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# Submission to the Australian Government's National Carer Strategy

Prepared by Everymind

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## About Everymind

Everymind is a leading national institute dedicated to the prevention of mental ill-health and suicide, with a vision of empowering people and organisations to implement change - for themselves, for each other and for the future. We have a long-standing reputation for designing, implementing and evaluating tailored policy advice, research and programs. This includes over three decades of experience designing and delivering programs, policy responses and translational research.

Everymind's Strategic Plan 2022-2026 outlines our commitment to transforming the supports available to families, friends and caregivers. We know that family, friends and carers are fundamental to supporting someone experiencing mental health concerns and suicidal distress. But we also know that the support role can increase a person's own risk of distress and mental health concerns. At Everymind, our programs for families, friends and carers translate the best available knowledge from research, lived experience and practice to provide practical and evidence-informed support across a range of settings. *Minds Together* is an Everymind program supporting family, friends and carers of people experiencing mental health concerns or suicidal distress.

## Submission summary

Everymind is providing this submission to inform the Australian Government's new National Carer Strategy. The time is right to set a reform agenda in Australia that positions the mental health and wellbeing of families, friends and carers as a national priority, requiring coordinated action across all settings and jurisdictions. In summary, we recommend the following.

1. A whole-of-government National Carer Strategy is required, including clear acknowledgments of the role and support needs of families and friends providing support to people living with mental health concerns and suicidal distress.
2. Families, friends and carers are significant contributors to mental health care and suicide prevention supports in Australia. Recognition of their role and resources to support them is critical.
3. Families and friends providing support to individuals experiencing mental health concerns or suicidal distress do not often identify as 'carers' and therefore may miss out on the support available. Language must be inclusive of all carers, including those who would not use the language of 'caring' to describe their role.
4. Families, friends and carers providing support to individuals experiencing mental health concerns or suicidal distress face an elevated risk to their own mental health and wellbeing. It is crucial to address the impacts of caregiving through scaling up prevention and early intervention programs and resources tailored to particular caring experiences.
5. Information, services and supports for families, friends and carers should be embedded into the diverse systems that people are most likely to interact with in addition to traditional carer services. For families and friends supporting someone experiencing mental health concerns and suicidal distress, that means integrating support into the services that their loved one is interacting with such as primary care, mental health care, suicide prevention and support services (such as aftercare).
6. While there are attempts to increase the inclusion of families, friends and carers in mental health services, limited interventions are available to support their wellbeing. Caregivers benefit from tailored interventions designed to alleviate the emotional distress they experience, and which build knowledge and skills to better care for the person and for themselves.
7. Programs for families, friends and carers should be free to access, be informed by evidence, and be developed with people who have lived and living experience.

## Further detail

### An increasing need for care

Mental health concerns and suicidal distress significantly impact individuals, families and communities. More than 40% of Australians will experience mental health concerns across their lifetime, over 3,000 people die by suicide and an estimated 65,000 Australians attempt suicide each year. Recent research indicates that the prevalence of mental health concerns and psychological distress is increasing. Most people experiencing distress will not seek formal help or will experience difficulties in accessing support. Family and friends therefore provide most of the practical and emotional support for those in distress, with the value of this care estimated at \$15 billion annually.

Providing support and care is a rewarding and valuable role. Still, the complexity and associated challenges of the caregiving role may lead to an increased risk of mental health concerns and suicidal distress for family and friends themselves. Caregiving is also associated with reduced engagement with employment, financial difficulties and social isolation. Increased recognition and support of caregivers is critical to prevent the onset or worsening of mental ill-health and suicidality for both the person being supported and the caregivers themselves. Additional legal, structural, and other tangible support is required to improve the health and wellbeing of family and friends supporting someone experiencing mental health concerns or suicidal distress.

### Unique experiences of caring for someone experiencing mental health concerns or suicidal distress

Providing support for someone with a mental health concern or suicidal distress brings unique challenges. Providing mental health support is often unpredictable and episodic in nature requiring caregivers to be 'on standby'<sup>9</sup>. This variability can make it challenging for caregivers in these situations to clearly define their roles, consequently making coping more difficult. Furthermore, the intensity of caregiving and emotional strain increases when supporting an individual who has either attempted suicide or is experiencing suicidal distress. The intensity of the caregiving experience is contingent upon factors such as: the chronicity and severity of the person's suicidal distress; the closeness of the relationship between the caregiver and care recipient; additional stressors affecting the caregiver; and the extent of individual and structural supports accessible to the caregiver<sup>10</sup>.

The 2022 Carer Wellbeing Survey<sup>11</sup> indicated that caregivers of someone experiencing mental health concerns or suicidal distress continue to have lower levels of wellbeing and higher levels of psychological distress compared to other Australians. Caregivers of someone with a mental illness are also more likely to be diagnosed with a mental illness themselves or experience suicidal distress.

### Families, friends and carers receive little support and deserve better

Following mental health or suicidal crises, families, friends and carers have reported feeling isolated, abandoned and unsupported<sup>39</sup>. Carers providing mental health support have expressed unmet needs, including a lack of financial assistance, respite and emotional support for themselves<sup>40</sup>. In some instances, carers can experience higher rates of depression and anxiety than the person they are caring for<sup>46</sup>.

Support and caring roles are commonly associated with disproportionate rates of stress, relational distress, loneliness, fatigue, neglect of own needs, and poorer physical, emotional and mental health outcomes<sup>11,47-49</sup>. Furthermore, carers report a lower quality of life, poorer sleep, and less physical activity than the general population<sup>50</sup>. People in caring roles commonly report financial strain, reduced employment and employability, diminished recreation, and fewer familial and social contacts<sup>48,51,52</sup>. Similarly, studies are indicating that informal carers experience higher levels of suicidal distress<sup>53,54</sup>.

Every major review undertaken in Australia until 2023<sup>†</sup> has recognised the integral role of carers in preventing the development of mental health concerns and suicidal distress. These reviews have recommended a significant increase in the provision of support to carers. Access to strategies, tools, and coping mechanisms has been identified as important supports for carers who have described feeling unsupported. These resources can assist them in building skills and enhancing their mental health and wellbeing. Carers also report that evidence-based online programs are particularly helpful in accessing content at a suitable time and place.

### **It is possible to improve the wellbeing of families, friends and carers**

Carers play a fundamental role in promoting wellbeing and sustaining recovery for those experiencing mental health concerns and suicidal distress yet there is little support for the people providing the care. A holistic approach that considers the wellbeing of both individuals facing mental health challenges and those offering support is needed.

Research shows that by providing targeted training, skill building and resources for mental health support, the following outcomes are possible for carers:

- Increased mental health and wellbeing for themselves by providing supports that improve mental health literacy, build communication skills, self-care skills, emotional regulation skills and support social connection. These supports can reduce distress and increase their coping and self-efficacy.
- Improved mental health and wellbeing of the care recipient. Carers, when working in partnership with those experiencing mental health concerns or suicidal distress, can support therapeutic goals, identify changes in wellbeing and advocate for professional services.

### **Language considerations**

Families and friends providing support to individuals experiencing mental health concerns or suicidal distress do not often identify as ‘carers’ and therefore may miss out on the supports available. Everymind has conducted research with people who have a lived and living experience of supporting someone experiencing suicidal distress to better understand language preferences. People with lived experience noted that language should be inclusive for all cultures and genders and relevant to the type of care and support being provided. From this research, 43% of people preferred the term ‘family and friends’ (now most commonly used by Everymind in our communications), with some preferring the term support person (17%) or supporter (17%). Almost all participants did not prefer the terms ‘caregiver’ and ‘carer’. Language must be inclusive of all carers, including those who would not use the language of ‘caring’ to describe their role.

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<sup>†</sup> Reviews include the Australian Government’s Productivity Commission Report into Mental Health, the National Suicide Prevention Advisor’s Final Report, the Royal Commission into Victoria’s Mental Health System and the Australian Parliament House of Representatives Select Committee on Mental Health and Suicide Prevention.

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