

Paper Four: 'The Different Types of Unpaid Support People (and Their Differing Needs)'

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Our position on the different types of unpaid support people is informed by the lived experience of mental health family members and friends.

The experience of a mental health family member or friend is often different to the experience of others who fall within the definition of carer¹. That is, people who provide personal care, support and assistance to another with an experience of disability (physical or intellectual), a medical condition or being older.

Disability is a lifelong experience. This is reflected in the lifetime approach adopted by the National Disability Insurance Scheme (NDIS) and NDIS eligibility criterion (for example, the requirement for applicants to demonstrate that they will need support under the NDIS for their lifetime). Similarly, once someone begins to experience older age-based conditions, or chronic or terminal illness, they will likely continue to experience those conditions for the remainder of their life.

Using the lifetime approach to inform care practices for the experience of disability, a chronic or terminal medical condition or for aged care makes sense. However, mental health family members and friends tell us that this approach does not fit the lived experience of the people that they support.

Approaches to care for mental ill health are recovery-orientated in nature. We see this reflected in care plan actions at the service delivery level and more broadly within State and National healthcare planning. For example, the *Rethink 2020 State Plan for Mental Health in Tasmania (2020-2025)*, the key actions of which support the treatment and recovery of people with mental ill health. Because mental ill health is treated for recovery, many mental health consumers do not feel comfortable applying for NDIS supports, as they do not consider their condition 'lifelong' in nature. As State and Federal funding is funnelled into NDIS psychosocial disability support programs, mental health families and friends have expressed concern that alternative, recovery-orientated, care (for consumers and unpaid support people) may become less accessible, or defunded altogether. If alternative supports become unsustainable or inaccessible, and people experiencing mental ill health do not wish to apply for NDIS access, a mental health specific care gap will emerge. **It is mental health family members and friends who most often fill this gap with the provision of unpaid support and care.**

When we talk about recovery, we understand that the recovery journey of a person experiencing mental ill health and or substance misuse is unpredictable and spasmodic in nature. An individual's experience of mental ill health and or substance misuse can fluctuate from mild to moderate through to acute and back again, sometimes with little to no warning, and for varying durations. As such, the support needs of someone experiencing mental ill health and or substance misuse conditions can vary on a daily basis. **When the needs of the person you support vary often, and unpredictably, it can become difficult to plan ahead, consistently attend work, study or volunteer commitments, create personal routine and make time for self-care.** Mental health families and friends tell us that they face unique challenges in all facets of life because of this.

¹ As defined in Section 5 of the *Carer Recognition Act 2010* (Aus) - <https://www.legislation.gov.au/Details/C2010A00123>

In contrast, the caring role of someone providing unpaid support to a person who experiences disability, older age, or a terminal or chronic medical condition is relatively consistent and predictable*. This means that plans can be made, appointments can be scheduled well in advance and life and work can be more reliably organised around unpaid support duties and care schedules. When someone supports another with an unpredictable trajectory and set of needs, they are not able to reliably make plans and predictably organise their life around the support needs of another. Appointments are often made, cancelled, and accepted last minute, requiring a constant reshuffling of daily priorities. **Care plans within this setting are highly dynamic and families and friends tell us that it can be difficult to make longer term decisions about their application** (particularly where recovery is the focus, as, by nature, things will change).

** This is not to say that these support roles do not face their own significant challenges, only that they differ to the mental health family and friend experience.*

"I put up with poor recognition and inclusion by health professionals, and spending a great deal of time trying to navigate a fragmented mental health system on behalf of my care recipient. I get grouped with carers of older people and people with intellectual or physical disabilities. My role as a mental health carer feels different, it doesn't fit."

Currently, almost one in two Australians (46%²) will experience mental ill health at some point in their life. This means that almost half of the Australian population is likely supported by an unpaid family member or friend. With over 12 million Australians receiving unpaid support from a family member or friend and, as mental health family members and friends face unique challenges in supporting someone with mental ill health, it follows that separate support programs and advocacy for mental health family members and friends is required.

This has been recognised at a State and Federal level and is reflected in the funding of separate peak bodies to support and advocate for the interests of mental health family members and friends (Mental Health Families and Friends Tasmania) and people in caring roles more generally (Carers Tasmania). This distinction is also reflected at a national level (for example, our National Body, Mental Health Carers Australia, which specialises solely in advocating for the needs of unpaid mental health support people).

Over the past 37 years, MHFFtas has worked to build collaborative and supportive relationships with those representing different types of support people (that is those supporting someone experiencing disability, and or aged-based and medical conditions).

Going forward, MHFFtas welcomes the opportunity to further discuss the language of caring and the unique support experiences and needs of mental health families and friends in Tasmania.

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Our Vision

Families and friends of people affected by mental ill health are understood, respected, valued and supported to build their capacities and improve their quality of life.

² National Survey of Mental Health and Wellbeing, 2007 - <https://www.abs.gov.au/statistics/health/mental-health/national-survey-mental-health-and-wellbeing-summary-results/latest-release#data-download>