Carer Consultation: Recognising Carers in Health Systems in Australia

OUTCOMES REPORT

CARERS AUSTRALIA
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Executive summary

Carers Australia brought together unpaid carers from diverse caring roles, backgrounds, and regions to talk about carer recognition in health systems in Australia. The two carer consultation sessions, held on 23 and 25 February 2026, were about hearing directly from carers about their experiences engaging with health systems and their ideas for practical ways health systems could better identify and recognise carers and refer them to supports. This report summarises the key insights from the two consultation sessions.

While some carers reported positive experiences, including being recognised and supported by general practitioners (GPs) and allied health professions, most said they felt unrecognised, under supported and overlooked, despite being central to delivering care.

Carers emphasised that administrative identification by itself is insufficient and meaningful recognition requires health professionals to understand, value, and include carers in decisions about the person they care for. Time was identified as one of the biggest barriers to carers being recognised and included in health systems (this included time in consultations for carers to ask questions and provide information and time to focus on their support needs).

Carers described significant challenges navigating Australia's health systems, highlighting that they frequently encounter a series of disconnected care interactions rather than a coordinated and integrated system.

Recurring themes across the two carer consultations were:

1. Carers are often recorded in health systems, but they are not included in processes (such as care planning) and health professionals fail to understand the role of carers.
2. Carers find it difficult to access clear, timely, and relevant information about the person they care for and about supports for themselves.
3. Fragmented systems require carers to repeatedly provide the same information, adding emotional and administrative costs.
4. Cultural and language barriers further prevent carers from being recognised and included in care decisions.
5. Early, proactive recognition of carers is essential to ensure they receive timely support and can continue to care effectively.

Carers identified several ways our health systems could be changed to improve carer recognition and inclusion. Table 1 sets out recommendations based on carers' insights.

Table 1: System level recommendations based on carers' insights

1. Establish national identifiers to recognise carers
2. Standardise carer inclusive care planning
3. Strengthen communication and information access for carers
4. Invest in digital infrastructure for information sharing
5. Establish dedicated navigation support roles for carers
6. Improve access to wellbeing and respite services for carers

Carers Australia extends its sincere thanks to the carers who participated in these consultations and generously shared their experiences, insights and ideas. Their lived experience and perspectives were invaluable to informing this report and identifying opportunities to strengthen carer recognition and inclusion within health systems. We also acknowledge the important caring work carers undertake every day, often alongside emotional and practical demands, and recognise the significant contribution carers make to the health and wellbeing of individuals, families and communities across Australia.

About the consultations

Carers Australia held two, online discussion-based carer consultations on Recognising Carers in Health Systems in Australia on 23 and 25 February 2026. The carer consultations were designed to hear directly from carers, from across Australia, about their experiences engaging with health systems. Carers were also asked for their ideas on practical ways health systems could better identify and recognise carers, and refer them to supports.

Some background and context

The carer consultations aligned with Carers Australia's strategic objective of strengthening systemic recognition of carers and ensuring proposed solutions reflect carers needs and priorities. The carer consultations shared carers' perspectives on themes identified in Carers Australia's National Policy Forum, which was held on 7 November 2025, on the topic of recognising unpaid carers in Australia's health systems.[1] This Forum brought together government officials, policy makers, academics, representatives from peak health bodies and members of the National Carer Network to discuss the barriers preventing carer recognition in our health systems.

Drawing on a list of identified barriers, forum participants voted on the most urgent areas requiring attention. They were:

- more proactive referral of carers to supports
- stronger carer identification, recognition, and navigation in health systems.

The *Carer Recognition Act 2010* provides the foundational context by defining carers as people who provide care to family members and friends who have disability, a chronic condition, terminal illness, mental illness, or who are frail aged.[2] The Act requires government agencies and service providers to acknowledge, respect, and involve carers.

The national direction for improving carer inclusion is further shaped by the *National Carer Strategy 2024–2034* with its objectives to ensure that carers are identified, recognised, respected, and valued; and are empowered to have fulfilling lives while engaging in their caring role.[3] The Strategy strengthens the policy mandate for systems to better include carers, aligning with broader government efforts to support unpaid carers.

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[1] There are over 3 million unpaid carers (almost 12% of all Australians) including nearly 400,000 carers under the age of 25. Australian Bureau of Statistics (2024) *Disability, Ageing and Carers, Australia: Summary of Findings*

[2] Parliament of Australia (2010) Carer Recognition Act 2010 *Federal Register of Legislation Carer Recognition Act 2010*

[3] Australian Government Department of Social Services (2024) *National Carer Strategy 2024–2034*

Consultation approach

External facilitators led the discussions using a semi structured guide. The conversations explored carers' experiences across diverse health settings (hospitals, primary care, specialists and other health services), barriers to carer identification and recognition, and opportunities to reduce duplication and improve coordination.

Participants

Eight carers participated in the first carer consultation and five in the second. The carers represented a diverse range of backgrounds and lived experiences, including carers from all states and territories, young carers (up to 25 years), adult carers, Aboriginal and/or Torres Strait Islander carers, carers from culturally and linguistically diverse (CALD) backgrounds, carers who identify as LGBTIQA+, and carers living in rural and remote areas.

The carers participating in the consultations cared for parents, partners, children, siblings, and grandparents and the people they cared for were living with mental health, neurodivergence, dementia, stroke, chronic disease, disability, age related frailty, and alcohol and other drug related conditions.

Limitations

The consultations were qualitative and exploratory and designed to draw insights rather than statistically representative findings. The discussions revealed carers' common experiences engaging in the health systems across Australia, as well as practical suggestions from carers about how to improve carer identification, recognition, and inclusion.

Key themes

Recurring themes from the two consultations were: carers are identified on paper but not recognised in practice, carers are often required to repeat complex histories, and fragmented systems make this worse, carers find it difficult to access clear and timely information from health professionals, and to access supports for themselves. While some carers reported positive experiences (mainly in general practice and with allied health professionals – occupational therapists, physiotherapists and dietitians) these experiences were the exception rather than the rule.

Carers are identified on paper but not recognised in practice

Carers repeatedly emphasised the gap between being administratively recorded as a carer and being treated as an active partner in care. Carers described situations where their names appeared in health records or legal documents, but clinical teams did not acknowledge or respect their caring status during care planning, ward rounds, or discharge discussions. The disconnect was most pronounced in hospital and mental health settings, with carers describing that they felt ‘invisible’, viewed as ‘just family’, ‘disregarded’ and made to feel ‘unimportant’.

Many carers said they were not included in critical decisions, such as treatment changes and medication adjustments, despite being the person responsible for implementing the changes at home. Several carers reported rushed hospital discharges and inadequate explanations about follow up requirements.

What carers said:

> *“I’m acknowledged as a carer, but not recognised as a carer. I have to constantly emphasise that I am not just a parent.”*
>
> *“In the record I’m listed as the carer and guardian, but in practice I’m still not recognised. They make care plans without me.”*
>
> *“They treat me like a visitor, even when I’m the one who knows his daily care best.”*
>
> *“They asked me to leave the room while my parent wanted me there.”*
>
> *“Health professionals don’t understand what guardianship means.”*

Carers also highlighted that health systems can exclude parents once a young person turns 18 years old, regardless of legal arrangements in place or the capabilities of the person being cared for. One carer reported being asked to leave the room because of privacy concerns, even though they held guardianship. Some carers spoke about a tension between health professionals medico-legal responsibilities underpinning the clinician-patient relationship and the potential engagement with carers in the care process – one participant said there is a conflict between the ‘medical lens’ and the ‘carer lens’.

Carers stressed that meaningful recognition requires health professions to understand the role of carers, listen to what they have to say (the knowledge and insights they have on the person they care for) and include them in decisions. Also, health professionals should not assume that patients can communicate the required information independently.

Carers were more likely to report positive experiences where they had an ongoing relationship with a health professional rather than one-off episodes (such as with a specialist or in an emergency department). One carer described her GP, who had her own lived experience as a carer, as an exemplar of good practice. The GP had spent time with the carer, listened with empathy, and asked the question '*How can I help you as a carer?*'. Carers participating in the consultations agreed that genuine listening skills and empathy are critical.

Interactions with support workers were also described by some carers as 'positive' and 'inclusive'. However, it was noted that while social workers can provide valuable support (including during emotionally difficult experiences), they are less able to help with broader or ongoing needs, such as navigating health systems.

Carers struggle to access clear and timely information

Carers reported that it can be difficult to obtain clear, timely, and accessible information from health professionals. While carers reported that some GPs and allied health professionals were good communicators (occupational therapists, physiotherapists and dietitians were highlighted as having good communication skills and more likely to have received carer awareness training), the communication skills of hospital specialists and rotating clinical teams were viewed less favourably. Some carers spoke about health professionals using terminology that discouraged or prevented dialogue with carers and the importance of information and advice provided in plain English.

Others mentioned rushed or incomplete updates (in large part because of the time pressures faced by health professionals) and situations where health professionals directed questions only to the patient, including in one case where the patient could not communicate their needs.

What carers said:

> *"I just need an answer, but they don't take me seriously. I feel invisible."*
>
> *"There was no follow through. They asked the questions but didn't help with the pathways."*
>
> *"Information is critical but too often health policy is obstructive. I found it hard to get information."*
>
> *"I feel most carers do not have access to the information they need. Doctors don't give much attention to you. Hard to get attention for the person you are caring for."*

When carers are not well informed about the care required, they risk being unprepared and overwhelmed. Providing care without appropriate guidance is also likely to affect the quality of care and the wellbeing of the person being cared for.

Fragmented systems place an additional burden on carers

Carers spoke about having to navigate through a complex array of separate, discrete care events rather than participating in an integrated system. Hospitals, general practice, the

National Disability Insurance Scheme, aged care, and other systems do not routinely share information, and carers are often the ones left to fill the gaps (and join the dots). This not only wastes time (of health professionals, carers and the person being cared for) but it can also be exhausting and traumatising for carers (recounting distressing experiences repeatedly). A theme across the carer consultations was the emotional toll on carers of repeating care needs, medical information, and histories.

What carers said:

> *"Telling your story again and again is so exhausting and frustrating, and it wastes time."*
>
> *"My parents' and son's information can't be accessed across hospitals. I have to repeat everything. It's draining."*
>
> *"You need one golden source of information so carers don't have to keep explaining themselves."*
>
> *"We usually must tell our story again and again because medical teams keep changing. There is a lack of continuity in the healthcare workers we must interact with."*

Cultural and language barriers exacerbate carer exclusion

Carers from culturally and linguistically diverse backgrounds described significant challenges navigating forms, terminology, and unfamiliar systems. Many reported that medical terminology makes it difficult for carers to understand updates and to advocate for the person they care for, particularly when health professionals don't check for comprehension or provide plain language explanations.

Carers spoke about interpreters being offered when they weren't needed, and interpreters not being offered when they were clearly needed. Migrant carers who were unfamiliar with Australia's health systems and unaware of available supports for carers found this particularly challenging.

Other carers highlighted that navigating multiple service systems without clear, accessible information created overwhelming pressure, particularly for carers who spoke English as a second language or who had recently arrived in Australia. They stressed the need for culturally safe practices, improved communication training for health professionals, and accessible information pathways to ensure carers are included, respected, and able to be included in care decisions.

What carers said:

> *"Doctors don't take me seriously. Because my father is from overseas, they offer interpreters when he doesn't need one but ignore what I'm saying as his carer."*
>
> *"I'm from overseas. We don't know these systems. No one tells us there is support for carers."*
>
> *"Health professionals need to understand that bombastic language is a barrier. They should be trained on this."*

The importance of early, proactive recognition for carers

Early and proactive recognition of carers is critical to ensuring they receive support at the right time and can participate meaningfully in care planning. Carers participating in the consultation said the ideal was early, proactive recognition – at the initial GP interaction or diagnosis stage. Identifying a carer early allows health professions to provide guidance on their potential care journey, link them to supports, and help them navigate the health systems.

Several participants highlighted the benefits of GPs recognising carers early in the care journey, including reduced emotional strain, improved coordination during care transitions, and carers being supported from the outset rather than in crisis situations (including carer burnout).

Some carers relayed that they had discovered Carer Gateway or local supports only by accident, long after significant strain had accumulated. Others said that even when health professionals asked them if they were carers, there was no conversation about supports available or referral.

What carers said:

> *"The best point to be recognised as a carer is at the GP; the sooner the better."*
>
> *"I didn't know there were organisations for carers. I've been a carer for nine years."*
>
> *"There should be a template for GPs to ask carers what support they need. My GP did this and it made a huge difference."*

Carers ideas on how to improve recognition and support

1. Early and proactive identification of carers

   Establish a way for health professionals (particularly GPs) to identify carers early in the care journey to enable timely support and help prevent carer burnout. One suggestion was something like the sunflower lanyard for neurodivergent people.

2. Genuine recognition and inclusion in care planning

   Go beyond recording carers in health records and care plans and make them partners in care, including in treatment discussions, decision-making, and discharge planning. Extend appointments to allow additional time for carers to ask questions, relay information and get support for themselves.

3. Clear, respectful and culturally safe communication

   Mandatory training for health professionals on communicating with carers, the use of plain English and responding to cultural and language needs. This will improve the safety and effectiveness of care.

4. Reduced repetition through better system coordination

   Sharing information across health systems will reduce the need for carers to repeatedly recount complex or traumatic histories (reducing emotional strain and the risk of errors). Carers suggested a universal digital record or app where approved information could be safely shared across systems.

5. Accessible navigation support and information pathways

   Carers called for practical navigation support, such as liaison roles or clear guidance on processes, and access to simple, plain-language information about rights, supports and services.

6. Support for carer wellbeing, mental health and respite

   Carers identified the need for emotional, mental health, and respite supports that sustain their wellbeing and continued capacity to care, particularly given the cumulative stress of their role.

Recommendations

The consultations highlighted opportunities to strengthen the way carers are identified, recognised and supported across Australia's health systems. The recommendations below translate the insights from carers into system level changes.

1. Establish national identifiers to recognise carers

Establishing a national visible identifier, such as a lanyard or pin that carers can wear when interacting with health services, would help early identification of carers within health systems. Integrating a carer identifier into routine workflows could also mean there is less reliance on individual health professionals recognising carers early in care journeys.

GPs are often the first and most frequent point of contact for carers and the people they care for which makes them well-placed to identify carers early in the care journey. One study found that carers are 21% more likely to use GP services than non-carers.[4]

Time pressures on health professionals, however, can reduce meaningful communications with carers. And currently, Medicare does not provide incentives for health practitioners to spend time with carers when a patient is receiving a diagnosis or treatment (even though the point of diagnosis can profoundly affect both the patient and the carer).

A lack of training on carers' roles, referral pathways, and available supports for carers further limits integration into care planning.

To address these issues, Carers Australia, in its 2026–27 Pre-Budget Submission, proposed two primary care initiatives: funding for GP education and training on carer recognition and new and extended Medicare Benefits Scheme (MBS) items for carer consultations (box 1).

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[4] Harris-Roxas, B., Kabir, A.Y.M.A., Ong, R., Webster, G., Woodland, E. & Barr, M (2023) *Characteristics and health service use of a longitudinal cohort of carers aged over 45 in Central and Eastern Sydney, Australia*. Health Services Research, 2023, Article ID 5032583.

Box 1: Primary care initiatives in Carers Australia's 2026-27 Pre-budget submission

Carers Australia in its 2026–27 Pre-budget submission, proposed two initiatives in primary care: [5]

- **Fund GP education and training on carer recognition**
  Carers Australia recommended funding GP education and training to help GPs identify carers, understand their needs, and refer them to appropriate supports.

- **Establish a new MBS item for carer consultations and extend the MBS item for mental health carers to all carers**
  Introducing a dedicated MBS item for carer consultations will help incentivise carer consultations, increasing the likelihood that they will receive timely information and support. Timely access to supports will improve carers' health and wellbeing, which in turn can affect the quality of their care, their participation in paid work, and their ability to continue providing care. Productivity gains and reduced costs for healthcare and welfare systems will be the outcomes.

2. Standardise carer inclusive care planning

General practices, hospitals, and community health services should adopt consistent processes that ensure carers are actively included in care planning (consistent across the states and territories and healthcare systems).

Carers participating in the consultations suggested several ways to help healthcare teams consistently include carers in care planning and provide clear referral pathways to support.

- Using a dedicated template or checklist within carer-integrated health policies to help health professionals identify, recognise, include, and support carers as they engage with health systems.

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[5] Carers Australia (2026) *Prebudget Submission 2026-27*. Initiative 3.

- Promoting system-wide public messages, such as "*Carers matter*", to raise awareness about carers and highlight the importance of their role.
- Involving carers, including via visible identifiers, in the patient's care planning process.
- Implementing structured mechanisms, such as standardised questions, that ask carers about their needs and support requirements.

3. Strengthen communication and information access for carers

To strengthen communication capability across health systems, investment needs to be made in training health professionals to communicate clearly and with cultural awareness. The training should be focused on building skills in carer friendly communication (avoiding technical medical terminology and checking understanding), cultural safety, trauma-informed approaches, and tailoring communication to diverse needs. Integrating these communication capabilities across health settings will help health professionals to provide carers with plain-language and culturally safe information,

In addition to strengthening communication capability, carers also highlighted the need for accessible information relevant to them. A number of carers participating in the consultations said they learned about supports, such as respite and the Carer Gateway, only by accident. Information for carers should be available across health services. Providing consistent, accessible information and recognising carers as valuable contributors to care will improve patient outcomes, reduce misunderstandings, and help carers navigate systems with greater confidence and less emotional strain.

4. Invest in digital infrastructure to enable information sharing

There is an urgent need for digital infrastructure that allows shared access permissions and interoperability across general practice, hospital medical records, and other relevant systems, such as the National Disability Insurance Scheme and aged care platforms.

Technology enabled solutions should place essential information in a single accessible location. The national digital health record with a carer-specific application or portal should allow carers, health professionals, and emergency staff to access up to date care information when needed. This approach will improve efficiency and safety during care transitions.

Digital solutions would also help health teams quickly understand carers' roles, responsibilities, and legal authority (such as guardianship), reducing situations where carers are overlooked or excluded. Investing in integrated, carer-accessible digital infrastructure would strengthen continuity of care, reduce emotional burden, and significantly improve system navigation for carers.

5. Establish dedicated navigation support roles to carers

Introducing dedicated carer liaisons (carer liaisons, system navigators or case managers) would provide carers with a point of contact who could guide them through complex processes, explain options, and ensure follow through on referrals and care plans. These roles should prioritise carers with higher vulnerability, including those from the CALD backgrounds, young carers, carers of people with complex needs and those navigating multiple service systems simultaneously. System navigators can help prevent these carers from falling through service gaps.

Dedicated carer liaisons, social workers or practice managers trained in health-system navigation are well placed to address the fact that health professionals often have limited time and heavy clinical workloads. Establishing these roles would strengthen carers' confidence, reduce stress, and improve continuity and quality of care by keeping carers informed, connected, and able to participate effectively in care planning.

6. Improve access to wellbeing and respite services for carers

Carers highlighted major gaps in respite, mental health care, and crisis support, especially during high-pressure periods such as hospital admissions, care transitions, and traumatic service interactions. Governments and health services should expand flexible and timely respite options (including emergency and short-term arrangements) and strengthen proactive referral pathways to mental health, peer, and crisis supports.

Health systems should also introduce routine wellbeing checks and health professionals should be trained to recognise early signs of strain on carers. Wellbeing assessments would help with early identification of carers' needs (reducing crisis situations) and carers awareness of available supports and where to access them.

Conclusion

Recognising and including carers is fundamental to delivering safe, quality care across Australia's healthcare systems. While carers play a critical role in the care of Australians who have disability, mental illness, chronic condition, terminal illness, an alcohol or other drug dependence or who are frail aged, they continue to feel unrecognised, under supported, and excluded from key care planning processes.

The insights gained from the carer consultations point to a set of practical solutions for strengthening carer recognition and inclusion. The next steps involve working with governments to advance changes that strengthen the way carers are identified, recognised, respected, and supported across Australia's health systems.

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