

### **TKC Client Shares her Powerful Story with Providence Journal: Part 3**

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By The Providence Journal's G. Wayne Miller

Katie's Story, part three: Challenges on the way to recovery

Katie Hart begins to get her life together but encounters hurdles almost everywhere she turns. Still, with newfound strength and the support of her family, she has hope as spring arrives.

Still angry with her mother, Jean Hart, she decided she would live in her car.

At 2:15 a.m. on Dec. 5, a relative telephoned Jean with that worrisome news.

Jean called the police in West Warwick, where Katie apparently was headed, and an officer said they would try to find her. Then she drove to state police headquarters in Scituate to ask their assistance, but the officer was not helpful, according to the log Jean kept.

Jean had been frantically dialing Katie's cellphone — and finally, before dawn, Katie called back. She said she was planning to sleep in the parking lot of the Walmart store in Coventry.

Jean drove to the Coventry Police, where the "kind and understanding" sergeant on duty, Jean wrote in her log, dispatched two officers to the parking lot.

The officers, Jadine Ferri and Keith Clarke, "spoke to Kathleen in great lengths to determine her well-being," Alexander DeMolles, a Coventry police officer, wrote in his report. "Kathleen did not appear to be a danger to herself or others at this time."

She could not be held against her will. But the officers kept talking, and finally persuaded Katie to drive herself to Butler Hospital.

At 6:30 a.m., they confirmed to Jean that she had arrived safely and been admitted.

Katie was in a good place now. Founded in 1844, Butler is the flagship hospital of the Department of Psychiatry and Human Behavior at Brown University's Warren Alpert Medical School, one of the leading such departments in the nation.

Priced out of recovery

Katie's health had improved significantly when she was released from Butler on Dec. 12, 2014. Her anger with her mother having subsided, she moved into the small house in Johnston that Jean rents. Savannah was living there, too. They marked the Christmas season with harmony and cautious optimism. After more than five years, stability seemed within reach.

One promising factor was Katie's agreement to take Abilify, used to treat depression and bipolar disorder. She had experienced good results with the medication before, and at Butler, she had received an intramuscular dose that would last about 30 days. Along with other post-

hospitalization directives, staff wrote a prescription for the pill version for Katie to fill in mid-January.

Her private insurance company, made available through Rhode Island's Rite Care program, refused to cover it, according to Katie and Jean.

I'll pay out of pocket, Jean told the pharmacist.

But the cost of a 30-day supply of five-milligram Abilify pills ranges from \$922.23 to \$983.09 in the Rhode Island market, according to goodrx.com, a drug-price comparison site founded by former executives of Yahoo and Facebook that is rated favorably by Consumer Reports.

That was more than Katie's entire monthly retirement disability income. Jean, who suffers from lupus and has income only from the federal Social Security Disability Insurance program, could not afford to pay that, either.

Katie's psychiatrist could not convince the insurer to pay for Abilify. Instead, the insurer approved the drug Seroquel, available in generic form at prices ranging from \$10.60 to \$55.45 for a 30-day supply in Rhode Island, according to goodrx.com. But Seroquel left Katie sleepy — and after several weeks on it, she was sometimes hearing voices again.

"I don't think it's right," says Katie, 42.

"It's cruel," says Jean, 62. "You fight five months to get her well, they put her on something, she starts getting well and they put her on something that doesn't work as well and she's left in limbo. We're left in limbo as a family."

#### Another Catch-22

Despite the setback, despite feeling drowsy, Katie took many steps to rebuild her life as the historic cold, snowy winter of 2015 unfolded.

She joined a gym. She looked for work. She kept a normal routine with Savannah, 16, driving her to and from school and her part-time job at a Burger King. She received counseling at the Kent Center, along with help from a Kent social worker in exploring housing options. She continued to abstain from alcohol. She and her mother and daughter even found moments of humor, recalling the voices of last summer and fall.

"I couldn't stop laughing," Jean said after Katie reenacted one exchange she'd had in her head.

But the medication issue went unresolved. A Kent Center clinical nurse specialist tried Risperdal, another low-cost alternative to Abilify that the insurer covered, but it was no more effective than Seroquel.

Like her mother, Katie documented key events and kept copies of records, which she shared with The Journal.

On Feb. 17, she applied for an overnight position stocking shelves at a Walmart store in Johnston — comparatively easy position that she believed she could handle — but she was not hired. Having worked at Mohegan Sun in Connecticut for almost three years, she applied for unemployment from that state.

On March 19, the Connecticut Department of Labor, Employment Security Division, sent her a form letter. "Dear Sir or Madam," it began. "Since you are not physically able to work because of your medical condition, you are not eligible for benefits."

Katie hoped to receive SSDI benefits, like her mother — but an SSDI representative told her she did not qualify, since the Cranston public school system decades ago opted out of Social Security in favor of its own system. The representative was correct.

How is that possible? Katie said. I've been working since I was 16 years old.

I understand it's not fair, but that's the way it is, the representative said.

And there was another Catch-22: because she did not qualify for SSDI, Katie did not qualify for certain types of subsidized housing. Given her paltry income — \$9,840 a year — she did qualify for other government-supported housing, but the two apartment complexes she visited, in Warwick and West Warwick, reported waiting lists of at least two years.

Katie plans to appeal to SSDI, but not immediately.

"I'll do it at some point," she says, "but I'm exhausted with all the paper work. You have no idea: you can have every paper in the world and you still don't have what they need. I've got to slow it down. It's just too much."

Says Jean: "It's 'pass the buck, let's just tell her this and she won't bother us again.' If it wasn't so tragic, it would be a comedy, you know? And she's trying so hard."

Family help is key

After an interview at the Walmart in Coventry, Katie was hired in March to be a cashier, but she lasted only a day; the stress, she says, was too great.

"I couldn't concentrate," she says. "I got really upset."

"We knew it would be too much," Jean says.

"I thought I could do it because it would distract me from myself — my inner conflicts or whatever you want to call it," Katie says. "I think what's going to end up happening is that I'm going to have to try to find a job with a small company doing something not big — maybe some office work or filing, just to supplement my pension, and I'd be fine. Not with a lot of people."

Earlier this month, Katie received encouraging news: weeks after applying, the state Office of Rehabilitation Services' Vocational Rehabilitation Program accepted her. She will soon begin a two-week evaluation that should lead to placement in a job appropriate for her.

She also has an appointment later this week with a new psychiatrist who, she hopes, will be able to sort out her medication issues.

"It just seems like I've had a string of bad, bad karma, or bad luck," she says. "Whatever could go wrong went wrong."

"I don't see an end unless we get her well," Jean says.

Still, Katie says that she has been fortunate: despite disagreements with them, she has a mother and daughter who have stood by her. She takes pride in Savannah, a high-school junior who takes Advanced Placement courses, works part time, sings in two school choral groups and has a supportive circle of friends.

"When people say what a good kid she is," says Jean, "I always credit her mother."

Jean, who volunteered many years on Kent Hospital's psychiatric unit, knows well the frequent fate of people less fortunate than Katie.

"That bothers me more than anything," she says, "the thought of other families losing loved ones because they can't get help, or they burn out, or they're not smart enough, or they believe what the professionals are telling them and they just drop it and people end up on the streets and they die. It's outrageous."

"People have died because of lack of organization," says Katie.

With spring here, Jean finds pleasure in gardening and the family's new pet: a goat they saved from slaughter that now lives in their barn. "Lucky," they named him.

"It's sinful," Jean says. "I have a goat out there that's being better taken care of than our mentally ill."

*End of series.*