



Strategic Plan

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ACKNOWLEDGEMENT OF COUNTRY

Eating Disorders Families Australia (EDFA) would like to acknowledge the Aboriginal and Torres Strait Islander peoples as Australia's First People and Traditional Custodians. We value their cultures, identities, and continuing connection to country, waters, kin, and community. We pay our respects to elders past, present, and future. Storytelling plays an important role in Aboriginal and Torres Strait Islander culture as a way of passing on knowledge and learning. This resonates strongly with us at EDFA as we believe in the power of storytelling to reduce stigma and generate a greater understanding of the family experience of eating disorders. EDFA is committed to providing a culturally safe workplace for Aboriginal and Torres Strait Islander people.



A NOTE FROM THE EXECUTIVE DIRECTOR

From very humble beginnings as a support organisation founded by a group of passionate parents in Melbourne in 2016, Eating Disorders Families Australia (EDFA) has grown to become the only national organisation providing a sole focus on the support and education of carers and families impacted by an eating disorder.

EDFA now offers support, education, advocacy, and counselling services throughout Australia and is supported by a largely part-time workforce equating to 6.6 full-time equivalent staff, assisted by a small army of volunteers. We are immensely proud of all that we have achieved so far in advancing the interests of eating disorder families in Australia and we are so excited about what is ahead.

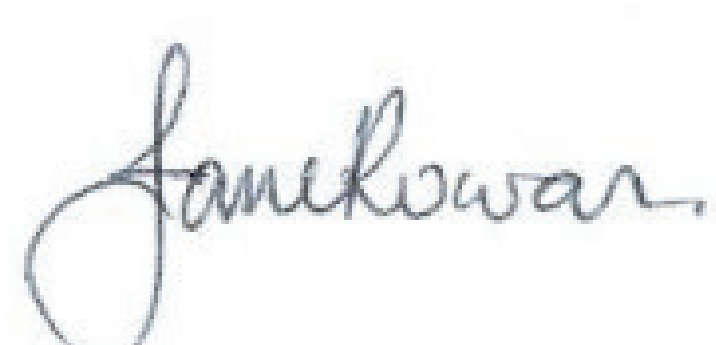
Our vision for the next five years of EDFA's development is ambitious, but it is rooted in the unwavering belief that every family touched by an eating disorder deserves understanding, empathy, and access to the resources necessary for recovery. By 2028, we want eating disorder families to receive timely and effective support from all facets of our community, including health care professionals, the government, and the community. We expect families and carers to be placed at the centre of the treatment and recovery team, regardless of the age of their loved one, and to be valued as an essential partner on this journey.

Most importantly, we want to see the National Eating Disorders Strategy well on its way to full implementation with every aspect of its stepped system of care engaged in providing the services and support those with an eating disorder and their carers need for lasting recovery.

EDFA is committed to working collaboratively across the eating disorder sector to effect this implementation, to reduced duplication of effort, and to maximise outcomes for all impacted by eating disorders. This philosophy underpins our strategy and informs all of our activities.

Finally, EDFA's strategic plan is more than a document, it is a pact - a commitment to the individuals and families whose lives have been touched by the often-hidden struggle of eating disorders. Together, we will work tirelessly to create a future where every person affected receives the understanding, support, and care they deserve.

Warm Regards,



Jane Rowan

ABOUT EDFA

WE ARE THE ONLY NATIONAL ORGANISATION THAT FOCUSES SOLELY ON CARERS AND FAMILIES SUPPORTING A LOVED ONE LIVING WITH AN EATING DISORDER.

WE ARE A MENTAL HEALTH CHARITY THAT WAS FOUNDED BY CARERS FOR CARERS. WE BELIEVE IN THE POWER OF LIVED EXPERIENCE AND SHARING OUR KNOWLEDGE WITH OTHERS TO REDUCE THE TIME AND SUFFERING THE WHOLE FAMILY ENDURES. LIVED EXPERIENCE IS THE FOUNDATION OF ALL FOUR OF OUR SERVICES - SUPPORT, EDUCATION, ADVOCACY, AND COUNSELLING - AND WE BELIEVE THAT FAMILIES AND CARERS SHOULD BE RECOGNISED FOR THEIR ROLE AS THE FRONT LINE OF THE RECOVERY TEAM.

FACTS

1

1.1 MILLION AUSTRALIANS ARE CURRENTLY LIVING WITH AN EATING DISORDER, WHICH MEANS AT LEAST 4.4 MILLION AUSTRALIANS ARE IMPACTED BY AN EATING DISORDER.¹

2

FAMILIES AND CARERS OF THOSE LIVING WITH AN EATING DISORDER OFTEN EXPERIENCE HEIGHTENED LEVELS OF STRESS, ANXIETY, DEPRESSION, AND SOCIAL ISOLATION.

3

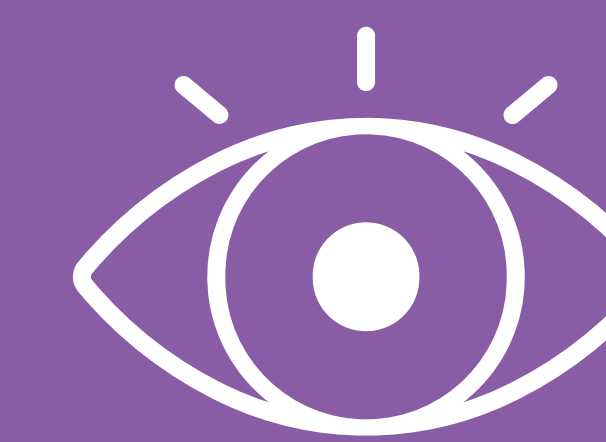
FAMILIES AND CARERS ARE THE FRONT LINE OF CARE AND CRUCIAL TO THEIR LOVED ONE'S RECOVERY.

OUR PURPOSE



THROUGH LEADERSHIP, EDUCATION, AND RESEARCH, EDFA IMPROVES THE LIVES OF EATING DISORDER CARERS. WE WORK TO CREATE STIGMA-FREE COMMUNITIES WHERE EATING DISORDER CARERS ARE RECOGNISED FOR THEIR VITAL ROLE AND RECEIVE THE ASSISTANCE THEY NEED. WE ACHIEVE BETTER OUTCOMES FOR THOSE WITH EATING DISORDERS BY HELPING THEIR CARERS TO NAVIGATE THE COMPLEX HEALTHCARE SYSTEM.

OUR VISION



FAMILIES AND CARERS IMPACTED BY AN EATING DISORDER ARE RECOGNISED, SUPPORTED, EDUCATED, AND EMPOWERED.

OUR MISSION



TO ENABLE FAMILIES AND CARERS TO BE EFFECTIVE SUPPORTS AND RECOGNISED AS A CENTRAL MEMBER OF THE RECOVERY TEAM FOR A LOVED ONE WITH AN EATING DISORDER.

¹ Mihalopoulos C, Hay P, Madden S, Touyz S, Wade T, Squire S, Wilton M, Farrar-Rabbidge M. (2024). Paying the Price Report, Second Edition. <https://butterfly.org.au/wp-content/uploads/2024/02/Paying-the-Price-Second-Edition-2024-FINAL.pdf>

REACH AND IMPACT

EDFA currently provides services to more than **3000** parents and carers of those living with an eating disorder. We have helped thousands more since our establishment in 2016.

92
Support Groups

In 2023, EDFA hosted 92 Carer Support Groups. We have hosted 352 Carer Support Groups since they went online in 2020.

21
EDucation Webinars

In 2023, we added 21 EDucation Webinars to our library, which now contains more than 160 hours of expert and lived experience educational resources.

118
Eating Disorder Carers

We supported 118 eating disorder carers through a total of 235 one-on-one counselling sessions with lived-experience counsellors between Oct 10 and Dec 31, 2023.*

*EDFA's Fill The Gap Counselling Service was launched on October 10, 2023 with funding from the Federal Department of Health.

POINT OF DIFFERENCE

Where we fit in the eating disorder sector:

EDFA provides critical support to families and carers of those living with an eating disorder. This is our sole focus and ensures those who inevitably end up with the main responsibility for successful eating disorder recovery are resilient, strong, and mentally well enough to fill their important role.

We take an unbiased approach to treatment, clinicians, and pathways of care, knowing that every recovery journey is different and what may work for one family may not work for another. Through research and our support, education, and evidence-based counselling services grounded in the lived experience of those who have been through it before, we help families navigate a complex system to improve recovery outcomes.

EDFA's Positioning Statement

EDFA is the only national organisation providing support, education, advocacy, and counselling SOLELY for carers and families impacted by an eating disorder.

Values

The goals outlined in this strategy reflect the long-standing core values of the EDFA Community, the most important of which is **Hope**. These values will continue to inform the way we work and deliver on our 2024-2029 Strategic Plan.

Hope

Underpinning everything we do is a strong belief we can make a difference to the lives of carers. We know recovery is possible for those living with eating disorders.

Empathy

We are best placed to support families and carers guided by our own lived experience journeys.

Respect

We are member and carer-focused, respectful, and compassionate.

Integrity

We are credible, a sound investment, honest, transparent, and reliable. We embrace research-informed, quality methods.

Innovation

We are focussed on continuous improvement - in our activities, in supporting carers, and evidence-informed services for those living with eating disorders.

Collaboration

We collaborate with stakeholders, we are inclusive, we embrace the value of diversity, and we create and faithfully represent our constituency.

The Challenges We Face

The COVID-19 pandemic caused a significant increase in eating disorders between 2020 and 2022, triggered by the significant social changes that occurred during this time including shifts in social routines, physical isolation, and disruptions to accessing healthcare.

72
International Studies included in a systematic review conducted in 2022 found an increase in disordered eating behaviours associated with the COVID-19 pandemic. It is fair to assume there was a similar trend in Australia.²

There is a growing body of evidence showing that eating disorders also have a significant impact on those around the person living with the eating disorder, including parents, siblings, partners and spouses, extended family members, friends, and colleagues. A 2023 study found parents reported worse than normal:



In addition:



Prevention, early intervention, better treatment options, and a greater focus on relapse prevention are essential for both the person with the eating disorder and their families. Greater community awareness and a reduction in stigma are also needed to ensure families receive the support they need.

²McLean C, Uptala R, Sharp G. (2022). The impacts of COVID-19 on eating disorders and disordered eating: A mixed studies systematic review and implications. *Frontiers in Psychology*. <https://doi.org/10.3389/fpsyg.2022.926709>

³Wilksch S. (2023) Toward a more comprehensive understanding and support of parents with a child experiencing an eating disorder. *International Journal of Eating Disorders*. <https://onlinelibrary.wiley.com/doi/full/10.1002/eat.23938>

Australia's Current State

1 Eating Disorder Prevalence

In 2023, 4.45% of Australians had an eating disorder diagnosis, equating to 1.1 million Australians, while 1.7 million people will be diagnosed with an eating disorder in their lifetime. Most diagnoses occur during adolescence, with highest rates in those aged 15-19. Women are disproportionately affected, accounting for two-thirds of eating disorder diagnoses.⁶

2 Public Investment

Research has identified a range of successful interventions for eating disorder prevention and early intervention, but public investment in Australia is low. For example, in Queensland, an average of \$681 is spent for each eating disorder episode of care, significantly lower than for other mental illnesses (anxiety disorders = \$1,065 per episode, depressive disorders = \$2,549 per episode).⁵ Successful recovery is often dependent on dedicated involvement from carers. However, recognition and support of carers in Australia is inadequate. Much of the increased eating disorder funding from the Federal and some State Governments is focussed on the person with the eating disorder with few funds dedicated specifically for carer support.

3 Cost to Society

In 2023, the total economic and social cost of eating disorders in Australia was \$67 billion, up 36% since 2012, and equivalent to \$60,654 per person with an eating disorder.⁶

4 Impact on families and carers

As the prevalence of eating disorders increases, families and carers find themselves under mounting pressure to provide the necessary care, while the scarcity of well-funded eating disorder prevention and treatment interventions in Australia also exacerbates this burden. This underscores the urgent need for improved support for families and carers. Where carers are properly supported, they are better able to care for their loved one with an eating disorder, and this can improve eating disorder outcomes.

⁴ Le L, Barendregt J, Hay P, Mihalopoulos C. (2017). Prevention of eating disorders: A systematic review and meta-analysis. *Clinical Psychology Reviews*. <https://doi.org/10.1016/j.cpr.2017.02.001>.

⁵ Queensland Government. (2023). The Health of Queenslanders: Expenditure by Condition. Retrieved 10/01/2024, from <https://www.choreport.health.qld.gov.au/our-investment/expenditure-by-condition>.

⁶ Mihalopoulos C, Hay P, Madden S, Touyz S, Wade T, Squire S, Wilton M, Farrar-Rabbidge M. (2024). Paying the Price Report, Second Edition. <https://butterfly.org.au/wp-content/uploads/2024/02/Paying-the-Price-Second-Edition-2024-FINAL.pdf>

Dream State For Carers by 2028



Families caring for someone with an eating disorder receive timely and effective support from the health system, government, and society in general. This happens through professional or community avenues that meet each carer's individual needs.



Families and carers are placed at the centre of the treatment and recovery team, and are seen as an equal and valuable partner.



State and federal governments collaborate and knowledge share to ensure seamless, accessible and integrated care is available, and to make the most efficient use of resources and avoid duplication of services.



Person-centred prevention, early intervention and treatment measures, reflecting the diversity of eating disorders, are available and will lead to a decrease in the incidence, severity, and impact of eating disorders and less pressure on eating disorder services.



Those who are living with an eating disorder as well as their families feel safe to talk about their experiences and to seek help without fear of judgement.



Greater education and training of clinicians allowing for more positive experiences for families and carers when accessing eating disorder treatment.



The National Eating Disorders Strategy has been implemented providing those with eating disorders and their families and carers with the services and support they need to maximise the opportunities for lasting recovery.

EDFA's Goals by 2028

Skilled and Resilient Carers

1. Well-subscribed EDFA services established in all Australian states and territories
2. Establishment of prevention and early intervention programs to help families and carers reduce the amount of time it takes to recover from an eating disorder
3. Advocate at the state and national level for broader support for carers during treatment and recovery
4. Sufficient resources and services to enable carers to quickly and easily navigate the healthcare system.



The National Peak Organisation for Eating Disorder Carers

1. Increase awareness of EDFA among carers, clinicians, researchers, government, and the general public
2. Collaboration with national and state eating disorder organisations



Improve Treatment and Support

1. Contribute to research addressing carers' lived experience and role in treatment and recovery
2. Advocate for the closure of treatment gaps and inclusion of carers in the treatment team regardless of the loved one's age
3. Community education campaigns
4. Support translation of innovative research into practice with valuable stakeholder input



The Eating Disorder Landscape

Before developing this strategy, we wanted to ensure it was grounded in insights that truly reflect the landscape of eating disorders in Australia. We conducted an extensive environmental scan to inform our objectives and path to impact.

Highlights include:

Families and carers need more support

- Eating disorders are a very isolating disorder for families while a loved one is recovering
- More effective prevention and early intervention is needed to limit the impact on families
- Families often find it challenging to find and then access support for themselves
- Education allows carers to remain resilient and be an effective part of the recovery journey

EDFA can provide low-cost support to those who need it

- EDFA's strong lived-experience volunteer base enables us to keep our costs low
- EDFA's provision of online-only services means our overheads are low
- EDFA provides significant value for money when seeking government funding support

EDFA can support disadvantaged families and carers

- EDFA knows that eating disorders impact families from a diverse range of backgrounds living in all parts of Australia
- EDFA can reach these families, including those in remote and socio-economically disadvantaged communities with online support that is tailored to their needs
- EDFA can address the needs of Aboriginal and Torres Strait Islander people and CALD families with considered support and access

There are opportunities in every state and territory for EDFA

- More support is needed in every state and territory in Australia
- There is significant opportunity in states without a state-funded eating disorder service, which include South Australia, Western Australia, New South Wales, the Northern Territory, and the Australian Capital Territory

EDFA has the potential to reach many more families and carers

- EDFA estimates that at least 4.4 million Australians are impacted by an eating disorder when family members and carers are taken into account
- With only 3,000 members throughout Australia at present, there is significant scope for growth
- EDFA should target carers for a broader range of eating disorder diagnoses as well as greater representation in several states and territories
- Awareness among clinicians, particularly GPs, provides a unique opportunity to collaborate with the medical community

The policy landscape also aligns with EDFA's model:

- The National Eating Disorders Strategy emphasises the important role played by carers in eating disorder recovery and highlights the need for carers to be included in treatment and recovery
- A new National Carers Strategy is being developed and a peak organisation for families, carers and kin of people living with mental health conditions is being established
- Both strategies must continue to recognise the unique role of EDFA as the only organisation focussed solely on supporting families and carers of those living with eating disorders
- There is a greater focus on eating disorder initiatives, particularly at the Federal Government level but also within many state governments. This includes the incorporation of lived experience involvement in the development and delivery of policies and services through a peer support workforce.

Strategic Approach

We envisage a future where families and carers receive comprehensive support to assist a loved one through eating disorder recovery and where their vital role as the front line of the recovery team is recognised and acknowledged not only by the other members of that team, but by our communities.

This recognition should focus on both the wellbeing of the person they are caring for as well as the wellbeing of the carer and their other family members.

EDFA recognises the importance of a structured approach to measuring and monitoring its progress and success in executing the Strategic Plan to achieve our vision.

The Vision is a long-term objective, set for 2028, while the initiatives will be broken down into short, medium, and long-term goals.

This is an ambitious strategy that will require a sustained effort. Our goals will be achieved through steady, meticulous planning and a comprehensive process commencing now in 2024.

Strategic Priority Pillars - Summary

EDFA has chosen three strategic priority pillars to focus on as we aim to reach our 2028 goals.



IMPACT

Investing in essential, scalable programs and activities to create a real impact on the ability of our carers to support a loved one through eating disorder recovery.



INFLUENCE

Becoming a leading and trusted voice to positively influence the systems and relationships that determine a carer's ability to effectively manage and maintain their role as the front line of the recovery team.



SUSTAINABILITY

Strengthening our position as a sustainable charity that has adequate resources to support our strategic goals and vision.

Strategic Priority Pillar 1: IMPACT

Having a genuine, positive impact on eating disorder carers and families is at the core of EDFA's mission. As the environment changes, we will adapt our model to meet the needs of our community through meaningful partnerships with carers and those who support them, including other eating disorder sector organisations, government, and health care providers. This adaptive model will leverage technology and be scaled efficiently, enabling EDFA to expand our reach and deepen our impact. This will be supported by impact measurement and feedback for continuous improvement.

OBJECTIVE

Investing in contemporary, scalable programs and offerings to have a real impact on the ability of carers and families to support a loved one through eating disorder recovery.

INITIATIVES

Develop an adaptable suite of programs and complementary offerings

Increase EDFA's presence nationally

Develop and implement an organisation-wide impact framework

OUTCOMES

Families and carers feel confident in their role as the front line of the recovery team and can become eating disorder advocates in their own local communities.

Improved eating disorder knowledge for carers and families, clinicians, and the community.

Improved eating disorder outcomes for those living with eating disorders due to the enhanced skills and knowledge of the carers and families that are supporting them through an adaptable suite of programs and complementary offerings.

Meet the demands and needs of our community through increased organisational capacity.

Strategic Priority Pillar 2: INFLUENCE

EDFA has always been a platform for carers and families to share their experiences of supporting someone with an eating disorder. To fully address the challenges facing these families today and into the future, we must extend that platform as trusted leaders.

We will grow the EDFA community and build the capacity of carers and families as eating disorder and lived experience advocates.

Using data and research to build new knowledge, and leveraging the power of EDFA's brand and reputation, we will drive best practice alongside our carers with government, services, researchers, educators and policymakers to ensure their expertise is included in the decisions that impact them.

OBJECTIVE

Become a leading and trusted voice to positively influence the systems and relationships that determine a carer's ability to effectively manage and maintain their role as the front line of the recovery team.

INITIATIVES

Extend our role as advocates for carers and families by developing strategic relationships and networks, including at the state level, and enhancing the tools and strategies available to carers.

Expand the scope of EDFA's influence strategy, bringing together data, insights, research, and advocacy.

Evolve our brand and communications strategy for systems change.

OUTCOMES

Carers and families feel confident and equipped with skills to advocate for how systems can better meet their needs.

Key decisions related to government policy on eating disorders involve input from carers and families.

Improved experiences and outcomes of carers and families engaging with eating disorder services in Australia due to better-informed offerings.

Greater representation of lived experience eating disorder carers and families in Australian media.

Eating disorder prevention, early intervention, treatment and/or recovery is a core component of the Federal Government budget each year.

Increased knowledge, understanding and recognition in the broader community of the impact of eating disorders and the vital role of families and carers in the front line supporting the recovery of those with eating disorders.

Fully coherent verbal and visual brand with the flexibility to adapt to the changing needs of EDFA and carers and families.

Increased brand awareness, trust, and understanding.

Ability to measure brand health, analyse data, and adapt strategy to ensure continued success.

Strategic Priority Pillar 3: SUSTAINABILITY

We will continue to build a foundation that proactively enables efficient, scalable, and innovative growth, ensuring impact and connection to our community, and long-term financial security for EDFA.

We will achieve overall organisational sustainability by focusing on three main areas: finances, our people, and our external community.

OBJECTIVE

Strengthening our position as a sustainable charity that has adequate resources to support our strategic goals and vision.

INITIATIVES

Refine and evolve EDFA's financial sustainability model.

Continue to invest in a sustainable organisational structure and efficient systems.

Evolve and nurture a sustainable people plan to build an enviable working environment.

Receive external feedback from organisational professionals both in and outside of the eating disorder sector to ensure innovation, governance, and best practice.

OUTCOMES

A financial model that provides long-term security and enables scalable impact that aligns with our strategic goals.

A membership fee and offering that provides greater benefits to carers and families while also maximising sustainable self-generating revenue.

A thriving, efficient, and cost-effective organisation and team structure that is highly impactful in supporting EDFA's mission and vision.

Well-regarded place of employment in the sector, and an organisation individuals want to work with.

A self-sustaining community of leaders supporting and mentoring new cohorts of advocates based on the skills and confidence they developed at EDFA over the years.

Recognised for having high-quality governance and services that are efficiently run and provide value for money for funders with high levels of accountability.

Path to **IMPACT**

How can EDFA support, educate and empower carers and families of those living with an eating disorder to reduce pressure on communities and the health care system?

1

Growing the EDFA community

We start by upskilling, educating and supporting carers and families to enable them to become powerful lived experience advocates

Through our comprehensive support, education, advocacy and counselling services, EDFA will help carers and families to become better supports for their loved one and give them a place where they can share their stories in a safe and impactful way.

We will enable carers to be recognised for their vital role at the front line of the recovery team, to normalise conversations about eating disorders, and help to build a stigma-free community

The immediate outcomes of this growth are:

- A** Increased skills and confidence to support their loved ones eating disorder recovery
- B** The ability to lead positive and safe conversations about eating disorders and the family experience
- C** Increased positive attitudes towards their own journey and a reduction in self-blame and self-stigma
- D** Increased skills and confidence to share their lived experience
- E** Increased eating disorder advocacy skills

Carers and families collaborating with EDFA to provide insights and advocate for better eating disorder services, policies, and programs for their loved ones and themselves (including EDFA's own).

2

Extending our reach

Trained and ready, our community of carers and families reaches out more widely to other families and communities through lived-experience prevention and early intervention programs, delivered at scale

We share our lived-experience stories of eating disorders and the family experience with a focus on hope, strength, resilience, and the knowledge that recovery is possible.

We educate by sharing knowledge, tools, strategies, and help-seeking pathways that support the mental health of our carers and families

We normalise conversations about eating disorders and the family experience through positive and engaging programs and activities

Leads to immediate outcomes for carers and families and their communities:

- A** Increased knowledge of the signs and symptoms of eating disorders
- B** Improved awareness of available services for both their loved ones and themselves
- C** Greater knowledge of how to navigate the eating disorder health system
- D** Strategies and self-care practices to maintain a good standard of mental health
- E** Increased feeling of emotional connectedness and reduced feelings of isolation

Which leads to immediate outcomes for those carers and families:

- A** Increased awareness of eating disorders and more positive attitudes towards self-compassion
- B** Reduced stigma towards eating disorders and help-seeking
- C** Reaching out for support before a state of significant distress or crisis

Which spread to create community outcomes:

- A** Increased understanding of the family experience of an eating disorder
- B** Increased positive conversations about eating disorders within communities
- C** Increased community connection and resilience
- D** Reduced community stigma and increased empathy towards families who are caring for someone with an eating disorder
- E** Greater willingness to provide financial support to eating disorder organisations

And system outcomes:

- A** Reduced hospital preventions and severity of eating disorders
- B** Streamlined pathways to the most effective support for families and carers
- C** Reduced strain on mental health services accessed by the person with the eating disorder as well as the carers and families

Faster and sustained eating disorder recovery, more support for carers and families, and improved outcomes for communities.

