

## What I Wish I'd Known

“No one knew what to do. The doctors only knew how to diagnose, not where to get help. My son didn’t want to hear that he had a problem. He just didn’t ‘want’ to go back to college or work; he didn’t ‘want’ to leave his room. He said with much more force, ‘I don’t need a shower.’ I wish I had known more.” -- Jennifer, Mother.

### What to know at the onset of a diagnosis of Mental illness:

- Mental illness recovery is a marathon, not a sprint. (I’m sorry you are having to read this.) It will not be cured with “a” pill.
- **The whole family is affected.** “The Health of the family depends on the health of its members.”<sup>[i]</sup>
- **Family involvement in treatment leads to fewer relapses, fewer hospitalizations**, medication compliance, and accelerated recovery. “**Families are the greatest undeveloped and unused treatment and recovery option.**”<sup>[ii]</sup> Dr. Doug Turkington
- **A team built early on of your loved one, friends, family and clinician will help you** through this and is essential. You can find information on Open Dialogue, family and teams, on the website or in the book, *Every Homeless Person Has a Mother (Fall 2025)*.
- **50% of those living without housing succumbed due to poor mental health care** and estrangement from family. Take this seriously.
- Tell your loved one, “We are family. **We are with you and will always be here for you.**” “This is when families stand together.” Let them hear it, and know it. Even if it is just two of you. Especially then.
- Anosognosia: 50-70% of people, are challenged with an **inability to recognize mental illness**. Many believe that is “imminent danger.”
- There is **no National mental health care system**. The U.S. f Health & Human Services by zip code: <https://findtreatment.gov/>
- **Clinicians, providers, police officers, judges and others can be your ally.** Ask questions, provide information. Be their ally.
- **A Release of Information signed by your loved one is essential.** Or a Psychiatric Advance Directive (PAD),<sup>[iii]</sup> AHCD or POLST.
- **HIPAA allows a clinician to determine what is grave danger**, including the inability to make health care decisions and provide safety, food and shelter. **They can talk with anyone who can help prevent it.** *HIPAA 164.510(b)(3).*<sup>[iv]</sup>
- **Clinicians, providers and hospitals can take information from you.** *HIPAA HR 2646.* Create and give the a Health History with dates, providers, medication, hospital visits and symptoms. Include your contact info. Record the date and who received it.
- **Certified Private Case Managers** can help your loved one, coordinate care and advocate or you.
- **Officers with Crisis Intervention Training CIT**, can be requested if you ask for help from the police.
- **Classes and support for families are offered free through NAMI** (National Alliance on Mental Illness) and CBT (Cognitive Behavioral Training) to learn to communicate with your loved one.
- **Volunteering with other mothers, families and NAMI, helps a lot.**
- **You do not need to share everything with everyone.**
- **Plan financially** and track money including medical care, housing, food, insurance, transportation, and all else.
- **MOST IMPORTANT: Take care of yourself** and commit to finding ways to gain your own peace of mind and happiness.

**Join us for Success Circles:** <https://jacquelinejanssen.com/wp-content/uploads/Success-Circle-Overview.pdf>  
3rd Tuesday of Every month at 4PM PT Listen to, and join in with your success and what works. Be inspired.

More information is available. But there is a lot to take in as you are beginning to navigate this river. There are Facebook groups where families post live time issues and members have answers. [Support for Family and Caregivers of love ones with Schizophrenia](#)

<sup>[i]</sup> <https://namimarin.org/about-nami-marin-county/marin-family-partnership-policy/>

<sup>[ii]</sup> *Cognitive Behavioral Therapy (CBT) Informed Caring for Families Workshops—NAMI Marin County.* (2024a, October 25). <https://namimarin.org/support-and-education/presentations/cognitive-behavioral-therapy-informed-caring-workshops-2/><sup>[ii]</sup>

<sup>[iii]</sup> *California | NRC PAD.* (n.d.-b). Retrieved October 25, 2024, from <https://nrc-pad.org/states/california/>

<sup>[iv]</sup> <https://www.hhs.gov/hipaa/for-professionals/faq/3002/what-constitutes-serious-imminent-threat-that-would-permit-health-care-provider-disclose-phi-to-prevent-harm-patient-public-without-patients-authorization-permission/index.html>

