



12 January 2022

Mrs Lucy Wicks MP
Chair - Select Committee on Social Media and Online Safety
PO Box 6021
Parliament House
Canberra ACT 2600

Dear Mrs Wicks

Eating Disorders Families Australia welcomes the formation of the Select Social Media and Online Safety Committee and the opportunity to make a submission to this important inquiry.

About Eating Disorders

An estimated one million Australians have eating disorders. Although eating disorders can impact people of all ages, genders and backgrounds, women and girls are most affected. Increasingly, eating disorders are taking hold at younger pre-teen ages, an issue of relevance to this inquiry.

The causes of eating disorders are not fully known, and the profound impact they have on individuals, family members and carers is not fully understood or acknowledged. Eating disorders are a mental health condition which often occur in combination with other mental health conditions such as depression, anxiety, and suicide ideation.

There are a range of eating disorders including Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder and Avoidant-Restrictive Food Intake Disorder. Anorexia Nervosa (AN) – along with Schizophrenia – has the highest mortality rate of any mental health condition, with an estimated 20 per cent of those diagnosed dying within 20 years because of the physical or mental impact of the disease. Eating disorders are often lifelong, requiring ongoing management and support and, for some, frequent and often long hospitalisations.

There is stigma and misconceptions about eating disorders. They are not primarily about eating; they often relate to a complete loss of self-worth that manifests itself in a constantly reinforcing mindset about being undeserving of nourishment and the need to strive for a naturally unattainable body shape. Effectively, the eating disorder takes control of the mind and the body, with many of those affected reporting loud screaming or scrambling noises that disrupt their thought patterns, saying

the noises can only be temporarily quelled by acceding to the wishes of the eating disorder. Anything that allows the negative mindset of the eating disorder to be reinforced strengthens the hold on the affected person, an issue of relevance to this inquiry.

For families and carers, having a loved one with an eating disorder is an overwhelming, traumatic, isolating and life changing experience. As the eating disorder takes control, their loved one can become virtually unrecognisable both physically and in terms of their personality. There is the need to provide full time care – including in some cases overseeing six meals every day – often at the expense of being employed, while also navigating a complex and under-resourced health system with its many gaps, long wait times and overall lack of connectedness. Worst of all, there is the constant fear of their loved one self-harming or worse, at the whim of the eating disorder.

About Eating Disorders Families Australia

Eating Disorders Families Australia (EDFA) is a national, not-for-profit organisation with Deductible Gift Recipient (DGR) status. Our role is to support and advocate for the families and carers of loved ones with eating disorders.

EDFA formed in 2016 and launched in 2017 in response to the lack of practical support available for families and carers of people living with eating disorders. EDFA's board members have lived experience as carers of people with eating disorders and EDFA's work is overwhelmingly undertaken by volunteers.

In 2020, EDFA received Federal Government funding for its **strive** carer support groups, which operate in every state and territory and, during COVID, are being delivered via Zoom, led by trained volunteer facilitators with lived experience. **strive** stands for *Support, Teach, Reassure, Inform, Validate and Empower*. The **strive** carer support group meetings provide a safe environment in which parents and carers can connect, learn, share, and support each other. There are also **strive** groups for siblings and male family members.

As well as the **strive** support groups, EDFA organises expert education sessions for families and carers and provides personalised support through its Facebook community, enabled through fundraising and philanthropy. We also advocate for greater practical support for families and carers and encourage the use of family-friendly treatment models such as Temperament Based Treatment with Supports (TBT-S).

EDFA is a member of Eating Disorders Alliance Australia (EDAA) which includes the Butterfly Foundation and the Australian & New Zealand Academy for Eating Disorders (ANZAED). EDFA works closely with these organisations as well as state and territory eating disorder organisations, clinicians, and academic researchers.

Facebook/Instagram Whistleblower

In October 2021, former Facebook employee turned whistleblower, Frances Haugen, revealed through documents she had gathered before resigning from the company that internal Facebook research shows that Instagram makes eating disorders and thoughts of suicide worse in teenage girls. According to the internal studies revealed by Haugen, Facebook found that 13.5% of teenage girls say Instagram makes thoughts of suicide worse and 17% of teenage girls say Instagram makes eating disorders worse. Separately the Wall Street Journal has cited an internal Facebook document which states that for teen girls who had recently experienced body image issues, the app exacerbated those feelings for one in three of them.

Appearing on 60 Minutes, Haugen stated:

“And what’s super tragic is Facebook’s own research says as these women begin to consume this eating disorder content, they get more and more depressed. It actually makes them use the app more..... they end up in this feedback cycle where they hate their bodies more and more.”

Haugen also revealed that the Facebook research found that Instagram is “distinctly worse than other forms of social media” and that “social comparison is worse on Instagram” than other platforms because its focuses on the entire body and a person’s lifestyle.

Despite these findings, Facebook recently revealed it was not proceeding with plans to build a version of Instagram targeted specifically at children under thirteen. Facebook also criticised the Wall Street Journal reporting in a Senate hearing claiming that the documents it cited were “not bombshell research” and “that more teen girls actually find Instagram useful.”

Follow Up from the Haugen Revelations

Shortly after the Haugen revelations, the Office of Senator Richard Blumenthal and CNN undertook separate real-life investigations into how Instagram’s algorithms direct young at-risk girls to accounts that encourage extreme dieting. Despite Instagram’s own rules prohibiting the promotion of extreme dieting, both Senator Blumenthal’s office and CNN found that the app directed accounts registered to a 13-year-old girl who had expressed in weight loss and dieting to accounts with titles such as:

“I have to be thin:

“Eternally starved”

“I want to be perfect”

“Sweet skinny”

“Prettily skinny”

“Wanna be skinny”

As Senator Blumenthal told CNN, soon Instagram’s algorithm began almost exclusively recommending the young teenage accounts should follow more and more extreme dieting accounts. These accounts would include images of extremely thin people as well as information about a person’s current weight and their “goal” weight. Both are extremely problematic for people with eating disorders as they validate the need to lose more weight by engaging in unhealthy behaviours. The dominance of Instagram among adolescents and its use of artificial intelligence to direct users to accounts that confirm what the person believes or wants to be true has an extremely dangerous, multiplier effect on people with eating disorders. As the National Eating Disorders Association told CNN:

“While Instagram and other social media sites may not cause eating disorders and other body image issues, we know it’s definitely a strong risk factor in these situations.”

Tik Tok and Other Social Media and Internet Sites

Increasingly, eating disorder support advocates and charities are raising similar concerns about the impact of other social media and internet sites, particularly Tik Tok which is the dominant video app for young people and under-aged adolescents. The issues are similar in that Tik Tok's algorithms direct users to videos that are relevant to their interests, searches, and own videos. In many cases, users do not have to search for the weight loss content, it is proactively suggested to them.

For example, if a user watches a "pro ana" (i.e., pro Anorexia) or "pro mia" (i.e. pro Bulimia) video, then they are likely to be supplied with more weight loss and "thinspo" (i.e. content to encourage them to lose weight) content, again resulting in validating and triggering behaviour which is known to intensify the deleterious impact of eating disorders. The impact of these social media sites is exacerbated by the fact they are visual and comparative in nature as well as encouraging users to be competitive in their postings, all of which are inherently problematic for young people battling with eating disorders.

An example of potentially problematic content on Tik Tok (as well as Instagram) is the proliferation of What I Eat in A Day (or WIEIAD) videos which have proliferated in recent years, with various versions that actively advocate for dangerously low-calorie intake, extreme thinness and an unrealistic and unattainable ideal body shape and size. With both Tik Tok and Instagram overwhelmingly used by impressionable adolescents, these WIEIAD videos can increase anxiety and the loss of self-worth, as well as being triggering and reinforcing for young people at risk of or diagnosed with eating disorders. The very title of these videos (What I Eat in A Day) can also be problematic for families and carers of young people with eating disorders who have the responsibility of ensuring that their loved one is eating their required meal plan every day, including during Family Based Therapy (FBT) and similar eating disorder therapies.

Tik Tok claims that it takes down such content with its guidelines stating that "content that promotes eating habits that are likely to cause health issues is not allowed on the platform." However, like Instagram, eating disorder advocates are concerned that Tik Tok is slow to remove offending content which remains easy to access and that there is a lack of transparency from the company about the techniques it uses to remove content and whether they are effective or not.

Other social media and video sites such as Facebook, Snapchat, You Tube, and Tumblr are also sources of content that may be detrimental to people with eating disorders. A simple search of Google and other similar search engines can provide access to "pro ana" and "pro mia" sites, which originated on the dark web but have now become more mainstream on the internet.

Research into the Link Between Eating Disorders and Internet Usage

The link between internet usage, heightened body image and eating issues is well-established. In 2016, a review of the empirical research by Rogers and Melioli identified sixty-seven separate studies and concluded that"

"The existing data supports a relationship between Internet use and body image and eating concerns, and adolescents may be particularly vulnerable to the impact of the Internet. In

particular, engagement with visual, appearance-focused social media platforms is associated with heightened concerns.”¹

In 2019, Sherlock and Wagstaff studied women aged 18-35 and found a clear link between the frequency of Instagram use and exposure to beauty and fitness Instagram images and a range of depressive, self-esteem, and body dissatisfaction issues. The results show that:

“The frequency of Instagram use is correlated with depressive symptoms, self-esteem, general and physical appearance anxiety, and body dissatisfaction and that the relationship between Instagram use and each of these variables is mediated by social comparison orientation.... beauty and fitness images significantly decreased self-rated attractiveness, and the magnitude of this decrease correlated with anxiety, depressive symptoms, self-esteem, and body dissatisfaction.”²

In 2017, Sidani et al examined the association between social media use and eating concerns in a large, nationally representative sample of young adults aged between 19-32. The research found that “participants in the highest quartiles for social media volume and frequency had significantly greater odds of having eating concerns: and that “there were significant positive overall linear associations between the social media use variables and eating concerns.” The researchers concluded that:

“The results from this study indicate a strong and consistent association between social media use and eating concerns in a nationally representative sample of young adults aged 19 to 32 years. This association was apparent whether social media use was measured as volume or frequency.”³

In 2019, Wilksch et al undertook research into the relationship between social media use and disordered eating in young adolescents with a sample of 996 Grade 7 and 8 students in Australia. The research found that the more social media accounts each adolescent had and the more time they spent on them, the more likely they were to demonstrate disordered eating. In particular, girls who spent more time on Instagram or Snapchat showed significantly higher rates of disordered eating while “girls with Snapchat and Tumblr accounts and boys with Snapchat, Facebook and Instagram were significantly more likely to have both [disordered eating] behaviours and over-evaluation of shape and weight in the clinical range.” The study concluded:

“A clear pattern of association was found between SM usage and DE cognitions and behaviours with this exploratory study confirming that these relationships occur at a younger-age than previously investigated.”⁴

In 2018, Mills et al studied the relationship between posting selfies and mood and body image utilising an experimental design of female, college-age students in Canada. They found a

¹ Rachel F Rodgers and Tiffany Melioli, *Adolescent Research Review* volume 1, pages95–119 (2016)

² Sherlock, M., & Wagstaff, D. L. (2019), “Exploring the relationship between frequency of Instagram use, exposure to idealized images, and psychological well-being in women”, *Psychology of Popular Media Culture*, 8(4), 482–490. <https://doi.org/10.1037/ppm0000182>

³ Jaime E Sidani, Ariel Shensa, Beth Hoffman, Janel Hanmer, Brian A Primack, “The Association between Social Media Use and Eating Concerns among US Young Adults”, *J Acad Nutr Diet*, 2016 Sep;116(9):1465-1472.

⁴ Simon M. Wilksch PhD, Anne O’Shea PhD, Pheobe Ho BSc, Sue Byrne PhD, Tracey D. Wade PhD., “The relationship between social media use and disordered eating in young adolescents, *International Journal of Eating Disorders*”, First published: 03 December 2019

unidirectional causal relationship between posting selfies to social media and worsened mood and body image, concluding that:

Women who took a selfie and posted it to their social media profile had increased levels of anxiety, decreased confidence, and lowered perceived physical attractiveness compared to those who did not take a selfie.⁵

The harmful effects occurred regardless of whether the posted selfies were re-touched or not.

In 2017, research by Cohen, Newton and Slater found that: “appearance-focused social networking site use, rather than overall social networking site use, was related to body image concerns in young women. Specifically, greater engagement in photo activities on *Facebook*, but not general *Facebook* use, was associated with greater thin-ideal internalisation and body surveillance. Similarly, following appearance-focused accounts on *Instagram* was associated with thin-ideal internalisation, body surveillance, and drive for thinness, whereas following appearance-neutral accounts was not associated with any body image outcomes.”⁶

A 2018 literature search on “PubMed” and “Ovid Medline” undertaken by Memon et al of nine relevant research articles found that social networking websites are utilised by suicidal and self-harming youth as a medium to communicate with and to seek social support from other users. The study found that:

Online social networking also leads to increased exposure to and engagement in self-harm behaviour due to users receiving negative messages promoting self-harm, emulating self-injurious behaviour of others, and adopting self-harm practices from shared videos.....In conclusion, greater time spent on online social networking promotes self-harm behaviour and suicidal ideation in vulnerable adolescents.⁷

In 2017, McKean et al supported by La Trobe University undertook a pilot study into the effectiveness of a social media literacy intervention for adolescent girls on risk factors for eating disorders. The participants in the study who received the three literacy lessons showed significant improvements for body image and media literacy, with:

“The outcomes of the pilot study suggesting that social media literacy is a potentially useful approach for prevention of risk for eating disorders in adolescent girls in the current social media environment of heightened vulnerability.”⁸

In 2018, Hunt et al worked with University of Pennsylvania students to research the impact of reducing social media usage on loneliness and depression. The participants who reduced their Facebook, Instagram, and Snapchat use to 10 minutes, per platform, per day for three weeks showed significant reductions in loneliness and depression. Both groups showed significant

⁵ Jennifer S.Mills, ^aSarahMusto, ^aLindsayWilliams, ^aMarikaTiggemann^b. “Selfie harm: Effects on mood and body image in young women,” <https://doi.org/10.1016/j.bodyim.2018.08.007>

⁶ Rachel Cohen, ^aToby Newton-John, ^aAmy Slater^b, “The relationship between *Facebook* and *Instagram* appearance-focused activities and body image concerns in young women”, <https://doi.org/10.1016/j.bodyim.2017.10.002>

⁷ Aksha M. Memon, Shiva G. Sharma, Satyajit S. Mohite, and Shailesh Jain, “The role of online social networking on deliberate self-harm and suicidality in adolescents: A systematized review of literature”, *Indian J Psychiatry*. 2018 Oct-Dec; 60(4): 384–392.

⁸ Siân A. McLean PhD, Eleanor H. Wertheim PhD, Jennifer Masters PhD, Susan J. Paxton PhD, “A pilot evaluation of a social media literacy intervention to reduce risk factors for eating disorders”, *International Journal of Eating Disorders*, First published: 28 March 2017

decreases in anxiety and fear of missing out over baseline, suggesting a benefit of increased self-monitoring of social media usage. Overall, the study concluded that the findings:

“strongly suggest that limiting social media use to approximately 30 minutes per day may lead to significant improvement in well-being”.⁹

The Views of People with Eating Disorders, their Families, Carers and Advocates

Families and carers who are members of EDFA’s closed Facebook community regularly express concern about the impact of social media and the internet more broadly on their loved one’s recovery from their eating disorders. These concerns take a number of forms. Certain social media sites such as Instagram, Facebook and Tik Tok are regularly referred to by parents as being problematic. The overall high-levels of usage of social media by their loved ones are often cited, with young people with eating disorders often being isolated from their school and other friends and too unwell to participate in normal adolescent physical activities. This issue of young people with eating disorders forming their own communities on various social media platforms can also be problematic if members of those online communities are encouraging unhealthy eating or self-harm behaviours.

As an example of the feedback provided by families and carers about the adverse impact of social media on their loved ones with eating disorders, one member recently informed EDFA that:

“I am writing to let you know about my now x-year-old daughter’s influence from Tik Tok and it’s negative impact on her Anorexia Nervosa and her mental health when she was weight restored.

My daughter was x years old when diagnosed with Anorexia Nervosa. She had been suffering for y months before diagnosis. In the midst of her undiagnosed Anorexia Nervosa, she was watching ‘glow-ups’ on Tik Tok.

These Tik Toks depicted girls showing photos of ‘before’ puberty and ‘after’ puberty photos. They led the viewer on a journey that showed the Tik Tok girls as fat and ugly before puberty then skinny and pretty after puberty. The ‘after’ photos were showing the girls as if they had a makeover with new clothes, manicures, and makeup. My daughter kept watching these and were featured on her For You page. She really wanted to be like these Tik Tok girls, and it contributed to her conviction to lose weight.

Also, Tik Tok was featuring self-harm and depression on her For You page. At this stage she was weight restored and in the second phase of Family Based Therapy (FBT). She says it was through this page she learnt about self-harm and how to do it. My daughter was shown images of blades with blood, ‘barcodes’ on arms created by blades and told this was a powerful coping mechanism. She began to cut herself with a sharpener or to scratch herself.

Thanks so much for making a submission on behalf of the eating disorders families. I really hope it makes a difference!”

One of the inherent issues with having an eating disorder is that the disorder can dominate every waking moment of the person’s life, with issues around food, weight, and body size and shape, an

⁹ Melissa G. Hunt, Rachel Marx, Courtney Lipson and Jordyn Young, “No More FOMO: Limiting Social Media Decreases Loneliness and Depression”, Published Online: 5 Dec 2018 <https://doi.org/10.1521/jscp.2018.37.10.751>

all-encompassing obsession. The controlling nature of eating disorders draws the person to social media content that validates and reinforces their destructive eating behaviours, in turn strengthening the disorder's physical and mental hold over them.

Organisations that advocate on behalf of people with eating disorders in Australia and overseas jurisdictions are acutely aware of the impact of social media and the internet on people with eating disorders and encourage various approaches to help address the issue. Across-the-board, there is recognition that society's over-emphasis on body images that are unrealistic and unhealthy is a fundamental problem that is accentuated in the online world. While it is recognised that the main causes of eating disorders are genetic and personality based, various social media (and broader media) content can be triggering and reinforcing, making it a substantial risk factor for people who have or are at risk of eating disorders.

Ridding the internet of all problematic content for people with eating disorders (and related mental health and self-harm issues) is difficult. However, there is a widespread concern that digital platforms and social media companies pay lip service to these issues and should be doing more to identify and take down problematic content in a timely manner. They should also be more transparent about the actions they are taking as well as being more responsive to complaints and proactive in encouraging and directly supporting the development of social media content that encourages healthy eating and positive and diverse body images.

In Australia, organisations like the Butterfly Foundation and Inside Out provide guidelines and tips for people with eating disorder in relation to the use of social media as well as directing them to online safety sources such as the Federal Government's Office of the eSafety Commissioner. During Mental Health Month in 2021, the Office of the eSafety Commissioner offered a free webinar to parents and carers to support teenagers manage their mental health when they are online. EDFA is also able to provide guidance and support for families and carers through its **strive** carer support groups, its Facebook community, and its education sessions.

Increasingly, both in Australia and overseas, eating disorder support organisations are turning to young people with lived experience with eating disorders to provide advice about the safe and responsible use of the internet and social media. These lived experience mentors and body image recovery coaches can relate with adolescents who have or are at risk of eating disorders. In Australia, the Butterfly Foundation is successfully using this approach. There are also examples of young people who have recovered or are recovering from eating disorders who have taken it upon themselves to produce their own positive body image social media content. Triple J's *Hack* program has also focused on young people's body image concerns, eating disorders and social media.

Overall, the efforts to reduce the harm that social media and the internet can inflict upon young people with eating disorders have been piecemeal, with the issue considered secondary compared with the issue of excessive social media usage and inappropriate access to adult sexual and violent content. Legislators, regulators, and online safety programs, including in schools, have not focused sufficiently on the clear link between social media, eating disorders and adolescent self-harm.

Consequently, there has been little pressure on digital platforms and social media companies to take down harmful content or proactively encourage positive body image and health eating habits. Online literacy programs for young people often skirt around body image issues and there is a dearth of online literacy programs that focus specifically on eating disorders. Similarly, there is a lack of materials for parents, teachers and clinicians who work with young people with or at risk of eating disorders explaining the risks of social media and how to effectively combat them. As a result, those

with responsibility for supporting young people with eating disorders often feel powerless, ill-equipped, and isolated in mitigating the serious risks posed by harmful social media content.

What Can Be Done

Eating Disorders Families Australia encourages the Select Committee on Social Media and Online Safety to consider a number of actions to help address the risks posed by social media and the internet on young people who have or are at-risk of eating disorders:

1. Internet and social media providers be legally required to take-down harmful content that encourages extreme dieting, eating disorders and self-harm under the Online Safety Act. This could be facilitated through the Basic Online Safety Expectations (BOSE) and Industry Codes and Standards making explicit reference to this harmful content.
2. Internet and social media providers be legally required to ensure their algorithms do not push harmful extreme dieting, pro eating disorder and self-harm content to users. Again, this could be facilitated through the Basic Online Safety Expectations (BOSE) and Industry Codes and Standards.
3. As part of the BOSE, internet and social media providers be required to institute complaint processes that enable families and carers who are concerned about the impact of harmful content on their loved ones with eating disorders to have their issues addressed in a timely and effective manner.
4. The Office of the eSafety Commissioner should encourage visually based social media providers such as Instagram, Tik Tok, Facebook and You Tube to develop and implement programs that encourage positive body images and inform users about the risks of harmful eating and extreme body image online content. The Office of the eSafety Commission would report annually on the development and implementation of these programs.
5. The risks entailed in social media content that promotes unhealthy body images and extreme dieting and how to avoid and combat such harmful content be included in existing internet and social media literacy programs that are provided through schools and online.
6. Funding be provided for the development of specialised body image related internet and social media literacy intervention programs that can be used by people with or at risk of eating disorders, their families and carers, clinicians, and recovery coaches and mentors. Where possible these specialised programs should utilise people with the lived experience of eating disorders as well as their families and carers. These programs should be available to be rolled out through organisations such as the Butterfly Foundation and EDFA.

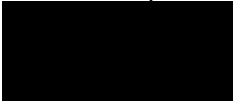
Conclusion

The impact of extreme dieting and self-harm related internet and social media content on people with or at risk of eating disorders, particularly children and adolescents, is well established through a strong body of Australian and international research. Recent revelations that Facebook's own internal research shows that Instagram makes eating disorders and thoughts of suicide worse in teenage girls have shone an overdue light on this issue, including the abject failure of social media and internet providers to take the necessary action to reduce the serious harm they are causing these vulnerable users. The combination of a lack of understanding and stigma around eating disorders has meant that governments and regulators have been slow to act in requiring internet and social media providers to remove this harmful content and ensure their algorithms are not pushing it to at-risk users.

There is a need for strong regulatory action to ensure that providers are acting responsibly and are more responsive to community concerns. Issues relating to the preponderance of harmful body image and self-harm related content need to be included in broader online safety programs for children and adolescents along with the development of specialised internet and social media literacy intervention programs that help reduce the risk and impact of eating disorders. Wherever possible, these programs should utilise people with lived experience of eating disorders and their families and carers and be made available through eating disorder organisations such as the Butterfly Foundation and Eating Disorders Families Australia (EDFA).

On behalf of EDFA, I appreciate the opportunity to make this submission and am happy to add to it at a hearing should that be of value to the Committee.

Yours sincerely



David Quilty /

Director – Eating Disorders Families Australia



<https://edfa.org.au/>