



BODY BRAVE
recovery for every body



KAREN'S EXPERIENCE: BUILDING A SUSTAINABLE SELF-CARE & SUPPORT PLAN



Sonia successfully completed the 12-week program at the residential treatment program.

However, there was no follow-up of any kind, and no support for caregivers either. Three weeks after discharge Sonia's symptoms began to return, and she had a full relapse shortly thereafter. Her hopes of recovery dashed, Sonia retreated into a world of despair.

Now what do we do? I wondered, fighting down a sense of panic. I was sure that Sonia would not agree to go back onto another interminable waitlist for hospital treatment, at least not at this point. We had to find something different – but what?

Doing a desperate internet search, I discovered an organization called Danielle's Place, a community-based non-profit providing support for people with eating disorders and their caregivers. I noticed that they offered groups both for people with eating disorders as well as their caregivers. I managed to convince Sonia to come with me to check the place out.



Danielle's Place was located on the basement level of a shopping mall in a nearby town.

When we arrived there several days later, the receptionist at the front desk invited us to join a support group that same evening. Sonia and I exchanged surprised glances. We'd never been offered help without a mind-numbing waiting list.

The receptionist directed Sonia to a room at the end of the hall and took me to another room. She opened the door and said to the facilitator,

"Nancy, here's another Mom to join you tonight."

I slipped into a chair, embarrassed at barging into a meeting that had already begun. Nancy, a middle-aged woman with a pleasant smile, welcomed me warmly.

"Let's do another round of introductions! Can you begin, Jen?", she said, turning to the woman seated beside me.

I'd noticed her as soon as I'd walked into the room. Jen was a woman about my age, whose straight brown hair was pulled back into a tight bun. Tension was evident in every line of her body. She was sitting at the edge of her chair, tapping her foot restlessly.

"I'm Jen and my daughter has bulimia," she said abruptly, turning to the man sitting next to her.

Jim was a big man with a gravelly voice.

“Hi there, and welcome to the group,” he said, nodding kindly at me. “My wife has anorexia – she’s suffered for over 25 years with it.”

The introductions continued. Heather, a woman sitting opposite me, said in a choked voice

“It’s my son – he’s really ill...” She fell silent, unable to continue.

Beside her sat Dave, a middle-aged man who was sitting hunched forward in his chair, his brow furrowed with concern.



As the discussion resumed, I soon realized that the men and women gathered around this table were all trying their best to understand the illness, to learn how to help their loved ones, and how to cope with their own anxiety and grief.

Since the earliest days of Sonia’s eating disorder, I’d been struggling with a pervasive sense of guilt, worrying about things I’d done and things I’d left undone. Now, I was listening to the stories of other parents, and I heard the same undercurrent of guilt in what many of them were sharing.

The stories I was hearing made me sad, yet at the same time I felt a profound sense of relief. ***They know what it’s all about – the fear, the anger, the confusion.*** The tight feeling in my chest began to ease slightly, and I drew a long, deep breath. I realized that part of my own suffering had been the sense of isolation I’d felt. I hadn’t shared Sonia’s story with other people, because I knew she wanted to guard her own privacy. But then I had to carry that story with me, in all its pain and all its unanswered questions.

Later in the discussion, Heather told us her son was suffering from anorexia. He was so ill that he'd gone into heart failure a few days previously and had been rushed to hospital where he was now in the ICU. I looked around at the other parents in the room. Their faces reflected that terrible fear that we all shared. What if my child never recovers? What if she dies?

The woman sitting next to Heather reached out and gently touched her hand.

"This is so difficult..." she murmured. "We are here for you. We're ready to help in any way we can."

Gradually, other participants began to share ways that they were attempting to care for themselves while their loved ones were struggling with the illness. One woman spoke about how important her book club was to her self-care.

"I don't talk about my daughter's illness there at all. But it's my time, when I just don't think about anything other than the book I've been reading..."

Dave said,

"I've been playing squash lately. It feels good to get out on the court and really get physically tired..."

"Same with me...I just need to get outside and go for long walks," Jim remarked. "Emotional exhaustion is so much more draining than physical fatigue."

In a tentative voice, Jen said,

"I just couldn't keep all this pain inside me anymore. I decided to get therapy for myself."

Several group members murmured their agreement. Dave said,

“I never imagined going to a therapist myself. I thought that was for people who just couldn’t get their act together. But it really helped me.”

Nancy added,

“Often a therapist will recommend doing some writing about the journey you’re going through. It’s a difficult journey for sure – but writing about it might help you release some of the pain. You might even find some hidden meanings within that narrative you create.”

Jen reached into a bag at her feet and pulled out a multi-coloured journal.

“Here it is!” she said, with a quiet note of triumph in her voice. “I write in it almost every night.”

A lively discussion ensued with group members sharing ways that they were caring for themselves. I began to realize how little self-care I was doing. It seemed as if I was always involved in some way with Sonia’s illness – taking her to appointments, obsessing about her food intake, worrying about next steps in the journey.

As the session came to an end, Nancy thanked us all for our openness in sharing our struggles and encouraged us to think about what each of us could do to care for ourselves during this difficult time in our lives.



After the group, several participants welcomed me and encouraged me to return.

I felt as if the burden of worry that I was carrying was lifted ever so slightly.

I met Sonia in the reception area soon after I'd left my group. I scanned her face anxiously, looking for signs of distress. She seemed surprisingly calm, and she stopped at the reception desk to pick up some brochures about upcoming events. On our drive home, I asked about her experience in the support group she'd attended.

“Well, I don't know how much use it will be, honestly,” she replied. “But I liked the way the facilitator didn't bombard us with advice. She mostly just listened to us.”

“Yes, what a gift that is. To be truly heard...” I murmured.

~Dr. Karen Trollope-Kumar

