

Eating Disorders Victoria: Position Paper

Lived Experience and Peer Work

Definitions of key terms relating to eating disorders

Lived experience

individuals who have either recovered from an eating disorder, or those who are actively engaging in recovery, or as a carer who provides care and support to someone with an eating disorder.

Lived experience worker

someone who is employed to draw on their lived experience of an eating disorder or as a carer to an individual with an eating disorder to inform their work (e.g., policy development and reform, or program design, implementation, delivery, or evaluation).

Peer worker

an individual who draws on their lived experience of an eating disorder and understanding of treatment pathways to provide mutuality, and social, emotional, and practical support to facilitate improved quality of life and recovery in others experiencing eating disorders.

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.

Recovery

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. Recovery is something that everyone experiences in their own way after challenging life events, including people who have experienced illness, their family members and other supporters.”

(NEDC, 2019b, p.5)

What is lived experience and peer work?

Lived experience and peer work is a human rights and social justice response that empowers those who are generally disempowered by the institutions that are designed to treat them (Mead et al., 2001).

This work serves to provide a person centered, trauma informed, and mutual support treatment approach for recovery.

Eating Disorders Victoria (EDV) advocates for the integration of lived experience and peer work across the continuum of eating disorder care. EDV has a 40+ year history of providing lived experience community support, and currently provides world-leading and comprehensive peer support programs.

EDV recognises the unique experience and complexity of eating disorder experiences. Through our lived experience and peer workforce, we inspire hope and motivation at every stage of eating disorder help-seeking, treatment, caring roles and recovery.

Brief history of peer support and lived experience work at EDV:

- 1984** EDV first introduced **support groups** for consumers and carers affected by eating disorders.
- 1991** Support groups were being established across Victoria, with a focus on group **'Leaders'** having lived experience.
- 1992** EDV's **Recovery Stories** were recorded and purchased nationally, and distributed throughout schools and to more than 25,000 organisations internationally.
- 1995 – 2005** Attendance to support groups increased and locations expanded. **Stories of Recovery volunteers** shared stories of hope with community and media. Continuously refined peer support work training and professional development for GPs and educators.
- 2008** EDV launched **family & carer workshops**.
- 2017** EDV's **Peer Mentoring Program (PMP)** launched, matching recovered mentors with those exiting inpatient treatment programs.
- 2020** In response to COVID-19 pandemic, EDV launched the **Carer Coaching Program** and peer-facilitated **Online Support Groups**. EDV also launched the lived experience driven **Candid Conversations** Podcast.
- 2022** EDV launched the **Severe and Enduring Eating Disorders (SE-ED) Program**, co-designed and delivered by those with lived experience of SE-ED.
- 2023** EDV secured a grant through the Australian Research and Translation Centre to build an **online professional development learning platform for peer workers** in the PMP. EDV awarded one of three Department of Health grants to host five eating disorder **lived experience cadets**.

What does lived experience and peer work look like in the eating disorder sector?

Globally, there is a wide spectrum of peer-led and lived experience informed eating disorder services (Lewis & Foye, 2021).

While not an exhaustive list, this includes;

- **Independent roles:** Sharing narrative of recovery (e.g., blog posts, videos, or speeches)
- **Active or continuous roles:** Online and face-to-face peer mentoring programs (community and hospital based)
- **Peer-led** service design and delivery of intervention programs
- Peer support **training** and **professional development**

“When I first started this journey to be a Stories of Recovery ambassador, never would I have imagined how much I would also get out of doing this. It’s such a rewarding experience and so not possible without all the work EDV puts in, in educating ambassadors, creating opportunities and creating a safe space for us.”

- Ming,
EDV Ambassador



Current Lived Experience services and resources offered at EDV:

- [Stories of Recovery](#)
- [Candid Conversations Podcast](#)
- Co-design workshops (internal and sector-wide)
- Lived experience advisory groups for program and service design

Current Peer Support services offered at EDV:

- [Peer Mentoring Program \(PMP\)](#) (face to face, or online) fortnightly meet up over a 6-month period
- [Online peer support groups](#), multiple groups, monthly
- [Severe and Enduring Eating Disorders \(SE-ED\) intensive 12-week program](#), with group-based peer support sessions
- [Carer Coaching Program](#), weekly coaching with a carer peer worker over an 8-week period

All peer support programs at EDV are developed through co-design with people with lived experience.

What does the evidence say?

Australian evidence

The National Eating Disorders Collaboration (NEDC), an initiative funded by the Australian Federal Government Department of Health and Aged Care, reviewed nine peer support programs, receiving input from 44 peer support workers, 31 clinicians, and 19 consumers (NEDC, 2019a, p. 24). They found that all nine programs delivered significant improvements and benefits, particularly in regard to hope and motivation for recovery (NEDC, 2019, p. 25).

Other major benefits identified through evaluations included a sense of belonging and social connectivity, increased self-efficacy, decreased eating disorder behaviours and thoughts, increased treatment retention rates, increased understanding of eating disorders and increased workforce capacity to work with eating disorders (NEDC, 2019a, p. 25).

In 2019, the evaluation and results from the clinical trial of **EDV's Peer Mentoring Program**, were published in the International Journal of Eating Disorders. The clinical trial was a collaboration between Eating Disorders Victoria (EDV) The Melbourne Clinic, Austin hospital and the Body Image and Eating Disorders Treatment and Recovery Service (BETRS). The PMP involved 13 mentoring sessions of up to 3 hours, every 2 weeks over a period of six months. The mentees (individuals with eating disorders) were observed to have significant improvements in eating disorder symptomatology, quality of life, mood and perceived disability (Beveridge et al., 2019).

Mentees reported that the experience provided hope and inspiration, motivation and agency, roles and boundaries, re-engagement with the world and others, and that the mentor's lived experience was impactful (Beveridge et al., 2019).

The exploration of the experienced benefits to peer mentors in the program revealed a connection with self and others, constructive exploration of their own recovery and reciprocal gains of the work (Beveridge et al., 2019). The challenges for peer mentors included, self-doubt and the need for supports, challenges associated with role clarity and boundary management (Beveridge et al., 2019). This research highlights the beneficial role of peer support for those in recovery from an eating disorder. Importantly, it highlights the positive and negative impacts on eating disorder peer support workers, and the need for training and appropriate support (Beveridge et al., 2019).

International evidence

A set of guidelines known as Intentional Peer Support (IPS) were developed by Shery Mead, a pioneer in peer support work. IPS is a peer support framework that is used globally, providing a unified approach for peer work training, relationship building, and community development (Mead et al., 2001; Intentional Peer Support, 2013).

Byrne et al. (2018) call for global leadership for lived experience work. Their findings from reports of peer work and lived experience work in North America, Canada, New Zealand, Australia and the United Kingdom all revealed themes of issues relating directly to the workforce.

This included adequate remuneration, access to training, support, supervision and professional development, a career trajectory in the mental health workforce, and professional integration into leadership roles (Byrne et al., 2018). This is an important global call to action for eating disorder organisations to recognise the value of lived experience in the sector.

Significant developments in Australia have recognised this, with executive level roles in public mental health services and government departments, and a 300% increase in lived experience roles in the workforce (Byrne et al., 2018). Importantly, recovery-oriented policies exist in Australia and New Zealand, however are still considered as an emerging movement (Byrne et al., 2018).

Hong Kong and Singapore have demonstrated more widespread recognition, integration, and public health workforce development of lived experience and peer support roles (Mak et al., 2021; Poremski et al., 2022). However, throughout South-East Asia peer support and the existence of a lived experience workforce are scarce and tightly controlled, with treatment defined almost entirely through a biomedical model (Byrne et al., 2018).

The introduction of lived experience leadership roles and workforce development revisions would be impactful in leading and progressing systemic change (Byrne et al., 2018).

Current Policy Context

In Victoria, the state government has developed standards and a framework that prioritises peer support in the mental health care sector as an essential and contributing part of the service system.

This has been adapted since the 2019 Royal Commission into Victoria's Mental Health Care System (RCVMHS) that recognised the failings of the system in supporting people affected by mental illness of psychological distress.

The standards are detailed in [Victoria's Mental Health and Wellbeing Workforce Strategy 2021 to 2024, pp. 14-15.](#)

At the federal level, there is the [National Lived Experience \(Peer\) Workforce Development Guidelines.](#)

EDV Position Statement

- EDV strongly advocates for all lived experience and peer support work to meet the standards and framework outlined in the Mental Health and Wellbeing Workforce Strategy 2021 – 2024.

What are we advocating for?

Ongoing access to lived experience expertise and peer-led programs.

Lived experience and peer work for eating disorders aims to promote hope and motivation for recovery, improve self-advocacy and enhance community living skills. It also helps individuals to navigate treatment pathways, increase help-seeking capacity, and self-determination (Chinman et al., 2014).

Benefit to the lived experience and peer workforce

Lived experience and peer support recognises the unique and valuable insight gained through lived experience of eating disorders or caring for someone with an eating disorder. It allows those who have recovered or cared for someone to translate meaning and build community, providing an essential pillar alongside the hierarchical nature of the medical model to mental illness (Mead et al., 2001).

The work allows individuals to engage empathically with others through shared experience and reach mutual agreement on what is helpful and what is not for recovery (Mead et al., 2001).

This serves to provide mutual benefit, by providing individualised care, and also challenging peer support and lived experience workers on their existing belief systems around recovery (Mead et al., 2001).

Benefits to consumers

Lived experience and peer workers play a crucial role in the treatment of eating disorders, offering valuable insights and knowledge, while also helping to break down shame and stigma (Lewis & Foye, 2021).

The pervasiveness and complexity of eating disorders in daily life presents clear opportunities for peer support intervention (NEDC, 2019a, p. 20). Peer support work provides person-centered care and recognises that recovery from an eating disorder is not solely reliant on clinical treatment. It also requires integration of positive habits and practices into daily life to improve sense of self and empowerment to facilitate sustainable recovery (NEDC, 2019a, p. 23).

Community access to the relatable and reciprocal nature of peer support work also promotes social connectivity, and provides crucial support during transitional eating disorder treatment, particularly during hospital treatment, where relapse risk is high (NEDC, 2019a, p. 23).

Benefits to carers

For carers and families, carer peer support is a helpful complementary service to facilitate an understanding of eating disorders, alleviate caregiver distress, and facilitate validation and connection with the individual with an eating disorder (Hannah et al., 2022).

Support provided by carer peer workers can help build practical understanding and skills required for the care giving role, particularly when supporting a young person with an eating disorder. Carer peer workers provide hope that full recovery for a loved one is possible, alongside reducing feelings of isolation and shame connected with the carer role.

Benefits to the broader system of care

Placing the lived experience and peer workforce at the forefront of system design, policy reform, and program development and implementation, empowers individuals and helps to break down societal stigmatisation and stereotyping of eating disorders. Importantly, engaging those with lived experience, both personal and as a carer, can move towards equitable service design and delivery for those most at need and provide an accurate representation of the diverse community that is affected by eating disorders (Lewis & Foye, 2021).

Lived experience and peer-led training for other health care professionals and community members is another imperative opportunity to empower lived experience and peer workers and influence and inform best practice (VMIAC, 2020).

EDV Position Statements

- EDV strongly advocate for eating disorder lived experience and peer workers to be considered essential in eating disorder recovery.

We call on the mental health sector to acknowledge that these roles are unique and specialised, and should not be replicated by non-eating disorder specific lived experience and peer workers in any treatment setting.

We also advocate for appropriate remuneration and industry recognition of this work.

- EDV strongly advocates for mental health services to prioritise the dismantling of historical and potentially harmful practices when integrating eating disorder lived experience and peer work.

What are we advocating for?

Lived experience and peer workforce advancement.

An often-overlooked consideration is the vulnerability required of individuals in lived experience and peer work roles, and the fundamental need to ensure that employers and organisations provide this workforce with adequate training, support, role clarity, professional development and a career trajectory (Byrne et al., 2018).

Additionally, it is vital that eating disorder organisations and key stakeholders are aware of the prevalence of lived experience among their workforce to ensure professional support is tailored, de-stigmatising, and responsive (Beveridge et al., 2019). Ensuring workforce safety, support, and progression is fundamental to strengthening and growing the lived experience and peer workforce (Byrne et al., 2018),

EDV Position Statement

- EDV is committed to providing appropriate peer-led supervision and professional development opportunities. We hold a commitment to the advancement of and leadership for the lived experience and peer workforce.



"High-quality peer work is a result of a commitment to enhancing the important and unique support offered by peer workers. We achieve this commitment through our peer-led program models, which includes specific peer mentoring training, professional development and a combination of individual and peer-led group supervision."

- Rachael Duck, PMP Manager

This paper was developed from the perspective of eating disorder lived experience, eating disorder carer lived experience, and sector expertise.

For further resources, please head here: [NEDC](#), [CEED](#), [VMIAC](#), [Tandem](#).

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Need help?

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

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