

1. Summary

EDV Submission

Eating Disorders Victoria (EDV) makes this submission to provide an example of an innovative program for people with eating disorders leaving hospital treatment, and to promote investment in providing recovery support for people across a continuum of care.

Specifically, highlights of the Peer mentoring program include:

- the demonstrated effectiveness in:
 - reducing readmission rates;
 - improving quality of life for participants, and;
 - affirming the recovery of mentors.

- the specialist needs of people with eating disorders are addressed by providing hope, improving quality of life and reducing demand for intensive hospital treatment services.

Background

EDV is the primary source of support, information, community education and advocacy for people with eating disorders and their families in Victoria.

Over the last three years, EDV developed, implemented and evaluated a comprehensive and highly effective peer mentoring program with a focus on reducing hospital readmissions for people with eating disorders. Funded primarily through philanthropic means, a one off Victorian Government contribution in 2018/19 provided a boost to this program and offered public endorsement of the value provided to the Victorian public hospital system. An additional one year funding from DHHS will continue the program for a fourth year in 2019/20.

People are being admitted to hospital for clinical programs and discharged home with limited support available that, inevitably, results in steady and high readmission rates. The EDV Peer Mentoring Program has been shown to reduce readmission rates, improve participants' quality of life and save the government money on future hospital admissions. The program has had great support from participants, mentors, family members, friends, clinical staff from the referring hospitals, and researchers.

2. About Eating Disorders Victoria (EDV)

For over 30 years, EDV has been listening to the stories of people affected by eating disorders. It provides us with a unique insight into their issues and what works for them. Guided by this lived experience and clinical expertise, we develop and provide a range of evidence based peer support, education and professional services, which respond across the spectrum of need.

Eating Disorders Victoria is a trusted and recognised organisation. We have an excellent track record of achieving outcomes, a “can do” attitude and positive relationships across the clinical, primary care and broader health and community sector.

In 2017/18 EDV connected with more than 460,000 people through our website, phone line and education programs. Specifically, we responded to ~2,000 direct requests for support, provided 528 psychology sessions and provided training to more than 900 people. For people whose lives were affected by eating disorders, we supported access to services and provided the hope they needed for recovery.

Our Victorian government recurrent funding accounts for approximately 50% of our budget. This supports our core activities of helpline, support groups, stories of recovery speakers and education services. It also provides us with a strong foundation which, along with our reputation, enables us to attract additional funding from a range of diverse sources, including philanthropic foundations, fee for service and fundraising.

3. The impact of eating disorders

Over 4% of the population suffers from an eating disorder¹. This means there are approximately 1 million Australians with a diagnosable eating disorder. This includes 235,000² Victorians trying to manage an eating disorder in any one year.

Eating disorders are serious mental illnesses that are characterised by eating, exercise and body weight or shape becoming an unhealthy preoccupation of someone's life. They have the highest mortality³ of all mental illnesses, with 20% of deaths in those with anorexia nervosa caused by suicide. They also have a high disease burden both acutely and chronically compared to all other serious mental illnesses⁴. They do not discriminate, affecting men and women of all backgrounds and age groups. They are the third most chronic illness for young

¹ Deloitte Access Economics, 2012. Paying the Price: The economic and social impact of eating disorders in Australia. Butterfly Foundation.

² Based on - Population data source: www.profile.id.com.au (.id SAFi) - ABS Census 2011 data used for population forecasting

³ 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.

⁴ Deloitte Access Economics, 2012. Paying the Price: The economic and social impact of eating disorders in Australia. Butterfly Foundation.

women⁵, with evidence that prevalence is increasing^{6 7}. Relapse rates are high at between 33 - 60%.⁸ As a result, eating disorders cost our community tens of millions of dollars⁹ every year.

The Victorian Government funds three specialist eating disorder treatment services for adults - The Austin Hospital, Royal Melbourne Hospital and Monash Medical Centre. Reports from the clinical teams indicate that readmission rates for those who are hospitalised as a result of their eating disorder are as high as 60%, and many of these people have multiple readmissions¹⁰. Lengths of stay for each admission can range from two weeks to six months, which provides severe disruption to other aspects of life.

However, there is an opportunity to make inroads into these statistics. Evidence from the EDV Peer Mentoring Program shows that discharge to the program reduces the rates of readmission and increases the likelihood of recovery, reducing the overall cost to government¹¹ with a cost benefit ratio of 2.5.

4. Policy and Program Context

Both the Victorian Ten Year Mental Health Plan and the Fifth National Mental Health Plan have strong themes of increasing effort into early intervention activities – as part of a commitment to improving lives and reducing demand for services. The Primary Health Networks (PHN) also provide a suite of responses supporting people with a mental illness, and the NDIS is beginning to provide individual support packages for people living with psychosocial disability as the result of their mental illness. However, we note that, to date, people with eating disorders are not identified as a priority group or in any strategic directions in any of these plans or new services.

The Royal Commission into Victorian Mental Health System will provide opportunities for the community to share and hear of the challenges for those seeking treatment for eating disorders in our community. Undoubtedly there will be experiences told of despair created by the illness, trauma created by lack of access to good quality care, and ongoing disconnection from social and occupational pursuits.

⁵ Yeo, M, Hughes, E. (2011) Eating disorders: early identification in general practice. *Australian Family Physician* 40(30), 108-111

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 The National Eating Disorders Collaboration, 2010. Eating disorders prevention, treatment & management: An evidence review. Sydney: NEDC.

⁸ Deloitte Access Economics, 2015. Investing in need: Cost-effective interventions for eating disorders. Butterfly Foundation.

⁹ Deloitte Access Economics, 2012. Paying the Price: The economic and social impact of eating disorders in Australia. Butterfly Foundation.

¹⁰ Economic Evaluation of the Peer Mentoring Program – Eating Disorders Victoria, 2018. Prepared by The Incus Group

¹¹ Appendix 1 – Cost Benefit Analysis infographic.

From 1 November 2019, Medicare will provide additional rebates for people seeking treatment from psychologists and dietitians for treatment of a diagnosed eating disorder. This recognises that eating disorders are serious mental illnesses that warrant specialist treatment. For the first time people across Australia will, arguably, be able to access a best practice, team-based approach to treatment that will provide support in their local area. The announcement of this new funding generated a commitment from both national leaders of the major political parties at the end of 2018 to battle the group of eating disorder illnesses.

5. Supporting Peer mentoring for people with eating disorders leaving hospital – what we have done and what we can do.

In 2016 EDV first received funding from three philanthropic foundations to pilot a Peer Mentoring Program (PMP) for people leaving hospital. The program uses a peer support model and harnesses the experience of those who have recovered as mentors, who are provided with regular debriefing and supervision. Mentors are paid as employees of EDV, rather than volunteers, and as such, this structured model is unique for people with eating disorders. Fortnightly mentoring sessions are conducted over a six-month period, where participants work towards achieving outcomes specified in a Wellness Plan developed in the first session¹². EDV offers participants continued support in a monthly PMP Alumni Group and access to other EDV services once they end the mentoring relationship.

- Outcomes achieved in the first two years are available at Appendix 2.
- Testimonials from participants and mentors who have participated in the program are available at Appendix 3.

There have been an additional 24 further referrals and mentoring relationships to date in 2018/19. These referrals have come from three hospitals. We know that it achieves positive outcomes¹³, including:

- 66% of participants were **not** readmitted to hospital
- 100% of participants report improvement in quality of life.
- 100% of participants report improvements in eating disorders assessments, especially in the areas of eating and body shape concerns.
- 100% of participants report a reduction in anxiety, depression and stress.
- More than 95% of mentors found the program reconfirmed their own recovery.

The Austin Hospital and St Vincent's Hospital are founding partners, and with the support of their specialist eating disorders staff we have developed a robust pilot program that has generated an important evidence base. In May 2018 a protocol paper was published¹⁴, and a

¹² PMP Protocol paper: <https://pilotfeasibilitystudies.biomedcentral.com/articles/10.1186/s40814-018-0268-6>

¹³ Appendix 2 – PMP outcomes infographic

¹⁴ PMP Protocol paper: <https://pilotfeasibilitystudies.biomedcentral.com/articles/10.1186/s40814-018-0268-6>

paper outlining pilot data is due for publishing in mid-2019¹⁵. There is much interest from across Australia and internationally for the program.

EDV advocated in 2018 and 2019 to secure recurrent funding for the program. From initial philanthropic funding in 2016, this was extended to a third year in 2018/19 to grow the evidence base. It was supported by a modest one-off grant from Minister Foley and the Victorian Government. EDV has obtained further funding from Minister Foley for the program in 2019/20. However, there are no recurrent funds committed for the program until the RCMHS makes its recommendations. Without government funding this successful and innovative program will cease, and so the program lurches from year to year despite the strong consumer engagement and proven successful outcomes.

We know that our Peer Mentoring Program is highly effective and can create an enduring impact on the rates of readmission and consolidation of recovery from an eating disorder, which for a modest investment will incrementally reduce impact and costs. Furthermore, this program has been demonstrated to be an important addition to the development of a continuum of care for people with eating disorders.

6. Request

- i. That the Royal Commission into Victorian Mental Health System supports the development of a statewide framework for eating disorders that includes a continuum of care for people with all types of eating disorders.
- ii. That the EDV Peer Mentoring Program be acknowledged as a valuable evidence based program and investment be allocated to expand this program across Victoria.

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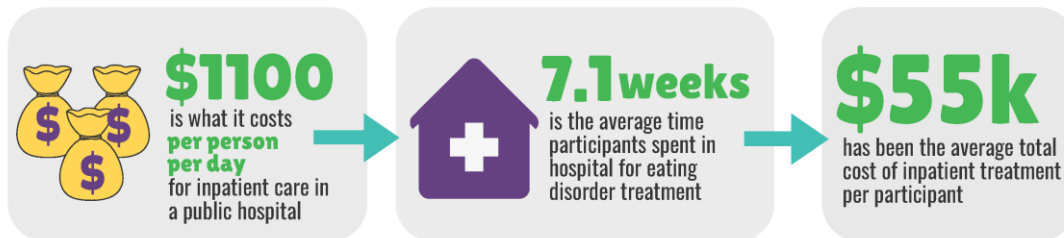
¹⁵ Peer mentoring for eating disorders: Results from the evaluation of a pilot program
<https://jeatdisord.biomedcentral.com/>

Appendix 1 – PMP Cost Benefit Analysis Infographic

Peer Mentoring Program

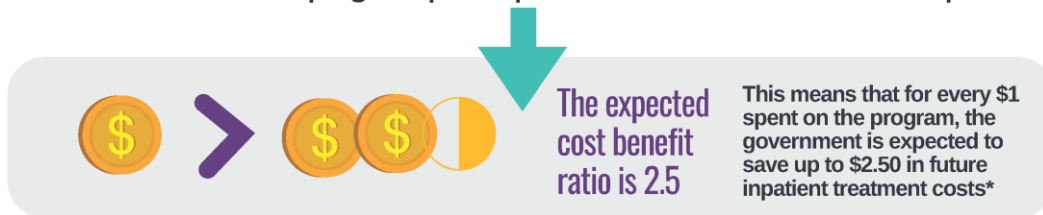
COST BENEFIT ANALYSIS

EDV procured an independent economic evaluation of the Peer Mentoring Program in September 2018 to determine the potential cost benefit of investing in the program. The results of the analysis are based on data from the 23 participants who have completed the Peer Mentoring Program so far.



Cost of the Peer Mentoring Program per participant = **\$13,000**

Given that 65% of program participants are NOT readmitted to hospital



THE ASK: **\$2m** over 4 years will allow for **200** new participants **& REGIONAL VICTORIA** from Melbourne

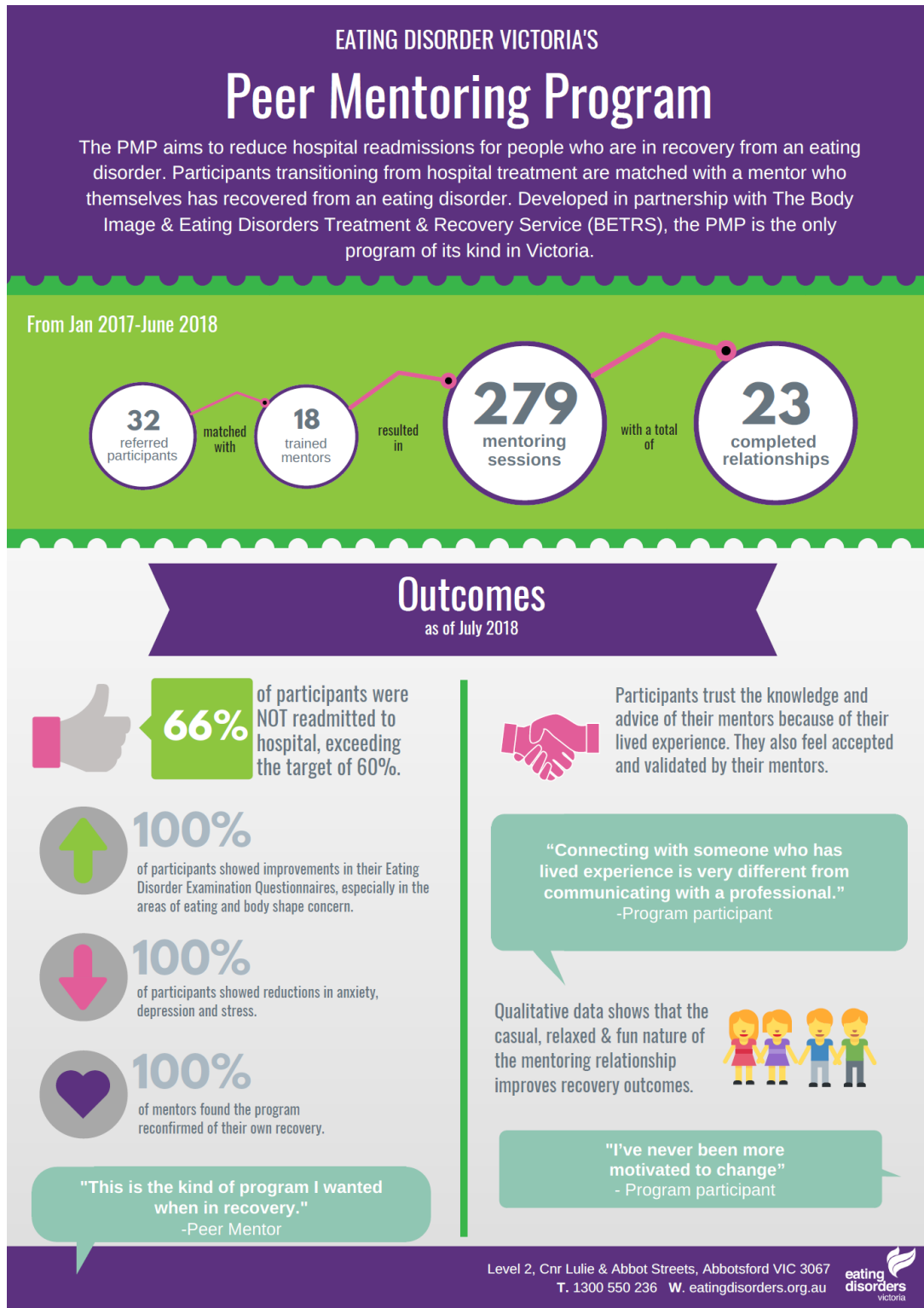
SUPPORT PEER MENTORING FOR EATING DISORDERS BEYOND 2019 #PeerMentoringforED



*Independent economic evaluation conducted by The Incus Group. For more information please contact EDV on 1300 550 236 or edv@eatingdisorders.org.au

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T. 1300 550 236 W. eatingdisorders.org.au

Appendix 2 – PMP Outcomes Infographic



Appendix 3 – Testimonials from program participants and mentors

“I have suffered from disordered eating for about 5 years, however it was only a year ago that it developed into orthorexia. My overexercising, avoiding fear foods that my ED termed as unhealthy, my erratic sleeping patterns and my decline in body weight all caused my family to become concerned in my health. I was admitted to the Austin Hospital with a dangerously low heart rate and blood pressure which was due to being severely underweight. After 2 weeks I was transferred to the Acute Psychiatric Unit of the hospital where I underwent cognitive based therapy in a hope to restore my body weight. During my 3-week admission, I was able to communicate my emotions to the nurses, psychologists and to peer mentors, to whom I am thankful for. I am still dealing with my ED through a day patient program called BETRS where I able to connect to a peer mentoring program provided by EDV. Through the program I can safely express my feelings and emotions, challenge my fear foods in a safe environment, and be provided support and encouragement from someone who has recovered from an ED themselves. It puts into perspective that my relationship with food and exercise can become balanced, I can be flexible in terms of social events and that one day I can recover.” – Participant

“I was formally diagnosed with Anorexia Nervosa late 2017, with 2 inpatient admissions in 2018 totalling to around 10 weeks, and spent around about 4 months in a day patient program following, at this current moment I am writing from hospital due to a setback in my health over the Christmas period, however I did manage to stay out of intensive treatment for around 5 months between the ending of 2018 and beginning of 2019 which my team saw as a huge achievement, however I see as being linked to having the extra support from my peer mentor. Below I have dot pointed only some of benefits I have found the peer mentor program to have given me and hope you can see why it is so useful and beneficial for people with eating disorders to have this program extended.

- *Gave me a sense of hope that I could recover as I hadn't met anyone recovered before*
- *Allowed me to challenge foods and experiences which I have avoided for years e.g. going to the movies and just sitting there (being still is a massive issue for me)*
- *Someone I could talk to about my struggles who really understood*
- *An opportunity to see life after anorexia*
- *Encouragement to stick to my meal plan and follow my dieticians' orders in regard to exercise*
- *Support when I was told I had to go back to hospital and a visitor to make my admission less painful*
- *Someone where I didn't feel the need to be fake, I could be me. I don't need to censor what I say or put a brave face on when eating. I can cry, shake and panic and my mentor will be with me throughout it all and encourage me to strive to go that one step further*

Finally someone to do stuff that isn't ED related, with the focus of my life always on my ED being able to have someone to do things that don't have to focus fully on my ED and can explore what I might actually enjoy/different ways of coping/general life experiences puts a life where my ED is at the forefront towards the back for a small period of time allowing a break and time for my brain to settle slightly.” – Participant

“I was diagnosed with Anorexia Nervosa in late 2017. I began treatment in early 2018 and soon after became part of the Peer Mentoring Program. The program allowed me to interact with a past eating disorder sufferer and gave me tremendous support in overcoming my illness. My mentor showed me what it was like to live without a crippling mental illness, and installed many coping strategies in me that I still use to date. The program not only benefitted my life in so many ways, but it has helped my family too – as they saw the improvements in my mental health whilst participating in the program, and therefore were given confirmation that I was getting better.” – Participant

“The program is the best thing I ever did. Through my treatment I had only ever met other sufferers and wondered if anyone actually ever got better. The peer mentor program showed me that recovery is possible – and worth it. The most valuable message my peer mentor gave me was that has been most valuable is that if someone had told her how amazing life was once you recover, she would have made the decision to recover years ago. Since the program I’ve been able to take up full time work for the first time as well as move out of home. The program and the support and inspiration I received through it was the catalyst to achieving these big milestones. I would hate to imagine where I would be in my life if I hadn’t partaken in the program.” – Participant

“I was diagnosed with binge eating disorder, anxiety, depression and body dysmorphic disorder after many years of experiencing these illnesses. It’s been a long and at times, really tough journey, but one that I’m proud to say I’m now recovered from. It was my lived experience that connected me to Eating Disorders Victoria and soon after I was provided with what has been a life changing opportunity to commence working as a Peer Support Mentor. Up until this point in time, I had never met someone who had recovered from an eating disorder and this is when I realised just how unique and also vital the Peer Mentoring Program (PMP) is. In the last three years of being involved with PMP, I have had the absolute honour of being able to share my story on many occasions, be part of the most empowering team of peer mentors and EDV staff and most importantly, support several individuals throughout their experience of recovery from an eating disorder. The positive outcomes and the many steps forwards in these individuals recovery has the PMP to thank for that. I ask that you kindly consider the incredible value the PMP not only to the effected individuals, but their families and the wider community.” – Mentor

“I began work with EDV as a peer mentor and was incredibly excited and inspired not only by the program but by the organisational staff, the other mentors and most of all the program participants. The program offered me a sense of purpose and the acknowledgement that a difficult time in my life could actually be of use to someone else took the sting out of 'losing' so much time and effort to the illness and recovery process. Nothing like this existed when I was struggling with my eating disorder, I had never met a person who had recovered until joining this program as a mentor. This fact made it very difficult at the time to think that I would ever recover, and it was easy to believe the stigma that I would be 'stuck' with the illness from that time on....this is not the case. I can't fully articulate how comforting, inspiring and therapeutic it would have been to simply talk to someone who had had a similar experience.” – Mentor

“My eating disorder was all consuming and I struggled to seek formal treatment. A key turning point in my recovery was meeting others who had had similar experiences. The journey to recovery was long with many setbacks. I am very grateful to have survived this experience and now be in my fourth year of studies to become a Psychologist. As a mentor with EDV I have seen the powerful impact connecting people of shared experiences can be. It offers hope for both participants and mentors. I am continuously reminded of the importance of self-care, choosing recovery and seeking help. The coordinators of this program assure the wellbeing of mentors throughout and support us to create safe boundaries with our participants. My participants share openly with me about what they are going through and our sessions are rich with recovery focused conversations. This unique relationship which is not friendship, not clinical but somewhere in between makes recovery feel possible.” – Mentor

“My personal experience involves a diagnosis of Anorexia Nervosa when I was 16 years old, after this diagnosis I see-sawed through other variations of eating disorders such as binge eating disorder, bulimia type behaviours, depression, anxiety and self-harm until I was around 24 years old. I had a hospital admission of 3 weeks in Adelaide of which was a very mixed experience for me. For my entire length of illness I had never met anyone of whom had recovered from an eating disorder. Until recently, being the beginning of the program, when going through the interview process in late 2016 where I met many other individuals who have not only recovered from an eating disorder, but like me have been involved in the peer mentoring program. The program provided an avenue to transform what was largely a difficult experience into something where I was seen to have knowledge that others did not and therefore enabled me to provide support to other people currently unwell. As someone who has previously had an eating disorder it would have been incredible to have a program such as this to exist. In the midst of illness it can feel like you will never be well, this program provides proof that people will and do become well. The participant I worked with in the community for a period of 8 months said that it was the single most effective intervention for their journey to recovery in their many years of being unwell. As a new mental health nurse I see people with eating disorders in the acute mental health sector. Please support these community based and consumer driven programs, I have seen this program make a world of difference to so many individuals.” – Mentor