Position Paper
Families, Supporters, Kin and Carers

Definition of Key Terms

At Wellways, we value and uphold the right for people to choose how they identify. We acknowledge and respect different preferences for describing experiences and the meaning and connection language holds and how it changes and evolves with time. For the purposes of this position paper, we want to be clear what we mean when we use certain words or phrases and have defined the following terms.

Family/families

Families are the relationships or networks we connect in. We recognise that every individual exists within broader networks and that these networks can be described in various ways, such as family of birth, family of choice, kinship group, kin, friends, children or significant others.

Supporter/s

Many people supporting friends, peers and community members prefer and relate better to the word supporter. This sentiment is often expressed among younger people.

Kin/kinship

Using the language of kinship care is an essential dimension when addressing informal care and support roles and relationships within First Nations communities. Kinship care can also be used to describe grandparent carers or formal or guardianship relationships.

Carer/s

While 'carer' is the term established in legislation like the Carer Recognition Act, we must recognise that this language can mask the real impact on families, normalising unpaid contributions as inevitable and legitimate.

Many people providing informal support don't identify as carers, they see themselves simply as family caring for each other. Conversely, for others the term 'carer' is central to their identity and advocacy for support and justice.

Children and young adults under 25 are now commonly called young carers or young people with caring responsibilities, acknowledging that young people also have unpaid care duties that profoundly impact their lives.

About Wellways

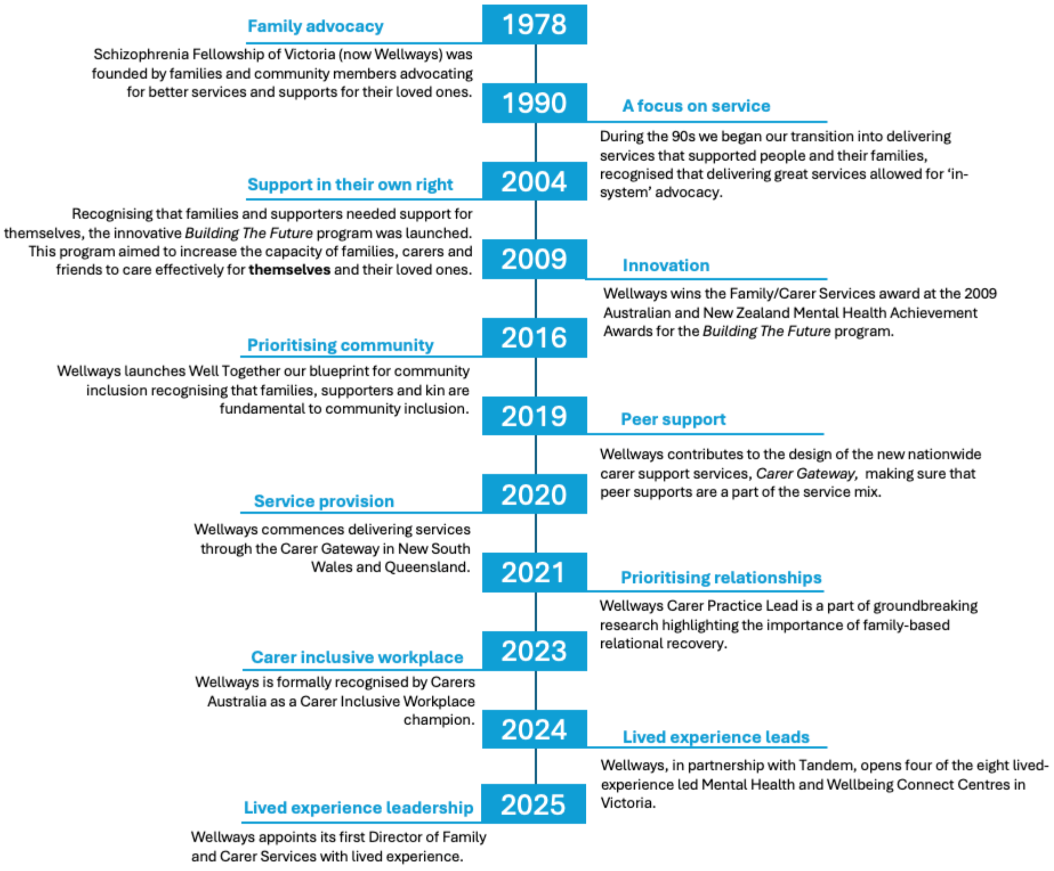
Established in 1978, Wellways Australia Limited (Wellways) is a recognised specialist provider in mental health, disability support and carer services.

The Schizophrenia Fellowship, now Wellways, was founded in 1978 in Victoria by families, kin and supporters advocating better services, information and support for their loved ones who were experiencing mental health challenges. This intention has not changed, although the scope of our advocacy has broadened to include work in mental health, disability, and caring spaces with national reach.

At Wellways, we know the immeasurable contribution that families, kin and supporters make when they are supporting their loved ones. We see the value that they add to the effectiveness of our services through their commitment to improving outcomes for their loved ones.

In this position statement, we respond to what we have heard families, kin and supporters are advocating for and outline the key ideas that we believe will allow our organisation, the broader service sectors and the government to better recognise, support and work with families, kin and supporters.

A history of embedding family and carer experiences



1978
Family advocacy
Schizophrenia Fellowship of Victoria (now Wellways) was founded by families and community members advocating for better services and supports for their loved ones.

1990
A focus on service
During the 90s we began our transition into delivering services that supported people and their families, recognised that delivering great services allowed for 'in-system' advocacy.

2004
Support in their own right
Recognising that families and supporters needed support for themselves, the innovative *Building The Future* program was launched. This program aimed to increase the capacity of families, carers and friends to care effectively for **themselves** and their loved ones.

2009
Innovation
Wellways wins the Family/Carer Services award at the 2009 Australian and New Zealand Mental Health Achievement Awards for the *Building The Future* program.

2016
Prioritising community
Wellways launches Well Together our blueprint for community inclusion recognising that families, supporters and kin are fundamental to community inclusion.

2019
Peer support
Wellways contributes to the design of the new nationwide carer support services, *Carer Gateway,* making sure that peer supports are a part of the service mix.

2020
Service provision
Wellways commences delivering services through the Carer Gateway in New South Wales and Queensland.

2021
Prioritising relationships
Wellways Carer Practice Lead is a part of groundbreaking research highlighting the importance of family-based relational recovery.

2023
Carer inclusive workplace
Wellways is formally recognised by Carers Australia as a Carer Inclusive Workplace champion.

2024
Lived experience leads
Wellways, in partnership with Tandem, opens four of the eight lived-experience led Mental Health and Wellbeing Connect Centres in Victoria.

2025
Lived experience leadership
Wellways appoints its first Director of Family and Carer Services with lived experience.

Background and context

Each year, families (carers) in Australia provide 2.2 billion hours of unpaid care, a service that would cost nearly $80 billion to replace with formal paid care[i]. In fulfilling their caregiving roles, families (carers) frequently sacrifice their careers, retirement plans, educational aspirations, social connections, and even their own health and wellbeing, often without adequate financial, social or emotional support[ii] [iii].

Families (carers) also frequently express that they are unrecognised and excluded in workplaces, communities, and in social service systems[iv]. The establishment of the Carer Recognition Act 2010 has done little to alleviate this invisibility. As a result, many families (carers) experience feelings of being a burden, frustrated, exhausted, isolated, overlooked, hopeless, and undervalued[v].

The unpaid contributions of families (carers) are also being increasingly being relied on to compensate for service gaps and systems' failure. This stems from the failures of our ineffective mental health, alcohol and other drugs, aged care and disability systems, which leave families (carers) struggling to navigate between systems to find the support their loved ones require[vi].

Supports provided by these systems are also grounded in individualistic and bio-medical models of care which neglect the somatic, personal, social, environmental and cultural supports that impact on wellbeing[vii] [viii].

Many individuals who provide care, including young people, First Nations kinship groups, LGBTIQA+ people and those from culturally and linguistically diverse (CALD) communities, may not recognise the term "carer" or identify themselves as such. This lack of identification can mean that services are not tailored to these groups and do not provide the right kinds of support[ix].

Our current systems also create barriers for diverse families (carers) as they do not recognise the diversity of family structures, particularly those whose experiences challenge dominant cultural, social or medical narratives[x].

Recent submissions to reviews and committees[xi] [xii] [xiii] have provided further insight into how this often-overwhelming level of responsibility and expectation is unsustainable and causes negative impacts on every aspect of the lives of families (carers).

What are we advocating for?

1. Protecting rights

We know that those that provide informal support often have their rights and needs ignored or overlooked. Families (carers) should have their rights clearly outlined and protected including the right to be acknowledged as key contributors to the health and wellbeing of those they care for. Families (carers) should also have full autonomy over the nature and scope of their caregiving role, along with access to the same rights, opportunities, and freedoms enjoyed by all Australians, no matter where they live.

We advocate for consistent policies and laws across all states and territories that recognise, protect, and support care relationships by clearly defining what governments and service systems must provide to families (carers) and their communities.

2. Support to thrive in their own lives

Only recently have governments begun to recognise that families (carers) are individuals with their own needs. This has led to the design and delivery of support services that address these needs directly. Instead of viewing families (carers) solely through their caregiving role, this shift has begun acknowledging their right to wellbeing and fulfilment in all aspects of life. However, many families (carers) still face significant barriers to accessing support, especially those in rural and remote communities.

We advocate for diverse service options that recognise and support the needs of families (carers) and their wider communities, no matter where they live.

3. Building community

We know that families (carers) provide care across all communities in Australia. They span age ranges from the young to the elderly, reflect the richness of Australia's multi-cultural communities and play a significant role in First Nations culture and community. When communities learn together, support one another, and share knowledge, they can shape better outcomes for families (carers) and those they support.

We advocate for community-based approaches that see families (carers) as part of wider support networks, built on local strengths and resilience, moving beyond narrow definitions of "carer" to embrace diverse cultural understandings of care relationships and flexible funding that respects each community's unique needs.

4. Prioritising relationships

Many of our support systems have existing policies that acknowledge the needs of families (carers). However, in resource-stretched and time-poor systems, such as NDIS, aged care and mental health systems, it is often families (carers) who are forgotten and the policies not followed. This gap between policy and practice means that families, kin, supporters (carers) often are forced to make challenging choices when supporting their loved ones, increasing their own distress.

We advocate for a shift away from the traditionally individualistic or bio-medical models of care, along with attitudes, practices, policies and funding that supports and recognises the importance of relationships.

5. Recognising their expertise

Families (carers) often face significant stigma and discrimination. Their knowledge and experiences may be dismissed, or they may be judged by those who don't understand caregiving challenges. Historical stigma around conditions like mental health challenges or disabilities has unfairly blamed families (carers) leading to isolation.
These experiences create additional barriers that harm their emotional, financial, and social wellbeing.

We advocate for families (carers) to be respected and valued across our social service system and our broader society, acknowledging their contributions and eliminating any discrimination they face.

6. Addressing the impacts of caring

Families (carers) often experience high levels of stress, fatigue, and emotional exhaustion, which can negatively affect their own health and their economic and financial prospects. People who receive government financial aid still struggle, especially with the rising costs of living. Many caregivers who work also face financial problems, as their income is eroded by hidden caregiving costs. Unfortunately, these issues are often ignored, and families (carers) don't get the support they need to stay financially secure and stable.

We advocate for better support for all carers who are struggling, whether they receive government payments or have jobs, by increasing income support, adding retirement contributions to reduce the economic disadvantages of caring and ensuring everyone has access to safe and suitable housing.

7. Increasing employment and educational opportunities

Families (carers) often face significant challenges when trying to balance their caring responsibilities with paid employment or education. Despite the increased workplace and educational flexibility that has emerged since the COVID-19 pandemic, the findings of the 2024 Carer Wellbeing Survey show that finding an employer or educational institution who is both understanding their caring responsibilities and willing to provide the necessary flexibility is difficult.

We advocate for the adoption of nationally aligned legislation that protects families, kin, supporters (carers) right to request flexible work or study arrangements while upholding protection against discrimination.

8. Lived experience insights and leadership leading reform

Engaging with people with lived experience leads to more effective service and support design, understanding of community concerns and needs, and addresses inclusion and diversity through engagement with families (carers) across different communities and locations. However, families (carers) are often de-prioritised in co-design and other participatory processes.

We advocate for robust frameworks for engagement with families, kin, supporters (carers) lived experience in all research, policy and legislative work across government and support sectors.

Endnotes

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[ii] Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carer. Evaluate 2022.

[iii] Durie, T. and Cavanaugh, E. (2017) Guaranteeing Women's Super: How to Close the Gender Gap in Superannuation, The McKell Institute.

[iv] Carers NSW (2024). 2024 National Carer Survey: national highlights. nationalcarersurvey.com.au

[v] Sharafizad, F., Franken, E., Jogulu, U., & Teo, S. (2023). "Being a carer, you just get forgotten!": exploring the experiences and opportunities of informal primary carers in Australia. *International Journal of Care and Caring*, 1-17.

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[viii] Wyder, M., Barratt, J., Jonas, R., & Bland, R. (2022). Relational recovery for mental health carers and family: Relationships, complexity and possibilities. *The British Journal of Social Work*, *52*(3), 1325-1340.

[ix] Carers NSW (2024). 2024 National Carer Survey: First Nations carers. nationalcarersurvey.com.au

[x] Tenley Ryan Sam Ellis Colin. (2024). "Queer people are excellent caregivers, but we're stretched so very thin": Psychosocial wellbeing and impacts of caregiving among LGBTQI cancer carers. *BMC cancer*, *24*(1), 36.

[xi] Inquiry into the recognition of unpaid carers – Parliament of Australia (aph.gov.au)

[xii] https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis/part-four-five-year-transition/foundations

[xiii] https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Work_and_Care