



BODY BRAVE  
recovery for every body



## KAREN'S EXPERIENCE: CAREGIVER STRESS, BURNOUT & MENTAL HEALTH



*Sonia was on a waiting list for a residential treatment program at a hospital in a nearby town.*

*This program is partially government subsidized, but parents still must pay a hefty daily charge of \$300 per day. No support was offered for people on the waiting list. As weeks dragged by, Sonia's symptoms continued to escalate and she looked increasingly discouraged. Finally, the word came that a bed was available.*

*"I'm so relieved," said Sonia, looking hopeful for the first time in months. "I know this is what I need. Just imagine- I'll be able to get back to my normal life!"*

*I was thrilled to hear how determined she sounded. This will be the answer at last, I thought. It's an intensive program and she is finally motivated to recover.*

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***Filled with a new sense of hope, Pradeep and I drove Sonia to the hospital.***

We helped her find her room, which she was sharing with another young woman. A staff member welcomed us and offered to show us around the facility. She showed us therapy rooms, an arts and crafts room, and finally a lovely space filled with plants, for horticulture therapy.

The last stop on our little tour was the lounge, where Sonia flopped down on a comfy sofa. I felt a shiver of fear as I surreptitiously observed the other people in the room, who I assumed were patients. Most were young women, with stick-thin limbs, thinning hair and hollow cheeks. Their eyes had a haunted look, their faces a mask of despair. An emaciated young woman was sitting nearby, absorbed in a book. Curious to see what she was reading, I shifted over slightly on the sofa so that I could see the cover of the book more clearly.

*“Toxic Parents”, the title boldly proclaimed. A chill ran up my spine, and all my fears about our parenting approach came flooding into my mind. Ever since Sonia had become ill with the eating disorder, I’d been struggling with unanswerable questions. Was it my fault in some way? Was it something that I said or did? Was there something I missed?*

An orientation session for parents was scheduled to start in 15 minutes. Pradeep and I left Sonia to get settled while we set off for the conference room. The room was slowly filling with people, most of them looking uneasy.

The woman sitting next to me asked where I was from. When I told her I was from Hamilton, she said

***“Aren’t you lucky to live close by. We’re from Newfoundland.  
There’s no residential facility in our province. We had to***

*mortgage our house to afford the fees for this place. But of course, it's worth it to save our daughter's life."*



*Before the session began, I looked around at the people in the room.*

*Most were parents of adult children, although I learned that for two of the participants, it was the spouse who was ill.*

*A woman came in, holding some flyers and a clipboard. She introduced herself as a social worker in the program. She was joined by a male psychiatrist, also on the staff.*

*"The program for most people is 12 weeks long and combines nutritional rehabilitation and normalization of eating patterns," she explained. "We also work on skills to help patients with regulating strong emotion. We require all patients to follow strict protocols around food and eating. If they cannot do so, they'll be asked to leave."*

*The psychiatrist said:*

*"Eating disorders are very serious conditions - many people struggle with this disorder for years despite getting treatment. Others die of this illness. So please don't expect that after completing this program, your loved one will be suddenly restored to full health. It doesn't work that way."*

*I felt a sudden tightness in my chest. My mind filled with disjointed thoughts...but wait a second...surely after twelve weeks...we're counting on this program...what*

*will we do if...if...*

*After an awkward silence, one of the parents in the group asked,*

***“Will we be involved in therapy sessions? We would really like to know how to help our kids, especially when they get out of this program.”***

***“No. It’s only in pediatric programs that parents are involved. Your children are adults. It’s important for you to know that due to privacy concerns, we won’t be able to share anything with you about your adult child’s progress. They will decide what to share with you.”***

***“However, while your family member is admitted, you may visit regularly,” said the social worker, trying to sound reassuring.***

*When the session was over, I stumbled slightly as I rose from my chair. The woman from Newfoundland steadied me.*

***“I hope all goes well with your daughter,” she said softly.***

***“I’m sorry you won’t be able to visit,” I murmured.***



***Pradeep and I spoke very little on the drive home.***

*Darkness had fallen and it was pouring with rain, making visibility poor. I couldn’t*

stop thinking - This treatment has got to work – Sonia just can't go on suffering like this...

Finally, I said to Pradeep,

***“Don't you think it's strange that you and I are not a part of this treatment program at all? Surely the parents should be involved in some way. If I'm a toxic parent, I want to know why! What am I doing wrong? How can I fix it? But the treatment team seems to cut us out altogether.”***

Pradeep nodded slowly.

***“And what about when she is discharged? We will again be her caregivers – and we need to know what to do.”***

~Dr. Karen Trollope-Kumar

