

Preventing hospital admissions and improving community care of Victorians affected by eating disorders

Pre-budget submission prepared by
Eating Disorders Victoria (EDV)

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Thank you for reading Eating Disorders Victoria's 2020 pre-budget submission.

Approximately

1 in 20

Australians has
a diagnosable
eating disorder.

That's around

234,000

Victorians, or

enough people to
fill the

MCG 2x

Eating Disorders Victoria (EDV) is the leading 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 offer a unique blend of clinical and non-clinical support services. This includes the EDV Hub (a free and confidential phone, email and face-to-face support service), comprehensive website, in-house psychological and dietetics service, psycho-educational programs, support groups, recovered speakers, accredited professional training programs and a pioneering Peer Mentoring Program. EDV has a team of 10 staff and a base of 50 active volunteers.

Executive summary

This submission reflects the innovative and responsive ways Eating Disorders Victoria can deliver effective community care that keeps more Victorians out of acute hospital treatment.

Eating disorder diagnoses¹ are increasing in Victoria. From 2008-09 - 2017-18, eating disorder principle diagnoses¹ increased 11.1 per cent annually, the largest increase of any mental health condition.¹ This increase is indicative of the overall increase in eating disorder prevalence globally.² Despite this, funding for eating disorder related services has not increased year on year to keep up with increasing demand.

As we await the final recommendations of the Royal Commission into Victoria's Mental Health System, we must continue to address the **current** needs of people and families affected by eating disorders.

Best practice guidelines stipulate that people experiencing eating disorders should be treated as outpatients (i.e. in the least restrictive environment) as much as possible.³ Eating Disorders Victoria is uniquely placed to provide community-based support services that can't be replicated in a hospital or private treatment setting.

Eating Disorders Victoria is asking the State Government to fund the following initiatives in the 2020-2021 state budget.

Funding proposals

1. Extend and increase current funding of EDV's Peer Mentoring Program. ***\$1 million over two years.***
2. Fund a pilot Eating Disorder Family/Carer Coaching Program. ***\$0.5 million over over two years.***
3. Co-fund the Patient Pathways Telehealth Nurse Service so that this role can meet the need of the community on a full-time basis. ***\$0.2 million over two years.***
4. Prevent hospital admissions through increasing access to 40 MBS items for severe eating disorders. ***\$0.08 million over 1 year.***

Proposal 1

Extend and increase current funding of EDV's Peer Mentoring Program.

Background and rationale

The Royal Commission into Victoria's Mental Health System interim report identifies that expansion of the paid Lived Experience workforce will be a key part of a reformed system.⁴ EDV's Peer Mentoring Program is an example of a well-established peer support program for adults with eating disorders that:

- utilizes a paid peer workforce
- has established structures for robust supervision and,
- frameworks to ensure participation is mutually beneficial for both the consumer and the peer worker.

The program was created to address the high rate of relapse (up to 50%) experienced by adults who receive treatment for eating disorders in a hospital setting. The three-year pilot program commenced in 2016 and was funded through a combination of philanthropic and state government funding.

An evaluation of the first two years of the pilot confirmed the feasibility of the program.⁵ Key outcomes from the conclusion of the three-year pilot include:

- **23 people who have recovered from an eating disorder recruited and trained as Peer Mentors.**
- **467 mentoring sessions resulting in 37 completed mentoring relationships.**
- **73% of participants were not re-admitted to hospital throughout the six-month duration of their mentoring relationship. This far exceeded the program goal of 60%.**
- **89% of participants showed improvements in their Eating Disorder Examination Questionnaires, especially in the areas of eating and body shape concern.**
- **100% of mentors found the program re-confirmed their own recovery.**

An eating disorder bed costs approximately \$1100 per patient per day. An independent economic evaluation of the program estimates a cost benefit ratio of 2.5.⁶ With an average hospital stay of 7.1 weeks per participant in the first two years of the program, the program points to a significant cost benefit for the public health system.

The Victorian Government supported the continuation of the program in 2019-2020 with a one-off injection of \$250,000. As of July 2020, the program has no recurrent funding.

Increased investment needed

Currently in its fourth year, the program is on track to exceed the participation target by 25%. EDV expect that with continued investment, we can double the amount of participants in the program per year over two years (year four = 40 participants, year five = 80 participants) and expand the service to people in rural and regional areas.

Investment

\$1 million over two years commencing 2020 - 2022



Program testimonials

"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."

"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."

"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."

"An opportunity to see life after anorexia."

"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."

"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. It 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." - Peer Mentor

"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." - Peer Mentor

"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." - Peer Mentor

Proposal 2

Fund a pilot Eating Disorder Carer Coaching Program that provides weekly coaching for 24 families per month.

Background

The Royal Commission into Victoria's Mental Health System interim report identifies the need to educate and empower families. Through doing this we improve the mental health status of both the carer and person they care for.⁷

Whilst being a carer is difficult in all areas of mental health, caring for someone with an eating disorder presents unique challenges. The nature of severe eating disorders such as anorexia nervosa mean that patients are often resistant to professional interventions and can actively disengage from treatment until crisis in the form of severe medical instability and hospitalisation occurs. Carers of people with eating disorders are found to have high levels of distress, poor quality of life, high levels of caregiver burden, and their own mental health conditions such as depression and anxiety.⁸

Gaps in the current eating disorder carer support system

In the public mental health system, carers of those under 18 with a diagnosis of anorexia nervosa are encouraged to undertake Family Based Treatment (FBT). FBT provides the strongest evidence base for lasting recovery and requires families to create a "hospital in the home". This approach requires 24/7 commitment from carers in the form of supervision, re-feeding and distress management. Support from clinicians is only available to carers 1-2 hours per week and these interactions are often with the presence of the young person, making it difficult for carers to access one-on-one support. Carer peer support workers exist in CAMHS/CYMHS services, however they often do not have the specialist skills or knowledge required for FBT.

For carers of adults with eating disorders, the default position of medical privacy means that carers are often locked out of treatment discussions. This can leave carers disempowered and ineffectual in their caring capacity. Whilst there are some carer peer support workers in the public mental health system, they do not specialise in caring for people with eating disorders. Furthermore, many adults with eating disorders are in the private outpatient system, making access to public mental health carer peer support workers not possible.

CEED Carer Consultant

The CEED Carer Consultant role is primarily a support for public mental health clinicians and services, providing carer input into secondary consultations, development of carer focused resources, supporting outpatient teams with focused single sessions on FBT, and supporting the two carer peer support workers working in CAMHS.

Carers are not able to contact the Carer Consultant directly. If direct sessions are held they are one off sessions to support a family who may be particularly stuck in treatment. The Carer Consultant and the CEED clinician who attend this session provide the carers and the team with suggestions for other services and resources, of which one may be a Carer Coach available through this project.

The case for specialised eating disorder carer support

Addressing the needs of carers is essential if we want to improve recovery rates and decrease carer burden. A key part of addressing this need is recognising that caring for a person with an eating disorder is a long-term and skilled commitment.

Skilled and empowered carers contribute to improved long-term recovery outcomes. This is true both of parental carers, as well as partner and sibling carers.

*"The rationale for parental involvement in adolescent AN is intended to address the motivational deficits inherent in AN and the unique ego-syntonic nature of this illness. Likewise, motivational deficits and ego-syntonicity are issues in adult AN and may be improved by the enlistment of carers to manage and oversee initiation and maintenance of recovery-oriented behaviours in a modified, age-appropriate manner."*⁹

*"Not only are adults with AN frequently in relationships, but patients emphasize the centrality of their partners in the recovery process. For example, in a follow-up study of 70 women who had been treated for AN 10 years earlier, we explored the women's perceptions of factors contributing to their recovery. The most commonly cited factor associated with recovery was having a supportive partner. In fact, women with AN reported that a supportive relationship was the "driving force" in their recovery."*¹⁰

Proposed solution: Eating Disorder Carer Coaches

Eating Disorders Victoria have successfully modelled a Peer Mentoring Program (PMP) for people in recovery from eating disorders. The PMP has proven how important it is for people affected by eating disorders to connect with those with lived experience to validate their experience and gain hope for recovery. Like people in recovery from an eating disorder, carers also need to develop toolkits, skills and importantly hope for their loved one's recovery.

There is currently no eating disorder specific peer support program for carers in Victoria. **The Carer Coaching Program will employ people who have lived experience of caring for someone with an eating disorder to provide Victoria's first direct peer support service to eating disorder carers.** Carer Coaches will be trained within the Intentional Peer Support framework using EDV's extensive knowledge of best practice peer support.

We propose that the following carers will be eligible to access this service:

- Carers currently undergoing Family Based Treatment (FBT) or those who have completed FBT within a six-month period.
- Carers who's loved one has been in an eating disorder inpatient, outpatient or intensive day program in the past six months.
- Carers who's loved one is currently accessing an Eating Disorder Plan through the Medicare item numbers.

The Carer Coaching Program will provide people with direct support on issues relating to re-feeding, distress management, containing compensatory behaviours, managing family life, sibling support and self-care.

Carers will be matched to Carer Coaches based on need and experience. Coaching sessions will be conducted over the phone to reduce travel time and cost and thus expand the capacity of the program. With this model we expect to employ 1.6 EFT Carer Coaches who will support 24 carers per month with a weekly one-hour coaching session. Carers will have weekly access to their coach over a 1-2 month period.

Carer Coaches will receive robust supervision and training through a Carer Consultant. We will also build in an external evaluation of the program to ensure ongoing feasibility.

Proposed outcomes:

Measurement tools:

- External evaluation based on the framework used by Eating Disorders Queensland's Carer Coaching program that has been funded by Queensland Health and successfully running for two years.
- Family Coping Questionnaire for Eating Disorders (FCQ-ED)
- Carer feedback

We anticipate the following outcomes:

- **Decrease in eating disorder hospital admissions**
- Improvements in the Family Coping Questionnaire for Eating Disorders (FCQ-ED), particularly in the Parents versus Anorexia Nervosa scale for adolescents with eating disorders and the Accomodation and Enabling scale for adults with eating disorders.
- Decrease in reported carer burden

Investment needed

- 1.6 EFT carer coaches providing a five day a week phone/video coaching service
- 24 families/carers supported per month with weekly phone coaching sessions
- 1 carer consultant to provide coordination, support and training to the peer coaches
- Development of a suite of online education modules for carers

Investment

\$0.6 million over two years commencing 2020 - 2022

Proposal 3

Co-fund the existing 2-day per week Commonwealth funding for EDV's Patient Pathways Nurse.

Background and rationale

The Royal Commission into Victoria's Mental Health System has identified the very real and distressing challenges for people with mental illness and their families in navigating our mental health system.

Eating disorders are no exception to this. The current service system for people with eating disorders is fragmented, siloed and confusing. This is compounded by poor eating disorder recognition from primary health providers (eg. GPs) and an overall inadequate knowledge of treatment referral pathways.

With the absence of an informed primary health provider, most people with eating disorders are required to self-navigate or rely on family to advocate and navigate the system on their behalf. For adults with eating disorders, this process is further hindered by AHMS services generally not treating eating disorders and specialist services having high demand and difficult entry requirements (e.g. BMI, motivation and insight).

Given the ego-syntonic nature of eating disorders, a person with an eating disorder may lack the motivation or insight to seek help themselves, leading to high rates of disengagement and relapse.

Addressing the need for navigation support: EDV's Telehealth Nurse

Since July this year, EDV have been part of a Telehealth Nurse pilot, known as the Patient Pathways Program. The Patient Pathways Program is a three-year Commonwealth funded initiative of the Centre for Community-Driven Research (CCDR) and involves 11 organisations Australia-wide. EDV is the only mental health organisation in this trial.

The program has allowed EDV to employ a telehealth nurse two-days per week. **This is Victoria's first telehealth nurse specifically for eating disorders.** Given that anorexia nervosa has the highest mortality rate of any mental illness, this support service is much needed and long overdue.

The telehealth nurse is a free service that provides personalized case management and advocacy for individuals affected by eating disorders and those that care for them. People can self-refer to the nurse service or can be referred through our existing information and support service, the EDV Hub.

Data from the first five months of the program highlight the increasing demand for the telehealth nurse service. Most notable has been the significant increase in contacts during this period (phone calls, emails, contact with treatment teams). This figure indicates the ongoing connection that the telehealth nurse has with individuals who are linked with the program. Given that many individuals with eating disorders struggle to stay motivated and engaged in treatment, this ongoing connection is a highly positive sign.

	July 19	Aug 19	Sept 19	Oct 19	Nov 19
Referrals: Person with eating disorder	4	3	8	5	4
Referrals: Carer	2	4	2	3	8
No. of contacts with nurse	14	14	35	111	131

Investing in the need: EDV using reserve funds

Following the positive results of the first few months of this trial, EDV's Board felt that it was important to continue to invest in this service so that the telehealth nurse can continue to connect with and support more Victorians.

The decision has been made to dip into our scarce surplus to fund this role for an additional two days per week, however this is only feasible until the end of June 2020. **We are asking the Victorian Government to co-contribute to the existing Commonwealth funding to enable the expansion of this role into a full-time position for the remainder of the trial period.**

Note: The expansion of the telehealth nurse role into a full time position will not compromise the trial with the Centre for Community Driven Research (CCDR). The CCDR have given their full support to the expansion of the role.

The impact of the telehealth nurse service: a real-life case study

Below is a real-life case study that outlines the pivotal role the telehealth nurse can play in navigation, advocacy and coordination of care.

A 24-year-old female with a history of anorexia nervosa as a teenager (10 years prior) was having a recurrence of symptoms with associated medical instability requiring weight restoration. The client self-referred to EDV whilst still an inpatient within an eating disorder adult unit. The client wanted to make a discharge plan including referrals to community-based ED clinicians prior to leaving the inpatient program to ensure adequate support was in place.

The Telehealth Nurse (THN) completed a comprehensive assessment over the phone, including the client's medical, psychological and social history, her current diagnosis and her current goals. From this assessment, it was identified that the client would benefit from referrals to private clinicians but lacked the confidence and knowledge to do so independently. The THN coordinated a referral to a private psychologist after investigating suitable options and waitlist times. The THN scheduled weekly follow-up phone calls to monitor the client's progress. The THN also provided the client with tangible tools to assist with distress management at home (mindfulness, safety plans and anxiety wave tools).

The client then showed signs of risk-related behaviour (an admission to ED for medication overdose/anxiety crisis). The THN, with client's consent, coordinated the client's care by establishing regular communication between the health professionals involved in client's care team. This worked to improve information sharing on the client's progress and to identify any potential risks associated with the client's physical and mental wellbeing. The client has subsequently shown improvements in her weight restoration/medical stability, a reduction in risky behaviours, improvements in her ability to identify and manage distress, increased confidence/motivation for recovery (as communicated by the client over the phone), and an overall increase in engagement with treatment.

Proposed outcomes:

- **Decrease in hospital re-admissions**
- Increase in clients engaging in treatment and a multidisciplinary team
- Increase in clients with defined family / external support

Regular feedback intervals are also built into the program pathway enabling the collection of qualitative data.

Investment

\$0.2 million over two years commencing 2020 - 2022

Proposal 4

Preventing hospital admissions through increasing access to 40 MBS items for severe eating disorders.

Background

In November 2019, new eating disorders item numbers were introduced into the MBS Schedule providing rebates for up to 40 psychological therapy sessions and 20 dietetic sessions in 12 months to eligible Australians with eating disorders. This significant increase in rebates for eating disorders has the potential to provide access to evidence-based treatment for a significant number of people with moderate to severe eating disorders.

Access to the full 40 psychological therapy sessions is reliant on a psychiatrist review after 20 sessions. This presents a significant challenge for both metropolitan and regional/rural Victorians due the limited availability and long wait times of general psychiatrists, compounded by the scarcity of psychiatrists who specialise in eating disorders. (EDV currently have just four psychiatrists on our referral database for the whole of Victoria who have a special interest in eating disorders)

Proposed solution: EDV Psychiatrist (in-person and telehealth)

EDV currently operate a private clinic with four contract eating disorder psychologists and one contract eating disorder dietitian. This fee-for-service social enterprise program has been successfully operating at EDV for over seven years.

We would like to add a psychiatrist to the EDV Psychology and Dietetics service to facilitate access for clients across Victoria **to the second 20 psychological sessions available through the MBS**. We currently provide psychology and dietetics services with MBS funding at a reduced cost to clients to facilitate affordable access. We are also looking to introduce a telehealth provision of these services in 2020 to increase our reach to people across Victoria.

Adding a psychiatrist to our service is currently not viable without additional funding due to a number of significant set up costs that are required for this service. Once established, we plan to support a psychiatrist in an ongoing capacity through MBS rebates.

Project requirements

Recruit and set up facilities for a psychiatrist* to be able to provide an in person or telehealth Eating Disorder Plan review (and where appropriate the initial Eating Disorder Plan assessment where client cannot access a willing GP).

We would need to set up video conferencing facilities, medical equipment, set up clinical governance structures and market the service to PHNs, eating disorder services, AMHS and CAMHS.

*We have a Victorian eating disorders specialist psychiatrist already interested in the role, especially in providing telehealth.

Proposed outcomes:

Increased access to the full 40 MBS rebateable sessions for Victorians with an eating disorders from any location, measured by:

- **Decrease in hospital admissions and intensive treatment options**
- Numbers of clients (6 per week, 280 per year)
- Numbers of clients accessing 40 sessions
- Number and percentage of rural and regional clients supported

Investment needed

- Recruitment of psychiatrist
- Set up rooms, IT infrastructure and clinical governance
- Marketing of service

Investment

\$0.08 million over 1 year commencing 2020

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