

EDV Position Paper: Carers, Family, and Supporters of Adults (>18yrs) with an Eating Disorder

Definitions of key terms

Active carer	A person who actively provides care and support to an individual with an eating disorder. They may provide treatment assistance, supervision, support and advocacy throughout the duration of the illness. They may live with the individual with an eating disorder.
Supporter	Supporters of an individual with an eating disorder provide practical and emotional support, often in a less intensive role than carers. They are often partners, siblings, friends, or individuals in someone's local community.
Carer Peer Worker	A person who draws on their lived experience as a carer of an individual with an eating disorder and understanding of the treatment system to provide mutuality, and social, emotional, and practical support to others caring for or supporting an individual with an eating disorder.
Recovering	When a person is actively engaged in eating disorder treatment and are currently experiencing physical, psychological or behavioural symptoms of an eating disorder. Further, as defined by the NEDC, recovery is “a process of gaining personal control and working towards a meaningful life that is not dominated by the symptoms of an eating disorder” (p.5).
Recovery/ Recovered	Defined by EDV as a person who is free of physical, psychological and behavioural symptoms. There may be some unhelpful eating disorder thoughts sparingly or from time to time but are managed swiftly and with a sense of ease.



Carers, family, and support people are integral members of a person's treatment team. Eating disorders are complex, and therefore require certain knowledge and skills when supporting a loved one.

What is the role of carers, family and supporters of adults with eating disorders?

Historically, eating disorders have been framed as an issue that warrants blame toward families and carers, despite the known complexity and multifactorial relationship between social, psychological and biological factors that lead to the development of eating disorders.

The role of carers, family, and supporters of adults with eating disorders will depend on several factors, such as the age of the individual with the eating disorder, living arrangements, family/supporter dynamics and approaches to treatment. It is vital that where possible, carers, family and supporters involved in the care of an adult with an eating disorder are supported in their

own wellbeing, while also gaining knowledge and skills to best support the needs of their loved one.

At EDV, we recognise that carers and supporters of adults with eating disorders can be anyone, including partners, siblings, and friends. We also recognise that not everyone has access to family or a support network in their eating disorder journey, and that carer support is likely to evolve as the individual enters different life stages. This role has a significant impact on carers, families and supporters and there is no 'one size fits all approach', each individual and their supports have unique needs and experiences.

What does the literature say?

Social and support networks are vital in the journey to recovery from an eating disorder (Stillar et al., 2016). A collaborative approach from carers, families, and supporters, rather than a directive approach, is preferred and leads to better recovery outcomes for individuals (Geller et al., 2016).

There are consistent themes in the literature on the experiences of adults with eating disorders and their carers, families and supporters. Themes revolve around the challenges associated with the social and economic costs, the non-linear trajectory throughout the continuum of care, and the impact of supporting a loved one with an eating disorder (Bryan et al., 2022).

Common experiences include:

- Loneliness/isolation experienced by carers
- Difficulty accessing treatment
- Ambivalence about continued recovery and continuity of care role
- Loss of income and productivity costs, travel costs and treatment expenses
- Guilt and distress associated with caregiving and support role

While many themes speak to the challenges, the literature also speaks to resilience and a prevailing understanding and hope that full recovery is always possible. (Bryan et al., 2022; Stillar et al., 2016; Wilksh, 2023)

Intersectionality

Research highlights that the intersection of more than one marginalised social identity (race, class, ability, gender, and ethnic and cultural minorities) among carers and supporters is a significant consideration for health equity in eating disorder treatment and care (Burke et al., 2020). Due to the multicultural diversity in the Australian population (Australian Bureau of Statistics, 2022), particular attention is needed to ensure services have the capacity to provide culturally responsive support (Burke et al., 2020).

Research shows that migrants from culturally and linguistically diverse backgrounds face the greatest physical and mental health disadvantages and barriers to accessing mental health services compared to English speaking migrants (Cheah et al., 2020; Jatrana et al., 2018; Minas et al., 2013).

Carers and adults in rural and regional areas

While research is lacking, geographic barriers have been identified as a concern for those accessing mental health and eating disorder specific services in regional, rural, and remote Australia (Kavanagh et al., 2023). Lengthy waitlists place additional strain on carers and supporters. The impact of this is absorbed by carers who take on the caregiving responsibilities that are not being met by the healthcare system. This can be an isolating and uncertain experience due to the known complexity and potential severity of eating disorders. A scoping review by Kavanagh et al. (2023) identified key barriers to access and utilisation of mental health services in these areas as sociocultural attitudes, limited resources, a lack of culturally sensitive care, travel time, and distance of services. This has significant socioeconomic implications, linked to social isolation, time out of work, etc.

Economic impact

Eating disorders lead to significant economic burden on individuals, the population and the health care system. At a population level, the burden in Australia is expected to be \$80.1 billion when accounting for health system costs, productivity loss, and costs incurred by carers (Butterfly Foundation, 2022). It is estimated to cost individuals and their carers over 70 days of annual leave and between AUD\$10,000-\$20,000 in out-of-pocket private clinical care expenses, per year of treatment (Wilksh, 2023). It is essential to consider and recognise that eating disorder recovery and treatment periods are long-term, generally taking multiple years.

Ongoing illness

Research shows that up to 20% of people with Anorexia Nervosa (AN) and 10% with Bulimia Nervosa (BN) will develop a severe and enduring eating disorder (SE-ED) (Kotilahti et al., 2020). Although there is no set definition for SE-ED, the common criteria require the illness to have occurred over a long period of time (10+ years in the EDV SE-ED Program) and that attempts at treatment have thus far been unsuccessful.

Often people with SE-ED and caregivers feel like they don't 'fit' anywhere within the health system (Treasure, 2016). Importantly, carers are faced with the compounded impact of their loved one's illness itself, the societal reaction, and the economic and logistical impact of ongoing treatment support highlighting the need to support carers of individuals with SE-EDs (Treasure, 2016).

Current policy context

Medicare support

In 2019, Medicare extended support to individuals of all ages experiencing an eating disorder. Eligible young people with eating disorders have access to an Eating Disorder Plan (EDP). The EDP involves Medicare subsidies for 20 sessions with a private dietitian and up to 40 sessions with a private mental health clinician over a 12-month period. [Click here](#) for more information. Individuals who are not able to access an EDP can be referred to Better Access to Mental Health Care (MHCP), that provides up to 10 therapy sessions per calendar year (InsideOut, 2021).

While this added to services for individuals there was a missed opportunity to create Medicare Benefits Schedule (MBS) items for clinicians to work with carers and supporters.

Financial support for carers

Consumer and carer financial support is offered through the Mental Health Carer Support Fund provided by [Tandem Carers](#) in Victoria. The Australian Government agency, Services Victoria, also provide [Carer Gateway](#) for a range of supports and [payments for carers](#). This includes access to one-off and annual payments, and a concession card for assistance with health care costs.

Royal Commission into Victoria's Mental Health System (RCVMH)

Relevant recommendations that came from the RCVMH include Recommendation 30, to develop system-wide involvement of family members and carers. This details the role of carers and supporters using their lived experience in roles in the mental health system. Additionally, Recommendation 31 focuses on supporting families, carers and supporters. The result of this is the delivery of family and carer-led centres across all regions of Victoria. They aim to provide information, identify people's needs and connect them with appropriate supports, provide financial assistance for immediate daily needs, and to delivery carer, family, and support peer support groups.

Legislative and organisational support for carers

The integral role of carers is recognised under the Carers Recognition Act 2012 (Department of Health and Human Services, 2022). It defines the significance of caregiving relationships, and the obligations of Victorian government, local councils, and non-profit organisations to support and recognise carers. This includes carer support programs and services (Department of Health and Human Services, 2022).

Family support and crisis plans can be developed by health care professionals to manage the daily impacts of mental illness and involve other social support services (e.g., financial assistance programs, accommodation service) (Department of Health, 2015).

Victoria's new Mental Health and Wellbeing Act 2022 (the Act) was introduced on September 1st, 2023, as a recommendation from the RCMHS. This legislative reform provides a rights-based legislative framework for the health system and establishes new professional roles and entities to support consumers. Detailed information about the new Act is available on the Victorian Department of Health website [here](#).

Below is an outline of the main amendments to the Act that are of particular importance to carers of individuals with eating disorders:

- More patient autonomy, including broader advance statements with greater requirements for carer input. Advance statements are important to create a clearer pathway for carers and reduce burden on carers to make decisions in difficult or acute care situations.
- Explicit support and care for family members, carers, or supporters of someone with a mental illness.
- Clearer pathways for formal complaints for carers and support people.

What are we advocating for?



Inclusion of carers in treatment and care of individuals (aged ≥ 18 years old) with an eating disorder

The role of caregivers and supporters for those over 18 is typically considered to be less concerned with the implementation of treatment, and rather to be more involved in supporting independence, and thought and behaviour change (Wade, 2023). Importantly, the need for skill building, system navigation, psychoeducation, and peer support among carers and supporters is not restricted to the age of the loved one, and although the needs will evolve, they remain throughout different life stages and the duration of a loved one's eating disorder (Wilksh, 2022).

Role of carers in supporting treatment and recovery

Rather than an individualistic focus on the person with an eating disorder, there is a need for meaningful engagement and consent for the inclusion of carers and supporters in

ongoing treatment planning and discharge processes. This is based on the recognition that carers and supporters are often the main or only external advocates for the person with an eating disorder and bring useful and unique insights based on previous treatment experiences. Carers, families, and supporters who may be inclined to or accustomed to being actively involved in their loved one's care often ultimately become agitated when dismissed or left out of treatment discussions in an adult setting. Given the unique physical and mental intersections involved in treating eating disorders, carers and supporters should be recognised for their significant role in fulfilling very practical needs, such as purchasing food and preparing meals, providing meal support, monitoring for signs of physical and mental distress and coordinating and transporting to/from appointments. We encourage closer carer and supporter involvement that recognises cultural, social, and relational differences.

For Example: Addressing the problematic transition through age-based services

Turning 18 has significant implications on the delivery of care and supports in eating disorder treatment options. At a system level, parents and carers are disempowered to continue Family Based Treatment (FBT) if needed as the treatment is not offered in the public system to those over the age of 18 years old (Wade, 2023). Beyond FBT, the age transition from Child and Adolescent Mental Health Services to Adult Mental Health Services at 25 years of age can present issues due to the lack of cohesion between the services, leading to a burden on the individual and their caregivers to remain connected (Hill et al., 2018). Parents and

carers report that this critical transition in treatment and lapse of continuity increases the risk of relapse.

Research has explored the problematic transition between age-based services for young people with eating disorders who lose contact with the system but are still in recovery and require ongoing treatment (Wade, 2023). The key findings highlight the advantages of integrated, all age eating disorder services as prioritising the needs and concerns of consumers, accommodating for choice, maximising staff skills, flexibility, and retention, and helping to facilitate a shared culture and principles of care for those in recovery from an eating disorder (Wade, 2023).

EDV's Position:

- 1. Carers, families, and supporters of adults (≥ 18 yrs) are welcomed and actively involved in the care processes from assessment through to recovery.**
- 2. Treatment providers have clear processes to engage and openly communicate with carers.**

2

Supporting carers to be effective and confident through capacity and skill building

It is vital that carers have access to comprehensive supports to build confidence, skills, knowledge, and capacity to care for their own mental health while supporting a loved one. This is particularly important in cases of ongoing illness to support the changing needs of carers and supporters over time. To uphold this, it is necessary to consider what is involved in supporting an adult in recovery and treatment of an eating disorder. For example, meal support, transport, time and financial sacrifices, emotion coaching, and relationship management (CEED, 2019, p.6). Supporting carers enhances caregiving relationships and minimises the overall

burden on those involved, and on the wider health system.

Recommendations to facilitate capacity and skill building for carers is the development and access to inclusive treatment models, resourced training and education for carers, and meaningful social and community-based activities (Johns et al., 2019; Kavanagh et al., 2023). These recommendations offer support for sustained confidence and skill building, and work to reduce and prevent the risk of social isolation, ambivalence, and burden on carers and supporters.

Example of a carer inclusive treatment model: Temperament-Based Treatment with Supports (TBT-S)

There is a strong need for therapeutic models that explicitly include carers and families in treatment. This approach generates better outcomes for the health care system, individuals and for family dynamics. TBT-S is an experiential treatment option for adults with eating disorders and their carers or supporters that fills gaps between access, and effective ongoing treatment support (Knatz Peck et al., 2021). It achieves this by recognising the importance of the changes in neural circuitry over time and personality features that contribute to an individual's risk and severity of an eating disorder (Knatz Peck et al., 2021).

TBT-S provides psychoeducation on how biology and temperament influence eating disorder risk to enhance understanding and reduce blame on individuals, carers and their supporters (Knatz Peck et al., 2021). Further to this, it helps carers become more effective in their caring role through understanding their loved one's traits and adapting support as required. Research has shown that this significantly improves body image in the individual and reduces eating disorder psychopathology (Knatz Peck et al., 2021).

This is a complimentary treatment to other eating disorder treatment, with limited availability in the public health system.

EDV's Position:

1. EDV advocate for the development and availability of approaches that actively include carers and supporters.

3

Access to emotional, psychological, and wellbeing supports for carers and supporters

Awareness raising around the impact of this role on carers and the need for emotional, psychological and wellbeing supports is critical. Research shows that caregiving for someone with an eating disorder leads to higher levels of stress, anxiety and depression compared to any other mental illness (Martín et al., 2015).

This is based on the complexity of caring for someone with both physical and mental health medical requirements, the social and economic costs, and the non-linear trajectory throughout treatment and recovery (Bryan et al., 2022).

"Our daughter was ill for over 13 years which spanned all her teen years and into her 20's. We had difficulty adjusting our parenting style to give control and responsibility to Emma as she aged, and her health issues required such close management for so long. I understood this from my professional role as a nurse but found it difficult to accept as a carer. Her development milestones were delayed, and it was not until she was in her 20's that we felt confident to slowly hand back responsibility to her for managing many aspects of her life. Having access to a counsellor gave our family the ability to discuss these feelings of frustration..."

*- Lyle Hagan,
EDV Ambassador*

**EDV's Position:**

1. EDV advocate for the provision of access to wellbeing supports for carers, families, and supporters.
2. EDV advocate for treatment providers to recognise and refer to carer support resources.

How does EDV support carers?

EDV Hub

Free and confidential helpline, offering information, navigation, and support. Open to all Victorians impacted by eating disorders.

PH 1300 550 236

Email hub@eatingdisorders.org.au

[Web enquiry here](#)

EDV Carer Coaching Program

The Carer Coaching Program is an 8-week, 1:1 online coaching program for families with a young person who has been newly diagnosed with a restrictive eating disorder.

Developed in response to the spike in eating disorder presentations in young people (under 19) during COVID-19, the Carer Coaching Program offers primary carer gives the opportunity to receive coaching from EDV Carer Coaches while they await formal treatment.

EDV Carer Workshops

Collaborative Carer Skills Workshops (CCSW)

CCSW workshops are designed for parents, partners, siblings or friends of someone with an eating disorder. They are aimed at improving carer's wellbeing, developing coping strategies and increasing problem solving skills. The workshop series is based on research conducted by Professor Janet Treasure and is proven to reduce carer burden and distress.

EDV Carer Courses

EDV's Carer Courses are designed to support carers (parents, grandparents, partners and other loved ones in caring roles) in a practical way.

Courses are structured around weekly topics. EDV offer two courses for carers:

- **UPSKILL** – 6-week course suitable for families and carers who are currently utilising a family-led refeeding (or FBT/Maudsley) approach for their child and need skills and support to manage this process.
- **RENEW** – 4-week course most appropriate for people whose loved one has been unwell for longer than two years and are not currently participating in family-led refeeding, but they wish to gain and renew skills to support them in their journey.

EDV Carer Newsletter

Each issue covers a single topic related to the carer experience. Content is created by EDV's Carer Coaching team, who bring lived experience of supporting their own loved one through to recovery from an eating disorder. Subscribe [here](#).

EDV Telehealth Nurse/Counselling

The [Telehealth Nurse](#) acts as a central point of contact and can assist carers with accessing treatment for a loved one, locating specialised eating disorder services and health professionals and provide information and support to help people work towards recovery. [Telehealth Counselling](#) offers safe, non-judgmental support from a qualified mental health counsellor.

Online Learning Modules

Self-paced online learning modules to increase knowledge and develop skills in the caring role. Learn more [here](#).

References

- Ahn, J., Lee, J., Jung, Y. (2018). Predictors of Suicide Attempts in Individuals with Eating Disorders. *The Official Journal of Suicidality: Suicide and Life-Threatening Behaviour* 49, 3:789-796.
<https://doi.org/10.1111/sltb.12477>
- Centre for Excellence in Eating Disorders (CEED). (2019). Working with Families and Supports of Adults with an Eating Disorder. The Victorian CEED.
https://ceed.org.au/wp-content/uploads/2020/04/Working_with_Families_Carers_Adult_ED_FINAL.pdf
- Cultural diversity of Australia | Australian Bureau of Statistics. (2022, September 20).
<https://www.abs.gov.au/articles/cultural-diversity-australia>
- Bryan, D. C., Macdonald, P., Cardi, V., Rowlands, K., Ambwani, S., Arcelus, J., Bonin, E.-M., Landau, S., Schmidt, U., & Treasure, J. (2022). Transitions from intensive eating disorder treatment settings: Qualitative investigation of the experiences and needs of adults with anorexia nervosa and their carers. *BJPsych Open*, 8(4), e137.
<https://doi.org/10.1192/bjo.2022.535>
- Burke, N. L., Schaefer, L. M., Hazzard, V. M., Rodgers, R. F. (2020). Where identities converge: The importance of intersectionality in eating disorders research. *International Journal of Eating Disorders*, 53, 1605-1609.
<http://doi.org/10.1002/eat.23371>
- Butterfly Foundation. (2022). The reality of eating disorders in Australia. Sydney: Butterfly Foundation.
<https://butterfly.org.au/wp-content/uploads/2022/08/The-reality-of-eating-disorders-in-Australia-2022.pdf>
- Department of Health. (2022, February 25). Working with consumers and carers. State Government of Victoria, Australia.
<https://www.health.vic.gov.au/mental-health/working-with-consumers-and-carers>
- Department of Health. (2015, May 29). *Family support and crisis plans*. State Government of Victoria, Australia.
<https://www.health.vic.gov.au/working-with-consumers-and-carers/family-support-and-crisis-plans>
- Fletcher, L., Trip, H., Lawson, R., Wilson, N., & Jordan, J. (2021). Life is different now – impacts of eating disorders on Carers in New Zealand: A qualitative study. *Journal of Eating Disorders*, 9(1), 91.
<https://doi.org/10.1186/s40337-021-00447-z>
- Hamilton, A., Mitchison, D., Basten, C., Byrne, S., Goldstein, M., Hay, P., Heruc, G., Thornton, C., & Touyz, S. (2022). Understanding treatment delay: Perceived barriers preventing treatment-seeking for eating disorders. *Australian & New Zealand Journal of Psychiatry*, 56(3), 248-259.
<https://doi.org/10.1177/00048674211020102>
- Hill, A., Wilde, S., & Tickle, A. (2019). Review: Transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS): a meta-synthesis of parental and professional perspectives. *Child and Adolescent Mental Health*, 24(4), 295-306.
<https://doi.org/10.1111/camh.12339>
- Inside Out. (2021). *The financial burden of caring for someone with an eating disorder: Affordable treatment options*. (2021, March 26). InsideOut Institute.
<https://insideoutinstitute.org.au/blog/the-financial-burden-of-caring-for-someone-with-an-eating-disorder-affordable-treatment-options>
- Johns, G., Taylor, B., John, A., Tan, J. (2019). Current eating disorder healthcare services – the perspectives and experiences of individuals with eating disorders, their families and health professionals: systematic review and thematic synthesis. *BJPsych Open*, 5, e59, 1-10.
<https://doi.org/10.1192/bjo.2019.48>
- Kavanagh, B.E., Corney, K.B., Beks, H., Williams, L.J., Quirk, S.E., and Versace, V.L. (2023) A scoping review of the barriers and facilitators to accessing and utilising mental health services across regional, rural, and remote Australia. *BMC Health Services Research*. 23:1060.
<https://doi.org/10.1186/s12913-023-10034-4>

Kotilahti, E., West, M., Isomaa, R., Karhunen, L., Rocks, T., & Ruusunen, A. (2020). Treatment interventions for Severe and Enduring Eating Disorders: Systematic review. *International Journal of Eating Disorders*, 53(8), 1280–1302. <https://doi.org/10.1002/eat.23322>

Knatz Peck, S., Towne, T., Wierenga, C. E., Hill, L., Eisler, I., Brown, T., Han, E., Miller, M., Perry, T., & Kaye, W. (2021). Temperament-based treatment for young adults with eating disorders: Acceptability and initial efficacy of an intensive, multi-family, parent-involved treatment. *Journal of Eating Disorders*, 9(1), 110. <https://doi.org/10.1186/s40337-021-00465-x>

Martín, J., Padierna, A., van Wijngaarden, B., Aguirre, U., Anton, A., Muñoz, P., & Quintana, J. M. (2015). Caregivers consequences of care among patients with eating disorders, depression or schizophrenia. *BMC Psychiatry*, 15, 124. <https://doi.org/10.1186/s12888-015-0507-9>

Mond, J. M., Hay, P. J., Rodgers, B., & Owen, C. (2007). Health service utilization for eating disorders: Findings from a community-based study. *The International Journal of Eating Disorders*, 40(5), 399–408. <https://doi.org/10.1002/eat.20382>

NEDC (National Eating Disorders Collaboration). (2019b). Developing a Peer Workforce – Part B. National Eating Disorders Collaboration. <https://nedc.com.au/assets/NEDC-Publications/Part-A-Peer-Work-Guide-Evidence-Review.pdf>

Paxton, S.J., Hay, P., Touyz, S.W., Forbes, D. M., Sloane Giosi, F., Doherty, A, Cook, L., & Morgan, C. (2012). Paying the price: The Economic and Social Impact of Eating Disorders in Australia. Sydney: Butterfly Foundation. Retrieved from: https://butterfly.org.au/wp-content/uploads/2020/06/Butterfly_Report_Paying-the-Price.pdf

Surgenor, L. J., Dhakal, S., Watterson, R., Lim, B., Kennedy, M., Bulik, C., Wilson, N., Keelan, K., Lawson, R., & Jordan, J. (2022). Psychosocial and financial impacts for carers of those with eating disorders in New Zealand. *Journal of Eating Disorders*, 10(1), 37. <https://doi.org/10.1186/s40337-022-00565-2>

Treasure, J., & Nazar, B. P. (2016). Interventions for the Carers of Patients with Eating Disorders. *Current Psychiatry Reports*, 18(2), 16. <https://doi.org/10.1007/s11920-015-0652-3>

Wade, T. D. (2023). A systematic review: Solutions to problems caused by age transition between eating disorder services. *European Eating Disorders Review*, 31(2), 247–257. <https://doi.org/10.1002/erv.2945>

Wilksch, S. M. (2023). Toward a more comprehensive understanding and support of parents with a child experiencing an eating disorder. *International Journal of Eating Disorders*, 56(7), 1275-1285. <https://doi.org/10.1002/eat.23938>

Need help?

Eating Disorders Victoria help Victorians understand and recover from eating disorders.

PH: 1300 550 236

E: hub@eatingdisorders.org.au

W: www.eatingdisorders.org.au

