



Department of Social Services

National Carer Strategy Consultation

**Rare Voices Australia Submission
September 2024**

About Rare Voices Australia

[Rare Voices Australia](#) (RVA) is the national peak body for the estimated two million Australians living with a rare disease.

RVA provides a strong, unified voice to advocate for policy as well as disability, health, and other systems that work for people living with a rare disease. RVA's work is non-disease-specific and is based on the commonalities of the approximately 7,000 different rare diseases.

Our person-centred focus sees us working with all key stakeholders, including people living with a rare disease, over 100 RVA Partners (rare disease groups/organisations), governments, key peak bodies, researchers, clinicians, and industry.

RVA advocates for the best outcomes for Australians living with a rare disease, and their families and carers.

RVA welcomes the opportunity to provide a Submission to the consultation on the Australian Government's *National Carer Strategy* on behalf of the rare disease community.

What Is a Rare Disease?

A disease is rare if it affects fewer than five in every 10,000 people. There are approximately 7,000 different diseases and an estimated two million Australians live with a rare disease. Therefore, while the occurrence of individual rare diseases is uncommon, having a rare disease is in itself relatively common.

Around 80% of rare diseases have a genetic origin and due to the hereditary nature of some rare diseases, multiple people within the same family can be impacted.

Rare diseases are often serious and progressive, exhibiting a high degree of symptom complexity, leading to significant disability, health, and psycho-social challenges.

Most people with a rare disease meet the Australian government's definition of having a disability, being a "limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities". This includes the estimated 100,000 NDIS participants with severe to profound rare disease disability impacts.

For key decision-makers at all levels, greater knowledge of rare diseases can facilitate more responsive and appropriate services for people living with a rare disease and their families and carers.

National Strategic Action Plan for Rare Diseases

RVA led the collaborative development of the Australian Government's [National Strategic Action Plan for Rare Diseases](#) (the Action Plan)¹, the first nationally coordinated effort to address rare diseases in Australia.

The Action Plan is comprised of three core Pillars, with each Pillar outlining priorities, actions, and implementation areas.

The Pillars are:

1. Awareness and Education
2. Care and Support
3. Research and Data.

The three Pillars are interrelated and when considering a policy response to the needs of carers of people living with rare disease, the strongest response addresses priorities across multiple Pillars.

The Action Plan includes the following actions and implementation steps related to the needs of families and carers of people living with rare disease:

Action 1.2.1 Raise awareness among people living with a rare disease, and their families and carers, about the care and support services available to them.

“Increased awareness and education at the individual and community level is vital. It is common for people to have never heard of the rare disease with which they, or their child, are diagnosed. It can be difficult to find a practitioner who is educated about the disease. Yet, people living with a rare disease, and their families and carers, are reliant on services for both care and support.”

- *National Strategic Action Plan for Rare Diseases p15*

Implementation

1.2.1.1. Develop and maintain an accessible multi-purpose digital repository to detail available care and support services and to provide general rare diseases information. The repository can be used to identify gaps and opportunities for improvement. Promote the repository to rare disease organisations, for distribution to people living with a rare disease, and their families and carers.

1.2.1.2. Build on existing activities of rare disease organisations to raise awareness of care and support services available to people living with a rare disease, and their families and carers. Identify gaps and opportunities for improvement.

Action 2.1.5 Embed the voice of people living with a rare disease and their families and carers throughout structures and systems that impact rare diseases.

People living with a rare disease and their families also experience financial impacts, either due to out-of-pocket costs associated with care and support, or due to loss of income associated with taking on a carer role.

- *National Strategic Action Plan for Rare Diseases p9*

Implementation

2.1.5.1. Capture and promote the voice of people living with a rare disease and their families and carers by:

- involving people living with a rare disease at every level of decision-making;
- ensuring ongoing engagement to capture broader input from people living with a rare disease through surveys, focus groups, newsletters, and representation on boards; and
- calling for key structures and systems to routinely and effectively capture broader input from consumers, as done currently in some research settings and HTA (consumer hearings).

2.1.5.2. Enhance culturally safe and appropriate approaches for Aboriginal and Torres Strait Islander people, including aligning with existing initiatives to develop and implement ways to integrate Indigenous Australian languages to equitably enhance care and support.

Action 2.5.1 Ensure people living with a rare disease, including their families and carers, receive the community, clinical and digital mental health supports and services they need.

The experience of socio-economic disadvantage can have significant, cumulative effects on a person's health and wellbeing, including their ability to access and maintain engagement with services. Many people living with a rare disease, including families and carers, report psychological, emotional, and financial impacts.

- *National Strategic Action Plan for Rare Diseases p14*

Implementation

2.5.1.1. Enable people living with a rare disease, including their families and carers (with appropriate consent) to access information and resources (including digital) customised for rare diseases as part of Chronic Disease Management Plans and Mental Health Care Plans

RVA's Submission

In preparing this Submission, RVA engaged with our RVA Partners (rare disease groups/organisations), individuals, and families/carers living with a rare disease. Their observations, concerns, and recommendations are reflected in this Submission and quotes are included.

RVA supports the need for a streamlined and coordinated approach to meeting the needs of carers and welcomes the development of the Australian Government's *National Carer Strategy* as the roadmap for strengthening the commitment of all Federal, State, and Territory governments to the well-being, employment, education, health (including mental health), social inclusion, and safety of Australia's unpaid carers.

We also highlight some of the programs, initiatives, and resources that have been developed to support people living with rare disease and rare disease carers, for inclusion in the *National Carer Strategy*:

[RARE Helpline](#) - The RARE Helpline aims to provide timely access to information and answer key questions people living with a rare and complex disease and their families/carers often face. The RARE Helpline is staffed by Rare Voices Australia personnel, including those with qualifications/training in psychology, social work, and Mental Health First Aid.

[RARE Portal](#) - The Rare Awareness Rare Education (RARE) Portal contains current, reliable and straightforward information and resources for all rare disease stakeholders customised for the Australian context. This includes resources for families and rare disease carers including information on mental health services and resources available in Australia.

[RAREST Project](#) - The Rare Disease Awareness, Education, Support and Training (RAREST) Project was an Australian government-funded collaboration between Rare Voices Australia (RVA), the University of New South Wales, the University of Western Australia and Macquarie University. The RAREST Project developed and delivered rare disease awareness resources, education, support, and training including:

- [National Recommendations for Rare Disease Health Care](#)
- [Mental Health and Wellbeing Resources – Support for People and families living with a Rare Disease](#)

Rare Disease Carers – What does it look like?

RVA and our RVA Partners request that the complex needs of rare disease carers be explicitly recognised, understood, and reflected in the National Carer Strategy.

Rare diseases receive far less public and institutional attention than common conditions, leading to a lack of awareness around the profound impact these diseases have on both individuals and their carers. Advocacy efforts are often left to the families themselves, who must push for recognition, funding, and research. Carers must become "champions" for their loved ones, advocating for resources, appropriate care, and government support, all while managing intense caregiving responsibilities.

The typical carer role can include providing support and help with daily activities, personal care, mobility assistance, transportation, support with decision-making, financial management, distress intolerance, mood management, and crisis management.

However, there is a significant expectation for rare disease carers to have considerable health literacy to assist them in supporting their loved ones with their medical needs including providing nursing-style supports in the home.

The rare disease carer role may also include medication administration, hoisting, tube feeds, wheelchairs, oxygen administration, first aid, manual handling, safeguarding, working with people with learning difficulties, maintaining airways, communication partners, and providing disability-related health supports. This is in addition to attending numerous medical appointments, surgeries, hospitalisations, and general administration management.

The specific needs of the rare disease carer cohort are further reflected in the following:

Needs of the Care Recipient: The care needs of people living with rare disease, including children, can often involve intensive physical, emotional, and mental health support. There may be behavioural complexities associated with intellectual and communication disabilities, and psychosocial disabilities. In the case of progressive or degenerative conditions, there are palliative and end-of-life care needs, sometimes for several members of one family with the same inherited rare disease.

Carer–Care Recipient Relationship: The carer/care recipient relationship can be complicated by an inherited rare disease that results in multiple family members with the same condition needing care at the same time. In some cases, the carer also has a rare disease and/or disability and needs their own support while providing care to others in their family. Rare disease carers report that their extended family and networks are ill-equipped to support their loved one with a rare disease due to their intensive and complex support requirements.

“Our extended families are generally ill-equipped to handle our children with rare disease and behavioural complexities. There may be no options for outside school hours care or holiday care due to our children’s intensive medical/disability needs. Without family or childcare options carers have to take annual leave/unpaid leave or purchase leave to cover these periods.”

Service Systems: Rare disease carers often struggle to navigate a range of complex systems and interact with multiple agencies and service providers, many of these have no awareness or understanding of their loved one’s care and support needs.

Their administrative burden when navigating these systems is intense, and burnout is often experienced. Where the rare disease is undiagnosed or the progression of the disease is unknown, access to appropriate health and medical support can be extremely difficult and many carers report the stress and emotional trauma of the diagnostic odyssey, without a peer network to support them.

Rare diseases often have limited research, meaning carers frequently face a lack of information about the condition, prognosis, and treatment. This can lead to distress, and delays in accessing appropriate care for their loved one, compounding carer stress and strain.

Carer Support Services: When rare disease carers experience stress, strain, or need help, they report a significant lack of appropriate specialised support services available to assist. Their loved one with a rare disease is often considered too complex for respite or emergency short-term care services, or staff lack appropriate skills and training to assist.

Geographical Location: RVA has identified people living with rare disease and their families/carers who are in regional, rural, and remote locations as a priority population. There is often limited practical support available (e.g. meal preparation, house cleaning, and respite services); reliance on digital carer support is not always appropriate, available, or accessible. Social isolation and lack of access to peer support networks compound the challenges. This is true for the significant number of First Nations people, including teenagers, who are involved in unpaid caregiving roles.

Data

RVA recommends that the Survey of Disability, Ageing and Carers (SDAC) conducted by the Australian Bureau of Statistics (ABS) include specific questions that identify rare disease carers. Additional questions should also explore where there may be multiple care recipients in the one family, including a carer with a rare disease.

The Carer Gateway, the Australian Government’s national carer support system, should also collect and report on this data to highlight the diversity of carers accessing services.

“The greatest thing that could assist carers is ensuring we have the necessary support to enable us to return to the workforce. The government should be measuring the return on investment in terms of contribution to economic metrics like GDP, mental health improvements of the carer and the outcomes that it has on the entire family unit, including siblings.”

Support for Carers

Carers of individuals with rare diseases can experience high levels of emotional stress and social isolation, exacerbated by the rarity of the condition and a lack of peer support networks. There is also the experience of social stigma and lack of community understanding. Rare disease carers may feel excluded from mainstream carer groups or support services, as their needs are more niche and not always understood by broader carer support systems.

Rare disease carers can neglect their own health due to the demands of caregiving, leading to physical exhaustion and increased risk of chronic illness. They may experience ongoing grief related to their loved one’s diagnosis, as well as trauma from medical procedures or progressive deterioration in their condition.

“I have been involved with attending seminars around mental health, looking after yourself, and an individual counselling session which was good. My top challenges now are keeping up with the administration of my adult daughter’s life - it seems I have so much more to do now, not less despite my Support Coordination hours. Approving invoices, paying bills etc takes time every week and I need to be involved with coordinating therapy appts, day support, communicating with the group home etc. I’ve been trying to step back a bit, but the buck always seems to stop with me.”

There is a shortage of respite services tailored for individuals with rare diseases, meaning that carers may not have opportunities to take breaks and focus on their own well-being.

“They reported regular feelings of guilt due to the lack of attention they give siblings because of the demands put upon them by their caring role for a child. Several people suggested that respite services should enable taking other family members for a short break. Current respite services are generally inadequate for their needs and suggested having respite carers who understand individual medication needs; good communication would help improve this service.”

RVA recommends increasing funding for access to mental health services tailored to rare disease carers, including counselling, group therapy, and stress management programs.

Access to flexible and appropriate respite, including delivered in the home is needed for people living with rare disease, particularly in cases of high-dependency care. We also

need to expand the provision of tailored respite care options, particularly in rural and remote areas, allowing carers time to focus on their health and wellbeing.

“I have gone to Carer Gateway before to get respite and as I didn't use it in the month because I couldn't find anyone skilled enough to deliver the help we needed it got taken away from me.”

“We've accessed Carer services – they've been hit and miss, and generally financially limited e.g. meal vouchers and a time-limited cleaning service, where the provider didn't turn up twice (!)”

Employment and education

RVA highlights the significant challenges in combining informal care and paid work when caring for a loved one with a rare disease, complex medical needs and, in many cases, multiple significant disability impacts. Many carers reduce their working hours, or leave employment or education entirely to provide full-time care. This leads to loss of income, superannuation, and career advancement opportunities. This directly influences labour participation rates, financial security, and overall quality of life, particularly for women who represent over two-thirds of all carers².

“Financial stability! We know there is a disparity between women and superannuation balances, the delta is even greater for those that are carers, so we are doubly impacted in terms of our earning potential compared to male counterparts, and our financial future, especially during retirement. So potentially different taxation rates for those that are registered at carers or greater concessional or non-concessional contribution caps would be great.”

RVA recommends continued support for more flexible employment policies, such as remote work opportunities, carers' leave, and superannuation support for those who take extended breaks from paid work to provide care.

“The challenges I face as a carer is trying to actually continue full-time work and full-time carer to my 28-year-old. I spent 26 years out of the workforce or casual so not much super. I work hard now to keep a roof over our head and try to have a work-life balance but all I do is go straight to work and then straight to collect my adult daughter after work, then home. I have resorted to online grocery orders to get what I need because I can't go to the shops with her. If I have a day off from work it is to catch up on paperwork or doctors appts for my daughter.”

“We need further support legislated for carers - additional personal leave or annual days would be great, given the medical complexities of our little ones, not to mention therapies and even respite for ourselves.”

“Caring for someone with a rare disease can require all carer and personal leave to be gone with one hospital admission – we can have 10 admissions a year. There just isn’t the recognition that this is the ‘next level’ of caring. We are left needing to take leave without pay, and then keep falling further and further behind financially.”

RVA recommends the ongoing review of NDIS-funded supports for outside school hours care (OSHC) for children with rare disease disability impacts, especially for those who cannot attend or access mainstream OSHC services.

“I’ve returned to part-time work, however, this is an immense challenge with my son’s needs. He is unable to be adequately cared for in traditional childcare and the NDIA funds only half a day of care a week. This is completely insufficient and doesn’t recognise the societal and tax potential of our family.”

Peer Support

Carers access peer support networks for a variety of reasons and needs including: seeking peer support/feeling isolated; learning about the disease after getting a diagnosis; information about policy, services, and support; learning about experiences from other families; and to seek out relevant experts in the field. These interactions reduce isolation and assist with mental health and well-being.

RVA and RVA Partners believe there are excellent opportunities to expand the peer support networks and practical assistance to sustain rare disease carers.

RVA recommends the government support the creation of more rare disease-specific formal and funded peer support networks through partnerships with rare disease organisations.

This could be through partnerships with rare disease peak bodies like Rare Voices Australia and Carer Gateway.

Funding could be used to create more accessible, condition-specific resources for carers, including comprehensive online tools, handbooks, and webinars. This could also include virtual peer support options, recognising the challenges of geographical isolation or the intense demands of caregiving.

The government should also invest in training carers in medical and caregiving skills through programs that recognise the limited workforce and thin markets in certain regions and the requirements and needs of rare conditions.

“We do whatever we can to provide essential care in our homes to avoid hospital admissions – which in turn saves the government a fortune every single time. We do so with little training and at our own expense. I don’t need a morning tea once a year to recognise my role as a carer – I need practical and financial help!”

Government Financial Support

While some financial supports exist, such as Carer Payment and Carer Allowance, they often do not fully cover the financial burden of caring for someone with a rare disease. The extra costs of specialist medical care, equipment, travel to appointments, and other related expenses can be significant. This is further exacerbated for people living in regional, rural, and remote locations.

“My top issue is financial stability. If one parent becomes a full-time carer of their loved one with a rare disease, and their partner earns “too much” they aren’t entitled to financial support, making them completely reliant on their partner financially. They have little to no superannuation and a future of limited financial options. But in some cases, there are no care alternatives – especially if like us, you live in regional or rural areas.”

RVA supports the review of financial supports including the Carer Payment and Carer Allowance to ensure they are a modern and appropriate measure of financial support and better reflect the actual costs and financial strain associated with rare disease caregiving.

References

1. Commonwealth of Australia, Department of Health. *National Strategic Action Plan for Rare Diseases*. Canberra; 2020. Available from: <https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf> [Accessed May 2024].
2. Australian Bureau of Statistics. *Labour Force. Australia*. Canberra; 2024. Available from: <https://www.abs.gov.au/statistics/labour/employment-and-unemployment/labour-force-australia/latest-release> [Accessed September 2024]