

Out of the Fray, continued

At the time, Daniel was 21. He'd stopped attending ACCC where he was studying computer science and music. Barbara didn't know about his struggles -- she'd fallen out of contact with Daniel's father with whom she'd had a strained relationship.

During the next few months, Daniel's symptoms multiplied. He was noticeably talking to himself often, sleeping irregularly, and often playing loud music that bothered the neighbors during the day. He also would also mix up settings on the thermostat. When he got in trouble with the law at a casino, a call to a lawyer was a turning point.

The lawyer, who served on the board at Jewish Family Service, connected Barbara and her son to mental health support and services. Ultimately, her son received probation instead of jail time.

Barbara struggled to keep her son on track with the terms of his probation – phone calls, check ins – while working full-time, but she did. Eventually, he was prescribed medication that helped with his symptoms, and that, too, required a lot of follow-ups on her part.

Her love and determination kept her going through the toughest days, like

the time he took a train to New York City to attend a special event.

"I wasn't sure he'd ever come back," she said.

Other particularly hard periods were the hospitalizations. During conferences with doctors and social workers about discharge plans for her son, sometimes she was given the opportunity to speak. She advocated for long-term care to no avail. As a result, she stopped going to meetings.

Though she was disgruntled with the hospital system, she said the systems that were working included the agencies that supported her and her son as well as her GPS that steered her around unknown parts of the state to consistently visit her son. Those "positives" helped offset the serious worries she had for Daniel, which were layered with a nagging, persistent feeling of guilt.

"I wish I knew he needed help earlier," she says. "I didn't know about his stresses. His father and I were not communicating."

For about 3 years, her son lived with her except for the weeks when he'd been hospitalized. That pattern might have continued if it were not for an incident when she feared for her life.

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She called the police and, though she put him out, she supported him with basic needs while he stayed at the shelter.

Though she knows they are better off living separately, her guilt about removing Daniel from her home is an ongoing struggle.

Barbara is among the 28 percent of family caregivers for someone with an emotional or mental health issue. (She's also a caregiver who lives with a mental health disorder which started following the chronic stress of her divorce and custody battle.)

For the greater part of the decade, she's been her son's main caregiver. During one of Daniel's hospitalizations, her ex-husband told her he "couldn't continue to do it."

Now in her 60s, she looks back on the time she's had with her son and feels grateful for the good years – seven of them – since his diagnosis. During that time, he took his medication, accepted help from his support staff, and was well enough to attend family functions.

A special framed photo of him is on display at her home. It shows a smiling Daniel at Christmastime. An unopened present from his mother is balanced on his lap.

As the holidays near, the plans of what will be and won't be are already weighing on Barbara. Extended family have reservations about spending the holiday with him because of recent months when he declined medicine, experienced a period of homelessness, and was hospitalized.

Daniel has been taking a monthly injection for schizophrenia since early summer with astonishing results, she said.

Barbara's family is a topic she'll bring to a table of peers through her connection to the Intensive Family Support Services, IFSS, program. She receives support one-on-one as well as through group meetings.

"It helps a lot to see other people having the same angst and trying to work through it – find solutions, find help," she said.

Today, Daniel lives independently in an apartment and receives help from the Program of Assertive Community Treatment, or PACT.

"He knows both sides – on meds and off meds. It was for him to choose to work at being well again, she said.

"He had to be strong, and I'm proud of him."

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PACT will host a holiday gathering, she said, that may be a part of a new holiday tradition.

She will shop for gifts and lovingly wrap them, but she suspects family won't be there on the day they are given. Though the holidays won't look quite the same, she already has the gifts of hope, joy, and peace – they came through her son's decision to be well.

If you or someone you know has adult children who live with mental illness and/or substance use disorder, Intensive Family Support Services (IFSS) can help. [Click here for more information about MHANJ's IFSS programs in Atlantic and Union Counties and other counties across the state.](#)