this discussion.

1. To identify the reasons why there is lack of recognition of carers by health care providers.
2. To identify the blockers to the lack of carer recognition.
3. To use the '5 whys' technique[8] to drill down to more fundamental drivers of the lack of carer recognition.

The following key reasons for lack of carer recognition were identified by participants:

- Time constraints: Health care professionals have limited time to consider carers' needs.
- Carer reluctance: Many carers, including First Nations carers and CALD carers, do not self-identify as carers and see caring as part of normal family responsibilities.
- Systemic issues: Health care systems and processes are focussed on patients, not carers. Formal requirements to capture carer information are missing.
    - Privacy and consent rules prevent carers being included in patient care plans.
    - Payments for treatments do not incentivise engagement with carers.
- Cultural and social factors: Caring is not widely recognised as a distinct role in communities.
- Education gaps: Health professionals are not educated about the role and importance of carers. There is unconscious bias against carers within health systems which impacts on engagements with carers.
- Resource limitations: Lack of incentives, resourcing, and pathways for carer support.
- Legislative and policy gaps: Exclusion of carers in legislation and system design.
- Lack of awareness and training about the role of carers.
- Carers forgoing their own safety.

Participants identified the following as underlying drivers of blockers to carer recognition:

- The existing medicalised model of health care: This translates to a focus on treatment rather than holistic wellbeing. Participants observed that if we 'follow the money', the health care system could be seen to be measuring success based on numbers of procedures performed.
- Lack of inclusion and privacy law: Carers are often excluded from discharge planning and decision-making.
- Training deficiencies: Medical education rarely emphasises carer engagement. It appears that the role and benefit of carers do not feature in the courses to train medical professionals.
- System design: No structural mechanisms to recognise or support carers.
- Social norms: Caring is seen as a personal/family duty, not a formal role.

[8] The '5 Whys' is a problem-solving method that uses repetitive questioning to find the root cause of a problem by asking 'why' five times or until a root cause is identified. The process involves starting with a clear problem statement and then asking 'why' it occurred, followed by asking 'why' for each subsequent answer until the fundamental reason is uncovered.

Presentation 3 – Systemic barriers and enablers

Professor Trish Livingston discussed systemic barriers to carer recognition in the Australian health system and shared research findings about interventions aimed at improving support for carers, particularly those caring for cancer patients.

Systemic issues

- Fragmented services and lack of recognition of carers' roles.
- Inadequate support structures prevent including carers in care planning and decision–making.

Unmet needs

- 60% of carers report unmet informational needs; 30% are at risk of depression.
- Needs vary by age, relationship, living situation, treatment and cancer type.
- Early tailored interventions are critical.

Carer demographics & burden

- 90% of cancer patients have a carer; ~150,000 new cancer carers annually.
- Mostly women over 65, providing ~29–30 hours each week of unpaid care.
- Average informal care costs of $60,000 per carer, and this cost is estimated to rise by 30% in 2028.
- Carers face physical, mental, financial burdens and social isolation.

Carer Hub & Policy Impact

- Established a Centre of Excellence in Cancer Care Research Translation and Impact.
- Focus areas: unmet needs of priority groups, online interventions, clinician training.
- Advocacy for Medicare-funded carer wellbeing assessments and funding reforms.

Research & interventions

- Helpline Study: Carer support via Cancer Council Victoria's 13-11-20 program reduced unmet needs and improved confidence.
- Technical Solutions: Pilot of a smartphone app offering information, wellbeing resources, hospital maps, and contacts showed high user satisfaction (80% would recommend).
- New Portal (iCare): Interactive online platform for patients and carers, including wellbeing, nutrition, mindfulness, and communication tools.

Future Directions

- A whole-of-system approach involving the individual, advocacy groups, community, health system, and governments.
- Reduce system inefficiencies by integrating carers into care teams.
- Enhance carer wellbeing and create equitable, more responsive health services.
- Improve awareness of the services available to carers, and access to the support that carers need.
- Carers from priority groups, e.g. Aboriginal and Torres Strait Islander people, people from diverse backgrounds, regional and rural communities and LGBQTIA+ groups, face unique and often unmet support needs, shaped by cultural obligations, systemic barriers, and a lack of access to culturally safe services, underscoring the need for targeted, responsive care models.

Presentation 4 – Defining best practice: What exemplary looks like

This presentation was co-presented by Dr Sarah Javanparast and Professor Jennifer Tieman, Centre for Palliative Care, Death and Dying at Flinders University. Dr Javanparast explained that research at the Centre for Palliative Care, Death and Dying focuses on ageing, palliative care, end-of-life support, and carers (unpaid carers play a critical role in care delivery).

Topics addressed were:

- Nationally funded projects:
  - CareSearch and CarerHelp: which provides resources and information for carers.
  - Palliative Care Connect (South Australia pilot): which helps carers navigate the health system.
- Contributions to policy – recommendations in their submission to the *Inquiry into the recognition of unpaid carers* were cited in the Committee's Report '*Recognising, valuing and supporting unpaid carers'*.
- Research at the Centre focused on carers' perspectives, including death literacy and preparedness, access to health and aged care services, the use of online resources and bereavement experiences.

An international review of care support models, assessing what works and does not work and identifying lessons for Australia is being undertaken.

Key Insights from research at the Centre were:

1. A carer's journey begins before formal recognition and continues beyond the patient's death. Challenges include self-identification as a carer, navigating a complex health system, lack of time and resources, and poor self-care and exhaustion.
2. Critical role of GPs and nurses: Gateways for early identification and support.
3. Post-caring phase: Physical and emotional impacts persist after caring ends. Support for grief and return to employment is essential.

Best practice principles for carer recognition	• A whole-of-system approach. • Health systems alone cannot meet carers' needs. • Integration across health, aged care, disability, and social care systems. • Community engagement: Recognition and support start at the community level. Concepts like Compassionate Communities and social prescribing are vital.
Recommendations to achieve best practice carer recognition	• Proactive recognition and support for carers. • Training for health professionals to identify carers. • Evidence-based tools to assess carers' needs early and amplify their voices. • Policies and referral pathways for connecting carers to support services. • Collect and use carer-related data for monitoring. • Funding models to enable health professionals to support carers.
Suggested research priorities to advance carer recognition	• Evaluate effectiveness of care models: What works, for whom, and why? • Tailor successful models for diverse carer groups. • Demonstrate cost-effectiveness and sustainability. • Ensure models improve carers' lives.

Dr Javanparast concluded her presentation stating that health systems need to be proactive. Carers should not have to put their hands up for help. Rather, recognition and support should come from, and be driven by, professionals.

Discussion 3: Systemic drivers affecting carers

Following the discussion by Dr Javanparast and Professor Tieman on defining 'best practice', Forum participants were asked to consider the issue of applicability. This included considering blockers to best practice in health care systems (including in hospitals, general practice, emergency services, mental health services, aged care services and public health programs) and why existing providers of health care and aged care seem unable to change the status quo.

Points raised in the discussions	
Best practice	• Carer identification and recognition: Legal status, involvement in care planning, and advocacy. • Carer navigator role: Peer/professional navigators to connect systems and ensure 'no wrong door'. • Accessible multichannel services: Opt-in/opt-out options, clear timelines, crisis support and acknowledgment of carer journey stages. • Change the narrative: Emphasise 'good' care rather than perfection; patient/person-centric approach.
Blockers	• Systemic and resource constraints: Time-poor professionals, funding gaps, workforce shortages and high cost of individualised care. • Institutional resistance: Reward structures favour interventions over collaboration; ideological and power interests. • Practical barriers: Short appointments, lack of carer recognition, carer fatigue, and visibility challenges.
Why providers struggle to change	• Cultural and structural issues: Lack of awareness, motivation, and reliance on privatisation models. • Economic and political factors: Competitive cost pressures, political connections, and profit-driven models. • Attitudinal barriers: Gap between aspiration and practicality, entrenched narratives and reluctance to admit systemic flaws.

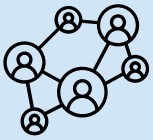
Discussion 4: Sharing blockers to recognition and any identified solutions

Participants were put in breakout groups for this discussion and asked to review the lists they created in Discussion 3 and rank them based on their effects on carers, the most challenging blockers to change and the changes offering the biggest gains.

Key themes identified by the plenary group

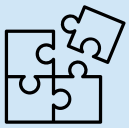
Awareness and recognition

- Community recognition and self-identification
- Health professionals' limited awareness of carers
- Broader sector needs awareness of existing strategies



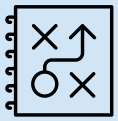
Communication and engagement

- Use existing platforms and advertising
- Expand engagement beyond digital channels
- Improve communication with carers (not just with people being cared for)



Systemic and cultural barriers

- Resource constraints and entrenched behaviours
- Complexity of systems and compliance focus
- Community attitudes and stigma



Additional challenges

- Carers being reluctant to ask for help
- Time, training, privacy issues
- Financial stressors and isolation due to the intrinsic nature of being a carer

All groups said there was a need to significantly raise awareness of the National Carer Strategy both in the carer sector and across broader sectors.

Proposed solutions included: education and training for external stakeholders; co-designing policies with carers; government guarantees for hardship services and emergency relief; and structural changes: a Minister/Commissioner for Carers, wellness measures, bipartisan support.

Voting

At the conclusion of the Forum, participants voted on a long list of blockers to carer recognition. Details are in appendix B. Table 1 lists the top ranked blockers.

Table 1: Top ranked carer recognition issues

Ranking	Issue
1	Lack of a 'push system'; there is a need to use health systems to proactively refer relevant supports (digital / call) to carers rather than wait for carers to identify that they need help
2	Lack of carer identification by health care systems and carer navigation role
3	Need for education and training (of health professionals and non-clinical staff) including pathways to support
3 or 4	Need a national campaign to promote the *National Carer Strategy 2024-34*
4 or 5	Need formal recognition in health care processes (e.g. identification of carer at diagnosis, during treatment, and other measures including carer name in discharge documentation)

Insights from the discussions

The Forum's discussions highlighted that while family and friend carers play an integral role in Australia's health and social systems, and they enhance the quality of the lives of the people they care for, they are often overlooked and not treated as integral partners in care by health professionals and service providers. Participants spoke about carers' insights and contributions frequently being excluded from clinical decision-making and discharge planning processes, and fragmented systems and legislation that fail to acknowledge the role of carers, exacerbating the situation.

Participants shared their knowledge of the consequences of health care systems not recognising and supporting carers, including carers being required to navigate hospital systems that do not accommodate their needs and carers being forced to leave employment to meet their caring responsibilities. They also spoke about the lack of support that leaves carers feeling isolated and overwhelmed.

Forum participants emphasised the need for (a) systemic reform – changing existing health care systems so that they recognise carers and (b) legislative backing, that is ensuring there is legislation in each jurisdiction that is up-to-date and coherent.

Participants stressed the importance of having unified messaging across departments and sectors to build a proactive, carer-centred health care system. They also explored what constitutes best practice supporting carers, with the aim of defining a model of exemplary carer inclusion and support.

The discussion highlighted that health care professionals traditionally hold significant decision-making power because of their clinical expertise and responsibility for patient care. Carers on the other hand can have detailed knowledge about the person they care for but be left out of decision-making due to a lack of recognition for their role and insights on the person they care for. Health care managers also exercise control through budget allocation, staffing decisions, and compliance requirements. These factors, along with key performance indicators, strongly shape service delivery and indirectly affect clinical decisions. Because carers are not viewed as part of the health care system, they are left out of decision-making, leaving carers feeling diminished, insignificant and/or invisible, with poorer outcomes for the people they care for.

The reality is that the value of work by unpaid carers is measured in billions of dollars. Carers contribute more than 2.2 billion hours of work annually.[9]

Notwithstanding the current structures, it was noted that there is a trend towards collaborative, team-based care in Australia's health care systems.[10] There is also evidence that positioning patients and their families as central to care teams leads to better outcomes.[11]

[9] Deloitte Access Economics (2021) *The value of informal care in 2020*. Deloitte Australia, Canberra

[10] Australian Commission on Safety and Quality in Health care, *National Safety and Quality Primary and Community Health care Standards*.

[11] Meiklejohn S, Cardiff L, Clark B et al. '*The patients first and foremost* collaborative practice in the Australian health care system: a qualitative study, MedEdPublish 2025, 14:131

Forum participants identified that the education of health professionals contributes to the culture of health care systems and health care curricula are yet to embrace education about the valuable role of unpaid carers. There was agreement that health care professionals need to be educated about the role of family and friend carers for achieving effective health care. Best practice carer support would have health care professionals trained to identify and recognise carers with GPs and nurses playing a critical role as gatekeepers.[12]

In some specialties, such as oncology and palliative care, there is structured carer training through dedicated modules and programs. An example is the Palliative Care Curriculum for Undergraduates (PCC4U) project funded by DHDA. PCC4U modules include content on supporting unpaid carers and improving students' ability to work with families.[13]

Patient records management is another area where recognition of carers can be improved. Forum participants noted development in NSW of digital patient records that would include details of a patient's carer.[14]

Participants emphasised the importance of practical outcomes and the need for a whole-system approach. Examples included:

- when a person being cared for has an appointment with their GP, the GP should know who the person's carer is (where applicable) and this information should be recorded
- the NDIS needs to identify from the outset who a participant's carer is
- when a person being cared for is admitted to, or discharged from, hospital, their carer should be identified, e.g. a discharge letter.

In discussions throughout the day, participants reiterated that current policy and service frameworks are not designed with carers in mind, often leaving them unsupported and excluded from key processes such as discharge planning and care coordination. Without recognising the role of carers, the health care system can be viewed as suboptimal. Health care providers can partner with carers to improve health outcomes and wellbeing – the wellbeing of those cared for and carers. The relatively simple task of ensuring health care systems formally recognise carers can be viewed as a foundation step in sustaining the carer workforce. There is evidence that by the time a cared for person no longer needs care, the carer soon becomes someone who needs care. Being able to prevent this progression has the potential to significantly improve the overall health and wellbeing of the general population.[15]

A number of forum participants acknowledged that while there was an intention to recognise carers via the *Strategy and the Action Plan 2024-34*, the lack of an up-to-date legislative

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[12] Javanparast, S. and Tieman, J. Defining best practice: What exemplary carer support looks like. Presentation to the Carers Australia 2025 Policy Forum. Research Centre for Palliative Care, Death and Dying, Flinders University.

[13] Professor Jennifer Tieman, Director, Centre for Palliative Care, Death and Dying, Flinders University. Email dated 10 December 2025 to Carers Australia.

[14] Advice provided by Sharon Gudu, CEO of Carers NSW, on the New South Wales Single Patient Digital Record. For more information, see: *Single Digital Patient Record | eHealth NSW*

[15] Javanparast, S., and Tieman, J., Presentation Defining best practice: what exemplary carer support looks like. Presentation to the Carers Australia 2025 Policy Forum, Canberra, 7 November 2025.

framework that clearly identifies carers and flow-on systems and processes to implement this, significantly hinders progress.

The reform agenda in the *National Carer Strategy 2024-34* has arguably been impacted by the recent government changes that saw responsibility for the carer sector move from the Department of Social Services to the Department of Health, Disability and Ageing. Some participants noted that this change was both a disruption and an opportunity, with participants urging for stronger cross-departmental collaboration and clearer accountability. Others did not consider it a significant change.

Comparative insights from international and local best practices highlight the potential for more proactive, carer-centred models. For example, state funded programs in New South Wales have successfully trained health professionals to identify and support carers including pharmacists and GPs. Internationally, proactive systems that embed carer recognition into referral pathways and care planning were cited as effective models. An example is the *NHS England Carers Toolkit*[16] which showcases best-practice examples where carers are routinely identified, supported, and signposted via established pathways.[17]

Other points raised during the discussions were:

- the carer journey continues even after end of life for those they cared for
- carers often do not identify themselves as carers
- long-term planning is challenging without stable supports
- carers are critical economic contributors
- carers reduce pressure on the formal health sectors
- short general practitioner consultation limit time to consider carers' needs
- longer appointments often lead to significant out-of-pocket costs
- multidisciplinary care is rare and expensive.

[16] Developed by NHS England, this toolkit supports health and social care organisations to identify carers early, incorporate carers into assessment and care planning processes, use a identify carers early—often at first point of service contact; incorporate carers into assessment and care planning processes; use a *Memorandum of Understanding (MOU)* to formalise multi-agency recognition of carers.

[17] NHS England (2024) *Carers toolkit*.

Agreed barriers

A range of barriers were identified as key obstacles to carer recognition in Australia health systems.

- Resource constraints with health professionals and providers' remuneration linked solely to the care they provide for patients, leaving carers excluded from the whole process.
- Carers are frequently left to navigate complex systems alone, without a dedicated, carer-centric pathway to guide them through services and support options.
- Burdensome assessment processes – an example is the application process for the Carers Allowance which can involve completing numerous forms – the process can take months.
- Carer fatigue due to the continuous nature of caring and the need to advocate, make appointments, attend appointments, clean, provide personal care and transport.
- Excessive bureaucracy – the same information needs to be provided to multiple agencies, e.g. Centrelink and health care providers. There are often long delays due to manual checks and carers spend hours on paperwork and phone calls.
- Unclear service pathways create confusion and hinder access to support.
- The need for greater public awareness of the National Carer Strategy with a call for the Australian Government to promote it through appropriate media campaigns.
- Cultural biases towards carers – there is a need for a cultural shift to foster a more empathetic and inclusive system that values carers. This could be achieved through education to reshape societal perceptions and ensure carers are recognised and supported.

Conclusion

As voted by participants at the conclusion of the Policy Forum, the two most urgent areas for attention were:

1. Making health care systems more proactive at referring carers to supports.
2. A health care system with stronger carer identification, recognition and navigation.[18]

Push system: using health systems to proactively refer relevant support to carers

The absence of a standardised process to identify and involve carers results in missed opportunities for referring them to relevant support, especially where carers do not self-identify. A push system is a better solution where health professionals proactively ask patients if they have a carer or proactively ask the carer and refer them to appropriate supports.

Carer identification in health care systems and carer navigation

There is no mandatory requirement to include carers in care pathways and time/resource constraints further limit engagement. Carer identification in health care systems involves proactive recognition, identification and navigation support for carers.

Health and allied professionals often lack the training and awareness needed to identify, support, and refer carers. Education and training programs are essential to equip professionals with the knowledge and tools to support carers effectively, including understanding referral pathways and the broader carer support ecosystem.

The Forum proved to be an effective problem-solving exercise and achieved consensus. It began with a shared understanding of the issues at hand. In complex environments such as health care and carer support systems, stakeholders can have differing perspectives on what are the most pressing challenges. There is power in consensus. It is an alignment of perspectives and represents a unified coalition for action.

[18] With reference to Table B.2 (Appendix B), the scoring for the top 5 voted issues was close with the education of health care professionals ranking 3rd, a national campaign to promote the National Carer Strategy 2024-34 ranking 4th and 5th being Formal recognition in health care process (e.g. identification of carer at diagnosis, during treatment, and other measures including carer name in discharge documentation).

Appendix A: List of participants

No.	Name	Organisation
1	Kartika Medcraft-Smith (Speaker)	Department of Health, Disability and Ageing
2	Afrooz Zanjani-Torrado	Department of Health, Disability and Ageing
3	Megan Street	Department of Health, Disability and Ageing
4	Zara Shehzad	Department of Health, Disability and Ageing
5	Jennifer Tieman (Speaker)r	Flinders University, College of Nursing and Health Sciences
6	Josh Fear	Palliative Care Australia
7	Katrina Armstrong	Mental Health Carers Australia
8	Kerrie McDonald	Australian Medical Association (AMA)
9	Louise York	Australian Institute of Health and Welfare (AIHW)
10	Mary Swift	Council of the Ageing (COTA Australia)
11	Sara Javanparast (Speaker)	Flinders University, Research Centre for Palliative Care, Death and Dying
12	Tammy Wolffs	Capital Health Network (CHN), ACT's PHN
13	Trish Livingston (Speaker)	Deakin University, Faculty of Health
14	Wendy Prowse	ACT Disability, Aged and Carer Advocacy Service (ADACAS) for the Older Persons Advocacy Network (OPAN)
15	Cain Beckett	Carers ACT
16	Kamla Brisbane	Carers ACT
17	Jim Toohey	Carers QLD
18	Judith Abbott	Carers VIC
19	Julia Overton	Carers SA
20	Richard Newman	Carers WA
21	Sharon Gudu	Carers NSW
22	Phil Martin (Facilitator)	Co-chair, National Carer Strategy Advisory Committee Action Plan Working Group
23	Annabel Reid	Carers Australia
24	Loretta Ogbonna	Carers Australia
25	Yulia Coleman	Carers Australia
26	Anna O'Neill	Carers Australia
27	Trevor Rowe	Carers Australia
28	Mellisa Champion	Carers Australia

Appendix B: Systemic issues – Voting results

Table B.1: The list of issues voted on and their voting scores

No.	Issue	Votes
1	Time constraints on medical system: 'Only get paid for direct care'.	2
2	System flow re Privacy and consent	0
3	Need 'holistic care' and wellbeing	1
4	Carers are not part of a discharge plan	6
5	Supported Decision Making with carer accepted (a) in system; and	3
6	Supported Decision Making with carer accepted (b) community	0
7	Education and Training (of health and other ?? professionals) including Pathways to support	11
8	Legal foundation – the need to update the *Carer (Recognition) Act 2010*	6
9	Disconnect between Federal and State/Territory governments where States and Territories have 'hands on experience'	0
10	Hidden problem and easy to ignore	0
11	Carer identification in health care systems and carer navigation role	13
12	Support people to level they need rather than in/out of systems	4
13	Connect the system design & proactive outreach Community connection in in training and recognition	8
14	Increase source and percentage of referrals to Carer Gateway	1
15	Importance of research to underpin best practice	4
16	Comprehensive Economic / productivity report to underpin program development and funding.	0
17	Low visibility and multi-layered promotion of Carer Gateway; Increase awareness	5
18	Cost of planning + delivery through individual Apps(?) …	0
19	Time poor and stressed health professionals	0
20	Institutional resistance to change	0
21	Recognise Carer as part of the Care Team	0
22	Carer fatigue	0
23	National campaign to create awareness of the National Carer Strategy	10
24	Push system; using health systems to proactively refer relevant Support (digital / call)	18
25	Formal recognition in process (discharge)	10
	a. Legislation (NDIS)	0
	b. With funding (like Medicare items)	0
	c. Frameworks (which drive behaviour)	0
	c. Standards	0
26	Assumed (younger)carer role & assumed career knowledge (e.g. health literacy or therapeutic)	2
27	System design: is government-centric, consumer-centric not carer-centric	0
28	Poor carer inclusion: co-design of policy	2
29	Carers in health curriculums and CPD (continuing professional development.	0

Table B.2: The top ranked issues and their ranking

No.	Issue	Votes	Ranking
24	Push system; Using health systems to proactively refer relevant support (digital/call)	18	1
11	Carer identification in health care systems and carer navigation role	13	2
7	Education and Training (of health care professionals including Pathways to support	11	3
25	Formal recognition in process (discharge)	10	4
23	National campaign to promote awareness of the National Carer Strategy	10	4
13	Connect the system design & proactive outreach Community connection in in training and recognition	8	5
4	Carers are not part of a discharge plan	6	6
8	Legal foundation – the need to update the *Carer (Recognition) Act 2010*	6	6
17	Low visibility and multi-layered promotion of Carer Gateway; Increase awareness	5	7
12	Support people to level they need rather than in/out of systems	4	8
15	Importance of research to underpin best practice	4	8
5	Supported Decision Making with carer accepted (a) in system; and	3	9
1	Time constraints on medical system: 'Only get paid for direct care'.	2	10
26	Assumed (younger) carer role and assumed career knowledge (e.g. health literacy or therapeutic)	2	10
28	Poor carer inclusion: co-design of policy	2	10
3	Need 'holistic care' and wellbeing	1	11
14	Increase source and percentage of referrals to Carer Gateway	1	11