

Experiencing Both Sides: A Psychiatrist's Journey of Three Generations

Summarized by Thomas T. Thomas

A local psychiatrist with an established practice as well as a long-time member of NAMI East Bay, our speaker (identified only as **Dr. Margaret** for reasons of confidentiality) at November's educational meeting talked about the course of her daughter's ten-year psychiatric illness. After many crises and several hospitalizations, her daughter's life has become stabilized, and the relationship between her and her young son has been preserved. Dr. Margaret brings a unique perspective to this now-familiar story, as both a family member and a mental health professional.

Her physician mother paved the way for a career in medicine. Dr. Margaret's choosing psychiatry was motivated by her sister's depression; her choice of specialties is now helping her understand and deal with the needs of her ill daughter.

After completing her psychiatry residencies, Dr. Margaret and her husband spent a sabbatical year in Paris, where she studied neurology at the Hôpital de la Salpêtrière. Its chief physician in the 1700s was Philippe Pinel, "the father of modern psychiatry," who pioneered humane treatment of the mentally ill.

The daughter who would later become ill was Dr. Margaret's second child. Early on she worried about her: with a very tempestuous temperament, she was often hard to soothe. At age 8, she stopped accepting hugs. And her way of thinking was different: though very bright, she jumped to conclusions with little deliberation. By adolescence, school couldn't hold her. She made poor choices of friends, with many difficult consequences.

During a semester the family spent in France she rallied and was successful in a bilingual high school, with grades good enough to be accepted into a fine college. Semi-independent living in Italy for two years to study art followed. "Those were her best years," Dr. Margaret said.

When she returned, her family was unaware of the earliest signs of psychotic illness. She was referred to a counselor, who in a single session advised her to drop out of school. Unfortunately, her family was not made aware of this important assessment. When it became clear to them that she could not continue her studies, she came home.

Thereafter much went wrong. Someone shared a psychedelic drug that broke the thread of her now very fragile life. Her parents, increasingly worried, traveled to meet her, and found a changed daughter: acutely psychotic and in despair, she vowed that she "would not eat until the world was a better place."

Psychiatric medications were started right away. But shortly after her return home, she disappeared. Fearing the worst, her parents began posting "missing person" fliers. When a friend called from Italy, they learned that she had returned

there, trying to regain the life she knew. But soon after her safe return, she said she must leave again: she wanted to “go home,” back East, where she grew up. When her parents said that was no longer home, and they thought things wouldn’t be better there, she said that if that was true, she couldn’t go on living. Her parents saw no alternative to hospitalization.

Dr. Margaret arranged for this at Langley Porter Psychiatric Hospital in San Francisco. But with the 5150 hold arranged in Contra Costa County, her daughter had to be taken to Martinez Hospital. The triage clinician, after refusing to accept information from Dr. Margaret, despite a new state law, concluded hospitalization was not needed. Seemingly trained to deny a hospital admission if at all possible, he was finally persuaded to authorize it.

At Langley Porter Hospital, too, staff refused to accept information about the daughter’s illness, despite the new law. The family was made to feel as if they were meddling! The hospitalization seemed too brief for a first psychotic breakdown. Poorly coordinated discharge planning failed.

Several months later, Dr. Margaret’s daughter shared with her parents that she had become pregnant, asking to set up house with the baby’s father some distance away. Her parents fully accepted her decision to stop her psychiatric medications during the pregnancy and nursing, to protect her developing baby, but worried about stopping treatment. On the baby’s day of birth, staff at the birth clinic told the young parents that, because of the mother’s illness, they would not be allowed to take their baby home unless extended family took them in to help. Dr. Margaret and her husband immediately offered their home to the young family. Suddenly they were co-parents!

Their daughter’s great emotional volatility, while never directed at her baby, severely strained her marriage and the other family relationships, with the risk of destabilizing her and her baby’s lives. Therefore, Dr. Margaret sought a 5150 hold twice more, persuading the Mental Health Crisis Team to authorize it, so that medication treatment that she resisted but urgently needed could resume.

Too late: during the second hospitalization, the baby’s father left her and her family’s home, taking the baby to an unknown destination. Dr. Margaret’s daughter needed to take legal action quickly, so she could not be accused of abandoning her child. After the husband filed for divorce and custody, her lawyer, who had never dealt with a case involving mental illness, responded to the court. To address the potential problem of stigma, all submissions to the court referred to the illness in biologic terms, as a “neuro-developmental disorder.”¹

There was no alternative to the father’s being granted custody of the child. A wise judge accepted a visitation plan that provides substantial continuity for the baby in his mother’s and maternal grandparents’ lives. Dr. Margaret’s daughter deeply loves her child, does all in her power to be a good mother, and is sad that they live apart. Supervised visitation helps her with parenting, since her illness makes it difficult to keep up with his ever-changing needs.

Her son, now 10, knows from us that his mother does things differently than others “because she is ill.” When he begins to ask specific questions about her

¹ She noted that for reasons of stigma Japan now discourages use of the term “schizophrenia” (“split-mind disease” in Japanese), substituting a term meaning “integration disorder.”

illness, Dr. Margaret and her family will answer him as well as they can, in a way that's understandable to a child.

Though their daughter faithfully took her medications, her persisting emotional volatility made living together too stressful. Her parents had to find an alternative: a house to rent with a live-in caretaker. But poor judgment led her to People's Park and dysfunctional acquaintances who freely shared various substances. She got worse, and her parents feared for her safety. Things had stopped working.

Following a NAMI lead, Dr. Margaret found a safe place for her daughter in a small, private group home in San Anselmo, "Residence Clubs," with strict, necessary rules. A nearby psychiatrist was found. He urged her (and her parents) to try the "gold standard" antipsychotic medication clozapine.

What makes families and psychiatrists hesitant to use clozapine is the risk of agranular cytolysis, a rare side effect in which the body stops producing white blood cells (WBCs). Regular blood tests are required to protect against this potentially fatal risk. If the WBC count drops too low, clozapine has to be stopped. With this safeguard, it can be taken safely. Clozapine is very beneficial for many severely ill patients, enabling them to return to their communities or resume school or employment. Clozapine has been very helpful for Dr. Margaret's daughter, who acknowledges feeling better and is clearly happier, though many illness symptoms remain. Dr. Margaret urges families with a very ill member to consider clozapine.

After Residence Clubs proved far too expensive in the long run, Dr. Margaret's daughter was able to move to Casa del la Vida, a well-run group home in Oakland now limited to transitional-age youths, for a stay up to six months, covered by SSI funding.

Next, in their search for permanent housing, Dr. Margaret and her husband decided to purchase a house for their daughter, creating a supportive household with two carefully chosen, supervised housemates who provide companionship and help. They found what they were looking for, a house not far from where they live, making it easy to get together. Two years down the road, this arrangement is working well. Future tasks include helping integrate their daughter further into her neighborhood community, and into the community of the mentally ill, with the hope that one day she might be able to volunteer or even work part-time.

A somber task for Dr. Margaret and her family is "succession planning," for a future in which they themselves can no longer help their daughter and her son. Recording in detail what they are doing now, and writing down what they hope others will do in the future, are important parts of this planning.

Underlying all their actions, Dr. Margaret and her husband strive to be compassionate with themselves and especially with their daughter, for she bears the greatest burden.

Dr. Margaret concluded with these words: "If at the end of the day we can say we have done our best, we will have earned our rest."