



EATING DISORDERS FAMILIES AUSTRALIA (EDFA)

EDFA Funding Proposal

20 January 2021



Message from EDFA Board

EDFA is a national organisation dedicated to providing much needed support, validation, education and information to families and carers of a loved one with an eating disorder, empowering them to advocate for their loved ones' needs in the often long recovery process, through nationwide **strive** support groups, education seminars, peer-to-peer support, and social events.

Eating disorders are serious and often life-threatening biological brain disorders that affect around 4% of the population (Deloitte Access Economics, 2015) and claim the lives of around 2,000 young Australians each year.

Not only are they harrowing for the person directly affected, eating disorders can also be mentally, emotionally, physically and financially draining on parents, partners, siblings and other carers involved.

However, evidence shows that recovery for people with eating disorders significantly improves when families and carers receive education and support.

Unfortunately families and carers are often overlooked by the healthcare system and fail to receive the training and assistance they need to effectively carry out this valuable but, extremely challenging role.

Founded by a group of Australian parents who have each cared for a young person with an eating disorder, EDFA has provided reliable, consistent and ongoing voluntary support for families and carers in order to avoid 'burn-out', physical and mental ill-health and fatigue, and family breakdowns since 2016. But we can no longer address this need on our own.

The number of families and carers we are helping has now reached a point that we require Government funding to continue.

Please see the attached funding proposal for further information about our organisation, the essential support services we provide, and our specific funding requests.

Regards

EDFA Board

EDFA Member Testimonial

*"I cannot say thank you enough. So many times when I have felt hopeless, lost or angry, or just plain exhausted, my **strive** support group has given me what I've needed to take the next step. **I can support my daughter because I also have support.** It is incredible how people who are facing the relentless emotional path of being a carer for someone with an eating disorder can also find time to support and encourage others. My EDFA **strive** support group represents the best of compassionate and empathic humanity."*

EDFA Member, caring for a 16 year old daughter with Anorexia Nervosa



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AN EDFA MEMBER'S STORY FROM 2020

I am a highly accomplished and well regarded primary and special education teacher. But I was unable to work throughout 2020, whilst I cared for my 16-year-old daughter who had 30 hospital admissions beginning in January 2020, and all through the COVID-19 months in Melbourne.

She had been restricting food for all of January and completely stopped eating in hospital in March. With each hospital admission she became more unwell (her weight plummeted from 55kg to 42kg), to the point she was unable to drink water.

My daughter's eating disorder negatively impacted both the mental and financial health of our whole family, including our extended family.

My husband became the sole provider. His mental health deteriorated considerably whilst he felt the pressure to continue working through COVID as I wasn't entitled to Centrelink benefits. He also felt continually torn to help and support my daughter and me.

Due to the sheer trauma from hospital admissions to keep my daughter alive, my mental health also deteriorated dramatically. Driving home, traumatised from long days in the hospital, I felt slamming my car into a tree was the only option.

EDFA support was my lifeline and kept me breathing and living so I could continue to advocate for better treatment for my daughter. They also gave me the strength and hope I so desperately needed to keep going.

EDFA met with me and walked me through how to best support my daughter whilst she was in the hospital and when she was home. They made me believe my daughter would start eating and that true recovery is possible.

I am ecstatic to report that since November 2020, my daughter has made tremendous inroads to recovery. She now eats freely and we have not had a hospital visit since.

*I could not have survived the horror of our situation without the support of the EDFA board members and the Carer community they provide. **Natalie K -EDFA Member, caring for a 16 year old daughter with Anorexia Nervosa***

EATING DISORDERS IN THE COMMUNITY

1. 'Carers themselves have their own practical and emotional reaction to the illness, which for the most part is helpful but can impede recovery if there is division within the family, collusion with some aspects of the illness and high expressed emotion. Siblings can develop their own problems or leave home prematurely as their needs may be neglected. Carers' distress and means of coping with the caring role may add to the distress of the individual with an ED, and a vicious circle develops. Poor coping leads to distress, and this, in turn, increases the tendency to either overprotect the individual and accommodate the illness or enter into unproductive fights' ¹¹
2. Educating and supporting carers and families is critical for a person living with an eating disorder to get well, and for the mental and physical health of the Carer (and Siblings), given the critical role they play. This is the focus of EDFA.
3. Last calendar year was particularly challenging for parents, siblings and carers of those who suffer with eating disorders. With uncertainty brings anxiety and fear, and many who live with an eating disorder turn to its "safety" as a way of coping when things become overwhelming and uncertain. As a result of Covid19, the support role has been even more intensive for parents and carers.
4. However, eating disorder symptoms are pervasive and intrusive into the family life, and interpersonal relationships become entangled with the disorder in a complex manner.¹¹
5. Eating disorders are estimated to affect over 4% of the Australian population. This means there are approximately 1 million Australians with a diagnosable eating disorder. The mortality rate for people with eating disorders is significantly higher than that of the average population and among the highest for a psychiatric illness. According to recent estimates, mortality is 5 times higher in individuals with anorexia nervosa than the general population.
6. Anorexia Nervosa has the highest mortality rate of all mental illnesses. Up to 1 in 5 die due to organ failure or suicide and 20% of deaths caused in those with anorexia nervosa are caused by suicide¹⁰.
7. During the height of Covid-19 lockdowns, Butterfly's National Helpline logged 15,835 calls and web chats about eating disorders and body image problems from March 2020 to August 2020, 43 per cent higher than the same time in 2019. Contacts during March, April and May - the height of the national lockdown - were 24 per cent higher than the previous three months.⁹
8. The prevalence of Eating Disorders has heightened in Victoria since the second wave of COVID-19 and stage 4 restrictions in metropolitan Melbourne. From January to July, Victoria represented 27 per cent of contacts to the Butterfly helpline, while in August it jumped to 35 per cent.⁹

IMPACT ON CARERS – KEY MESSAGES

The following is a summary of key messages from EDFA regarding this proposal:

1. The initiatives outlined in this submission are likely to be not only life-saving, mental and physical health improving and cost-effective, but cost saving for the government and the public and private health systems.
2. Eating Disorders impact the WHOLE family.
3. Most of the care, management and recovery from an eating disorder occurs in the family home.
4. Families get no respite as the care can often be a 24x7 effort in the home for many years.
5. Early intervention provides the best chance to recovery from an eating disorder – the family is generally who recognises and intervenes first in an eating disorder.
6. Families face challenges finding suitably educated GPs and clinicians who truly understand the complex and manipulative nature of eating disorders. It is so important that carers are best informed to be strong advocates for their loved one's care.
7. Families (parents, siblings, carers, etc.) suffer mental and physical health issues due to the stress of ongoing, often violent and prolonged care of the person with an eating disorder. The decline in their health places a huge burden and pressure on already overwhelmed medical systems nationally and impacts the economy.
8. There is a mismatch between the high mental and physical burden and cost of caring for a family member with an eating disorder and the historical low prioritisation in policy and resourcing.
9. Eating disorders are difficult to manage in the health system and in the home (where most of the 'heavy lifting' is done) . Money is spent on various initiatives assisting the person with an eating disorder at great expense to governments, families and individuals, while much-needed eating disorder carer-peer led, lived-experience effective support, community connection and education go unfunded.
10. EDFA's 2020 expansion nationally and COVID-19 has driven a 6 fold increase in the number of members and people reaching out for EDFA support. We can no longer sustain our level and quality of support without funding.
11. The support, education and lived-experience family (carer) community are paramount for an effective battle against these insidious mental illnesses. Lived-experience connection for families is extremely powerful as it helps provide a solution to isolation, loneliness, understanding, validation, empowerment and strength to 'carry-on' for years.
12. Different eating disorders require different education (skills) and support for Carers. There is no one solution for any of the eating disorder types let alone all of them grouped into one.
13. Siblings are overlooked due to the focus on the eating disorder person; hence, from lived-experience, and from research, we know they often suffer from mental health issues - some of them lifelong. To circumvent this, it is best to act in a preventative fashion and provide support for siblings of all ages. ^{1,6}

EDFA MEMBER TESTIMONIAL

"Putting out a call of thanks for the kindness, support and compassion shown by the passionate and caring volunteers at EDFA. The volunteers understand the stress, fear and challenges that come with supporting a loved one with a life threatening neuro-biological mental illness, as well as caring for the rest of the family & trying to keep a job, bills paid, the household running etc. These wonderful volunteers share their knowledge and wisdom, and provide on-line support to carers. Thank you to EDFA and volunteers for supporting and guiding carers with kindness and compassion"

EDFA Member, caring for a 14 year old daughter with Anorexia Nervosa

Posted on a nationwide public Facebook forum with 560K members

KEY EDFA STATISTICS

+500

Paid EDFA Members (Families) (15% increase in last 6 weeks over Christmas/New Year)

+25%

Increase in the number of members in our individual state based **strive** support groups online pages in last Quarter 2020

+108%
p.a.

strive attendance annual growth rate over Christmas period i.e. 20/12/20 to 18/01/21 (other ED orgs were closed)

+4,500

Social media followers

Number of Australians EDFA are supporting (carers & siblings)

+16,000

TBT-S clinicians (and to a lesser extent, carers) who have attended training TBT-S sessions

+500

Monthly growth in families joining our online support communities in 2020

7%

EDFA carer education workshop attendees per month

+80

KEY EDFA STATISTICS

600%

Growth in number of families reaching out to EDFA since COVID-19 (Mar 22nd 2020) – approx. (various channels)

Mondays Tuesdays
Wednesdays
& **Sundays**

Busiest days for our core volunteers

6am-11am & 4pm-11pm
(peak 8pm to 11pm)

Busiest times for our core volunteers

51% increase in engagement
66% increase in followers
28% increase in views

Social media stats over the last 28 days
(incl. Christmas/New Year period)

EDFA up 1.2%
Butterfly up 0.1%
EDV up 0.2%
EDQ up 0.3%

EDFA FB Page engagement vs. other peak eating disorder orgs. (in last 7 days to Jan 16 2021 – average over time as well)

ABOUT EDFA

Vision Statement

An Australia where eating disorders struggle to emerge, thrive or persist.

Mission

To facilitate and advocate for families and carers to ensure they are supported, equipped and acknowledged as a central part of optimising the recovery process for the person with the eating disorder.

- EDFA is a largely a volunteer, not-for-profit, registered charity organisation with full DGR status and ACNC compliance. EDFA was formed in Melbourne in 2016 by passionate volunteer parents who realised the power of lived-experience, peer support, and who were frustrated with the gaps in the existing offerings of government funded not for profit organisations. Amongst these parents, most were those whose loved one's suffer, or have suffered, from the deadliest of all mental illnesses, Anorexia Nervosa.
- EDFA is a member based organisation. Our membership fee is \$25 per family per annum, so this does not provide us with much funding. In addition to our paid members, we also support many other carers and families who cannot afford to pay our \$25 membership fee.
- EDFA is the only organisation solely dedicated to eating disorder carer and family support in Australia. EDFA is an essential service for support, information and carer and family wellbeing for those supporting someone with an eating disorder.
- With the growth in demand for support that we provide to carers and families, we require additional Government funding to continue to support the families that reach out to EDFA for assistance.
- Lived-experience peer support is critical for carers to gain the confidence and knowledge to support their loved one.
- An eating disorder diagnosis throws the whole family into unknown territory and impacts the mental and physical health of everyone in the household. It has a steep learning curve, with constant feelings of fear, worry and exhaustion, while trying to remain compassionate and calm towards a child or loved one with an eating disorder. This is not a normal parenting or carer environment, and families need to be taught what to expect and how to manage.

ABOUT EDFA (CONT'D)

- For carers, knowledge is power and hearing from those who have gone before is truly empowering. Our focus is to educate, empower and build resilience in eating disorder carers and provide a community where they belong.
- Since COVID-19 we have expanded and grown our eating disorder '**strive**' support groups in each State and Territory around Australia. EDFA has branded our support groups as '**strive**' which stands for Support, Teach, Reassure, Inform, Validate and Empower – all objectives to meet the needs of our attendees. Our aim is to provide carers with the knowledge, resilience and confidence to support their loved one in the home, rather than resorting to frequent hospital visits, thus helping to reduce the burden on the health system.
- Teaching parents and carers how to manage during these times of high distress, reassuring them they are not alone, validating their concerns and feelings, and empowering them to have the confidence to keep going, also helps their own mental health. We are active promoters of the importance of self-care during what can be years and years of a highly stressful carer role.
- We recently received our first Commonwealth Government funding to cover the cost of a part-time **strive** Project Manager for 12 months. Everything we have achieved to date has been through our own fundraising and initiatives, with every one of us volunteering our time and efforts for the last 4 years. In relation to our **strive** Project Manager, we would like to have guaranteed funding an additional 3 years, given the importance of this role.

EDFA VOLUNTEERS

In addition to our Board and management, EDFA is supported by a large number of volunteers who commit time and energy supporting their fellow Australians in a time of need.

EDFA has over 30 volunteers providing over 16,000 hours of community service in the 2020 calendar year, which includes 4 full-time volunteers.

Our volunteers play such a critical role in the mission of EDFA, including support group facilitators, website development, guest speakers at education workshops, administration support, program management, Facebook moderators, media and social media volunteers, and our volunteer Board.

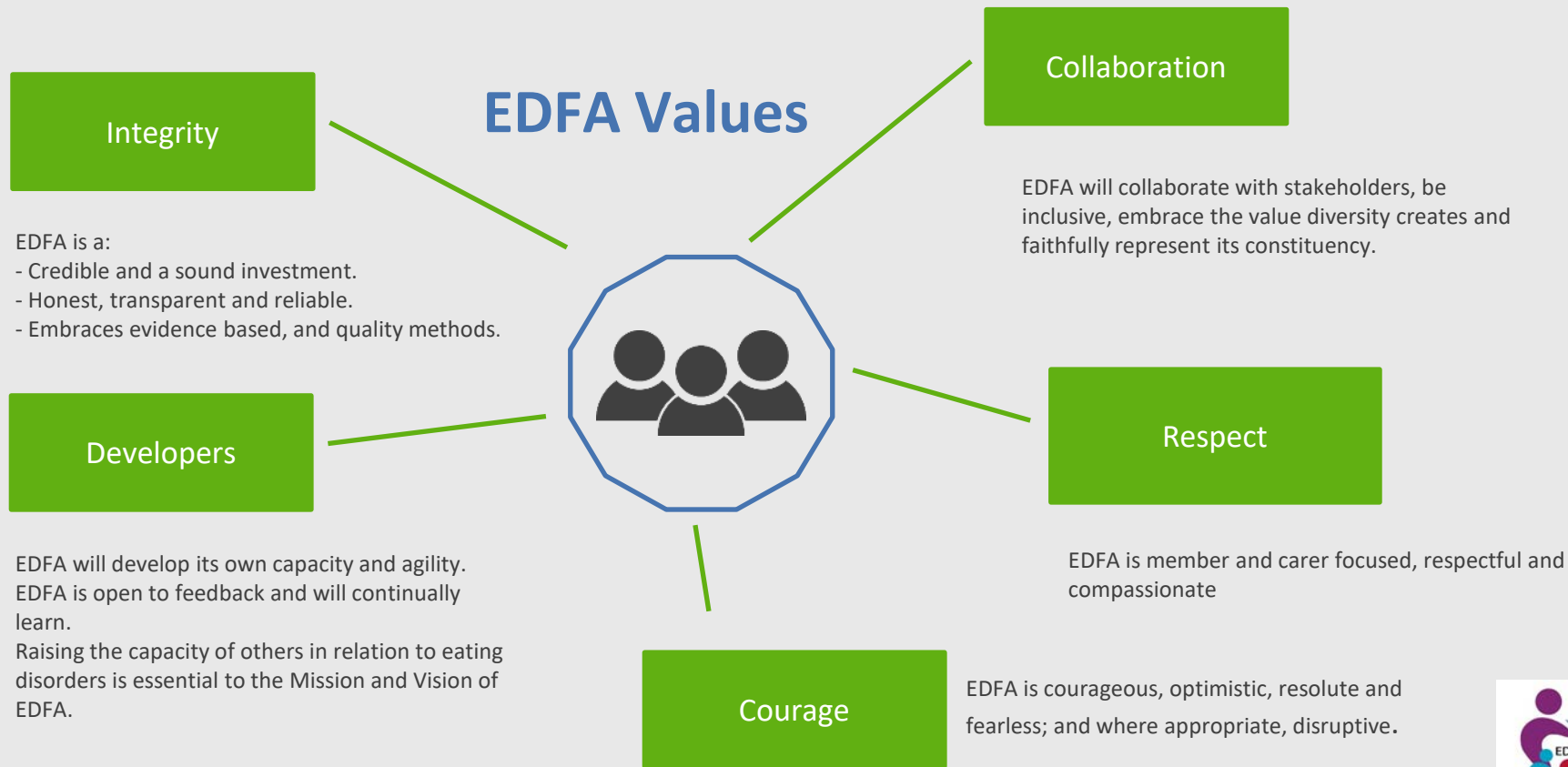
ABOUT EDFA (CONT'D)

- In addition to our **strive** support groups, EDFA provides many other services to carers and clinicians, including:
 - **Clinician up-skilling - TBT-S Training** – EDFA is mindful of the importance of developing and supporting skilled professionals, and making sure they are being used in the most effective and equitable way. TBT-s is training for clinicians (and carers) to learn more about one of the latest Eating Disorder treatments – Temperament Based Therapy with Supports (TBT-S); from US Neuropsychologist Dr Christina Wierenga, Clinical Assistant Professor in the Department of Psychiatry at The Ohio State University Dr Laura Hill, and US Psychologist Dr Stephanie Knatz.
 - **Education workshops – free for members** - every fortnight we run education workshops where we bring eating disorders experts (clinicians and educators) - both Australian and International, people with lived experience as carers or recovered sufferers . These workshops are provided via Zoom, and allow access to Australians in metropolitan, regional, rural and remote areas.
 - **Online communities** - private Facebook groups for each state and territory, and we support these families on a daily basis, be it online, by phone, meeting in person or at our monthly **strive** support group and our national twice monthly education sessions.
 - **Specialist support groups** - 2021 calendar year we are commencing online support groups for carers of **ARFID** (Avoidant Restrictive Food Intake Disorder) and **Bulimia Nervosa** sufferers and the **only** eating disorder specialised support groups offered for **Siblings** anywhere in Australia – and according to our research, *the world*
- Further information on our support programs can be found later in this document.

The image is a screenshot of a Facebook post from the page 'edfaustralia'. The post features a red and purple graphic with the text 'BREAKING NEWS!!' and 'EDFA IS THRILLED TO ANNOUNCE THAT THE RESILIENCE PROJECT'S HUGH VAN CUYLENBURG IS OUR NEW AMBASSADOR!'. Below the text is a photo of Hugh Van Cuylenburg, a man in a white t-shirt, speaking. To the right is the cover of the book 'THE NATIONAL BESTSELLER RESILIENCE PROJECT FINDING HAPPINESS THROUGH GRATITUDE EMPATHY & MINDFULNESS HUGH VAN CUYLENBURG'. A red speech bubble says 'More details coming in 2021!'. At the bottom left is the EDFA logo (a stylized family) and at the bottom right is the EDFA logo with the text 'Eating Disorders Families Australia'. The post also shows a heart icon, a comment icon, a share icon, and a bookmark icon.

ABOUT EDFA (CONT'D)

EDFA is a values based organisation, and our values drive our interactions with our members, carers and other stakeholders.



WORKING TOGETHER FOR BETTER HEALTH OUTCOMES

EDFA is committed to collaborating with other not-for-profit eating disorder organisations and mental health professionals.

EDFA was formed to be the 'voice of the Carer' and ensure the critical role carers play is given the recognition and respect that is needed to support people with eating disorders through to recovery.

We know that eating disorders have such complexity that a combined effort of many is required to address the needs of a person living with an eating disorder, and carers and families.

In response to the need to collaborate, the EDAA (Eating Disorder Alliance of Australia) was formed in April 2020 by organisations specialising in working in the eating disorder space. EDFA is the only unfunded organisation in the alliance but our work is significantly and importantly recognised to be included in this group. EDAA represents the voice of consumers, carers and health care professionals.

<https://www.eatingdisorders.org.au/joint-media-release-new-eating-disorders-alliance-australia/>

EDFA is also involved in national research projects with InsideOut Institute and various Universities.

EDFA sponsors and participates in annual conferences – e.g. ANZAED & FEAST



Eating Disorder Alliance of Australia (EDAA) members:



CURRENT EDFA PROGRAMS - Supporting and Empowering the Community

strive Support Groups

- Since March 2020, we have successfully launched a **strive** parent/carer support group in every state and territory of Australia, which run on a monthly basis and are facilitated by our trained lived-experience carers.
- EDFA had planned a face-to-face support group rollout of 33 groups nationally, in both metropolitan and rural areas over three years. However, with Covid-19 we quickly responded by converting existing face-to-face groups in Melbourne, Bendigo, Perth and Adelaide to online **strive** support groups for the whole of each State, giving wider reach to rural and remote families who did not previously have access to support.
- EDFA's online sessions are reaching many parents and carers who previously could not attend in-person due to various reasons, including an inability to leave their children home alone.
- The extension of EDFA's reach from urban to rural and remote areas nationally has made a significant impact, connecting families who are lonely, isolated and suffering.
- **strive** support groups are non-discriminatory and our carers include people who care for loved ones of any age and people of any colour, gender, race, ethnicity, religion and the LGBTQI community.

TBT-S Education Program

- EDFA is providing opportunities for Clinicians to learn more about one of the latest Eating Disorder treatments – Temperament based Therapy with Supports (**TBT-S**), from US Neuropsychologist from the University of San Diego, Dr Christina Wierenga, Clinical Assistant Professor in the Department of Psychiatry at The Ohio State University, Dr Laura Hill, and US Psychologist Dr Stephanie Knatz Peck.
- EDFA is passionate about educating clinicians and families about this latest emerging eating disorder treatment, because it recognises the value of including a trusted family member/friend/carer as a pivotal member of the treatment team and plan.
- While we remain agnostic when it comes to eating disorder treatment and therapies, we are excited about TBT-S.
- **TBT-S** helps the person with an eating disorder (and their Carers) understand how their symptoms can be explained by their temperament, where temperament is used as an umbrella term involving biology, brain functioning, genetics and personality traits. Personality traits such as perfectionism, impulsivity, harm avoidance and determination are common among people with eating disorders

CURRENT EDFA PROGRAMS - Supporting and Empowering the Community (CONT'D)

Carer Education Workshops

- In another response to COVID-19, early in 2020, EDFA commenced twice-per-month educational sessions where national and international world-renowned eating disorders specialists, educators, carer peers and recovered eating disorder sufferers speak on various aspects of eating disorders.
- Our education workshops are available online via Zoom and recordings are made available via our online support platforms. Consequently, our education workshops are accessible to individuals across metropolitan, rural and remote Australia.
- The combination of our **strive** support groups and education workshops has effectively tripled our direct contact and support for carers and families from 1.5 hours to 4.5 hours per month. In addition, we provide carers with the opportunity of daily support via our social media forums, including one-on-one phone support.

Carer Online Communities

- EDFA provides online support via social media platforms, phone and face-to-face (where feasible).
- Our model is repeatable and scalable as the knowledge and skills provided from carers (Peers) with lived experience are propagated throughout the community.
- Carers learn from other carers and create their own local community. Consequently, carers become each others' support team.
- Carers are empowered and confident to continue the battle of saving their loved one.
- The social media platforms are operational 7 days per week, 15 hours per day, 365 days per week (*no other eating disorder service provides this*).
- The support is provided by EDFA trained lived-experience volunteers, including EDFA founders, *Peak times are 7pm to 11pm, with Monday, Tuesday, Sunday being the busiest days.*
- Our online communities assist in keeping families out of hospital. Families feel connected, rather than isolated and alone.
- The skills learnt and support provided help prevent further progress of the eating disorder, helps in early intervention and provides tactics to manage chronic, longer term illnesses.

PLANNED EDFA SUPPORT PROGRAMS - 2021

Avoidant/Restrictive Food Intake Disorder (ARFID) and Bulimia Nervosa Support Groups

- Participant numbers in **strive** support groups are constantly growing and consequently it is becoming more challenging to manage the needs of all families, and the various eating disorders they are managing.
- Different eating disorders require different carer skills to effectively support their loved one.
- To this effect, EDFA is commencing monthly support groups in 2021 dedicated to carers supporting a loved one with ARFID or Bulimia Nervosa.
- To make these programs successful, EDFA needs to source and manage special lived-experience carer facilitators with the appropriate knowledge and skills for EDFA to run these additional unique and much needed carer support groups.

Early Intervention Carer Training

- Early intervention education for Carers to support evidence-based treatment.
- Continual 3 week program of 2 hours per week on a Saturday morning (so everyone can attend and not be hindered by work or the battle with evening meal).
- Recommended for newly diagnosed families on the brink of FBT treatment to complete the course and for those on the waiting lists in the health system.
- Early intervention carer training will help keep families out of hospital, families feel connected, not isolated and alone.
- The skills learnt and support provided help prevent further progress of the eating disorder and helps in early intervention.
- Benefits include reducing reliance on an over-burdened health system and reduces Government costs.

PLANNED EDFA SUPPORT PROGRAMS - 2021

Sibling Support Groups

EDFA Sibling Support Groups provide a safe place where the daily struggles of living with a sibling with an eating disorder can be acknowledged and the full range of emotions that result (i.e. sadness, confusion, isolation, helplessness, fear, anger, frustration) can be expressed.

Some takeaways from the groups will be: it is not their fault; not their job to fix their sick siblings; how they can make a difference; how to look after their own mental and physical well being, permission to move on and enjoy their own life; and their voice and feelings are valid.

EDFA Volunteers



PLANNED EDFA SUPPORT PROGRAMS – 2021 (Cont'd)

TBT-S Pilot

- EDFA is mindful of the importance of developing and supporting skilled professionals, and making sure they are being used in the most effective and equitable way. TBT-s is training for clinicians (and carers) to learn more about one of the latest Eating Disorder treatments – Temperament Based Therapy with Supports (TBT-S).
- TBT-S emerged from research in the United States from US Neuropsychologist from the University of San Diego, Dr Christina Wierenga, Clinical Assistant Professor in the Department of Psychiatry at The Ohio State University, Dr Laura Hill, and US Psychologist Dr Stephanie Knatz Peck.
- It has been tested in open trials over the last four years with very promising results.
- In early 2019, EDFA brought the leading TBT-S experts to Australia and conducted a series of sold-out workshops around the country. These workshops reached over 350 clinicians and carers in Australia and New Zealand. During 2020, we have conducted follow-up webinars for clinicians and carers with Dr Hill, Dr Wierenga and their colleagues.
- There is a strong interest from clinicians and carers in introducing TBT-S as a complementary eating disorder therapy and well as support from peak bodies, including NEDC, ANZAED and InsideOut Institute.
- The next step is to undertake a research pilot of TBT-S, involving Australian clinicians with existing knowledge of TBT-S from the workshops and webinars.
- There is strong interest from clinicians and eating disorder organisations in various states and territories for such a pilot, which could be conducted in the public or private systems.

Carer & Sibling Resource Kits – Pilot

- Carers provide 24/7 care for years with little respite. The greatest challenge of caring for someone with an eating disorder is “how do I keep going?”.
- Connection with a community of others going through the same challenges is vital. With Covid-19, the need for mental health support has increased across Australia, including in rural and remote areas, where mental health and eating disorders services for families are scant or do not exist.
- Distributing Carer and Sibling Resource Kits nationally will rapidly provide connection to a community, expand access to lived-experience, online support and education services to an extra 1,200 families in 2021 - or 4,800 people if family of 4 - (*estimated number of new member families within the next 6 months*).
- By connecting and supporting Australian families and those experiencing Covid-19 intensified mental health crises, we will reduce isolation, loneliness and fear experienced by carers and siblings and reduce the burden on the health system.

FUNDING PROPOSAL SUMMARY – CURRENT PROGRAMS

Current Program	Description	Per Annum (\$)	Over 3 Years (\$)
strive Support Groups	Funding for calendar years 2022, 2023 and 2024 – part-time strive Program Manager for 3 years plus related program costs. Currently Program Manager is Commonwealth Government funded in 2021.	\$150,000	\$450,000

Current Program	Description	Per Annum (\$)	Over 4 Years (\$)
TBT-S Program Education Workshops Online Communities	Funding for calendar years 2021, 2022, 2023 and 2024 – full time Program Manager for 4 years plus related program costs, incl. training of more lived-experience volunteer support providers, web/digital platform management, etc	\$250,000	\$1,000,000

FUNDING PROPOSAL SUMMARY – NEW PROGRAMS

New Program	Description	Per Annum (\$)	Over 4 Year (\$)
1. ARFID & BN Support Groups Sibling Support Groups Early Intervention Carer Training	Funding for calendar years 2021, 2023, 2024 and 2025 – full-time Program Manager for 4 years plus related program costs e.g. External educator costs, web/digital platform management, etc.	\$250,000	\$1,000,000
New Program	Description	Per Annum (\$)	Over 2 Years (\$)
2. TBT-S Research Pilot Program	Funding for calendar year 2021 & 2022	\$195,000	\$390,000
New Program	Description	Per Annum (\$)	Over 1 Year (\$)
3. Carer & Sibling Resource Kits	Funding for calendar year – pilot program	\$165,000	\$165,000
New Program	Description	Per Annum (\$)	Over 2 Years (\$)
4. Research and evaluation of family and carer support services and the impact of the services on the families and carers	Fund research and evaluation projects with The University of Melbourne (Prof. Isabel Krug, PHD), Deakin University (Assoc. Prof. Genevieve Pepin) and Swinburne University (Dr Andrea Phillipou)	\$125,000	\$250,000

FUNDING PROPOSAL – NEW PROGRAM

<p>Title</p>	<p>1. ARFID & Bulimia Nervosa (BN) Support Groups, Sibling Support Groups, Early Intervention Carer Training</p>
<p>Background</p>	<p>The whole family is impacted (including siblings) so, if an average family consists of 4 members, that means approximately 4,000,000 Australians can end up with mental and physical health issues.</p> <ul style="list-style-type: none"> • ARFID & BN: Participant numbers in strive support groups are constantly growing and consequently it is becoming more challenging to manage the needs of all families in the sessions and the various eating disorders they are managing. Different eating disorders require different carer skills to effectively support their loved one. To this effect, EDFA is commencing monthly support groups in 2021 dedicated to carers supporting a loved one with Bulimia Nervosa and ARFID. • Siblings Support groups: <i>THE FIRST and ONLY ONE OF ITS KIND IN AUSTRALIA</i> - The impact on siblings has been widely documented yet there is no program in Australia to support, educate, provide a voice for and empower siblings. EDFA know from personal (and members') lived experience, the devastating effects on siblings that can lead to lifelong issues if there is no early intervention. The support groups will provide a forum to help circumvent siblings from developing behavioural, developmental and mental health issues before it is too late. • Early Intervention Carer Training: Early intervention education for Carers to learn skills to support evidence based treatment in the home. Held on Saturday mornings (so Carers can attend and not be hindered by work or the battle with the evening meal). Recommended for newly diagnosed families on the brink of FBT treatment to complete the course and for those on the waiting lists in the health system
<p>Proposal</p>	<p>To make these programs successful, EDFA needs a professional program manager to source and manage special lived-experience carer facilitators with the appropriate knowledge and skills for EDFA to run the additional ARFID & BN which are unique and much needed carer support groups. The same program manager will also organise and manage the Siblings Support Groups program as well as the Early Intervention Carer Training program</p>
<p>Benefits</p>	<ul style="list-style-type: none"> • Reduce reliance on an over-burdened Health System and reduce government costs. • Reduce the fear and anxiety families experience when face with a newly diagnosed eating disorder and feel connected, validated, empowered and not isolated and alone. • Prevent further progress of the eating disorder and help with early intervention. • Improve the mental health of Siblings so that they are better placed for healthy development and participation in education and the workforce. • Reduce the prevalence of mental illness in the rest of the eating disorder family
<p>Request to the Federal Government</p>	<p>Funding for 4 years at \$250,000 per annum</p>

FUNDING PROPOSAL – NEW PROGRAM

Title	2. CARER AND SIBLING RESOURCE KITS - PILOT
Background	<p>Connection with a community of others going through the same challenges is vital. With Covid-19, the need for mental health support has increased across Australia, including in rural and remote areas, where mental health and eating disorders services for families are scant or do not exist.</p> <p>Navigating the complex system to find effective care and treatment for a loved one or for oneself is extremely difficult.</p> <p>Distributing Carer and Sibling Resource Kits nationally will rapidly introduce and provide connection to a community, expand access to lived-experience, online support and education services to an extra 1,200 families in 2021 - or 4,800 people if family of 4 - <i>(estimated number of new member families within the next 6 months)</i>.</p> <p>When there is a diagnosis of a serious illness in a family they receive toolkits. For example the 'Bag of Hope' for Type1 Diabetes</p> <p><u>Carer Kits and Siblings Kits Examples:</u></p> <p>https://www.nationaleatingdisorders.org/toolkit/parent-toolkit/eating-disorder-myths</p> <p>https://www.jdrf.org/t1d-resources/newly-diagnosed/children/bag-of-hope/</p>
Proposal	<p>Undertake a pilot to create and distribute a carer kit and a sibling kit (where appropriate) to new EDFA families. Collaborate with one of the University of Melbourne, Swinburne or Deakin universities, to track the outcomes and benefits of the resource kits.</p>
Benefits	<ul style="list-style-type: none"> • By connecting and supporting Australian families and those experiencing Covid-19 intensified mental health crises, we will reduce isolation, loneliness and fear experienced by carers and siblings and reduce the burden on the health system • Improve the ability to access effective eating disorder treatment for a loved one by having a better understanding of how to navigate the system
Request to the Federal Government	<p>\$165,000 for one year</p>

FUNDING PROPOSAL – NEW PROGRAM

Title	3. TBT-S PILOT PROGRAM
Background	<p>TBT-S is a research and patient/carer informed treatment that focuses on the temperament-based roots and symptoms of eating disorders. It began as a therapy for Anorexia Nervosa and is being extended to other forms of eating disorders. Other stand-alone therapies are interwoven into the TBT-S model; including ICT, DBT, RO-DBT, CBT-E, FBT, IPT and ACT. TBT-S can complement and be used in addition to other eating disorder therapies.</p> <p>TBT-S integrates cutting-edge scientific information about the brain-basis of eating disorders into treatment; arming clinicians with experiential activities and skills to teach patients and carers about why eating disorders occur, and the skills that can be used to combat disordered eating behaviour. As a therapy, TBT-S focuses on how a patient's temperament-based traits are relevant to their eating disorder and can be utilised as tools for recovery. It acknowledges and embraces families in the treatment process with demonstrated high levels of patient and carer motivation and satisfaction.</p> <p>ICAT - Integrated Cognitive Affective Therapy; DBT - Dialectical Behavioural Therapy; RO-DBT - Radically Open Dialectical Behavioural Therapy; CBT-E - Enhanced Cognitive Behavioural Therapy; FBT - Family Based Therapy; IPT - Interpersonal Therapy; ACT - Acceptance and Commitment Therapy.</p> <p>TBT-S emerged from research in the United States from US Neuropsychologist from the University of San Diego, Dr Christina Wierenga, Clinical Assistant Professor in the Department of Psychiatry at The Ohio State University, Dr Laura Hill, and US Psychologist Dr Stephanie Knatz Peck. It has been tested in open trials over the last four years with very promising results. In early 2019, EDFA brought the leading TBT-S experts to Australia and conducted a series of sold-out workshops around the country. These workshops reached over 350 clinicians and carers in Australia and New Zealand. During 2020, we have conducted follow-up webinars for clinicians and carers with Dr Hill, Dr Wierenga and their colleagues. There is a strong interest from clinicians and carers in introducing TBT-S as a complementary eating disorder therapy and well as support from peak bodies, including NEDC, ANZAED and InsideOut Institute.</p>
Benefits	The results of the pilot would inform the future development of TBT-S as a psychology-based eating disorder therapy in Australia, with the development of standards, guidelines and treatment materials as well as training of clinicians, integration with existing models of care and further evaluations.
Next Steps	The next step is to undertake a research pilot of TBT-S, involving Australian clinicians with existing knowledge of TBT-S from the workshops and webinars, Drs Hill and Wierenga and their colleagues as the leading TBT-S experts, Australian-based research/evaluation partners, EDFA and other eating disorder organisations. There is strong interest from clinicians and eating disorder organisations in various states and territories for such a pilot, which could be conducted in the public and private systems.
Request to the Federal Government	<p>TBT-S with its strong focus on treatments that involve maximum patient and carer participation closely aligns with the principles espoused in the Productivity Commission Report on Mental Health, the 5th COAG National Mental Health and Suicide Prevention Plan and the National Mental Health Commission Vision 2030.</p> <p>It is proposed that the Federal Government funds a TBT-S pilot program. The methodology would be developed jointly by the international TBT-S experts and selected Australian-based research/evaluation partners working with InsideOut and key eating disorder organisations including EDFA. The pilot would utilise clinicians who have participated in the TBT-S workshops and webinars, with the support of their employers. Ideally it would be undertaken in the public and private systems with the evaluation informing federal, state and privately funded models of care. The TBT-S pilot, including its establishment and evaluation would run over 2 years with the cost to be agreed between the participants.</p>
Funds requested	\$390,000 over 2 years



FUNDING PROPOSAL – NEW PROGRAM

Title	4. Research and evaluation of family and carer support services and the impact of the services on families and carers
Background	<p>Various Universities have approached EDFA over the past couple of years expressing a strong interest in completing research and evaluation of the work we do within the community.</p> <p>In particular, the University of Melbourne (Prof. Isabel Krug, PhD and Sarah Giles PhD candidate), Deakin University (Assoc. Prof. Genevieve Pepin) and Swinburne University (Dr. Andrea Phillipou). These academics have dedicated their careers in the eating disorders field and acutely aware of the critical role families play in the recovery of those with eating disorders.</p> <p>EDFA is keen to complete research on the effectiveness of our carer program and now, our sibling program, as there has been little dedicated research in this space.</p> <p><i>Note: Further information can be provided to support the proposed research.</i></p>
Proposal	<p>Fund EDFA effort to manage the research program in conjunction with agreed University. Note: University will contribute their own in-kind funding.</p>
Benefits	<p>The results of the research will provide well informed data for effective decision making for both the Commonwealth Government and for EDFA on improving the national carer and sibling community.</p>
Request to the Federal Government	<p>Funding for 2 years at \$125,000 per annum.</p>

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