

Eating Disorders Victoria: Position Paper

Carers, Family, and Supporters of Young People (<18yrs) with an Eating Disorder

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.

Definitions of key terms relating to eating disorders

Active carer (caregiver)	a person who actively provides care and support to an individual with an eating disorder and may or may not live with them. They may provide treatment assistance, supervision, support and advocacy throughout the duration of the illness.
Supporter (caregiver)	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.
Family-Based Treatment (FBT)	the most effective, evidence-based treatment for young people with restrictive eating disorders. Supports and empowers the primary carers to take a lead role in renourishing the young person.
Carer Peer Worker	an individual 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.

What is the role of caregivers in eating disorders?

The role of a caregiver for an individual with an eating disorder is unique due to the complexity of addressing both the physical and mental health implications of these illnesses. It is generally recommended that primary carers play an **active** and **skilled** role in the care of their young person with an eating disorder to help facilitate full recovery. Given the high mortality risk associated with restrictive eating disorders and the increased risk of suicidality across all eating disorder diagnoses, the caregiving role is often urgent and essential.

At EDV, we recognise the significant impact this role has on carers, families and supporters. We also recognise that everyone's carer experience and recovery journey will look different. It's important to know that there is no 'one size fits all approach' and each family must find the right tools that work for their unique circumstance (Wilksch, 2022).

Talking about recovery with a loved one

It is important to consider the complexity of recovery and the support carers need in communicating with their loved one about what recovery means and looks like. Recovery is a long-term process requiring involvement from multiple family members.

While the process is structured and intensive, it is vital to recognise break through moments and glimmers of hope for recovery. Carers and others who interact with young people are uniquely positioned to provide support and identify progression and steps towards recovery (e.g., healthy behaviour change).

To empower carers and supporters to engage in recovery conversations, access to recovery stories, peer support and lived experience resources and services is necessary. Read recovery stories [here](#).

What does the literature say?

Most research into the experiences of carers and families of young people with eating disorders focuses on restrictive eating disorders, such as Anorexia Nervosa and Bulimia Nervosa.

Research into experiences of carers and families of young people with Binge Eating Disorder and ARFID has also been emerging (Bohon, 2019; Brigham et al., 2018; Maunder & McNicholas, 2021). Caregiving for young people with Anorexia Nervosa, Bulimia Nervosa, ARFID or BED is a complex and demanding experience (Wilksch, 2022).

In general, common themes experienced by carers and families include:

- Loneliness/isolation
- Difficulty accessing treatment
- Loss of income and productivity at work
- Financial costs related to treatment and travel expenses
- Guilt and distress around meeting young person's needs
- Negative impacts on siblings

Among the literature of carers and supporters of young people, there is also a prevailing resilience and an acknowledgment of hope that full recovery is always possible (Fletcher et al., 2021; Maunder & McNicholas, 2021).

Family Based Treatment (FBT)

Family Based Treatment (FBT) is the most widely researched, effective and evidence-based treatment for young people with restrictive eating disorders who are medically stable and suitable for outpatient settings (Rieneke, 2017). Numerous randomised controlled trials have found that up to 90% of those under 18 years old reach full remission of their eating disorder and had continued improvements in their health and wellbeing beyond treatment when followed up 5 years after the trial (Rieneke, 2017).

At the core of the intervention, FBT is a restorative and manualised outpatient-based treatment, where recovery is based in a family's home environment (Rieneke, 2017).

As the name suggests, it requires families (usually parents) to deliver treatment at home using a structured process.

"Caring for a young person with an eating disorder is not intuitive, often contradicts existing or adolescent-appropriate parenting styles, and involves the use of strong communication and boundary-setting skills. The early messages of manualised Family Based Treatment (FBT) of "You know your child best" often leave families feeling more disempowered as we do not know how to feed a malnourished child or calm an extremely distressed child in the face of an irrational set of thoughts we do not understand.

While our family was lucky to get prompt access to FBT, we were not provided with any education or skills. I sought support through an online peer support community and some informal local peers who had done FBT before me. I credit that access to education, tips and encouragement with making our journey more efficient and effective than working it out on our own."

- Caldwell, B (2023)

Intersectionality

Research highlights that the intersection of more than one marginalised social identity (race, class, gender, 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 relevant support (Burke et al., 2020).

Impact of the social stigmatisation of eating disorders on carers

Community and social stigma related to stereotypes of eating disorders can be a barrier to carers seeking support and can contribute to the risk of burnout. The impacts of stigma on carers can include social isolation, self-blame and guilt, emotional distress, and further strain on caregiving and relationship dynamics. Additionally, research involving carers in outpatient settings indicates that the burden for carers of those with eating disorders is higher than for carers of individuals with other mental health issues (e.g., depression and schizophrenia) (Martin et al., 2015).

Carers in rural and regional areas

Treating eating disorders in young people tends to exacerbate geographic-based barriers to accessing medical and mental health services for those living in regional, rural, and remote areas (Butterfly, 2018, p.7). General practitioners are more likely to refer eating disorder patients to specialist services in the city rather than to local hospitals, ultimately placing additional strain and economic burden on carers and supporters when accessing treatment. Community education, resourcing, health professional upskilling, and meaningful social and community-based activities are fundamental to sustainable and lasting recovery for those in regional and rural regions (Mulders-Jones et al., 2017).

Current policy context

Child and Adolescent Mental Health Services (CAMHS) and Child and Youth Mental Health Services (CYMHS)

CAMHS and CYMHS provide services for young people (up to 18 in CAMHS, 25 in CYMHS), including for those with eating disorders. These services typically recommend FBT as the first-line response and treatment approach for restrictive eating disorders in children and adolescents.

If all community-based treatment avenues have been exhausted, or an individual is medically unstable, inpatient treatment is required.

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.

Medicare treatment 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.

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).

Financial support available to carers

Consumer and carer financial support is offered through the Mental Health Carer Support Fund provided by [Tandem Carers](#). In some cases, the Australian Government agency, Services Victoria, also provide [payments for carers](#).

What are we advocating for?

Increased funding and support for carers engaging in Family Based Treatment (FBT).

Primary carers of children and adolescents with restrictive eating disorders are most likely to be recommended FBT as a first line treatment approach. Despite this, carers in Victoria do not experience equal or consistent support when engaging in FBT. This can result in decreased efficacy of FBT and increased negative impacts on carers and families.

Timely diagnosis and commencement of treatment

Delays in the help-seeking phase, from first noticing early warning signs and visiting the GP, through to referral to the correct treatment and support, can result in families learning to be disempowered in the face of the eating disorder (Caldwell, 2023). The longer the delay, the more challenging it becomes to transform the experience of powerlessness and fear into a position of confidence and efficacy.

Education, training, clinical support

In addition, there is a widely shared experience of inadequate preparation, education, and in-home support provided to facilitate the manual and active role carers have in FBT (Fletcher et al., 2021).

Financial burden and work productivity costs

Due to the dependence on families of children and adolescents to deliver the treatment, caregivers of loved ones with an eating disorder experience high levels of psychological distress, and emotional and financial burden (Coomber & King, 2010; Maunder & McNicholas, 2021; Surgenor et al., 2022).

Carers of young people widely report needing to take over 70 days of annual leave and out of pocket private clinical care expenses between AUD\$10,000-\$20,000 per year of treatment (Wilksh, 2022). It is essential to consider and recognise that eating disorder recovery and treatment periods are long-term, generally taking more than one year.

EDV's Position

As FBT is classified as the best practice intervention for some eating disorders and is the primary model of treatment offered in Victoria, EDV advocates for comprehensive support from the health care system for carers and families.

1. There must be system level recognition of the essential and skill-based role of carers in the delivery of FBT.
2. There is a need for additional financial and in-home support for carers delivering FBT.
3. Carer peer support workers are an essential part of the treatment team for families undertaking FBT.

What are we advocating for?

Support for alternative treatment pathways.

There are a number of barriers for some individuals with restrictive eating disorders who are not able to engage in FBT. Importantly, it is also not recommended as the first line of treatment for other eating disorder diagnoses (e.g., BED). In these cases, it is crucial that young people and their families have access to evidence-based interventions and individually tailored treatment teams.

Barriers to implementing FBT

The barriers to implementing FBT in community-based settings must be recognised in order to design targeted and effective interventions (Astrachan-Fletcher et al., 2018). The main challenges include:

- Intervention specific factors – high demand on families (i.e., particularly for single parent households, parental mental health concerns), and therapists, or clinicians, not strictly adhering to components of the FBT protocol

- Complex or co-occurring mental health conditions for individuals with eating disorders and their carers, families, and supporters
- Home environment factors (e.g., administration load, appropriate house/space for family meals)
- Systemic factors (e.g., rural/regional location, lack of eating disorder specialised training) (Astrachan-Fletcher et al., 2018)
- Intersectionality - cultural and language barriers

Alternative treatment pathways

In cases where FBT is not effective or has been deemed by family to be not suitable, it is critical that services continue to support the young person and family. There are a range of alternative options available such as Adolescent Focussed Therapy, CBT-E for Adolescents and in some cases, an eclectic approach may be indicated using a multidisciplinary team. A key element of a responsive service system is providing an opportunity for young people, their carers, families and supporters to navigate alternative treatment pathways to recovery

EDV's Position

EDV acknowledges that FBT is not a suitable treatment pathway for all families or diagnoses based on a number of factors. EDV advocates for recovery support for all young people, regardless of the treatment pathway they are engaged with.

1. Eating disorder treatment pathways need to be individually tailored to meet the needs of families and individuals to facilitate lasting recovery.
2. Families navigating individualised treatment pathways require access to supports and resources.

What are we advocating for?

Stepped care approach for young people with eating disorders and their carers.

At all stages of an eating disorder, individuals, their carers and supporters require a range of different levels of support and services. This is what is considered a stepped system of care. This approach functions through coordination of services that are individually tailored. This recognises that the needs and experiences of an eating disorder and recovery are different for everyone.

Early intervention as the first line of a stepped care system can involve a wide range of individuals, from primary health care providers (e.g., GPs) through to first—line community responders (e.g., schoolteachers and sporting coaches). These are important groups that interact with carers, families, and young people, to facilitate entry points to treatment and support. Community initiatives that target these groups and educate people on recognising early signs of an eating disorders are vital.

Next, the **initial response** details comprehensive assessments, preliminary diagnosis and referrals to meet the individual's and family or supporter needs. This timely diagnosis and appropriate and timely referral can involve GPs, public and private health care settings (e.g., dietetics and mental health professionals), and community-based services. The latter can include treatment pathway nurses, like those available through EDV's Telehealth Nurse service. Eating disorder professional development and training for professionals who are involved in young people's lives can be a pivotal addition to support individuals and families navigate treatment options.

Treatment follows and includes a range of options, such as community-based treatments (e.g., public or private clinical psychology and dietetic services); community based intensive treatment (e.g., intensive outpatient day programs); and hospital treatment for those who require a high-level of treatment support for medical stabilisation, or medical or psychiatric intervention (e.g., residential programs, emergency departments, inpatient units). Importantly, support for young people being discharged into community requires cohesion and linkages with community-based organisations and services. This is due to the often-significant role for families engaging in FBT or supporting a young person to maintain recovery.

Recovery Support then follows, which is defined as community-based and online eating disorder services for the purpose of reducing risks of relapse or recurrence of illness and to readily support families and young people with ongoing recovery (e.g., EDV e-learning platform for guided self-help, GPs, dietitians, mental health professionals). The efficacy of evidence-based and lived experience informed community services can be increased with coordinated delivery with the broader system of care and other relevant services (e.g., Local Child Mental Health Services, CAMHS/CYMHS).

Ultimately, targeted step-down services need to be tailored for those at the intersectionality of marginalised social identities, those with existing mental health and medical comorbidities, and for those based in rural or regional areas. Support for a cohesive, stepped system of care helps young people stabilise and recover faster, ultimately reducing upward pressure on the hospital system. Expansion of services through an intersectional lens and coordination with the broader system of care is essential.

EDV's Position

EDV advocates for adequate resourcing and the implementation of a stepped system of care for eating disorders for young people, their carers and supporters.

1. All stakeholders within the stepped system of care must be trained to recognise and respond to all eating disorders.
2. Community-based services, such as EDV, must be supported to uphold the success of the stepped system of care through providing guidance and resources at every level.
3. Targeted interventions across the stepped system of care are necessary for Victorians with reduced health equity.

Resources for Carers

For carers engaged in family-based treatment

- [EDV Family Based Treatment Fact Sheet](#)
- [CEED Family Led Refeeding and Recovery](#)
- [Parents: Survive to Thrive Guide](#)
- [Treatment Goals for Families and Carers in FBT](#)
- [F.E.A.S.T First 30 Days Program: 30 Days of Educational Resources for Carers](#)

Other resources for carers

- [Externalisation of the Eating Disorder](#)
- [2020 Feast of Knowledge International Conference - Free Access to Video Presentations](#)
- [Eating Disorders and My Sibling](#)
- [How to Approach Someone You Are Concerned About](#)

Suggested reading for carers

- [How to Nourish Your Child Through an Eating Disorder – by Casey Crosbie](#)
- [When Your Teen Has an Eating Disorder – by Dr Lauren Mulheim](#)
- [Skills-based Caring for a Loved One with an Eating Disorder – by Janet Treasure](#)
- [Survive FBT – by Maria Ganci](#)

Other support organisations

- [Eating Disorders Families Australia](#) - support groups, education webinars and facebook group
- [Tandem](#) - peak body representing Victorian mental health carers
- [Butterfly Foundation](#) - national organisation for body image and eating disorder support

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 (Monthly)

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](#).

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