

Mental Health Royal Commission Establishment
Department of Premier and Cabinet
1 Treasury Place
Melbourne, VIC 3002

Jan 25th 2019

Eating Disorders Victoria submission on the Terms of Reference for the Victorian Royal Commission into Mental Health

About Eating Disorders Victoria

Eating Disorders Victoria (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 offer a unique blend of clinical and non-clinical support services to carry out our mission. This includes a free and confidential Helpline service, comprehensive website, in-house psychological and dietetics service, psycho-educational programs, accredited professional training programs and a pioneering Peer Mentoring Program. EDV also engage with key government and community stakeholders to help shape policy that is needed to reduce the impact eating disorders in the community. EDV is an incorporated association and a registered charity. Our revenue is derived from a combination of Victorian Government grants, philanthropy, fee-for-service programs and fundraising.

What are eating disorders

Eating disorders are serious psychiatric illnesses that do not discriminate- they affect people of all ages, genders, socio-economic status and backgrounds. The Diagnostic and Statistical Manual of Mental Disorders (DSM) 5 outlines the following diagnoses for eating disorders: Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, Pica, Rumination Disorder, Avoidant/Restrictive Food Intake Disorder (ARFID), Other Specified Feeding or Eating Disorder (OSFED) and Unspecified Feeding or Eating Disorder (UFED).

Over 1 million Australians are currently experiencing a diagnosable eating disorder, 234,000 of whom are in Victoria. Prevailing myths and stigma around eating disorders often results in a lack of understanding and delayed help seeking. Eating disorders are long-term illnesses, with the average duration for an eating disorder lasting 10 years. Anorexia Nervosa also has the highest mortality rate of any psychiatric disorder.

The Victorian Royal Commission into Mental Health

EDV commend the Victorian Government on their commitment to undertake this Royal Commission into Mental Health and to enact all the Commissioner's final recommendations. We thank you for the opportunity to contribute to the development of the Terms of Reference.

EDV believe that the Royal Commission into Mental Health provides an important opportunity to investigate and improve upon the service system for people experiencing eating disorders in Victoria. Eating disorders are complex mental illnesses that require

specialist, integrated care across both the mental health and medical sectors. The Royal Commission provides an immense opportunity to rectify the fragmented, confusing and for many people, ineffective, current eating disorder service system, and create a much-needed continuum of care for individuals and families.

The outcomes of the Commission also provide an opportunity to build upon the strategic policy work that has already been undertaken at both a state and national level. This includes the Victorian Eating Disorders Strategy (2014) and the National Agenda for Eating Disorders (2017).

Key focus areas for the Royal Commission

EDV fully support all ten themes that have been identified as key focus areas for the Royal Commission. Some themes are of particular importance to eating disorders and are highlighted in more detail below.

1. Prevention and Early Intervention

- Early intervention is vital to ensuring the best recovery outcomes for individuals experiencing eating disorders.
- ✓ EDV requests the Commission look at the barriers to help seeking for eating disorders, particularly around the lack of understanding, shame and stigma around eating disorders.

2. Accessibility and navigating the mental health system

- ✓ EDV requests the Commission look at the Victorian eating disorder service system holistically to specifically address:
 - **Lack of availability of eating disorder services.** Access to services requires the availability of services to exist in the first place. Victoria urgently needs more eating disorder services to treat and support individuals and families across the entire duration of the illness. Establishing a continuum of care is imperative to ensuring individuals can achieve and maintain long-term recovery outcomes.
 - **Lack of step down services from acute care.** Many people who require medical care access acute treatment, however the ongoing psychological causes of their illness remain inadequately addressed. This results in the continuation of the eating disorder and a pattern of cycling in and out of acute treatment facilities.
 - **Barriers to access based on geographical constraints.** Certain services are only available to people who live in certain geographic areas or catchment zones.
 - **Barriers to access based on specific criteria,** such as certain BMI levels. This excludes many people who aren't considered 'sick enough' for treatment. Often the combination of geographic and symptom criteria results in a double bind for people who are seeking treatment.

3. Community mental health services

- Eating disorders are long-term illnesses - the average duration of the illness is 10 years. Community mental health organisations, such as EDV, are more likely to be engaged with and accessed by individuals and families across the duration of the illness than acute care settings. Community mental health services are also uniquely placed to support individuals and families in the step up / step down process from acute care.
- ✓ EDV requests the Commission look at the investment and support of community mental health services and their ability to contribute to the sector through innovative and impactful services.

4. Acute mental health services

- The acute treatment settings for eating disorders currently has extremely narrow and constrained eligibility requirements. Too many people are unable to access to acute care because their illness is not considered severe enough.
- ✓ EDV requests that the Commission review the eligibility requirements for acute care settings so that access to services is more equitable.
- Eating disorders are unique in their cross over between the psychiatric and medical health systems. Outside the limited number of specialist eating disorder wards, patients who receive acute treatment in medical wards are often lacking psychological supports. Many patients and families complain of a lack of understanding from medical staff, insensitive comments and inadequate access to psychiatric services.
- ✓ EDV requests the Commission investigate the relationship between the mental health and medical health systems around eating disorders, with the goal to create a more integrated, patient centred care system.

5. Preventing suicide

- Anorexia Nervosa, whilst accounting for 3% of people who experience eating disorders, has the highest mortality rate of any psychiatric illness as a result of suicide and physical complications.
- ✓ EDV requests the Commission specifically include eating disorders as part of the investigation into suicide prevention and related services.

6. Workforce development and retention

- Eating disorders require specialist knowledge from people in the health system. GPs in particular are the front line for accurately assessing and diagnosing eating disorders. We know that too many people fall through the cracks of the health system and do not receive the help they need because workers are not trained to recognise eating disorders and respond appropriately.
- ✓ EDV requests the Commission consider the training requirements of primary health workers for eating disorders, notably GPs.

Additional Recommendations

EDV would also like the following to be included in the Terms of Reference for Royal Commission.

7. Carer/family support

Eating disorders are often all consuming illnesses that deeply affect the lives and wellbeing of carers and families. Many parents, siblings, grandparents, partners, friends etc. experience frustration, helplessness and burn out caring for someone with an eating disorder. However, research also shows that family involvement and support in treatment can lead to the best recovery outcomes. Unfortunately, it is the practice of clinicians/treatment services in Victoria to default to excluding family members/support people from inclusion in the provision of services for those with mental ill health, citing privacy reasons. We believe it is important for treatment services to encourage people to include their family/support people in their treatment and continue to advocate the importance of their inclusion.

- ✓ EDV requests the Commission address the involvement of families of origin and families of choice across all areas of eating disorder treatment. This includes focusing on the inclusion, education and empowerment of carers, as well as external supports offered to carers.

Achievements of the Royal Commission

EDV would like to see the Royal Commission recommend holistic, structured and integrated reform across the mental health and medical health systems so that a thorough **continuum of care** is established for people experiencing eating disorders in Victoria.

Key to achieving this outcome will be:

- Investment in more eating disorder specific services across all of Victoria
- Investment in community mental health organisations that support individuals and families affected by eating disorders, particularly in step up/step down services.
- Established, unified structure around pathways for help-seeking
- Reviewed eligibility criteria for treatment services that is more inclusive, both geographically and medically.
- Education/training of front line health workers that is eating disorder specific.
- The inclusion of families as an integral part of treatment, rather than an additional/optional support.

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