

Eating Disorders Victoria
Submission to the Victorian Royal Commission into Mental Health

About Eating Disorders Victoria (EDV)

EDV is the peak community organisation for Victorians affected by eating disorders. Our mission is to connect those whose lives are affected by eating disorders with the people, services and hope they need for recovery.

EDV is also the primary source of support, information, community education and advocacy for people with eating disorders and their families in Victoria. EDV invests in the development and provision of a range of evidence based peer support, education and professional services which respond across the spectrum of need.

In 2018/19, EDV connected with more than 560,000 people through our website, responded to 2000 direct request for support through the EDV Hub (previously called the Helpline) and provided 790 psychology and dietetics sessions. Two thousand (2000) people attended our training sessions and 24 referrals were made into the Peer Mentoring Program.

Our Victoria Government recurrent funding accounts for approximately 50% of our budget. This supports our core activities of the EDV Hub, support groups, recovery speakers and education services. Our other programs are funded through a combination of philanthropic, fee for service and fundraising.

This submission

This submission brings together the collective experiences of people with an eating disorder and their families, friends and carers. EDV sought specific input via an online survey, a public consultation, our Peer Mentors and from individuals attending our submission writing sessions. It also draws on our in-depth understanding of issues, needs and what is and what is not working gained from our daily contact with those with lived experience of an eating disorder and our learnings from developing and providing peer support, education and professional services. We also attended nine community consultations run by the Royal Commission and sessions led by Mental Health Victoria, the Victorian Council of Social Service (VCOSS) and Tandem (mental health carers).

Victoria does not have a strategy nor a policy guiding delivery and development of services for eating disorders. While additional investment in 2014 provided a positive start to improving prevention and early intervention, there is still no continuum of care, with specialist services not available in rural and regional areas, and gaps in and to the primary health care system. Eating disorders are misunderstood, with the serious implications from being ill such as increased mortality, suicide and comorbidity significantly under recognised.

EDV has made a separate submission with regard to our evidence based and effective Peer Mentoring Program as one part of the solution. However, a better mental health service system for people with eating disorders also needs:

- A comprehensive eating disorders strategy which responds to service gaps now and plans for the future.
- Well located and accessible services across the continuum of care, from early intervention to specialist care and across inpatient and community.
- Better support for, and inclusion of, families and carers.
- Development of eating disorders awareness and expertise across the “generalist” workforce.

1) What are your suggestions to improve the Victorian community's understanding of mental illness and reduce the stigma and discrimination?

Eating disorders are often misunderstood and sit on the outer of discussion on mental health. Misperceptions abound from them being a life style choice, that they are caused by family and that they are not a serious health issue. Many people do not know that eating disorders are mental illnesses, with significant cognitive and psychosocial impairment. The physical health and medical implications that accompany eating disorders adds to the confusion. Similarly, there are myths around it being a female or a young person's disorder only. These misunderstandings impact on individuals' understanding of what is happening to them, their capacity to self-identify that they are ill or at risk and willingness to seek help. It can make them feel shame or guilt, which further reduces help seeking behaviours.

EDV service users are aware that significant gains have been made in demystifying and promoting awareness of depression and anxiety through community education and people speaking out about their experiences. They would like to see a similar effort around eating disorders. This includes better availability and promotion of accurate information to improve the general understanding of eating disorders, as well as to improve recognition that it is a mental illness, its comorbidity with depression and anxiety and risk for suicide.

Strategies should include:

- Opportunities to hear about, and talk with, people who have a lived experience of an eating disorder and have recovered. This could include public talks and events for communities, as well as online platforms to increase awareness of available resources and services.
- A more targeted approach to schools, with information and resources to improve understanding and risk identification.
- Information for workplaces with a focus on creating a safe and supportive environment for staff who identify as having, or are recovering from, an eating disorder.

2) What is already working well and what ideas do you have to better prevent mental illness and to support people to get earlier treatment and support?

Early intervention leads to significantly improved outcomes for people with eating disorders, with treatment within two to three years of onset significantly increasing chances of recovery¹.

Access to early treatment and support relies on early diagnosis and identification of at risk behaviours and referral to appropriate allied health supports. However, this access is very dependent on where you live and ability to pay.

What is working well includes:

- General Practitioners (GPs) who can diagnose and identify at risk behaviours. EDV's Royal Australian College of General Practice (RACGP) accredited training has now trained more than 10% of all Victorian GPs and is growing the network of GPs with expertise and interest in receiving referrals. The reach of this program is limited by funding.

¹ Eating Disorders Policy Paper writing group. *Nip it in the bud: Intervening early for young people with eating disorders*. Melbourne: Orygen, The National Centre of Excellence in Youth Mental Health, 2016., p 10

- EDV's Hub which is a one stop shop for information and assistance to navigate the service system. However, it is limited in capacity to follow up and follow through with callers.
- Access to evidence based therapies, such as Cognitive Behavioural Therapy. However, they are generally fee for service unless accessed as part of an outpatient "day program".
- EDV's professional support program which assists individuals to link to specialist psychologists and dieticians at a low cost (requires GP referral and mental health plan). There are often waiting lists for these services.
- Psychosocial support which assists recovery and reduces relapse. The evidence based EDV Peer Mentoring Program provides this but only operates in metropolitan Melbourne.

Supporting people to get earlier treatment and support for their eating disorders needs to include:

- More universal information, education and awareness programs and targeting of programs in schools and to children, parents and teachers. There is evidence that these program do work². EDV and headspace have a developed and evaluated a program for schools but it requires funding to implement.
- More GPs with an awareness and understanding of eating disorders (including to provide more regular screening and understanding of treatment options).
- Training for other health practitioners who are likely to be first responders and be part of the referral pathway to improve identification of at risk behaviours and eating disorders. This includes allied health professionals and school wellbeing coordinators.
- Providing specialist low cost psychology and dietetics services, such as through community health programs and/or schools. These services are out of reach for many people who cannot afford the gap fees for psychologists and dieticians (even with private health and Medicare rebates).
- Expanding the reach of specialist mental health services and day programs for people with high and complex needs, but who do not yet meet criteria for an acute admission. This will bridge the gap when support needs are beyond the capability of the primary health care and private health systems³, preventing inpatient admissions and people becoming sicker before being able to access the care they need.
- Providing specialist programs in rural and regional areas.

3) What is already working well and what can be done better to prevent suicide?

Mortality rates for people with eating disorders are almost two times higher than for the general population, and almost six times higher for people with anorexia⁴. Suicide is a major cause of death for all people with an eating disorder⁵. There is still a lack of understanding that eating disorders, like other mental illnesses, alter thought processes and affect capacity for reasoning.

What works well is:

- Risk assessment as a standard part of assessment in any service.

² Eating Disorders Policy Paper writing group (2016). op.cit p25

³ For example, private inpatient providers will not work with a person with a BMI lower than 14, while the public system will not provide access until a person has a BMI lower than 12.

⁴ Arcelus, J. M., Mitchell, A., Wales, J., Nielsen, S. (2011). *Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies*. Arch RCH Gen Psychiatry 68(7), 724-731.

⁵ Pompili M1, Girardi P, Tatarelli G, Ruberto A, Tatarelli R. (2006). *Suicide and attempted suicide in eating disorders, obesity and weight-image concern*. Eating behaviors 7(4):384-94

- Screening for depression and recognising its high level of comorbidity with eating disorders.
- Providing hope and promoting connections and sense of self in the community. The EDV Peer Mentoring Program does this.
- Support post discharge, including peer support and family involvement.

To better prevent suicide we need:

- Increased awareness of the risk of suicide for people with eating disorders.
- Emergency Departments and GPs to screen for eating disorders and suicide risk.
- Suicide prevention training for families and communities.
- Faster access to services (i.e.: reducing waiting lists and providing more consistent access to specialist services).
- Routine/consistent access to programs which provide hope and psychosocial support through treatment and post discharge.
- More wellness focussed programs. These include those which draw on lived experience, create community connections, promote hope and provide authentic, non-judgemental and understanding support.

4) What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other?

Victorian's with eating disorders experience a fragmented service system with many unable to access the right support at the right time and at the right location.

Difficulties in finding a service

It can be difficult to find information about what supports and services are available, and particularly difficult to find primary health and other health specialists who have the expertise in treating eating disorders. This is because of a lack of supply in the workforce, as well as not many reliable information sources.

EDV is the primary source of information about where to find eating disorder services in Victoria for people with eating disorders and their families/friends, and health professionals. The Better Health Channel and other relevant information providers such as the Butterfly Foundation direct callers to EDV for Victorian service information. Around 60% of all calls made to EDV are for assistance with service navigation.

This unique service is highly valued, including because many of its volunteer staff have a lived experience of an eating disorder which builds trust, and because users can feel sure that they are getting the right information (i.e.: they are not needing to search further). However, demand and expectations are growing.

Continuing to provide a quality service into the future will require increasing capacity and more formal processes. This includes capacity to follow up people and provide a more integrated response for frequent callers, as well as to allow for increased marketing and awareness of EDV as a trusted place for information.

Access to specialist care depends on where you live

Victoria has three public specialist eating disorder services which are well regarded. However, they are located in metropolitan Melbourne, with no outreach or other programs in rural and regional Victoria.

With a limited number of specialist inpatient beds, patients unable to access a specialist bed and in need of acute treatment will receive treatment in a medical ward. EDV service users report staff without expertise and knowledge to respond sensitively, a focus on their physical medical needs only and poor or no interface and consultation with psychiatric services, and no specialist psychology support.

In rural and regional areas, it can also be the case that there is no eating disorders expertise in the local mental health service to draw upon as well as less options through the private system.

We need new models of care which combine workforce capability in eating disorders and provision of coordinated care to ensure access to specialist services regardless of where the inpatient admission occurs.

Service users would also like to see increased flexibility around access to existing specialist inpatient services with rigid geographic area based criteria removed.

No community based support

There are few community based supports to assist people transition between systems (i.e.: primary care to inpatient and specialist) or to provide psychosocial support to maintain or reintegrate with work, education, family and community. Service users also identify the importance of, and need for:

- Follow up and help to keep them motivated to remain in treatment or therapy.
- Access to support when and where they need it to reduce relapse and/or to keep them healthy.

The evidence based EDV Peer Mentoring Program is meeting this need, but is only available in metropolitan Melbourne and there are waiting lists. Service users emphasise the importance of being able to access this support quickly.

Health messages around obesity can be damaging

An increasing risk and issue for people with eating disorders, which can prevent access to treatment and support, are the unhelpful messages they receive around obesity reduction. These same messages can be traumatic for people in recovery.

There would be benefits in developing a more integrated approach to the development and delivery of health messages, including to educate the commercial weight loss industry about appropriate language and messaging.

5) What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

The rate of eating disorders is increasing⁶, with it being the third most common chronic illness in young women⁷ and increasing prevalence in boys and men⁸. The reasons for this are complex, but include changing social pressures and messages around eating and body image.

⁶ Hay PJ, Mond J, Buttner P, Darby A., (2008) *Eating Disorder Behaviors Are Increasing: Findings from Two Sequential Community Surveys in South Australia*. PLoS ONE 3(2): e1541. doi:10.1371/journal.pone.0001541

⁷ Yeo, M, Hughes, E. (2011) *Eating disorders: early identification in general practice*. Australian Family Physician 40(30), 108-111

⁸ The National Eating Disorders Collaboration. (2012). *An integrated response to complexity – National eating disorders framework 2012*. Sydney: NEDC

Limited access to specialist services (due to workforce, geographic location and cost issues), a lack of consistent early intervention programs and misunderstanding of eating disorders are key contributors to young people, people on low incomes and people living in rural or regional areas experiencing poorer outcomes.

EDV is concerned that there is little information about how eating disorders are being experienced in culturally and linguistically diverse and Aboriginal and Torres Strait Islander communities, and how this impacts their experience of and access to treatment and support. This is an area for further investigation.

6) What are the needs of family members and carers and what can be done better to support them?

Many family and carers experience difficulties in finding the right information at the right time, stigma and discrimination, feelings of sadness and grief and/or shame and guilt as well as frustration and stress in trying to navigate a fragmented service system. For family and carers of someone with an eating disorder, this is exacerbated by the lack of information and access to services as indicated above, and misunderstanding about eating disorders amongst the general community and health professionals. Narratives which blame or identify poor parenting as causing eating disorders are particularly harmful and unhelpful.

In addition to addressing the general lack of understanding of eating disorders, and improved information and service access, families and carers need to be empowered and supported by health professionals to have an active role in supporting a loved one; and support for their own health and wellbeing.

EDV service users note that while a family member is a child, the family has and is expected to have significant involvement in their child's care but this tends to stop when the child enters into the adult system, even when they are or remain to be the primary carer.

Better outcomes can be achieved by:

- Starting with an approach which sees the family (and other supporters) as part of the team. Families (of origin or choice) should be included in care planning, treatment and discharge decisions unless there is a reason not to.
- Continuing to support programs such as the Maudsley Family Based Therapy model (home based eating support) which provides an option for families to assist their child recover outside of hospital.
- Timely information and psycho-education for families and carers to understand the mental illness, how they can assist and their role in supporting the person for whom they care. Service users value the family programs available through the specialist services but the waiting lists are too long.
- Professional knowledge of carer supports (and referral of families to these).

For people over eighteen years, carers and families would also like to see increased effort and support to assist people with eating disorders to prepare Advanced Care Statements. This provides a mechanism to establish and clarify the family's role in the care and treatment when there is reduced capacity to make decisions independently.

Supporting families and carers to "look after themselves" is also important, including so that they can continue caring. We would like to see more carer support groups and carer workshops as a standard part of treatment. EDV service users identify that they prefer structured and "closed" groups which provide certainty about content and who is attending. They want opportunities to hear about hope, to understand that their experience is shared

and assistance to identify and respond to their own and family's needs (e.g.: as parents and siblings).

7) What can be done to attract, retain and better support the mental health workforce, including peer support workers?

Building capacity and capability within the eating disorders workforce requires a combination of training and development, and evidence of the valuing of this expertise within our health services (both general and mental). This is true for both the peer workforce and other professionals.

We would like to see a commitment to specialist positions in regional mental health services which can support the development of eating disorder expertise across the service and with partner primary health care providers, such as general practitioners, psychologists and dietitians.

EDV is supportive of the Victorian Government's directions and efforts to increase the lived experience role in all services, including through co-design, consumer consultant and peer support roles. We would like to see further commitment through dedicated resources to support the inclusion of people with a lived experience of eating disorders.

Our experience from our Peer Mentoring Program shows that training and support, appropriate remuneration and structure to the peer support role, including practice frameworks are important. Additionally, the capacity of the program to confirm and support our workers own recovery means it is both sustainable and delivering benefits beyond those who receive support.

8) What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

The best outcomes are achieved when treatment is integrated with work/study and social life. This reduces isolation and provides meaningful and relevant activity, and retains support connections.

However, many people with eating disorders require psychosocial support to do this. This includes support to set goals and work towards achieving them, and very specific types of assistance such as at meals or outings which involve food. Currently, only the EDV Peer Mentoring Program is providing this.

Support is also required to negotiate reasonable adjustments to support maintenance or return to work. Significant developments in workplace safety around mental health has been driven by the insurance industry, both in terms of prevention and return to work. However, eating disorders are not part of this conversation and there is minimal awareness of what is required to create a safe place for someone with or recovering from an eating disorder.

9) Thinking about what Victoria's mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise?

A defined early intervention response.

- This includes targeted early and secondary interventions (with a focus in schools and with GPs), across the treatment spectrum.

Increased and equal access to specialist eating disorder services. Specifically, to provide a seamless and integrated pathway from primary health care into the specialist system. This requires:

- Articulation of the pathway, including clarity around roles and responsibilities, from primary care and private health services into the specialist system.
- A service navigator role to assist people to identify the supports and services they need and support their journey to recovery. This could be a community based case manager role and/or could be provided by peer support workers.
- A stronger community based support system which provides the suite of medical, psychological and dietetics support and education programs. This could be a specialist hub or incorporated into existing services, such as headspace or community health. Importantly, they need to be no or very low cost and coordinated.
- Where specialist inpatient beds are not available, that admissions (either to general medical or mental health) receive combined and integrated general medical and psychological support.

Better access to psychosocial support in the community to support long term recovery

- This could include improving availability of the EDV Peer Mentoring Program and structured support groups, to support recovery as well as maintenance of health and wellbeing and reduce relapses.

Systematic inclusion and support for families and carers

- This includes a more systematic approach to the inclusion of families as part of the treatment team, and providing them with the direction and assistance to undertake these role as well support to maintain their own mental health and wellbeing.

Workforce development

- We need an increased awareness and understanding of eating disorders, and skills and expertise in its identification and treatment, across the generalist medical, allied and mental health workforces.

10) What can be done now to prepare for changes to Victoria's mental health service systems and support improvements to last?

Victoria requires a statewide strategy for responding to eating disorders to guide the development and monitoring of the service system now and into the future.

While the Victorian Government has increased its investment in eating disorder services over the last five years, EDV is concerned that prevention and early intervention for people with eating disorders is being, and will be, unintentionally lost in the current planning environment, along with the gains and capability that has been developed in this space. Real change and enduring impact will require a strategic response, particularly to prevent and reduce prevalence, and identify and respond early.

This strategy needs to:

- Describe the continuum of care for people with all types and in all stages of eating disorders.
- Address the interface between the primary health care, private and specialist systems.
- Identify and respond to service gaps, including those caused by geography.
- Plan for early intervention and reduction of prevalence.
- Identify and support carers, families and friends as treatment and support partners
- Identify and respond to workforce needs.
- Commit to monitoring its implementation.

EDV, along with consumers, carers and other service providers made a significant contribution to a 2014 Eating Disorders Strategy. There is an opportunity to refresh this work, and commit to a new plan and framework which can guide the service and workforce development required to ensure a comprehensive response to improve outcomes for the 235,000 Victorians trying to manage an eating disorder each year.

11) Is there anything else you would like to share with the Royal Commission?

EDV is committed to working within the community and with Government to improve outcomes for people with eating disorders. Our capacity to harness and utilise the lived experience provides credibility, expertise and guidance to our work. We have cemented ourselves as the primary source of support, information, community education and advocacy for people with eating disorders and their families in Victoria, and as quality provider of professional education and community support.

To remain sustainable and responsive in this role, and to continue to meet expectations around quality and effectiveness, we will need resources to build our capacity and formalise a number of our processes.

We would like the Commission to recognise the specialist and important contribution that community based organisations such as ours make to people experiencing mental health issues, and the mental health service system.

**Completed by Eating Disorders Victoria
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