

Communities of HEALing Program for Primary Caregivers Report

*Conducted by F.E.A.S.T.
by contract with Project HEAL*

*“I think peer support is what really
got me through this stressful journey
and I believe that it, along with
good professional support,
is what saved my daughter.”*



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Introduction

In 2018, Project HEAL initiated planning for an 18-month pilot program of their Communities of HEALing program for Primary Caregivers. In 2019, Project HEAL contracted with F.E.A.S.T. to prepare a report of recommendations for Project Heal based on stakeholder interviews and surveys of a range of stakeholder types.

In January 2020, a survey was distributed to both F.E.A.S.T. and Project HEAL communities, and a team from F.E.A.S.T. began one-on-one interviews. This report is based primarily on those responses and represents a snapshot in time of the community's insights on parent support, skills, and knowledge, as well as existing parent support resources. As the first of its kind, it is limited to resources the F.E.A.S.T. staff and community have solicited and gathered from as wide a circle as possible.

This snapshot, we hope, will serve as a benchmark for more research and learning in addition to informing the Project HEAL's Communities of HEALing for primary caregivers.

Report Scope

- Recommendations for the types of support, skills, and knowledge needed by primary caregivers
- Recommendations for the delivery of mentorship support
- Literature review on existing parent support programs for ED primary caregivers

Background

The history of family and caregiver support for those with eating disorders began poorly from the first time an eating disorder was identified and named. Sir William Gull, credited for naming anorexia nervosa, said relatives and friends were “generally the worst attendants” back in 1874¹. Things worsened for families, and particularly for parents, when the reason for being excluded from caregiving shifted to blaming the family not only for caregiving deficiencies, but for causing the disorder itself². This is now a discredited idea that lingers in treatment and in the public’s scant awareness of eating disorders. The distrust and distancing of parents extended as more diagnoses were added to the eating disorder spectrum, including bulimia nervosa, ARFID, and binge eating disorder.

Although evidence-based treatment for eating disorders now rests on a more family-inclusive foundation³, questions remain on how best to support families, and specifically the primary caregivers, as they live with and care for family members with eating disorders. At this point in history, most of those with eating disorders do not have access to diagnosis-specific care, and available treatment largely remains focused on the patient and does not include coordination or education with the family. Information for families on how to support those struggling with an eating disorder is generally still based on a model that sees the patient as in sole charge of not only their own treatment, but of coordinating and educating their own families. Support for caregivers and siblings in helping the person with the disorder, or for their own coping or support systems, is rare but increasing as time passes.

Research in the 1980s and 1990s, beginning mostly in the UK, challenged the assumption that parents were unhelpful and harmful, and indicated that in fact with information and skills and clinical coaching, they could be powerful drivers of recovery⁴. Siblings, too, were brought into the team with the development of a “family-based” approach to treatment. This approach, developed originally for anorexia nervosa, not only included parents in the treatment, but turned original ideas on their head: parents were put in charge of caregiving and this increased rates of recovery.

But caregiving, especially in the new “family-based” model, changed the expectation of caregiving by putting parents in an intense and unfamiliar role of feeding and monitoring, and keeping patients safe at home despite resistance and even self-harm and violence. Watching helplessly while the patient was hospitalized, or home but in charge of their own symptoms and

¹ Gull W: Anorexia nervosa (apepsia hysterica, anorexia hysterica). Transactions of the Clinical Society of London 1874; 7:222-228

² Minuchin S, Rosman B, Baker I: Psychosomatic Families: Anorexia Nervosa in Context. Cambridge, MA, Harvard University Press, 1978

³ Resmark, G., Herpertz, S., Herpertz-Dahlmann, B., & Zeeck, A. (2019). Treatment of Anorexia Nervosa-New Evidence-Based Guidelines. *Journal of clinical medicine*, 8(2), 153. <https://doi.org/10.3390/jcm8020153>

⁴ Grange, D. L., & Lock, J. (2011). *Eating disorders in children and adolescents: a clinical handbook*. New York: Guilford Press.

eating, was hard on parents. But being put in the role of active carer has presented different challenges and expectations. In response, parents are now asking for and often demanding more information, more strategies, and more resources in order to do their important job on the treatment team. Parents are willing to do the work to save their family member and give them a better chance of recovery, but many describe the experience as “the hardest thing I have ever done”.

Research on the effects of caregiver burden is well-established for eating disorders, just as it is for other serious illnesses and injuries⁵. The constantly emergent nature of eating disorders presents a special challenge: sufferers are rarely stable while ill, as their symptoms either hold them in worsening health, or when in active treatment those symptoms can accelerate. The needs of those with chronic eating disorders can be exhausting to their family and supports as the symptoms alienate and isolate the affected person. As the symptoms of eating disorders are often misunderstood, normalized, or considered choices, it is common for parents to lack support from their communities, healthcare providers, and extended family. Even those with access to early intervention with professional care find that an eating disorder diagnosis in the family is a grueling and often overwhelming challenge for all family members. It goes without saying that patients suffer when their support system is overextended and exhausted. As a result, family members individually struggle to cope both day to day and over time.

Family Needs

Helping families meet the challenges of supporting and caring for an ill family member involves education, strategies, and resources.

The first step in helping families support a family member with an eating disorder is education. Families and parents are not immune from believing the widespread societal myths around eating disorders, and often lack access to good information or the specific strategies known to help with caregiving for these paradoxical disorders. Families usually have to unlearn myths and absorb and incorporate new information that is complex and unexpected.

Among the difficult tasks is to see the eating disorder as a neuro-biological condition, not a set of choices or lasting beliefs: a bizarre turn for a parent who knows their child so intimately and struggles not to see their words and behaviors as “theirs.” While most sufferers of disabling and potentially lethal conditions recognize a need for help and feel a desire for recovery, with eating disorders the family often finds itself battling resistance to treatment as a terrifying and crucial part of battling the disorder. In addition, families struggle to stay true to the affected person’s goals and values when the eating disorder has hijacked their actions and speaks with their voice: rarely an aspect of parenting a family will have been prepared for or immediately

⁵ Zabala, M. J., Macdonald, P., & Treasure, J. (2009). Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: A systematic review. *European Eating Disorders Review*, 17(5), 338–349. doi: 10.1002/erv.925

understand. Because the beliefs and behaviors of an eating disorder often reflect or resemble those of our larger society that values weight loss, exercise, and extreme food choices, it can be hard at first to distinguish mental illness from normal behavior unless the health effects become noticeable and life becomes organized around the behaviors.

Parents often describe coming to that understanding incrementally, or because of a voice outside the family, and often each parent does not arrive at that understanding at the same time. Realizing the scale of the problem at different rates or intensity can split couples in good relationships. It can be deeply divisive in a family without a strong strategic alliance.

Alongside education about the nature of an eating disorder, parents need to learn strategies for caregiving and managing treatment. These strategies often differ from normal parenting and may be far from the kind of approach that was normally effective with their child before they were ill. Active eating disorders often bring out emotions and behaviors that are disturbing or dangerous to the person and to the family. Actions toward recovery, like restoring normal eating and stopping compulsive exercise, talking about the problem, and engaging in treatment, often presents even more challenging responses. Parents can easily mistake that resistance for errors in their own response, or as a behavioral or discipline issue. Good clinical care and non-clinical support for the family can reassure and teach strategies for the different situations and stages of recovery.

Parents also need help finding resources. Eating disorders require diagnosis-specific and multi-disciplinary resources: researching and vetting treatment providers, school and work accommodations, community support, respite, and help with siblings and other family members. Finding resources to pay for care, keeping records and doing paperwork, coordinating between treatment providers, and explaining the situation to others around the family are all part of the picture of caregiving. These resources, meager enough for any family crisis, are particularly rare for families facing mental health problems, and eating disorders are so poorly understood by the public that it is rare for community members to recognize an eating disorder diagnosis as a family crisis. Stigma around the topic also reduces the resources known to and offered to a family.

Defining Family and Caregiving

It must be noted that not all eating disorder sufferers seek or benefit from the treatment available and eating disorders can be a chronic or long-lasting condition. But being a parent is a lifelong position, regardless of health status, so even when the disorder is protracted, active caregiving is rejected, or the sufferer cuts off the family, parents remain focused on the problem and on hold, often for years, as they wait for an opportunity to help. These parents are as focused on the problem as parents who are in active caregiving roles, but they suffer from helplessness and inability to affect the outcome. Eating disorders present a unique challenge to the role of parent or caregiver unlike that of any other health condition or parenting challenge.

We must also acknowledge that not all eating disorder sufferers have family members able or willing to serve as direct caregivers. While sometimes the supporters and caregivers can identify chosen family, those relationships can test the bonds of non-familial relationships under the escalating strain of even effective recovery efforts. A direct caregiver must have agency and leverage and accountability, and not be someone who can walk away or be driven away during times of distress.

The Case For Peer Support

As individual and complex as eating disorders are, research supports what would otherwise seem obvious: that patients do better when their support system and caregivers are well-supported, informed, and actively involved⁶. Even the most functional and caring parents are usually confused and frightened by symptoms of an eating disorder and do not automatically know how to best respond even though their response is critically important to the outcome. Unfortunately, parental distress in the face of these symptoms, and the escalating distress of the sufferer who is moving toward recovery, has often been seen as dysfunctional or harmful parenting. Informed, supported parents who are considered a valued part of the treatment and support team are better at their caregiver role.

To that end, parents often seek both clinical support and personal support, especially in the form of other caregivers with experience with the specific challenges and hopes of families facing eating disorders. The truth is: eating disorders are dangerous disorders but also highly treatable disorders. The longtime National Institute of Mental Health Director, Dr. Thomas R. Insel, once called eating disorders a “success story”⁷ among mental health interventions-- one with full recovery as a reasonable goal of treatment.

As the expectation has grown that parents will be more active in treatment, the parent population has also grown more active in supporting other parents. While support groups and peer meetings in earlier eras focused on helping parents cope and accept, the need and expectation of modern peer support has shifted to one that emphasizes information sharing and strategies. Instead of coping, parents are sharing tips on research and legal issues. This shift from being excluded and blamed to being empowered and effective has paralleled that seen in treatment and in peer support. Parents are supporting one another in being advocates for their families as well as advocates in the areas of policy and research.

⁶ Inga Dennyhag, Eva Henje & Karin Nilsson (2019) Parental caregiver burden and recovery of adolescent anorexia nervosa after multi-family therapy, *Eating Disorders*, DOI: [10.1080/10640266.2019.1678980](https://doi.org/10.1080/10640266.2019.1678980)

⁷ Videos, F.E.A.S.T. “Dr. Insel Keynote Presentation.” *F.E.A.S.T. Conference Video 2011*, F.E.A.S.T., 25 Mar. 2012, youtu.be/CwqpM-dcHPk.

Peer support between caregivers, too, has research support in many domains, including preliminary use of multi-family group support for eating disorders – again pioneered in the UK⁸. Still lacking are good data on peer support between caregiving parents, though interest in this has grown in recent years.

Peer support for caregivers on-the-ground remains rare, partially because eating disorders are rare disorders: fewer than 10% of the population will experience an eating disorder in their lifetime. The numbers of those who are still living at home or depending on parents for caregiving are far smaller than that number: the median ages for the onset of eating disorders are largely over 18, anorexia nervosa and ARFID being the exception. This has led to the impression that anorexia nervosa is more common and largely affects females. In fact, most of the parents who have been actively involved in caregiving are dealing with anorexia nervosa because of the age of onset and diagnosis: before the patient has left home. The impression that anorexia is a more common disorder has also been skewed by weight stigma: those suffering from the same thoughts and engaging in the same behaviors in larger bodies are not diagnosed with eating disorders, they are often considered “normal,” a sad and dangerous history that many in the field are now working to reverse.

While the parent community most often speaks of and provides peer support around anorexia, parents of those with bulimia and binge eating disorder are just as worried and in need of support, yet they are not allowed by law or custom to be as involved, especially because these disorders tend to begin later in adolescence or in early adulthood. This makes it even more important that the parent peer community be there for the less visible, more isolated families.

The relatively small number of parents of diagnosed eating disorders is reflected in the fact that on-the-ground peer groups of eating disorder caregivers are rare. (See Appendix.) F.E.A.S.T. has been searching English and Spanish language support groups for over a year and soliciting names and locations of support groups in person and online and found 93 opportunities around the world. This covers so few families facing eating disorders that it would be an exception for any newly diagnosed family to find one near them geographically.

For this reason, in addition to the exigencies of intense caregiving, many parents and caregivers go online for peer support. These opportunities, too, are not numerous. Without large marketing budgets or name recognition, they are not widely known or shared by providers. As free services, they are of varying size and quality. The longest standing forum for parents, Around the Dinner Table, hosted now by F.E.A.S.T., has welcomed over 10K users in its 16-year existence, a small fraction of the families affected over that period.

⁸ Carrot, B., Duclos, J., Barry, C., Radon, L., Maria, A.-S., Kaganski, I., ... Godart, N. (2019). Multicenter randomized controlled trial on the comparison of multi-family therapy (MFT) and systemic single-family therapy (SFT) in young patients with anorexia nervosa: study protocol of the THERAFAMBEST study. *Trials*, 20(1). doi: 10.1186/s13063-019-3347-y

Facebook groups, including F.E.A.S.T.'s Around the Dinner Table Facebook alternative, remain small and hard to find compared to other parent peer support organizations.

Peer support between families of eating disorder sufferers is in its infancy. But it rests on the shoulders of other parent peer support work and experience and informs future efforts.

Parent Peer Program Examples

- [La Leche League International](#) is a global parent-founded organization supporting families with nursing children. Trained and experienced volunteer parent “Leaders” organize and host free monthly meetings in communities worldwide providing education, troubleshooting, and sharing of stories.
- [Parent Peer Support Volunteers](#) is a trained service of parents and guardians in Western Australia offered by the Government Mental Health Commission. These parents with lived experience with a child’s alcohol or drug use answer a phone helpline for parents based on 2-3 days of training and structured around a 6-week educational program for parents.
- [FORCE Parents In Residence \(PiR\)](#) is a team of parent peer mentors in British Columbia offering peer support, mentoring, and navigation of the system for caregiving parents facing youth mental health challenges. These mentors work in communities and hospitals alongside professionals and offer free monthly information and support evenings for families.

Peer Support Variables

<i>Electronic</i>	↔	<i>In person</i>
<i>Focus on supporting the caregiver emotionally</i>	↔	<i>Focus on skills and information</i>
<i>Informal peer support</i>	↔	<i>Facilitated by a professional</i>
<i>One on one</i>	↔	<i>Groups</i>
<i>Ongoing</i>	↔	<i>Episodic</i>

<i>Anonymous</i>	↔	<i>Known</i>
<i>Directive</i>	↔	<i>Troubleshooting</i>
<i>Coaching</i>	↔	<i>Empowering to find own solutions</i>
<i>At same stage</i>	↔	<i>Mentor/Mentee</i>

F.E.A.S.T. Support Community

The F.E.A.S.T. community has facilitated peer support between caregivers, primarily parents, since our origins on an online forum in 2004 that was hosted by one of F.E.A.S.T.'s founders. That forum, now called [Around the Dinner Table](#), is the longest-standing online community of parents of eating disorder sufferers in English, and possibly in the world. More

recently, a second F.E.A.S.T. forum was created on Facebook, and a Spanish language forum was created as well.

Since its founding, Around the Dinner Table includes members, and founders, of other organizations and forums that have been created since 2004. This community has facilitated the creation of in-person and professionally-facilitated peer support groups around the world. All of these communities are interconnected and share users, creating a powerful network of community worldwide.

The lessons from these peer support groups and networks form a growing wisdom and have influences on treatment, policy, and even research. The families who came forward for this project reflect some of those families, and those lessons.

The Survey

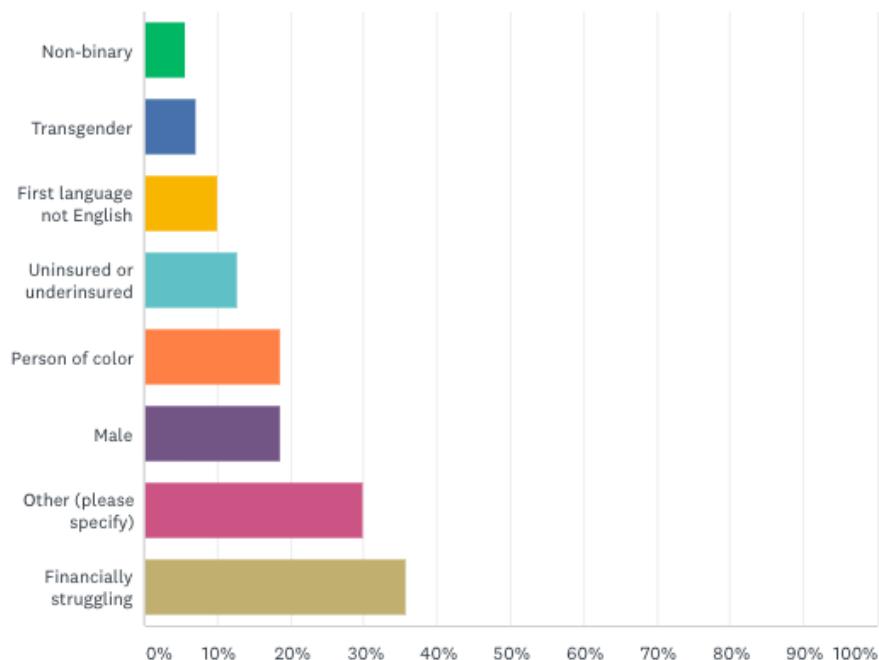
The 2020 COH Survey was open from January 9 to Feb 4, 2020 using the SurveyMonkey platform. A total of 546 responses were collected through two collector links: one distributed by F.E.A.S.T. (84% of respondents) and one by Project HEAL (16%). The 47 questions were assigned depending on stakeholder type, which included parents and caregivers (75%); people with personal experience with an eating disorder (14%); clinicians (3%); and other family members, friends, and other supporters (2%). Survey -takers completed the survey in an average of 11 minutes.

Survey respondents hailed from 21 countries, with 58% from the US. Most non-US respondents were from the UK, Canada, Australia, and New Zealand.

To assess whether the survey-takers included US consumers historically marginalized in ED service provision, including people of color, and poor or working-class consumers, the final question of the survey asked demographic information. No emails or identifying details were asked for. This question was included as part of the instructions of the grant.

To ensure that our research includes a diversity of voices, please indicate if you identify with any of the following groups often under-represented in eating disorder research and advocacy.

Answered: 70 Skipped: 143



The “other” category included a number of answers involving religion, sexual orientation, co-occurring health issues, and living in areas with little access to healthcare or where the family did not speak the language of the area fluently. Most mentioned financial struggle, which was also indicated by over a third of the US respondents.

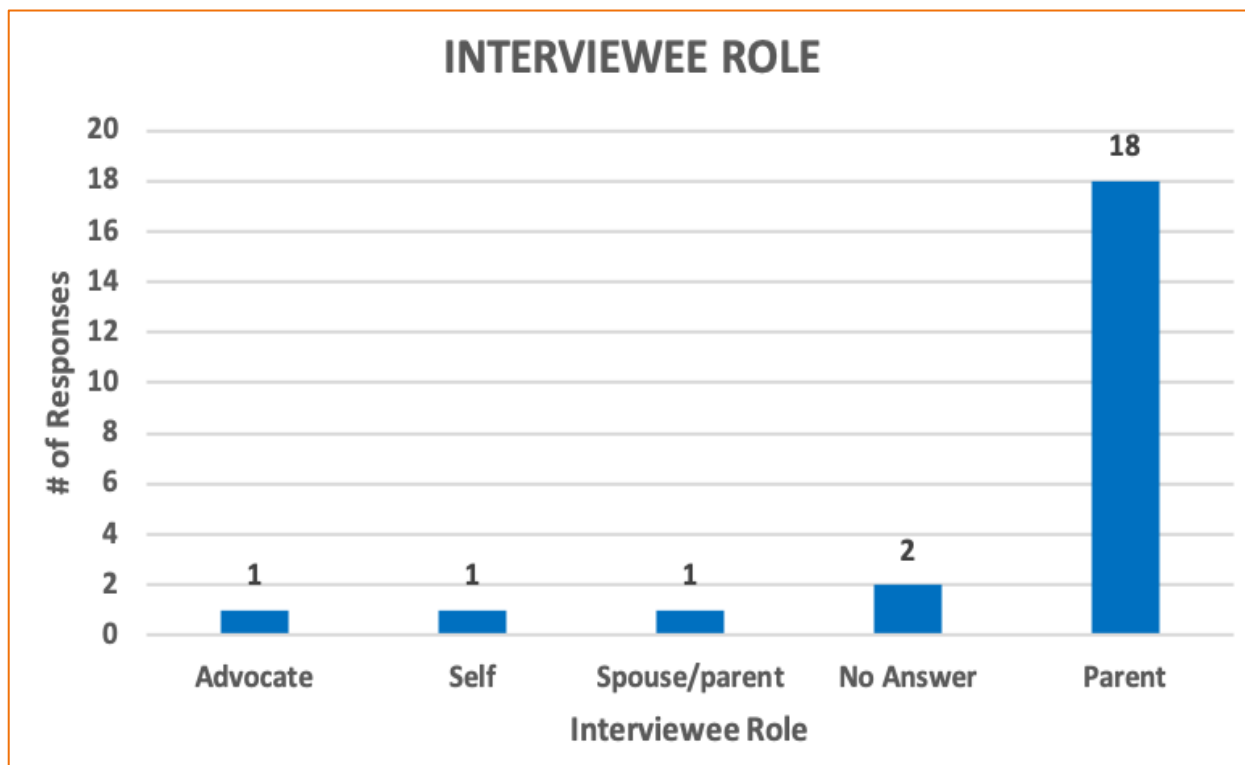
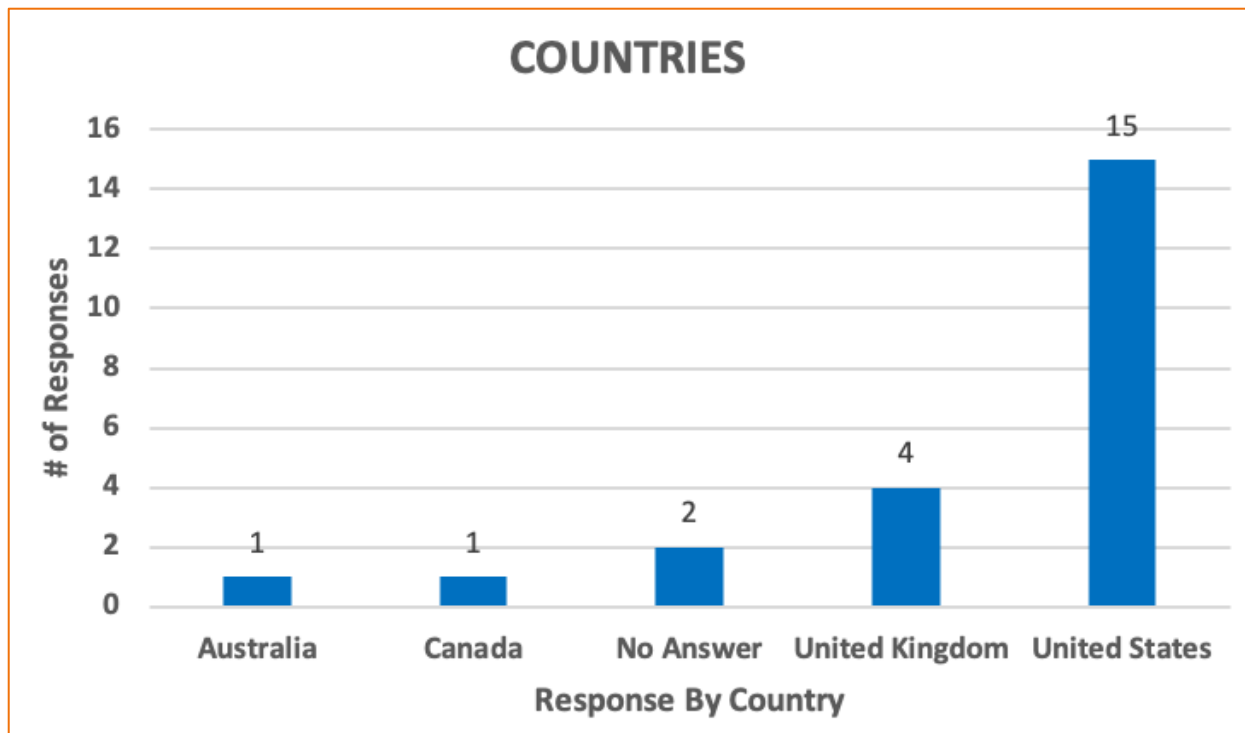
The Interviews

36 individuals from eight different time zones around the world who took the COH Survey went on to sign up for a 30-minute anonymous interview. All 35 available appointments were reserved in the first 24 hours. A team of five F.E.A.S.T. staff and board members conducted 22 in-person interviews which were recorded, transcribed, and de-identified. All but two interviewees were parent/caregivers. 15 interview appointments were cancelled, or the interviewee did not call in at the appointment time. Excerpts of the interviews, and notes taken, as well as additional comments emailed to us after the interview, are included in the appendix.

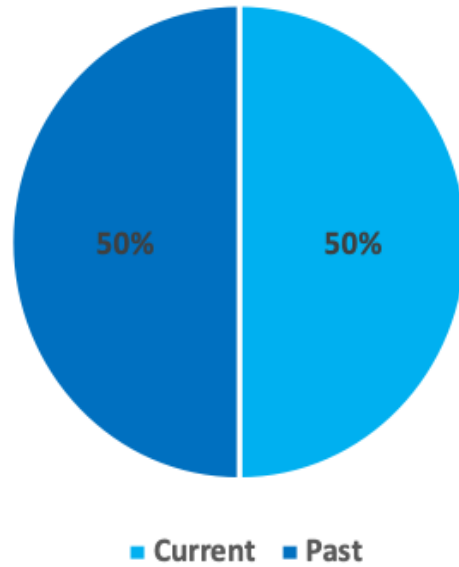
Because the survey was unable to capture the nuance or particulars of the respondents’ experiences, we drilled down into the experiences of those who volunteered to do 30-minute interviews, many of which extended longer than the prescribed time. Five volunteers conducted approximately 12 hours of interviews from which we observed many of the same patterns as in the survey, but some additional insights.

All but two of the interviews were with primary caregivers, but not unexpectedly some of the interviewees had more than one perspective: some had their own eating disorder history or were clinicians or had supported other people in their lives. Some were looking back many years into the past, so their perspective was both of early caregiving and from some distance. Several of those interviewed were experienced with both being mentored and being a mentor to other caregivers.

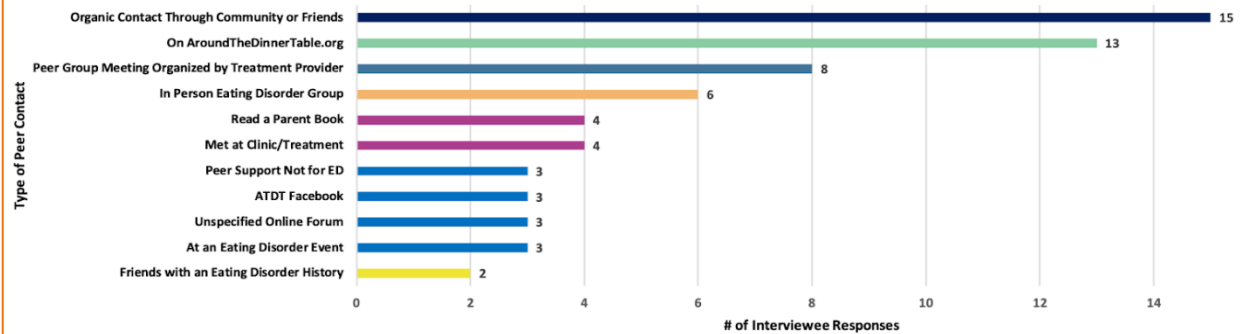
Because many of those who took the survey and did the interviews had the impression they were being interviewed as part of volunteering for a peer support program, they often had insights into their own desire to be a mentor to others, and why.



EATING DISORDER EXPERIENCE CURRENT OR IN PAST?

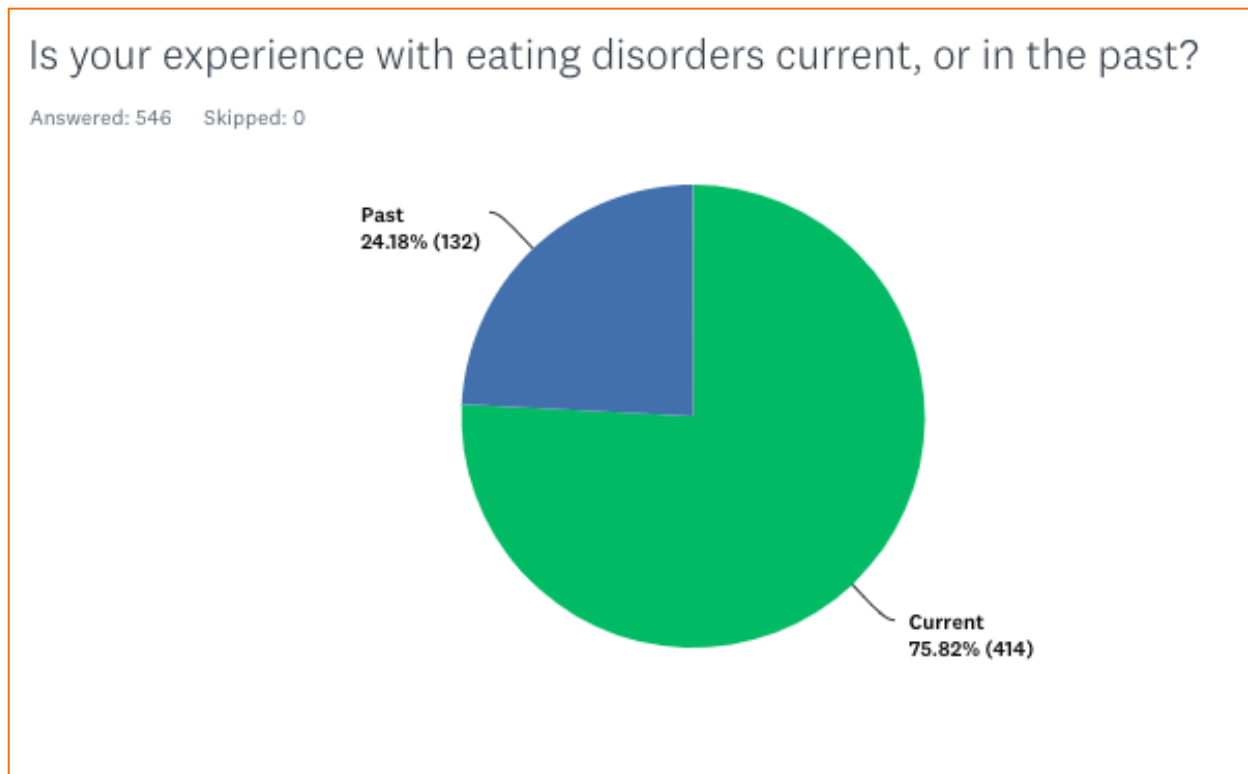


INTERVIEW RESULTS FOR PEER CONTACT Based on 23 Interview Responses



The Results

Some themes emerged in our survey and interviews. To better understand the insights the community shared, a bit about the pool of respondents.

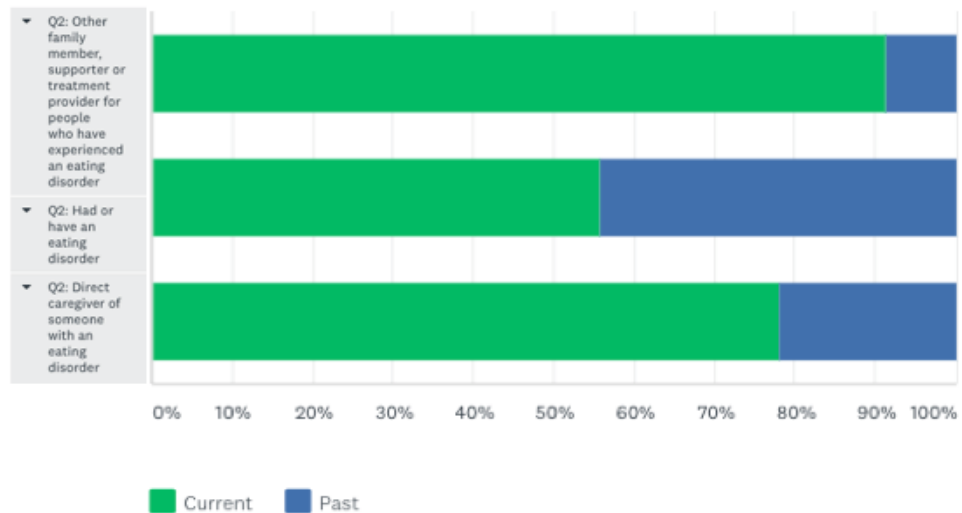


It was notable how many of the respondents were currently still dealing with unremitted eating disorders, either themselves or with the people they support. We took a look at the difference between those groups on several of the questions.

One large difference was between the primary caregivers and those with lived experience: a far smaller percentage of those who themselves had eating disorder experience were currently ill, while nearly 80% of the caregivers reported their experience was current. An even higher percentage of other family members and supporters, and clinicians, considered their experience current.

Is your experience with eating disorders current, or in the past?

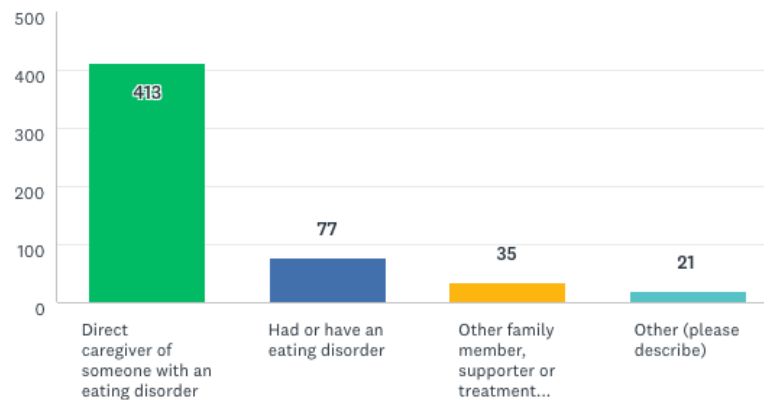
Answered: 525 Skipped: 0



The respondents were asked to choose how they described themselves, asking them to choose direct caregiver if more than one category applied, as that experience as a caregiver was most relevant to this survey.⁹

How would you describe yourself?(if more than one category apply to you, please choose the first one that applies)

Answered: 546 Skipped: 0



⁹ Probably due to the international audience and confusion over terms, many of the 21 “other” respondents would have fit into the other three categories, but since most of them were not primary caregivers and the other category routed them to the non-caregiver questions we feel the answers appropriately capture the right groups.

Of those who indicated that they are or were primary caregivers, only 6 said they were not parents or stepparents. Six were partners or spouses of the affected person, one was a legal guardian, and one a volunteer.

Our Report

The feedback to our question about the most significant challenges for caregivers brought up a passionate response, with certain themes.

Q4

Based on your experience, describe the most significant challenges for primary caregivers of those struggling with eating disorders?

Themes of the Responses

Treatment

When organized by theme, parent concerns over treatment featured in 42% of their responses. These concerns were about finding, vetting, understanding, managing, and struggling with professional treatment, or the lack of it. Poor, delayed, and weak treatment were the primary concerns. Treatment that was poorly grounded, unavailable, or withdrawn early were common complaints. Because parents are usually involved with treatment as the ones who first pursue it, research it, provide transportation and make appointments, pay for it, do the paperwork, and organize information sharing between providers, it means parent involvement extends far beyond the actual treatment itself. While in treatment, parents and caregivers are generally involved with compliance, and increasingly are not only in the treatment sessions, yet are responsible for carrying out the treatment at home between appointments. It is no wonder that much of parents' attention goes to the topic of treatment.

Because this was an international sampling of families, the problems described by US families centered more on finding and vetting options, as well as cost. For US parents, having the option of inpatient and residential care, options not typically available elsewhere, expanded the challenges of deciding on treatment and financing it. For families in most other countries, having national health systems where choice and payment were not factors, the problems had to do with understanding and managing the treatments offered, mostly at home.

Because the concerns of US families around eating disorder treatment differ so much from outside the US, it is important to distinguish where a family comes from when considering their concerns. US families bear the cost of treatment as well as the pursuit and vetting of treatment. Not all treatment options are equally priced or equally covered by health insurance, if the family has coverage. Each insurance policy has different co-pays, negotiates different rates, and

the deductibles vary widely. Treatments available in the US range from evidence-based to ungrounded, and insurance coverage rarely tracks with the evidence-based. Treatment providers accept payment out of pocket as well, so considerable expenses can be incurred outside of insured amounts.

Family

As is also natural, parents and caregivers are acutely focused on the overall family's functioning when one family member is mentally ill and struggling. Parents cited concern for siblings, for balancing various responsibilities as a family, and for relationships between spouses and partners. Brought up by 7% of the respondents, many expressed despair at the impossibility of maintaining a normal household and family life when the eating disorder was active or during early treatment or relapse.

Arguably, it is parents who are most concerned of all stakeholders about family functioning. In fact, there is no greater responsibility or identity or social mandate than to take care of one's family. Parents consider themselves, and are expected by others, to be in charge of the family's welfare. The frame for viewing a family member's illness is not limited to the patient. When family concerns are not foremost in the concerns of clinicians or treatment options, parents often feel even more protective and isolated. It can feel as if the focus on the patient undermines that patient's best interests by failing to both utilize and support the family.

While financial concerns may seem meaningless when weighed against a life-threatening illness, if the family loses their source of income, spends beyond their means, or empties retirement and educational savings during treatment, the effects are far-reaching. Siblings' futures are affected and often sacrificed. Caregiving for elderly relatives can be reduced or rendered impossible. For all these reasons and many more, the parents' focus on preserving the family unit is both their unique charge and their most important identity.

The basic responsibility to support one's family as parents is not optional or a luxury. Families often face impossible choices between competing priorities. Parents are the sole and final responsible parties and report feeling abandoned by society.

“When you are doing well fighting ED, ED makes your child scream/lash out directly at you. There is a high level of self-sacrifice in refeeding your child. It feels like emotional abuse for your child to turn on you. Few other caregivers (perhaps advanced Alzheimers) experience this. There is no social support or public acknowledgment for this challenge. Instead, the public assumes you broke your child to begin with.”

Symptoms

Being the parent or caregiver of someone with an active eating disorder is, as many reported in this survey:

“It takes over your whole life trying to keep them alive”

“24/7”

“... no respite.”

A small but significant portion of the responses to this survey question involved actual symptoms themselves: 5%. This is a poignant reminder that while logistics and emotions matter to parents, these are not just problems to think about, but an ongoing emergency in which there is rarely any break from the actual symptoms: behaviors and emotions.

Many of these symptoms are not just grueling to observe, but require 24/7 attention from others as well as disruption for all family members. Eating disorder patients are at high and ongoing risk of suicide attempts. Binging, exercising, purging, and checking behaviors can be compulsive and happen at any time of day or night. Secrecy features prominently for many, so family members are unable to trust the words or an appearance of normality. Symptoms cause frequent medical crises and can harm others through violence or impulsive attempts to avoid treatment. Many symptoms are socially unacceptable or shameful to families and sufferers, such as driven public exercise, anxious and panicked behaviors, and extreme demands around food choices and appearance.

The psychological symptoms of an eating disorder affect family members deeply. Anosognosia, a brain-based lack of insight into one’s mental and medical state, leaves family members living in an alternate reality from the affected person. Parents struggle to explain the situation or parent other children in the household normally when meals and activities are necessarily not at all normal or pleasant during treatment. Siblings and other family members who try to live a normal life or celebrate normal milestones find themselves distracted or feeling selfish. Family life becomes organized around routines that depend on the affected person’s treatment or distress. Contact with the world outside the family can become harder or impossible when the symptoms are obvious or need careful attending.

Worse still, successful treatment requires even more disruption as the patient’s anxiety and distress grows. Families can feel like they must choose between treatment and the stability of the whole family, leaving patients unwell but more cooperative and manageable. Without backup from outside the family, parents can feel forced to send family members out of the home into inpatient or residential environments to keep them safe and to prevent traumatic situations at home, where the disorder affects siblings and other family members.

Symptoms are not just an observed phenomenon for families: they are active and progressive crises for families and caregivers.

Money

Only 3% of the responses mentioned financial issues as a prominent concern: missing work or paying for treatment. This may reflect a lower priority among concerns rather than a lack of concern or be something parents feel ashamed of admitting. Concerns expressed around finances and missing work, interestingly, did not differ significantly between US and non-US respondents.

Caregiver Emotions

Four out of ten responses to this question involved the parent's own emotional health, as well as the existential impact of caregiving. Among the emotions shared were: fear, exhaustion, guilt, confusion, uncertainty, and tremendous fear for one's affected family member's future and survival. Parents, whose role in the family and identity as a caregiver is foundational to their existence, are ultimately responsible for their children. When their children suffer, it is not only a shared suffering with the child, but there is a natural belief that it is the parents' responsibility to have prevented the suffering and not to let up until it is resolved.

Tolerating distress was markedly high among the problems parents described. Seeing someone they love and are responsible for in extreme emotional distress is of course hard for any parent. Not being able to soothe or ameliorate that distress is an unnatural parental state. Feeling like a cause of that distress increases the anxiety that is already part of the experience, and even part of the parent's role during treatment. It rarely feels better for the patient when they are moving toward recovery, and parents are generally supporting that movement. Parents, who are at minimum watching alongside as a son or daughter is in treatment, and at maximum actively acting as a driver of treatment compliance, report finding tolerating that distress one of the greatest challenges.

Parents are also aware that our frustration, fear, and anger at the situation can be seen by treatment providers as dysfunctional and inappropriate, and even harmful. Parents unused to taking an authoritative stance with their children, or having stopped doing so as they grew older, find the inability to use reason or disciplinary measures unfamiliar, and even frightening. Much of the advice to parents during eating disorder caregiving used to be about boundaries and coping; now the advice is about actively engaging in treatment and remaining calm and unflappable in the face of the response. Parents are told that their attitude is part of the solution: that a caregiver's response is what will make the difference between success or failure in treatment. This immense responsibility to do something so unfamiliar and antithetical to normal life can cause parents to feel responsible for the outcome in a new way. Not only is the appearance of calm offered as a caregiver's job, failing to do so is seen as harmful to the person they love.

Not all outcomes of an eating disorder diagnosis are the same, and very few outcomes are rapid and conclusive. An eating disorder diagnosis is a crisis that lingers on even after recovery, with fears of hidden illness and in fear of relapse. Parents report being emotionally scarred and easily reactive even long after recovery is secured, and living in constant anxiety and sadness when recovery is not attained. Those who lose their son or daughter to the illness can spend a lifetime reflecting on what was and wasn't done, and what support was and wasn't available.

Survey respondents spoke often of recovery processes that were incomplete:

“We first noticed my daughter's ED about two years ago and she started treatment about 18 months ago. She's been in inpatient, FBT and outpatient CBT treatment since. She's doing better, but she's not fully recovered and has had one short relapse. The process is so, so long and nobody outside of our family really understands how sick she is and the level of care we need to provide.”

“I am not ready to offer peer support yet. My loved one is not completely recovered and I feel very weary...I think I need a little time to recover myself to be better able to offer peer support.”

Difference Between Caregivers and Others

When we asked non-caregivers the same question, about the greatest challenges for parents the focus of the responses differed from caregivers: clinicians and other family members most often mentioned issues around time and finding treatment—perhaps because these are the most common issues shared by caregivers with others—whereas non-caregivers focused more on what they most worry about or talk about with one another.

This disconnect between what caregivers really worry about and what others think they care about may point to an opportunity to better educate all stakeholders on the issue of caregiver perspectives, in order to build empathy and lead to different types of support for those in the caregiving role. While pressure around time and finding treatment need societal and systematic attention, parents and caregivers have specific needs around other issues that concern us alone.

The challenges cited by those with personal experience of an eating disorder, who were not themselves caregivers, differed yet again. Answers to the survey questions from these respondents ranged from sympathy to disdain. The most repeated issues revolved around lack of boundaries or lack of knowledge about eating disorders. These survey answers spoke of the

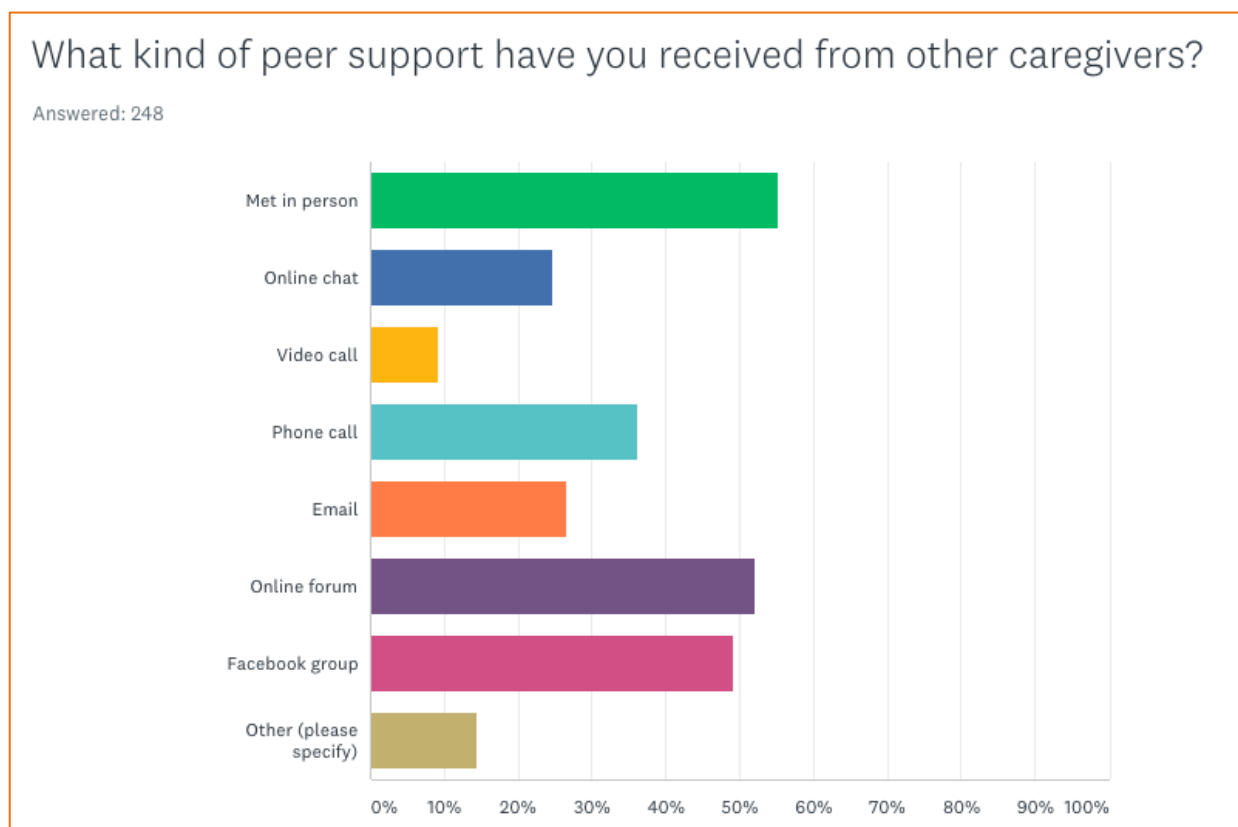
failings of parents and caregivers more than the challenges we face or our needs from fellow caregivers.

All the answers to this question, which amounted to over 300 often long descriptions, speak to a need for better education, resources, and strategies for the families of those with eating disorders, especially caregivers. The lingering effects of a family being uninformed and unhelpful to the sufferer is the opposite of the hopes and the opportunity for families to support their unwell family member and one another.

Prior Peer Mentoring Experiences

“There is just not enough of it!”

The overwhelming theme of prior peer support for parents and caregivers was: Not Enough. We asked parents and carers about their experiences with prior peer support from other parents and caregivers and 35% reported never having had that experience. For those who did, most reported meeting either on an online forum or a Facebook group, but over half say they met in person. In comments, many parents mentioned participating in groups organized at their treatment clinic.



“In person! (is there anything better than being in person??)”

When we asked parent/caregiver survey takers what they found most helpful about the peer support they had received, the answers were quite consistent: “Not Alone.” “Understood.”

Over 50% of the responses mentioned the value of shared experience, feeling understood without judgement or explanation, and not being alone.

Perhaps because the experience of being a caregiver for someone with an eating disorder is uncommon, and unexpected, parents clearly found the contact with others with the same experience to be more important than the content of the contact. The respondents described having no one else in their lives who understood the symptoms, the difficulties of caregiving, or the challenge of finding care. Many mentioned the emotional support they received from other caregivers, online and in person, and the advice and troubleshooting that they found nowhere else:

“I have learned more about eating disorders from the Facebook group than from any provider or book.”

“F.E.A.S.T.'s Around the Dinner Table online forum was the most significant factor in enabling me to successfully care for my son and turn his illness into a recovery journey.”

It was clear not only that the peer support was welcome, but that it was rare, and different from what could be provided by their friends or family who would normally be their support system. There were things about eating disorders, and caregiving, that isolated caregivers and made them feel unsupported from friends and family and their community.

Many survey respondents also mentioned that it was a benefit that the other person or members of the group were not clinicians or professionals. Many parents mentioned that they were unable to get the practical support and advice they needed from professionals, and still more said that they got information from peers that was not available from providers. Caregiving is a 24/7 task: appointments are usually a 50-minute hour with plenty of other issues to address within that limited time frame.

A quarter of respondents praised their peer supporters in the caregiving community for sharing vital information about the research and alternatives for treatment that they did not get elsewhere.

Parents most often cited fellow caregivers as being their access to information, although only 11% mentioned emotional support. The value of contact with other caregivers/parents, beyond validation and feeling understood, was mostly practical and part of information gathering. These parents were describing how they got support to help their children and their families, not support for themselves as individuals, despite the latter playing a large role in the challenges they mentioned as caregivers. They described their gratitude for the information that helped them do the work, rather than an expectation of others to solve their problems or make them feel better.

The Negative Aspects

We asked respondents to share any negative or difficult aspects of peer support, and the greatest stressor was upsetting stories: of protracted illness, extreme behaviors, and bad outcomes, including death. Although some expressed gratitude and accepted that these stories were important, many parents reported feeling repelled and scared by them.

Other negatives involved bad or unhelpful information, and “groupthink.” A common complaint was a pressure on online forums to “do FBT” (a specific treatment) and a feeling that those who choose not to or do not have success with care at home are being judged or shut down.

“The rhetoric on some of the online forums can be harmful. In promoting FBT, few peers talk about what to do when it fails. There seems to be this notion spread that if you love your child enough the ED will not win so the feeling of failure if FBT fails is exacerbated.”

Some comments about negative aspects of peer support involved group dynamics on online forums.

“I briefly tried an online forum and a facebook group, and I was totally turned off. The vibe felt aggressive and competitive—not for me.”

Many comments about the negatives of peer support reflected the dynamics of mixed groups. Online forums were perceived by some as dominated by users doing so well that people with more difficult paths felt they couldn’t speak up. Online forums were, at the same time, also reported by some as feeling unwelcome when situations were not serious enough. Complaints that people were too directive on forums were contrasted by those who felt they didn’t get enough clear and strong advice. These differences often had to do with timing: there were numerous descriptions of how what was negative or unwelcome early on became helpful later.

Those happiest with the online groups reported using them judiciously: seeing the users as individuals and weighing the information based on who offered it and their own personal judgement.

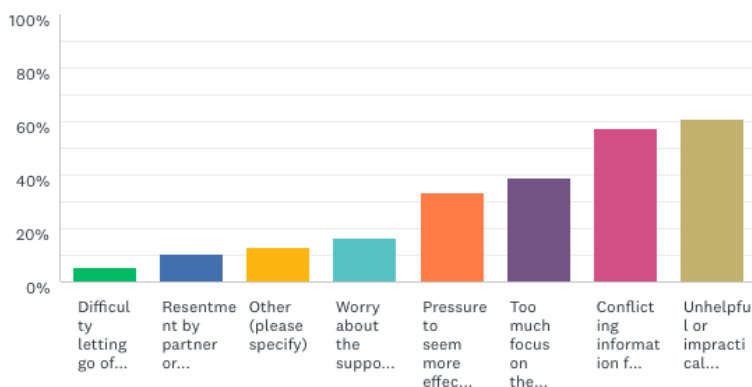
“The FB group has been incredibly helpful to me—lots of different approaches and experiences allow me to select what I think might work for me and I don't feel obligated to take anything that wouldn't work.”

As much as it means to feel heard and understood by others who share the experience, this sharpens the isolation and despair of those who feel shut down or judged by the same people. Parents who had left in-person and online groups reported the special isolation of feeling unseen and unappreciated in a group of people drawn together by that experience in the larger world.

“At the very beginning I felt that I was the only person whose child was not recovering as others' were.”

In your experience, what are possible harms or problems with receiving peer support from other caregivers?

Answered: 246



ANSWER CHOICES	RESPONSES	
▼ Difficulty letting go of the peer support	5.69%	14
▼ Resentment by partner or person with eating disorder of the peer	10.57%	26
▼ Other (please specify)	13.01%	32
▼ Worry about the supporter's situation or needs	16.26%	40
▼ Pressure to seem more effective or together than in reality	33.33%	82
▼ Too much focus on the supporter's experience	39.02%	96
▼ Conflicting information from the clinical team	57.72%	142
▼ Unhelpful or impractical advice	60.98%	150

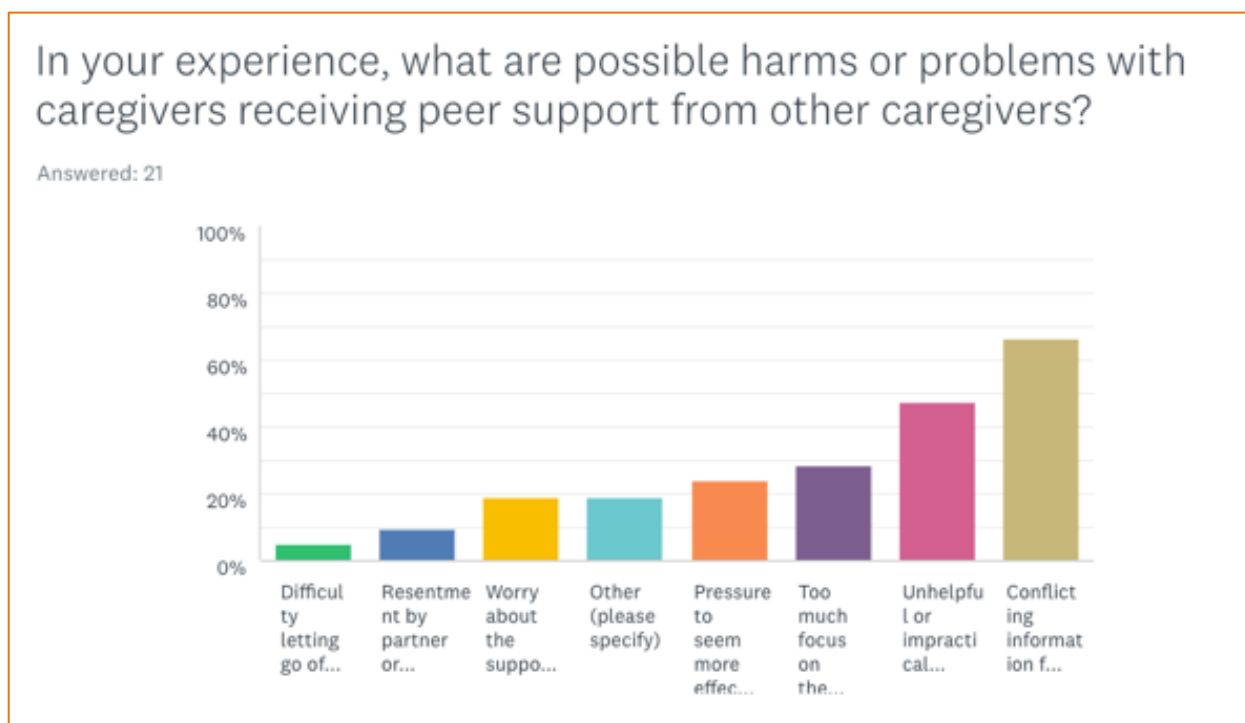
We asked about negatives of peer support in two ways: with pre-set choices and open-ended questions. The two questions brought out many of the same aspects, but the answer choices brought out some unique aspects when it came to concerns for the mentees. Unhelpful and impractical advice was a strong negative, as well as information that conflicted with clinical advice. Some aspects had to do with problems between the mentor and mentee, such as worrying about or over-emphasis on the needs of the supporter, or a pressure to “seem more effective or together” than they felt.

“It is such a private disease and helping someone takes so much emotional energy. Even asking for help becomes a stressor.”

Several caregivers expressed dismay at the attention they felt they needed to put into validating their supporter or mentor. This was reflected in complaints such as: “Caregivers who just want to talk about themselves.”

Of note, we asked the same question of those with personal eating disorder history (lived experience), and of other supporters and clinicians. Their answers were quite similar:

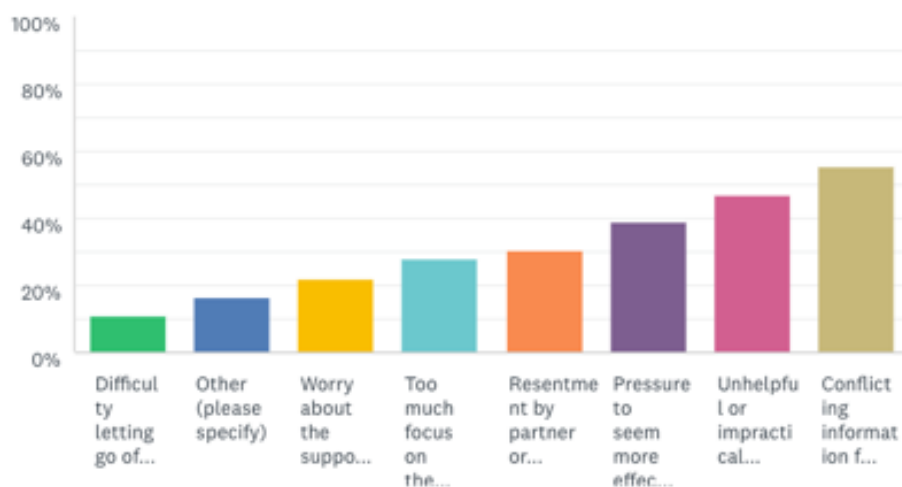
Lived Experience



Other Supporters

In your experience, what are possible harms or problems with caregivers receiving peer support from other caregivers?

Answered: 36



Clinicians, although only a small number participated in the study, focused primarily on harms associated with poor information and advice that conflicted with clinical information:

ANSWER CHOICES	RESPONSES
▼ Conflicting information from the clinical team	52.94% 9
▼ Unhelpful or impractical advice	41.18% 7
▼ Too much focus on the supporter's experience	41.18% 7
▼ Worry about the supporter's situation or needs	23.53% 4
▼ Pressure to seem more effective or together than in reality	17.65% 3

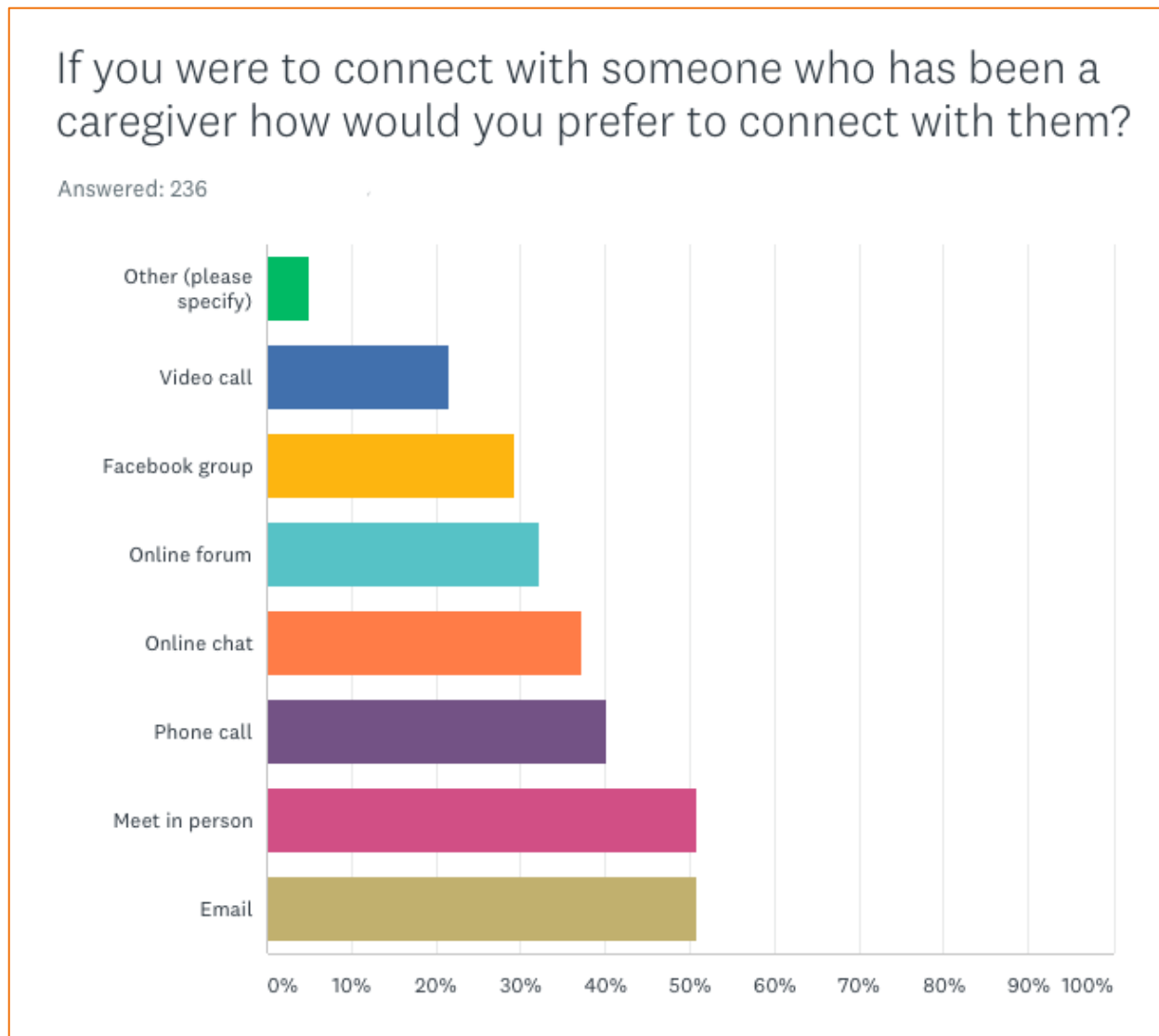
One clinician shared this:

“I think parents are the only ones that would actually really understand how hard it is to care for these children 24/7 for years on end.”

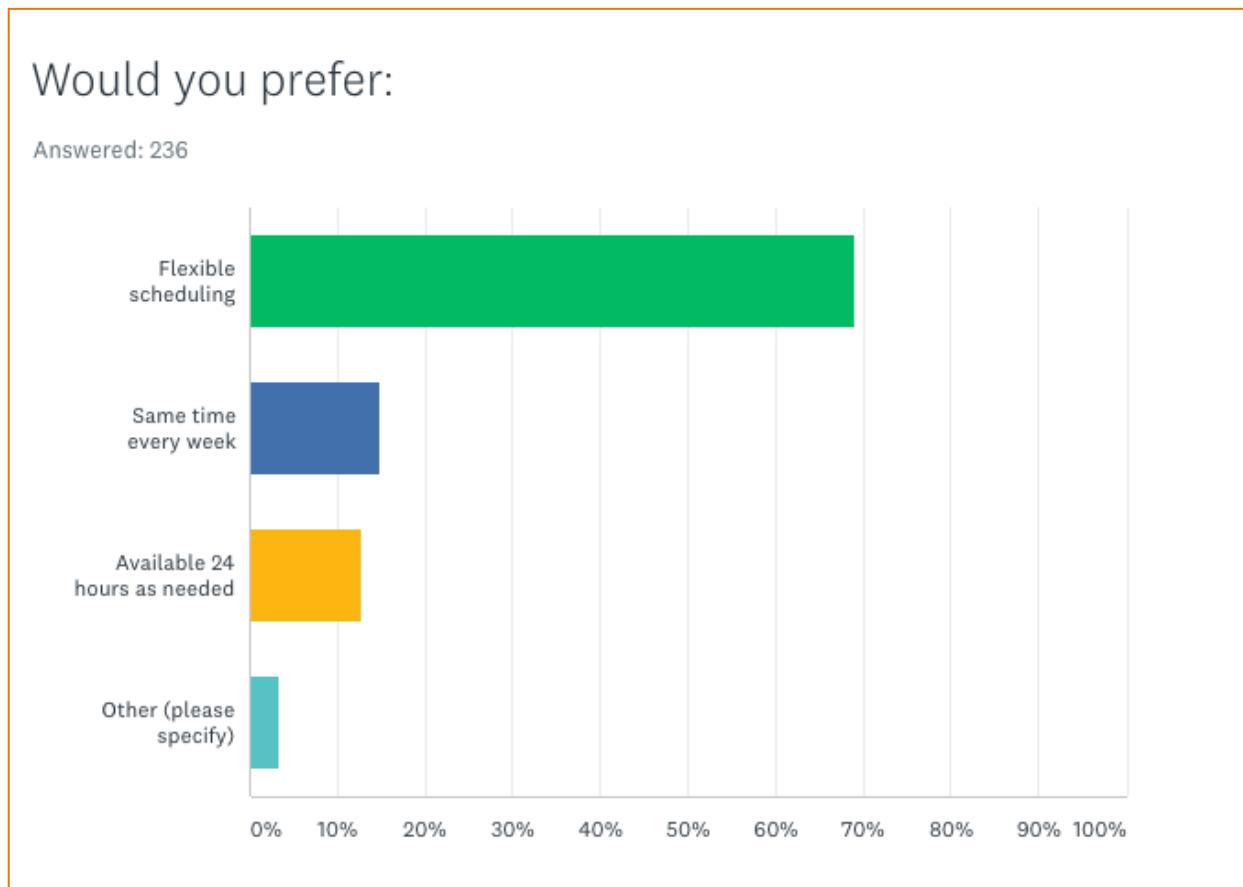
Interest in Being Mentored

One important line of questioning on the survey and interviews was to gauge interest in getting peer support. Those who reported currently being in a caregiving role showed strong interest in contact with other caregivers: 82%. When we asked how they would prefer to make that contact, there was equally strong interest in email contact and in-person contact: in other words, one-on-one and personal, followed by phone calls and online chat, also individual. Online forums, and then Facebook groups, followed behind.

Reflecting the sentiments of earlier questions, parents were eager for “any and all above” and stated that “anything would be helpful.” Yearning for more connection with other parents and caregivers was strong and passionate and clearly lacking.



Flexible scheduling for peer contact was the clear preference, but not spontaneous or on demand.



We asked respondents and interviewees to tell us how they have experienced peer support, and how those modes affected the experience.

In addition to the advantage of anonymity, online forums were lauded for access to years and years of experiences and resources that are searchable. On the other hand, online forums took criticism for being overwhelming, repetitive, and personality-focused. Descriptions of grave situations or extreme challenges tend to shut down conversation: users feel a pressure not to distract when another parent is really struggling, and parents feel they have to be caregivers to the other caregivers rather than asking for support themselves.

“...sometimes the caretaking direction has to be in the other direction.”

In-person peer support can be specific to the moment’s needs, and provide an opportunity to drill down on a topic, fully learn about a particular family’s experience over time, feel more personally connected, and to facilitate a personal relationship with someone “in real life.”

Privacy concerns threaded throughout responses of survey takers and interviewees. Unlike a health problem of their own, parents often feel constrained in sharing their experience because it is not their own story. There is also a special problem with eating disorders because of how common it is for those with an eating disorder to experience anosognosia and find the symptoms egosyntonic: they neither feel ill nor do others necessarily experience them as unwell. Parents report being under special pressure from their family members to stay silent and that it is “none of your business.”

This, and a natural desire not to be seen as different or needing assistance, are often described by parents as the reason they need to keep their ill family member’s identity secret. Parents avoid in-person eating disorder events, being seen in treatment clinics, and having their names associated with ED organizations. Donations to ED causes are often anonymous. There is also stigma around mental illness, and educational and job opportunities can be blocked when there is an eating disorder history, so these concerns are not trivial.

When it comes to peer support, these privacy concerns can isolate and leave parents without support that could help them and their families. Parents in the survey and interviews spoke of worry about meeting people they knew at an in-person support group, being seen on social media, or having their family member feel talked about or a burden.

On the other hand, some parents reported being quite open about their situations and becoming a community go-to for information and support. One mother described in her interview that she had “My Sheet” of resources she had used and often recommended. Another discovered after years of secrecy that revealing her experience led to having the unseen same experience going on with friends in her community. A parent got a perplexed call from their child’s boy scout leader: “Our guidance counselor told us to call this number, we had no idea you had experienced this, too!”

Surveys and interviews revealed interesting insights on the value of online groups in terms of privacy. Online, one can be fully anonymous, respect family members’ privacy, and allow for venting without fear of affecting relationships.

Another common issue brought up in this section was vetting of mentors.

“I would want to know their history of being a caregiver, who vetted them to be a peer support, what kinds of support have they received - what peer support networks are they connected with.”

“Individual needs to be non-judgmental and acknowledge that each recovery journey is unique and what works for one person's recovery may not work for another.”

“I would not have had reservations... providing those who are peers are appropriately trained, vetted... (assuming a formal peer support program)... the support I had was more informal...”

Some potential mentees worried about unmediated contact with other people’s experience.

“Establishing a relationship with someone based on mutually painful life events is in some respects like standing on quicksand. What if we pull each other down?”

“People who are more experienced can sometimes forget that the process from terrified newbie to effective refearer is a process and takes time and trial and error. As experienced parents we are automatically all about what worked for us and can forget that those techniques may not work for other situations. Some parents of ED kids have similar traits like black and white thinking and perfectionism that can get in the way of an empathic relationship and may cause harm to newbies who are extremely vulnerable or loved ones of people with SEED who are vulnerable in to equal but different degree.”

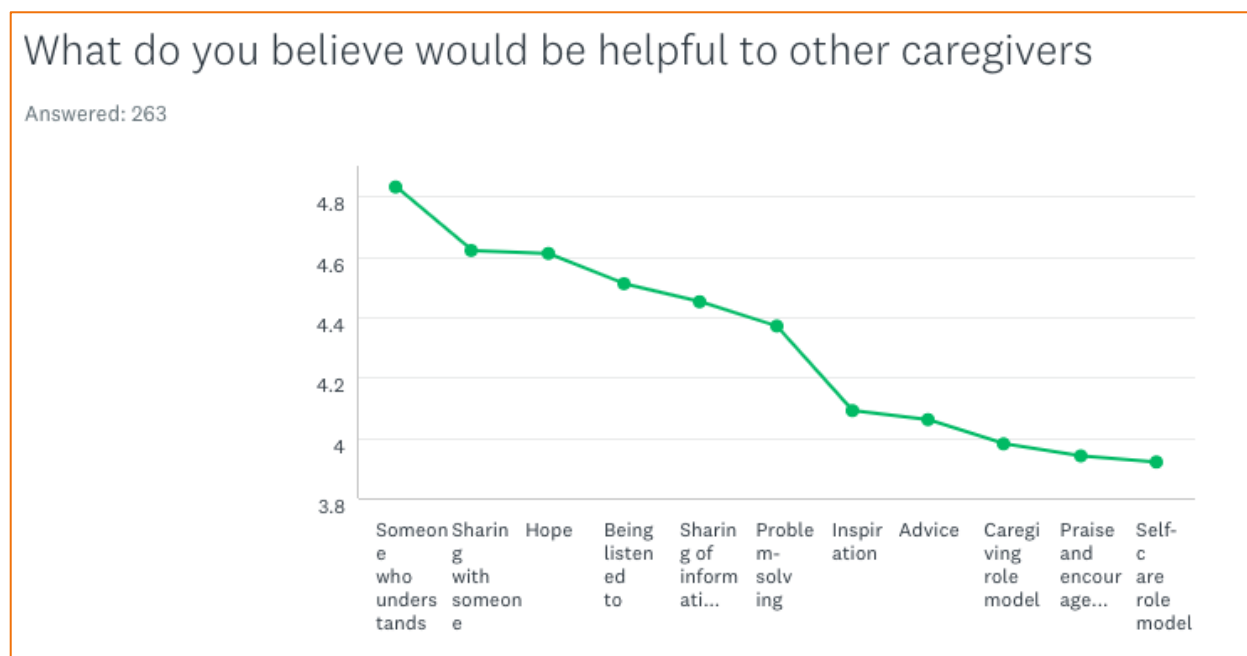
“Everyone's experiences will be different. No two people are the same. Do not want to be preached at. Nor smugness.”

As often came up during the surveys and interviews, parents remained focused on the concerns of the affected family member. One example was the answer to a question about any concerns about receiving peer support:

“...That my daughter will feel even more self-loathing because she has caused us to require support.”

Elements of Being Mentored

We asked parents and caregivers to drill down on the details of helpful aspects of peer support. Understanding, sharing, listening, and hope featured more strongly than inspiration and role modeling, and far above praise and encouragement.



On skills and knowledge, we noted a strong and consistent endorsement of respect, eating disorder knowledge, lack of judgement, empathy, and listening skills. Parents and caregivers showed a negative response to “tough love” and less interest in length of experience as a caregiver.

	LOW	LOW-MEDIUM	MEDIUM	MEDIUM-HIGH	HIGH	TOTAL	WEIGHTED AVERAGE
▼ Respect for parents and the caregiving role	0.38% 1	0.38% 1	2.68% 7	19.92% 52	76.63% 200	261	4.72
▼ Knowledge about eating disorders	0.38% 1	0.00% 0	3.80% 10	19.77% 52	76.05% 200	263	4.71
▼ Non-judgemental	0.38% 1	0.00% 0	5.36% 14	17.62% 46	76.63% 200	261	4.70
▼ Empathy	0.77% 2	0.39% 1	5.02% 13	22.39% 58	71.43% 185	259	4.63
▼ Listening skills	0.38% 1	0.38% 1	4.96% 13	24.05% 63	70.23% 184	262	4.63
▼ Knowledge about caregiving strategies	0.38% 1	0.77% 2	8.81% 23	26.44% 69	63.60% 166	261	4.52
▼ Belief in full recovery	1.14% 3	1.52% 4	9.13% 24	21.29% 56	66.92% 176	263	4.51
▼ Calm response	0.38% 1	1.92% 5	13.08% 34	26.54% 69	58.08% 151	260	4.40
▼ Optimism	0.39% 1	3.09% 8	13.90% 36	30.50% 79	52.12% 135	259	4.31
▼ Humility	0.38% 1	5.38% 14	20.00% 52	30.77% 80	43.46% 113	260	4.12
▼ Length of time caregiving	3.10% 8	13.18% 34	37.60% 97	30.23% 78	15.89% 41	258	3.43
▼ Tough love	8.91% 23	11.63% 30	33.33% 86	25.58% 66	20.54% 53	258	3.37

In matching peers with one another, we wondered how much the status of the more experienced peer's own ill person mattered to those seeking support. Same religion, ethnicity, and background were of least interest. The strongest desire was for someone whose family member was recovered: over 60% found this aspect important and only 12% said it was of no importance. There was also a strong desire for matching with someone of the same diagnosis, and severity. Same gender of patient was not a strong indicator on average, and only 10% found this a "very important" factor.

"Courage" and "Patience" featured most strongly as skills caregivers felt made them most successful as caregivers, along with many comments citing distress tolerance skills as pivotal alongside "Unconditional Love." Whether to characterize these qualities as skill or temperament or attitude to the illness is worth consideration. While a parent may need to practice strengthening these factors and may need clinical and personal support to make them possible, it may be helpful to look at these qualities as natural stances for parents and that the strains of facing this illness can weaken a parent's ability to exercise them. Good personal, clinical and social support, as well as well-grounded information about the disorder, and access to good care, all lend themselves to parents and caregivers being able to be courageous and patient, and to show their unconditional love.

"An inner strength I never knew I had and an inner belief that she would get better even if I faked that—as some days I did actually think she was NEVER going to get better."

In the area of the survey where we asked those with personal experience with an eating disorder what skills they valued in their own caregivers and parents; “Patience” was the strongest response. Clearly, all parties agreed on that priority.

Self-care, Strategies and Stages

When we asked for suggestions for topics to be covered in peer support sessions, three themes emerged that were reflected in most responses. The strongest theme was responsiveness to the stage and state and problems of that supportee’s situation at that time: not a prescriptive list coming from the supporter. The self-care needs and strategies that a supporter was able to offer would therefore depend on what was needed by that person, and that supporters needed to adapt and respond accordingly. This voice of lived experience reflects so many of the responses to other questions as well: the experience of caregiving is not only different for each person, but each stage along the way for that person and their family. Eating disorders are not a single, isolated problem nor does a person’s eating disorder remain the same over time. The nature of recovery and treatment is one of change and challenge and growth, and often setbacks. Parents and caregivers are responding in real time to providers and the rest of the family, and to household issues in addition to the patient’s symptoms and the patient’s overall needs. These experienced caregivers reflected that in their intuition of what mentees need as well-- a response to the moment at hand.

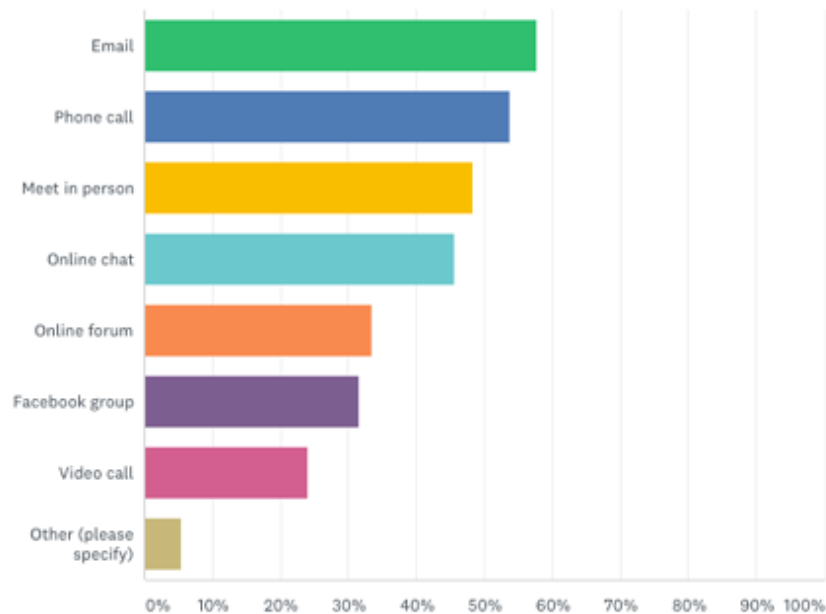
Responses from non-caregivers focused their answers to this question on teaching parents things about the disorder and fixing the parents more than on supporting the parents in their caregiving. Those with eating disorder experience expressed concern that parents need to listen to, individualize, and understand the patients. This too, reflects the need to be responsive to the present situation for the individual family, rather than prescriptions for all.

Serving As a Mentor

Two-thirds of the parents and caregivers who took the survey said they would consider serving as a peer supporter: 169 respondents. We were curious to compare how those using or seeking peer support match up with those who would be eager to offer it. We asked parents about connecting with other caregivers in the section about being a mentor or supporter, and then in the section about having a mentor or supporter, and contrasted their answers:

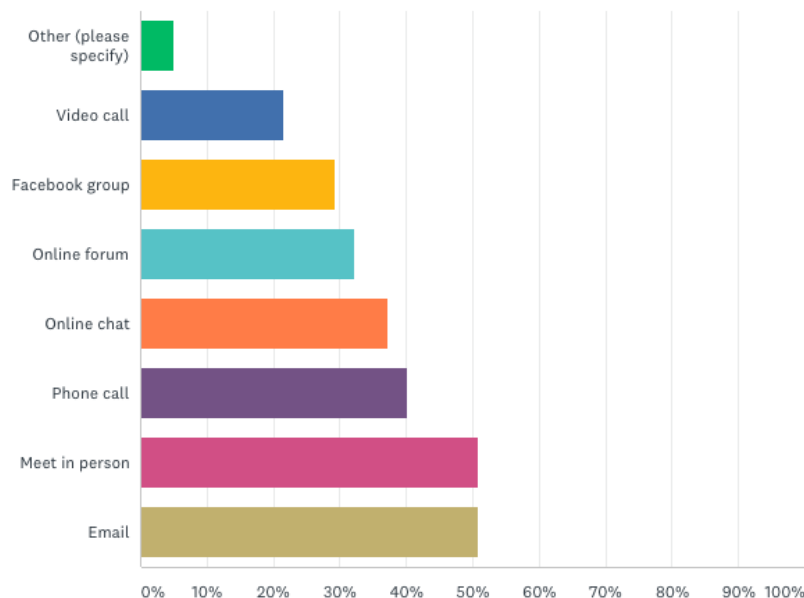
If you were to connect with someone who is currently a caregiver how would you prefer to connect with them?

Answered: 149



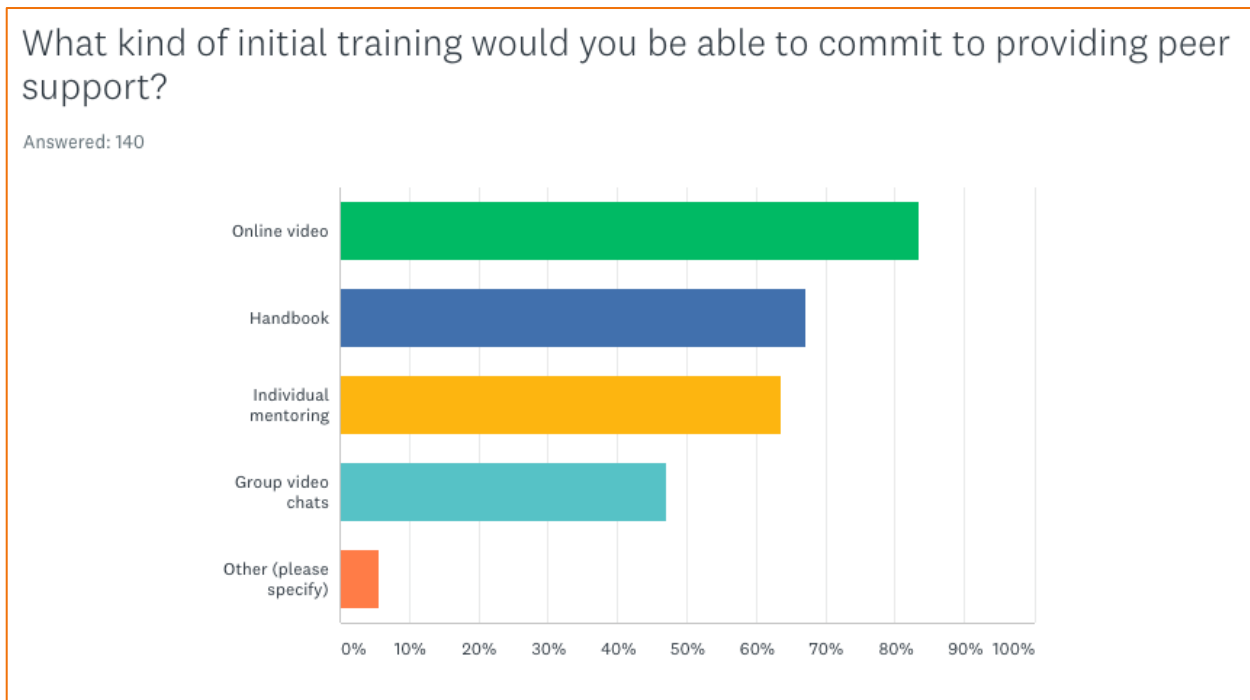
If you were to connect with someone who has been a caregiver how would you prefer to connect with them?

Answered: 236



The interest in meeting by email matched nicely in the responses as the most common. Meeting in person was of slightly less interest to potential mentors, but still important for about half of the respondents. Overall, potential mentors and mentees showed very similar levels of interest in ways of interacting.

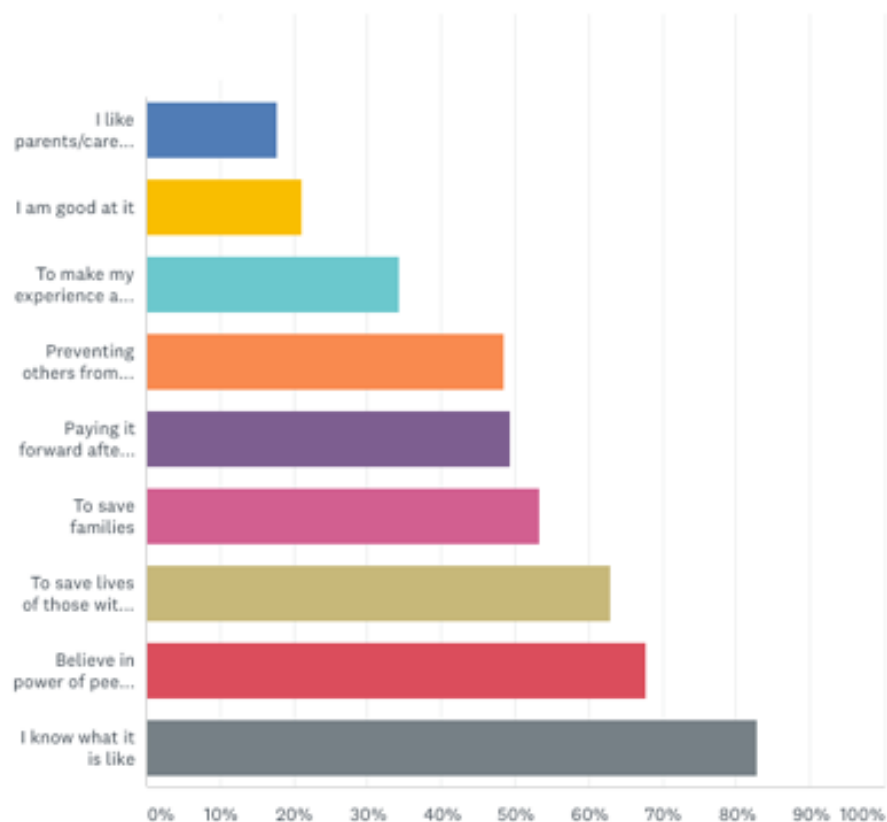
Hours available to be a peer supporter varied, but one hour a week was most popular. Additional comments most often mentioned numbers between 1-3 hours per week. For training, online video was overwhelmingly preferred.



Altruism featured prominently in respondents’ motivations to become a peer mentor but with a very personal connection: these caregivers felt that their experience as caregivers was of specific use to those experiencing the same issue. Saving families and saving lives through peer support came both from having experienced the caregiving but also from experiencing the benefits of peer support. The specificity of their experience’s value shone through. Interestingly, feeling very good at it and liking fellow parents and caregivers was significant but not prominent in the reasons to volunteer.

What motivates you to be a peer supporter for other caregivers?

Answered: 146



ANSWER CHOICES

- ▼ Other (please specify)
- ▼ I like parents/caregivers
- ▼ I am good at it
- ▼ To make my experience as a caregiver meaningful
- ▼ Preventing others from having my experience
- ▼ Paying it forward after getting peer support
- ▼ To save families
- ▼ To save lives of those with EDs
- ▼ Believe in power of peer support
- ▼ I know what it is like

To gauge what situations mentors might struggle with-or that might keep them from participating, we asked about what circumstances would be unacceptable:

ANSWER CHOICES	RESPONSES	
▼ Different diagnosis than my experience (1)	55.22%	74
▼ Methods I do not believe in (6)	44.03%	59
▼ Caregiver's person has passed away (8)	41.79%	56
▼ Suicidality (4)	39.55%	53
▼ Extreme behaviors (3)	23.88%	32
▼ No professional treatment (5)	20.90%	28
▼ No longer in active treatment (7)	8.96%	12
▼ Other (please specify) (9)	8.96%	12
▼ Different gender (2)	8.21%	11
Total Respondents: 134		

Diagnosis was a strong indicator: a slight majority of parents and caregivers felt that the difference of experience between different eating disorders was significant enough to be a mismatch for mentoring. A mentee using methods the mentor did not believe in was a strong indicator of mismatch as well. 41% of potential mentors did not feel comfortable mentoring someone whose family member had passed away, which indicates the majority of respondents would be willing to do so. Suicidality and extreme behaviors were concerning to a large proportion of mentors. Perhaps the greatest takeaway was how willing these potential mentors were, even with some reservations.

When we asked for risks to the mentor, we were not surprised to see that burnout was the strongest concern (54%) nor that worry about lack of gratitude (3%) was the least: those willing to support strangers through difficult times do so out of generosity of spirit and are often overextended due to the need and the confronting nature of the experience. Reliving difficult memories and anger at often inadequate treatment are in the nature of the topic.

Perhaps also to be expected is the high number of responses that involve conflicting or impractical advice. Since there is very little commonality between treatment clinics and clinicians when it comes to messaging, treatment, prognosis, or recovery from eating disorders, parents know well that any experience or information they share with another family may well not fit with the treatment team's advice for that family. Since all eating disorder patients are unique, and have may have different illness trajectories, one family's experience is rarely going to align with another's.

Mentors' emotional needs come into play when it comes to burnout, pressure to be a good example, reliving difficult memories, and worry for the other parents/caregivers.

ANSWER CHOICES ▼	RESPONSES ▼
▼ Burnout	54.79% 80
▼ Giving conflicting information from the clinical team	50.00% 73
▼ Worry about the supportee/patient	40.41% 59
▼ Offering unhelpful or impractical advice	37.67% 55
▼ Pressure to seem more effective or together than in reality	24.66% 36
▼ Anger at treatment system/providers	20.55% 30
▼ Reliving difficult memories	17.12% 25
▼ Difficulty avoiding being directive	15.75% 23
▼ Resentment by my family for not letting go of topic	13.70% 20
▼ Frustration with supportee's lack of effectiveness	12.33% 18
▼ Other (please specify) Responses	10.27% 15
▼ Envy of supportee's situation	4.79% 7
▼ Frustration with supportee not validating my experience	3.42% 5
▼ Lack of gratitude by supportee	2.74% 4

“...having a sounding board or a shoulder to cry on in those darkest moments when your child is ill - hearing someone say “I’ve been there” can provide peace and comfort. Dealing with EDs in your home is a daily event. Your world REVOLVES around the child and the eating disorder. Sometimes it is hearing a glimmer of hope in another person’s experiences that can get you through THAT day.”

Respondents interested in being a mentor did have worries about that role:

“While I would be interested, I would be concerned about what if I said the wrong thing... I would need to feel more confident.”

Interviewees talked about the humility necessary to that role:

“I would be okay talking about what worked for my daughter, but I don’t want anyone to think there is a magic answer. I realized through all this that every case is different, the more I learned to trust my voice, the stronger she got. That will be different for every individual.”

“For loved ones of someone with (longstanding eating disorder) it is more important to listen and be available for them to bounce ideas off you - they probably have even more knowledge than you.”

“My daughter is not recovered so I’m not exactly a role model of success, though I have tons of

*experience with treatment facilities
and modalities.”*

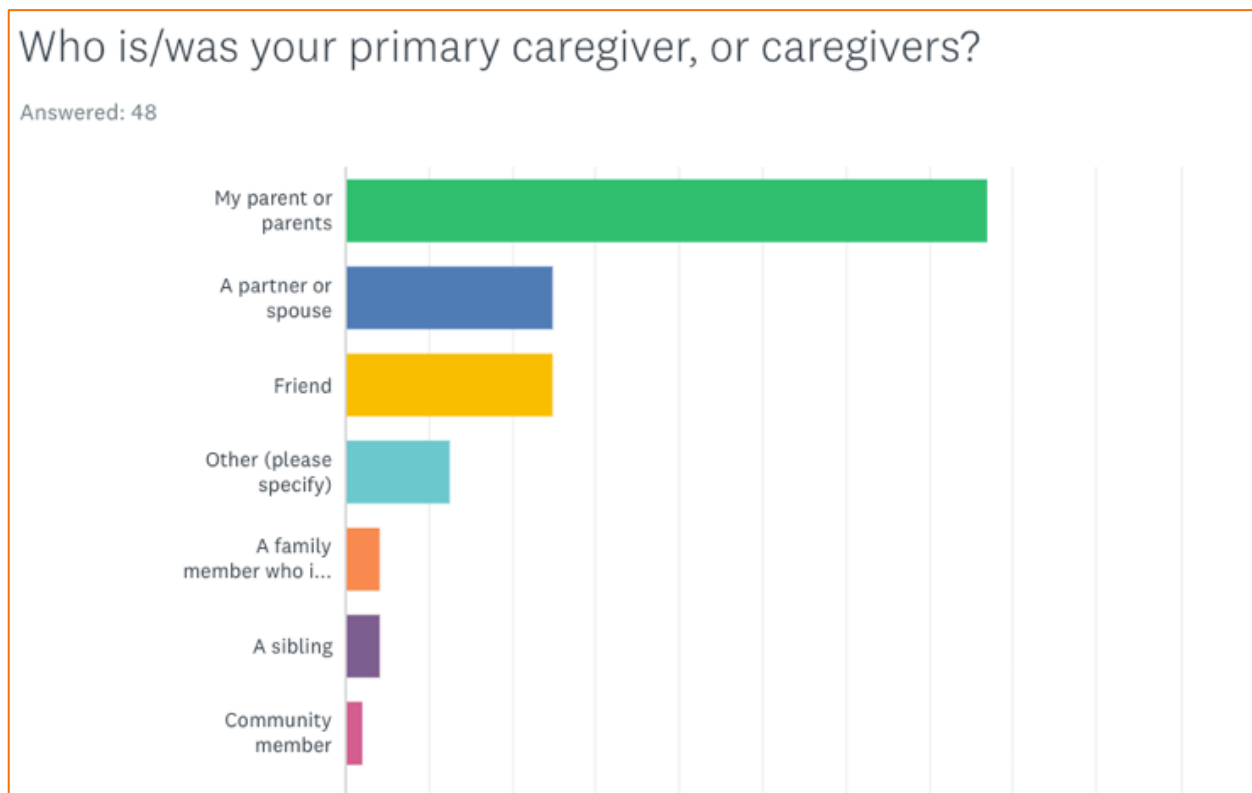
*“You don't have to be perfect or have all the answers. Empathy and
compassion go a very long way.”*

There were comments, too, on the limits of peer support in the context of current treatment access:

*“It isn't a replacement for the significant changes that still need to
happen within our health care system.”*

Lived Experience

As part of the design of this survey, we gathered survey results from those with lived experience of having an eating disorder to better understand their experience with their caregivers. 48 respondents reported being past (44%) or present (56%) eating disorder sufferers. Of those 48, 37 cited their parents or stepparents as their primary caregivers. A quarter cited a partner or spouse, and another quarter cited a friend. Other family members and siblings were mentioned by a small number. In comments, about half of the “other” category were grandparents or other relatives.



One person's answer to "What do you appreciate about the care you receive(d) from them" answered simply: "nothing."

Another said: "Amazing. Life saving."

As elsewhere in the survey, those with lived experience put a high value on patience from their caregivers. The words 'persistent' and 'love' and 'listening' also featured in the responses.

The chief concerns of those with eating disorder experience about their caregivers centered on inaction and lack of knowledge. A few cited ways their caregivers let them get away with eating disorder behaviors or failed to notice them. For some, guilt and feeling responsible for causing problems moved them to withdraw from caregivers. Several cited harmful attitudes or behaviors, like gaslighting, rejection, and weight stigma.

On the question of whether those with eating disorder experience thought peer support would be a good idea, the answer was nearly unanimous: "Great idea."

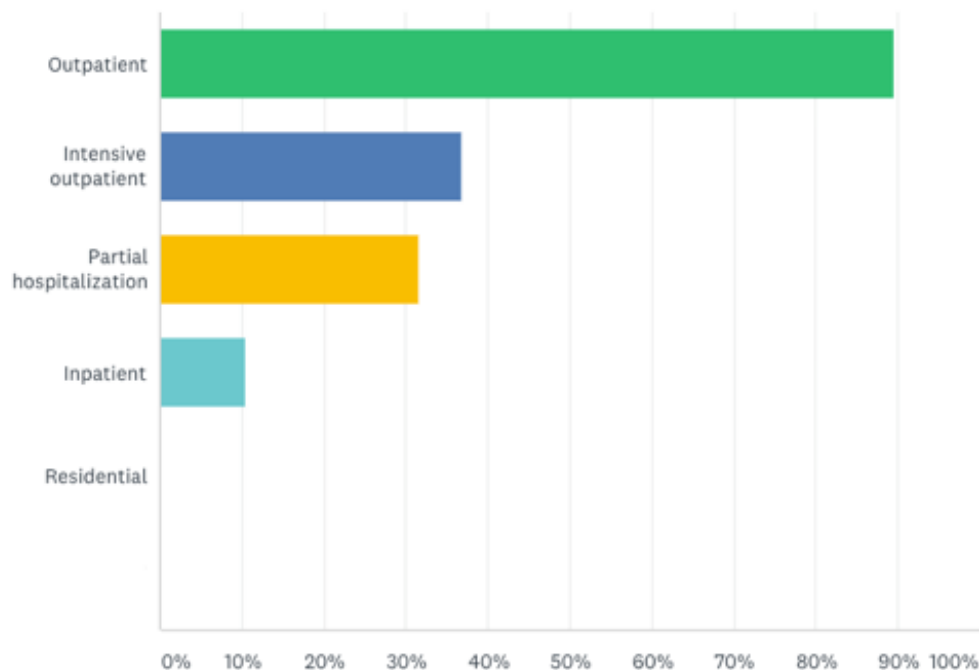
"If they had had others who had experienced having a child with an ED, perhaps they wouldn't have felt so alone and wouldn't have turned on each other in the process of trying to save me."

Clinicians

We also asked clinicians to answer questions about the needs and peer support for parents and caregivers. 19 clinicians participated, of which 13 were therapists.

What levels of care do you offer?

Answered: 19



Among the recommendations from this group, there was a stronger leaning toward group peer support vs individual pairing. Having mentors whose own affected person was recovered rated highly, as did specific diagnosis, mirroring the same answers given by parents and caregivers. A very low value was placed on how long a caregiver had been in that role, compared with other factors. Knowledge about eating disorders and caregiving strategies were rated moderately.

Hope scored high on the skills or qualities of caregivers serving as mentors (advice and problem-solving rated lowest). When asked about possible reservations about parent and caregiver peers being mentors to one another, the main concern, understandably, was contradicting the clinical team. One commenter had constructive advice:

"I have seen this be very helpful. Sometimes the advice given by a peer supporter may differ from the clinical team perhaps due to not knowing the full situation behind a recommendation, but this can be managed clinically, and the risk is small compared to the benefit."

Interview Insights

Some additional aspects of peer support came up in the individual interviews:

Peers by Accident: Several interviewees, when asked to describe contact that they had had with other parents of similar experience, the peer contacts turned out to be friends, family, and

colleagues who came forward after learning of the family's problem. These accidental contacts then became peer supporters, often just for one initial conversation, but pivotal in the family's experience in several instances.

Peer Professionals:

A number of interviewees reported reading books, websites, podcasts, speaking engagements and other media written by parents. These were cited by several as "peer support" and having an important role in informing and supporting them. These public figures were often accessible to the community and some provided coaching and interaction online or eventually as friends. Others offered paid services supporting other families. This was not an aspect anticipated in creating the survey.

Non-Eating Disorder Peers:

As we drew out the respondents seeking more in-depth information on parent to parent (or caregiver to caregiver) experiences, many respondents were interested in sharing experiences with other parents struggling not with eating disorders, but with other caregiving situations. These peers played important roles, as well, for these families, for many of the same reasons: feeling heard, troubleshooting, and finding resources.

Siblings:

While not frequent, the siblings of parents and caregivers came up as critical peer support for some families. Aunts, especially, were mentioned as strong allies to parents during treatment: researching the disorder, providing respite, listening, and being a communicator and ally among the larger family. Aunts and uncles also played roles in supporting the siblings of the affected child in the family.

"...my mom, brother, and some in-laws fought me so hard, and my sisters helped me so much."

Overall Conclusions

This survey explored the experiences of caregivers both overall and in terms of peer support. We also received information on caregiver experiences and peer support from the perspective of those with eating disorder experience themselves and from clinicians and other supporters.

Generally, experiences from caregivers reflected a wide spectrum of logistical and emotional challenges, of which only a narrower set of expectations and hopes centered on peer support. Peer support, from the parent and caregiver perspective, was a resource to support and validate and inform the caregiving experience. Peer support was largely seen as a way to support the caregiver, not to fix the situation the caregiver was facing. This view was in contrast to the input from those not in caregiving roles: those respondents framed parent peer support more directly about recovery for the patient and fixing the parent's response to the illness.

Peer support from the caregiver perspective involved an otherwise scarce resource: contact with others who not only cared about the one with the eating disorder but the whole family, and saw the parent as a vital resource, not the problem to be solved. This solutions-focused and empowered view of parents reflects a change in the clinical experience of many families, and especially in the F.E.A.S.T. community. Although many parents and caregivers spoke aspirationally, rather than because they had themselves experienced this sort of positive and inclusive regard, their interest in peer support reflected their hopes for other families in the future.

Parents and caregivers expressed in this survey and in the interviews not having access to others who understood their unique struggles and how much responsibility falls to the primary caregiver. The burden of caregiving was not seen as a burden, but as a very specific and irreplaceable and important role. Caregivers saw themselves largely as pivotal and needed, with all the attendant worry and fear of failure, and regret, of parents everywhere.

Parents for the most part had high praise and gratitude for the peer support they received, for the information and the compassion they otherwise lacked. This partly reflects the community which solicited these survey responses, but that community spans those with present and past experience, a wide range of treatment environments, and a spectrum of outcomes.

Contact with other primary caregivers was not without negatives. Fear of judgement, of not being enough, and of failure, were prominent in the responses. Overwhelming emotions, and exhaustion, and irritation were also expressed. Worse still, many parents reported feeling unwelcome or unwanted: their situations too different or too extreme, or their opinions not respected.

One aspect of peer support was reflected in how parents spoke of feeling alone even in the family, and not having the support of their partner—arguably their closest peer during the process. Parents spoke of how useful it was to talk AS a couple WITH other couples, on the rare occasions that occurred.

The data we collected on preferred ways to meet peers drew mixed results. But many comments indicated the pros and cons of ways of meeting, and that information informs our recommendations below.

Recommendations for Development of the Primary Caregivers Communities of HEALing Mentor Training

Types of support

This survey and the interview process revealed a strong and consistent need for any and all forms of support: group and individual, on demand and scheduled, in person and online, and emotional and logistical support. A stronger preference for email did emerge on both the mentor and mentee side.

Recommendation: *a program that emphasizes breadth rather than depth, offering a range of peer support opportunities for more people, rather than intense peer support for a few. Parents are eager for any contact with other peers and often report only needing it at the beginning of their journey. A program that can be accessible at-will immediately upon diagnosis and on demand as needed, is best suited for this population. Access to well-trained mentors with communications technical skills, topic knowledge, and temperamental skills to be there for parents and caregivers is a critical need. Meeting them “where they are” in terms of their current caregiving journey is more important than “where they are” geographically.*

Skills

Our community’s experience with peer-to-peer support, as well as the survey and interview results, pointed to empowerment and information rather than to skills. Parents seeking peer support did not often question their own skills or ask for skills training from peers. The chief goal of families in seeking peer support was access to the specific understanding and information that the more experienced families possessed: they wanted to feel connected and hear stories, not to be told what to do. Caregiving parents ask for and expect different help from providers than they do from their peers. Knowing about strategies, self-care methods, and how to understand the illness were paramount in what parents expressed they needed from others with the same experience. Parents wanting to give, and to get, peer support were largely aware that caregivers would need to choose among and personalize the information and ideas they got from one another.

Recommendation: *a program that models and focuses on empowering parents to do their own problem-solving is in keeping with the data on parent-supported recovery as well as coaching more generally. A strong set of central principles and clear “mantras” around the parent role can serve to “upskill” the parents with access to a peer support program. The range of skills necessary to caregiving tracked with parenting skills more widely, and also those that parents struggled to maintain when in crisis and without a robust clinical and community support system. Tolerating distress, which featured prominently in the survey and interview results, is something mentors can model, reinforce, and describe. Keeping those messages clear, repeated, and empowering is important to supporting caregivers in doing their job of getting the clinical and community support they need, something peers cannot help with on the ground. Because caregiving is never the same day to day or between two situations, being responsive to the mentees with core concepts is more likely to be useful and lasting, as well as bridging to new challenges in the recovery journey. Empowering and believing in the mentee also promotes confidence and self-efficacy-- important factors in successful caregiving.*

Knowledge

Unfortunately, the current world of eating disorder knowledge, treatment, and family support is chaotic, uneven, and highly individual. Matching mentors and mentees based on a common experience would be rare. Unlike diabetes or better understood disorders, there are no common standards of care, vocabulary, or expectations that could be assumed to be in place for any two families. Families need mentors without pre-set assumptions who are able to be with the other family in real time, where they need support most at that stage, on that day, in that hour. In addition, the research and science of eating disorders has changed rapidly in recent decades and will continue to evolve. While certain grounded principles can and should be set for any mentor and mentee situation, these must necessarily be broad and not dogmatic.

***Recommendation:** a program that is more librarian than book, facilitating sources and ways to research, rather than offering a narrow set of sources. Parents and caregivers who are given encouragement to read and evaluate information critically and widely are more likely to benefit. Mentors who share their own experience without prescribing it, focus on empowerment rather than being directive, and allowing families to learn and experiment and be resilient are more appropriate than prescriptive or unconditionally positive stances. Families facing eating disorders are surrounded by mixed messages and live in constant anxiety and vigilance. Having peers who can bear witness and offer a birds-eye perspective are invaluable assets.*

Delivery of Mentorship Support

Based on the survey and interviews, we recommend:

- Access for more people in more ways rather than intense support for a few
- Phone support combined with email support when connecting individual mentors and mentees; group support by electronic means like Zoom; on demand contact with experienced caregivers.
- Non-directive peer support
- Initial assignment of a peer navigator or navigator family for one-time or focused early support
- Validation of the reality of limited clinical resources and coordination
- Validation of a lack of an existing clinical and research consensus
- Problem-solving skills rather than specific techniques or tools
- Information seeking and vetting skills rather than providing specific information
- Training on accessing and confidently using peer support
- Access to peer support that is specific to the stage, age, diagnosis and healthcare system when possible
- Peer support that is well-integrated into the larger family and parent community
- Encouragement to build a personal network of clinical, personal, and non-ED specific support
- A focus on supporting parental management not only of the disorder, but the family as a whole
- Access for and outreach to the less visible, more isolated families--those dealing with bulimia, binge eating disorder, ARFID, OSFED, larger bodies, males, fathers, and ED sufferers dealing with co-morbid or co-existing conditions
- We further recommend that when possible that support be done not by and for individuals, but as caregiving couples
- Reinforcement of the efficacy and power of family involvement and education
- Special care to the risks of harm to both mentors and mentees
- An ethic emphasizing the importance of well-grounded expertise and research
- Empowering families and caregivers to work collaboratively and confidently with clinical team
- Strong privacy protection
- A robust mentor recruitment, vetting, and training program

Literature Review

Spotlight of Examples of Primary Caregiver Support Programs

Eating Disorder Families Australia

[Strive Carer Support Groups](#)

- Australia/in-person/group/ charity-run/parent-led/semi-structured
- Trained volunteer carers
- Knowledge-sharing and peer support.
- Information and resources and encourage empowerment of carers in their role during the recovery process.

International Eating Disorders Family Support

[IEDFS Facebook Group](#)

- Online/parent-led/group
Closed Facebook group peer-to-peer support community
- Moderated
- 1700 members worldwide

Hope Always ED Foundation of Newfoundland and Labrador

[Families Providing Families Support Group](#)

- Canada/in-person/clinician-led
- Free in-person group is led by a healthcare professional

BEAT Eating Disorders

[Echo Peer Coaching](#)

- UK/telephone/individual mentor/weekly
- Free telephone-based coaching service available for North West, Norfolk, Sussex, North East Essex, Tunbridge Wells, and Scotland.
- 30-minute phone conversations
- Skills book

In-Person Parent Support Groups

Organisation/ Group	Group Frequency	Peer/Professional Led	Cost	Group Focus	Target Group	Peer Support/Learning	Linked to Treatment Center
			USA				
Atlanta Center for Wellness: FED® Friends and Family of Those with Eating Disorders	Weekly - Friday	Professional (LCSW)	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Education, Resources, Support	No
BALANCE eating disorder treatment center - New York: 3 Groups							
- Contemplating Recovery	Monthly - first Saturday	Professional Melanie Rogers (CEDRD)	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers & Loved one	Support	Yes. Do not have to be a client
- IOP Multi-Family Group	Weekly - Tuesday	No information	Fee	AN, BN, ARFID, BED, Atypical AN	Clients (Caregiver & Loved one)	Support. Education	Yes
- Supporting A Loved One Group	Weekly - Tuesday	No information	Fee	AN, BN, ARFID, BED, Atypical AN	Clients (Caregiver & Loved one)	Support. Education	Yes
National Association of Anorexia Nervosa and Associated Disorders - ANAD							
- Atlanta Support Group	Weekly - Monday	No information	Free	No information	Caregivers only	Support	No
- Newport Beach	Weekly - Tuesday	No information	Free	No information	Caregivers only	Support	No
- Prairie Village	Link faulty						
- Peoria, Illinois	Link faulty						
- Mountain View	Bi-Weekly	No information	Free	No information	Caregivers only	Support	No

- Studio City/Valley Village	Link faulty						
- Rocky River Ohio	Monthly	No information	Free	No information	Caregivers only	Support	No
- Beachwood	Monthly - Tuesday	No information	Free	No information	Caregivers only	Support	No
- Oakland CA (Spanish)	Monthly - Saturday	No information	Free	No information	Caregivers only	Support	No
- Danville	Link faulty						
UCSD Eating Disorder Center for Treatment and Research	Weekly - Tuesday	Peer	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support. Skills based	?
Susan Wheeler - Fort Worth TX	Montly - 1st Wednesday	Peer	Free	No information	Parent/Caregiver	Support.	No
Carolina Resource Center for Eating Disorders	Montly - 1st / 3rd Monday	Peer (facilitated by licensed therapists/dietitians)	Free	AN, BN, ARFID, BED, Atypical AN	Parent/Caregiver	Support/Feedback	No
Eating Disorder Foundation of Newfoundland and Labrador 2 Groups							
- Families Supporting Families	Time vary dependent on participants	Healthcare professional and a parent	Free	AN, BN, ARFID, BED, Atypical AN	Parent/Caregiver	Information, treatment guidance, support	No
- Siblings of Hope	Monthly	Healthcare professional	Free	AN, BN, ARFID, BED, Atypical AN	Sibling (18 and older)	Support	No
- Bridge to Hope Education and Support (this course/group is a pre requisite to weekly Parents of Hope support group which is by invitaion)	1 evening/week 8 weeks	Professional	-	AN, BN, ARFID, BED, Atypical AN	Caregiver & family members	Education, Support	No
Eating Disorder Foundation 2 Groups							
- Denver Family & Friends	Weekly	Licensed counselor and a master's level practicum student	Free	AN, BN, ARFID, BED, Atypical AN	Parent/Caregiver and Siblings	Support	No

- Boulder Family & Friends	Monthly 1st / 3rd Tuesday	Licensed counselor and a master's level practicum student	Free	AN, BN, ARFID, BED, Atypical AN	Parent/Caregiver and Siblings	Support	No
Center for Eating Disorders Sheppard Pratt							
-Eating Disorders Collaborative Care Workshops for Caregivers	Weekly Saturday	Kelly Kurtz, LMSW	Free	AN, BN, ARFID, BED, Atypical AN	Clients (Caregivers only)	Education & Support	Yes Have to be a client
Organisation/ Group	Group Frequency	Peer/Professional Led	Cost	Group Focus	Target Group	Peer Support/Learning	Linked to Treatment Center
				USA (cont.)			
Aloha Center Eating and Feeding Disorder Treatment Center	Monthly 2nd / 4th Friday	Family Coach (MS, MFT)	Free	AN, BN, ARFID, BED, Atypical AN	Clients Caregivers	Resources, Support	Yes
Center for Balanced Living - Ohio	Monthly 1st & 3rd Tuesday	Volunteer & Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Strategies	Yes
Montecatini Eating Disorder Treatment Center - Carlsbad, CA	Monthly 1st Wednesday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	Yes
Eating Disorders Nova Scotia 3 Groups							
- Halifax	Monthly Tuesday	Peer	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Education	No
- Sydney	Monthly Tuesday	Peer	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Education	No
- Annapolis Valley	Monthly Tuesday	Peer	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Education	No

MEDA - Newton MA	Monthly 1st / 3rd Monday	Professional & Peer	\$20/person \$30/couple	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	No
The Alliance for Eating Disorder Awareness 6 Groups							
- St Petersburg	Weekly Wednesday	no information	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	No
- West Palm Beach	Weekly Wednesday	no information	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Information	No
- Orlando	Weekly Tuesday	no information	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Information	No
- Indiana	Weekly Thursday	Professional (PhD, HSPP & MSW, LSW)	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Information	No
- New Jersey	Weekly Tuesday	no information	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Information	No
- New York	Weekly Monday	no information	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Information	No
Rebecca's House Lake Forest, CA	Montly 2nd / 4th Thursday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Psycho- educational and process group	Yes
The Lotus Collabrative 2 Groups							
- San Francisco	Weekly Sunday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	Yes Do not have to be a client
- Santa Cruz	Weekly Sunday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	Yes Do not have to be a client
The Emily Program Seattle, WA	Monthly 1st / 3rd Thursday	-	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	Yes
UCSF Caregiver Group	Monthly 1st Monday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Learning, Support	Yes Registration required

NIED - CA	Dates vary	Professional Stephanie Griver MSW, RSW	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Education	No
McCallum Place 2 Groups							
- Multifamily Weekly Support Group St Louis	Weekly	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	Yes (only for families with patients U18)
- Family Based Coaching Group St Louis	Weekly	Professional Laura Bumberry, Psy.D	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Teaching	Yes (only for families with patients U18)
Red Oak Counseling Elm Grove, WI	Monthly	Professional Heidi Conto, LCSW, CIR	Free only to clients	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Eduction	Yes
Princeton Health Penn Medicine	Weekly Sunday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	2 groups - Caregivers or Cargiver and Loved over 18	Support, Eduction	Yes - Clients only
Lindner Center of Hope Cincinnati Children's 3 Groups							
- Harold C. Schott Eating Disorder Program, Family Support Group	Weekly Wednesday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Eduction	Yes
- Eating Disorders Support Group	Monthly Friday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers & Loved ones	Customized to audience	Yes

- Parent Skills Training Group	Monthly 2nd / 4th Tuesday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Teaching, skills	Yes (child has to be actively receiving treatment)
Farrington Specialty Center Fort Wayne, IN	Monthly 1st / 3rd Monday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver	Connection	Yes
SunCloud Health Illinois	Weekly Wednesday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support, Education	Yes
Desert Milagros Tucson, AZ	Monthly	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support, Education	Yes Clients only
Refrew 10 Groups							
- Baltimore Multi Family Group	Weekly	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver & Loved one for the first half then splits	Support, Education	Yes, current and past patients
- Bethesda Multi Family Group	Weekly	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver & Loved one for the first half then splits	Support, Education	Yes, current patients
- Boston Support Persons Community Group	Bi-weekly	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support & learn about Renfrew treatment model	Yes, clients only
- Charlotte Support Persons Community Group	Weekly	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Guidance, Support	Yes, clients only

- Chicago Support Persons Community Group	Weekly	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Guidance, Support	Yes, clients only
- Florida Multi Family Group	Weekly	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver & Loved one for the first half then splits	Support, Education	Yes, current and past patients
- Los Angeles Support Persons Community Group	Weekly	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Guidance, Support	Yes, clients only
- Orlando Support Persons Community Group	Weekly	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Guidance, Support	Yes, clients only
- Philadelphia Multi Family Group	Bi-weekly	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver & Loved one for the first half then splits	Support, Education	Yes, open to public as well as clients
- Coconut Creek FL Multi Family Group	Weekly	Professional	\$20/session	AN, BN, ARFID, BED, Atypical AN	Caregiver & Loved one	Support, Education	Yes, Current Past & Prospective
Silver Linings Foundation Calgary	Begins 28th October - 8 weeks 12 participants only. If full will be waitlisted for another group to start	Professional Lakshmi Krishnan RSW	\$100 for 8 sessions	AN, BN, ARFID, BED, Atypical AN	Caregiver/Family must be over 18	Support, learn skills, deeper understanding	No

Milestones in Recovery Richmond, VA	Quarterly	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver & Loved one	Learning about recovering	Yes
Phoenix Wings ED Recovery Hamilton ON	Monthly	Peer & Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support & share Information	No
Organisation/ Group	Group Frequency	Peer/Professional Led	Cost	Group Focus	Target Group	Peer Support/Learning	Linked to Treatment Center
			UK				
Carers Eating Disorder Association (CEDA) 2 Groups							
-Carers Eating Disorder Group	Monthly 1st Friday, 3rd Tuesday	Peer	Fee £2.50	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, Access to Services and Speakers	No
-Carers Support Group	Monthly 3rd Thursday	Peer	Fee £2.50	AN, BN, ARFID, BED, Atypical AN	Caregivers exclusive for parents with a child 10 - 18 years old	Support	No
NEEDS (North East Eating Disorders Support) Scotland 2 Groups							
- Aberdeen	Monthly 1st Monday	Peer/Facilitator	Free	AN, BN, ARFID, BED, Atypical AN	Starts with caregivers and loved one then separates to own group	Support	No
- Dundee	Monthly 1st Monday	Peer/Facilitator	Free	AN, BN, ARFID, BED, Atypical AN	Starts with caregivers and loved one then separates to own group	Support	No
Anorexia & Bulimia Care	Weekly Thursday	-	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	No
Bodywhys Eating Disorder Association of Ireland	1 x Week for 4 weeks Need to request for your area. Not constant	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	No

Eating Disorders Association Northern Ireland	Monthly Tuesday	Professional	Donation	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	No
Eating Disorder Support Amersham	Monthly 1st / 3rd Thursday	Professional	Donation	AN, BN, ARFID, BED, Atypical AN	Caregivers & Loved one	Support	No
First Steps ED Derbyshire Group & Workshops							
- All Ages Peer Support Group	Fortnightly Thursday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers & Loved one	Support, education,	No
- Skills for Carers Introduction (Foundation session)	1 Session 6th April 11 May	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support, education, Training	No
- Skills for Carers (Advanced) Derby	5 Sessions 29th Feb - 4th April	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers & Siblings	Support, education, Training	No
- Skills for Carers (Advanced) North East Derbyshire	5 Sessions 6th June - 4th July	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers & Siblings	Support, education, Training	No
The Linda Tremble Foundation 2 Groups							
- Forth Valley Eating Disorder Support Group	Monthly Last Monday	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	No
- Fife Eating Disorder Support Group	Every 2 months	Professional	Free	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	No
Organisation/ Group	Group Frequency	Peer/Professional Led	Cost	Group Focus	Target Group	Peer Support/Learning	Linked to Treatment Center
				AUS/NZ			
Eating Disorders Families Australia 3 Groups							

- Bendigo Victoria	Monthly 4th Wednesday	Peer	EDFA Annual Family Membership \$25	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support, Learning	No
- Flemington Melbourne	Monthly 2nd Wednesday	Peer	EDFA Annual Family Membership \$25	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support, Learning	No
- Perth	Monthly 3rd Tuesday	Peer	EDFA Annual Family Membership \$25	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support, Learning	No
Mental Health Foundation AUS	Monthly 2nd Monday	-	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support, Knowledge, Guidance	
The Butterfly Foundation 2 Groups							
- Hobart	Monthly 2nd Tuesday	Professional	\$20	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support	No
- Sydney	Monthly Wednesday	Professional	\$20/person \$30/couple	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support	No
Eating Disorders Qld	Monthly2nd Wednesday	Professional	-	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support, Skills building	

Eating Disorders Victoria	Monthly	-	\$5	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support, Strategies	No
Body Matters							
- Recovery Talks	Monthly Saturday	Peer (Talk by recovered person)	\$15	AN, BN, ARFID, BED, Atypical AN	Caregiver & Loved one	Support & Insight	No
EDANZ 4 Groups							
-Whangarei	Monthly Wednesday	Peer	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support & information on resoures	No
- Auckland	Monthly Tuesday	Peer	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support & information on resoures	No
- Wellington	Monthly	Peer	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support & information on resoures	No
-Like Minds Taranaki	Fortnightly Wednesday	Professional Family Advisor TDHB	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support, Knowledge, Coping Skills	No
Organisation/ Group	Group Frequency	Peer/Professional Led	Cost	Group Focus	Target Group	Peer Support/Learning	Linked to Treatment Center
				ISRAEL			
Judy Krasna	-	Peer	Free	AN, BN, ARFID, BED, Atypical AN	Caregiver	Support	No
Organisation/ Group	Group Frequency	Peer/Professional Led	Cost	Group Focus	Target Group	Peer Support/Learning	Linked to Treatment Center
				SWITZERLAND			
Boulmie Anorexia Association 2 Groups							
- Groups for Loved Ones (translated)	Monthly	Professional	CHF75 - CHF120 Members/Non	AN, BN, ARFID, BED, Atypical AN	Caregivers	Support	No

- Shared Groups (translated)	Monthly	Professional	CHF5 - CHF20 Members/Non	AN, BN, ARFID, BED, Atypical AN	Caregivers & Loved One	Exchange, interaction, support	No
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Online Parent Support Groups

Country & Organization	Group Name	Online Format	Description	Link
INTERNATIONAL				
<u>F.E.A.S.T.</u>	Around the Dinner Table (ATDT) Forum	Carers Forum	A closed online community for parents and caregivers.	<u>https://www.feast-ed.org/around-the-dinner-table-forum/</u>
<u>F.E.A.S.T.</u>	Around the Dinner Table (ATDT) Facebook Group	Facebook	A closed group for eating disorder family and carer support.	<u>https://www.facebook.com/groups/ATDTCarerSupportGroup/</u>
<u>F.E.A.S.T.</u>	Around the Dinner Table ATDTfb – Español	Facebook	Apoyo para familias y cuidadores de pacientes con TCA.	<u>https://www.facebook.com/groups/2460046987360926/</u>
<u>International Eating Disorder Family Support (IEDFS)</u>	International Eating Disorder Family Support	Facebook	A co-ed, peer-to-peer experienced and Educated support community.	<u>https://www.facebook.com/groups/International.Eating.Disorder.Family.Support.IEDFS</u>
AUSTRALIA				
<u>Aussie Support Group for Parents of Children with Eating Disorders</u>	Aussie Support Group for Parents of Children with Eating Disorders	Facebook	Support network in Australia for Australians. A peer-to-peer support group for parents and carers.	<u>https://www.facebook.com/groups/AussieSGPED/</u>
<u>The Butterfly Foundation</u>	Young Family & Friends Eating Disorder Support Groups (16-25)	Group	A support group to learn self-care and how to help a family member or friend overcome an eating disorder or body image issues. This group meets once a month.	<u>https://thebutterflyfoundation.org.au/our-services/support-groups/young-family-and-friends-support-group/</u>
<u>The Butterfly Foundation</u>	Eating Disorder Carer Support Groups	Group	A support group to learn self-care and how to help a family member. This group meets twice a month.	<u>https://thebutterflyfoundation.org.au/our-services/support-groups/carers-support-groups/</u>
AUSTRALIA (cont'd)				

Country & Organization	Group Name	Online Format	Description	Link
Eating Disorders Families Australia (EDFA)	Strive	Facebook	Melbourne eating disorder parent and caregiver closed Facebook Group.	https://www.facebook.com/groups/melbourneeatingdisordersupportgroup/
SANE Australia	Carers Forum	Carers Forum	<p>A support group that offers anonymous discussion for carers living with individuals with complex mental health issues.</p> <p>This group is moderated by mental health professionals.</p>	https://saneforums.org/t5/Carers-Forum/ct-p/carers-forum
UNITED KINGDOM				
BEAT	The Aviary Online Support Group for Carers	Group	The Aviary is a confidential support group for people supporting someone with an eating disorder. This group meets twice a week.	https://www.beateatingdisorders.org.uk/aviary
Anorexia & Bulimic Care (ABC)	Parent and Carer's Online Community	Carer Forum	An online community to help and support those who have a friend or family member with an eating disorder.	http://www.anorexiabulimiacare.org.uk/online_community
UNITED STATES				
Alsana	Alsana Eating Recovery Family Online Support Group	Group	A support group for family members providing education, support, and encouragement. This group meets once a week.	https://www.alsana.com/family-online-support/

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