A comprehensive approach to eating disorders

Introduction

An estimated one million Australians have eating disorders. Anorexia Nervosa has the highest death rate of any mental health condition. Increasingly, eating disorders are being diagnosed in pre-teen aged children and the COVID pandemic has exacerbated the impact of eating disorders on patients and made it more difficult to access timely treatment and support.

About Eating Disorders Families Australia (EDFA)

Eating Disorders Families Australia (EDFA) is a national, not-for-profit organisation. Our role is to support and advocate on behalf of the families and carers of loved ones with eating disorders. EDFA was formed in 2016 in response to the lack of practical support for families and carers. EDFA's board members have lived experience as carers of people with eating disorders and EDFA's work is undertaken primarily by volunteers. EDFA provides a range of services for families and carers including its **strive** carer support groups in every state and territory (with federal funding), expert education sessions, and personalised support through its Facebook community.

Why a Comprehensive Approach is Required

Progress has been made in recent years recognising and supporting people with eating disorders and their families and carers. This includes including Medicare-subsidised psychological and dietetic consultations; funding for residential eating disorder treatment facilities across the states and territories; and significant additional funding for eating disorders research.

However, the system remains ill-equipped to deal effectively with this national challenge in a way that is proactive, responsive, linked-up, efficient, targeted and sufficiently resourced. Services are overrun, difficult to access and often unaffordable; there is no continuum of care; and it is hideously complex to navigate an unconnected system that is beset by knowledge and information gaps.

People wait months for psychiatric or psychological support and face hefty out-of-pocket costs. Many experience the merry-go-round of going to the emergency department as the only treatment option available and being discharged without the necessary care or plan going forward. There is a significant lack of knowledge about eating disorders by GPs, other clinicians, care workers and educators. Families, carers, and their loved ones feel isolated, alone, and unsupported – they do not know where to go and tragically lose hope.

EDFA understands these issues cannot be fixed tomorrow. However, people with eating disorders and their families and carers **need the Federal Government to take the lead in committing to a comprehensive, integrated approach to eating disorders**, with the necessary investments in prevention, early intervention, treatment, family support, research, education, and awareness raising to address the health, social and economic consequences of eating disorders.

The Purpose of this Note

The purpose of this note is to stress the importance of a coordinated, integrated approach to eating disorders with the Commonwealth taking the lead working with the States and Territories and public and private providers. The note identifies additional areas of focus that EDFA considers are needed for a comprehensive approach to eating disorders that addresses known gaps and points of failure.

EDFA stands ready to work with government and the broader eating disorders and health sectors in developing and taking forward this proposed comprehensive approach. EDFA makes this request on behalf of the hundreds of thousands of mainly younger Australians and their families and carers who often feel powerless and isolated as they try to cope day-by-day with one of the most unrelenting, traumatic, and physically and mentally destructive health conditions.

Additional Areas of Focus

1. Acute In-Patient Care

- Require the States and Territories to provide sufficient specialised in-patient hospital treatment capacity for patients with acute eating disorders.
- Ensure patients with eating disorders and their families leave in-hospital care with a comprehensive post hospital care plan.
- Expedite the rollout of residential eating disorder facilities in each State and Territory.
- Provide step-down care for adults transitioning from in-hospital care into the community to reduce the cycle of relapse and re-admission, (i.e., day programs).
- Provide specialised training in eating disorders to relevant in-hospital physicians, nurses, psychologists, and other mental health staff.

2. Primary and Community Care

- Fund lived experience recovery coaches and mentors for people with eating disorders and their families, complementing clinicians and other supports.
- Fund in-home meal and behavioural support for carers who need practical assistance on their loved one’s first diagnosis and for adults living on their own.
- Reduce out-of-pocket costs for Medicare-funded eating disorder consults by psychologists and dietitians through block grants or consult-based incentives.
- Make eating disorders a *Head to Health* priority, providing entry level advice, knowledge about treatment options, system navigation, and acting as a hub for organising clinical and community-based support.

3. NDIS
   - Provide clarity regarding the eligibility of people with chronic long-term eating disorders for the NDIS, based on consistent criteria, without the need to be diagnosed with co-morbidities such as autism.

4. Workforce
   - Encourage the accredited training of GPs, allied health, counselling, and care professionals in the provision of eating disorder related treatment and support.
   - Develop innovative service delivery models to address long wait times, using telehealth, digital platforms, group-based support, and the accreditation of other relevant allied health professionals.
   - Enhance the coordination between GPs, psychologists, dietitians, and psychiatrists, using digitised patient care plans accessible by hospital and community providers.
   - Ensure that general mental health and suicide counselling entry points (e.g., Lifeline, Beyond Blue, Headspace) have the expertise to support and guide people with eating disorders and their carers towards more specialised support.

5. Research
   - Undertake research into innovative eating disorder treatments in Australia and internationally and develop/maintain a comprehensive eating disorders data set.

6. Families and Carers
   - Provide support for families and carers through lived experience carer support groups, coaching and mentoring; accessible information and education about eating disorders and their treatment; support for siblings; access to Head to Health; assistance with system navigation; and access to Carer Gateway support.
   - Practical patient consent and support arrangements for young adults with eating disorders, encouraging the sharing of information with family members involved in the patient's care (given anosognosia is a feature of the illness), access to joint and separate carer consults, regular review of patient consents, and efficient approaches to transferring treatment related decisions to immediate family members.

7. Schools
   - Introduce wellbeing, resilience, body image and online media education as part of the national curriculum from primary school age upwards.
   - Develop school support programs to enable students with eating disorders to remain in school if medically stable and well enough to do so, with meal and other support.
   - Provide training and information for teachers, school psychologists, social workers, and counselling staff in eating disorders.

8. Employment
    - Include people with long-term eating disorders in specialised mental health and disability employment programs, with providers receiving eating disorder training.

9. Body Image and Social Media
    - Develop a Responsible Body Image Strategy and Action Plan with positive role models, corporate/philanthropic partners, and government leading by example.
    - Require internet and social media providers to take-down harmful eating disorder content and ensure their algorithms do not push harmful extreme dieting, pro eating disorder and self-harm content to users.
    - Fund body image related internet and social media literacy intervention programs for people with or at risk of eating disorders and their families and carers, which utilise people with the lived experience of eating disorders.

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