Advocating for Someone with Anosognosia While Taking Care of Yourself

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Treatment Advocacy Center
Introduction
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The Treatment Advocacy Center advocates for the reform of laws, policies and practices that prevent those with serious mental illness from receiving treatment.
• 8.1 million adults live with diagnoses of schizophrenia or severe bipolar disorder - just over 3% of the US adult population

• About half of these individuals are untreated at any given time
Reasons for Non-engagement

• Inadequate community-based support
• Health insurance gaps
• Distance to provider/lack of transportation
• Substance abuse
• Side effects of medications
• Challenges with executive functioning
• Mistrust of doctors
• Stigma
• Anosognosia/lack of insight
Anosognosia and Non-adherence

• Lack of insight into one’s own illness
• NOT denial
• Brain-based. Out of the individual’s control
• Makes non-adherence logical

Psych. Services 2/06: Of 300 people with non-adherence tracked, 32% found to lack insight
If you build it, some still won’t come
Revolving Door of Treatment Non-Engagement
When Serious Mental Illness Isn’t Treated

• 1 in 4 homeless have a serious mental illness
• Or, 4 times the number of people who can fit into the NRG stadium
When Serious Mental Illness Isn’t Treated

People with untreated SMI are far more likely than the general population to:
  • be victims of violence
  • die by suicide
  • be killed during a police encounter
When Serious Mental Illness Isn’t Treated

- Individuals with untreated SMI are 3 times more likely to be violent than the general population.
- 29% of family homicides are committed by people with untreated SMI. Abuse of alcohol and drugs and failure to take medicine prescribed for serious mental illness are major risk factors for committing a family homicide.
In 1955, there were 559,000 state/county psychiatric beds, or 340 beds per 100,000.

In 2016, state hospital bed population dropped 96%, to 37,679 beds, or 11.7 beds per 100,000 people.
People with SMI may cope with symptoms throughout their lives, but treatment helps many to recover sufficiently and pursue life goals.

Goal is to get person to engage in treatment!
Averting a Crisis

- Safe proof your home. Hide medications, vehicle keys, knives, and ropes
- Remove guns
- Minimize alcohol availability
- Alert person’s mental health care worker of problems or concerns
- Visit local Police Department and inquire about Crisis Intervention Team (CIT)
- Ask for a wellness check
- Have a room to which you can retreat and be safe with secure lock. Bring
When a Crisis Occurs

- Try not to manage situation alone
- Stay calm, speak gently, use a quiet voice
- Find something on which you both agree
- Don’t threaten, criticize, or argue
- Don’t whisper, joke or laugh
- Keep instructions simple and clear
- Avoid eye contact, touching, standing over the person
- Stay between person and door
• Let dispatcher know:
  • you are calling about a mental health crisis and they should send a CIT trained officer(s)
  • About any triggering behaviors
  • whether person has access to any weapons
• Be an advocate - ask to have person transported to hospital rather than jail
Going to the Hospital – Things to Know

- Hospital selection can matter
- Advance directive?
- Emergency evaluation
- 72 hour hold
- Involuntary inpatient commitment
- Involuntary outpatient commitment (assisted outpatient treatment)
Involuntary Outpatient Commitment or Assisted Outpatient Treatment (AOT)
Kendra’s Law
Assisted Outpatient Treatment (AOT)

AOT is the practice of providing community-based mental health treatment under civil court commitment, as a means of:

1. Motivating an adult with SMI who struggles with voluntary treatment adherence to engage fully with their treatment plan.
2. Focusing the attention of treatment providers on the need to work diligently to keep the person engaged in effective treatment.
AOT and the Black Robe Effect

- Judge commands respect as symbol of authority
- Judge must embrace role of motivator
- Black robe effect works on treatment system, too
- Court order generally means a rapid response to non-adherence
AOT and the Consequences of Non-Adherence

- Extend length of time in AOT program
- Increase frequency of court appearances
- Order treatment plan to be reviewed
- Pick up ordered for evaluation
- Rehospitalization if medically necessary
• Ask officers to take medication to jail or call jail to see if you can drop it off
• Call jail and let them know about the person’s diagnosis, medications, potential triggers, techniques that may help avoid agitation
• Find attorney with expertise in handling cases involving someone with SMI
• If assigned a public defender/court appointed attorney, request one with experience in MH. (Contact local Bar Assn.) If not, attempt to educate attorney
• Competency Evaluation
• Competency Restoration
• Diversion programs
  o Pre conviction
  o Post conviction
  o Specialty Courts
    • mental health court
    • drug court
    • veterans court
Mental Health Court

• Prosecutor offers plea deal to defendant. Defendant pleads guilty and receives a sentence. Defendant decides whether to stay in regular court or go to mental health court.

• If mental health court, sentence is suspended.

• If person successfully engages in treatment, case is dismissed.
Mental Health Court

- If person changes his mind or does not comply with, he/she goes to jail
- Program is typically 1 - 2 years long
- Veteran’s courts and drug courts run similarly
Assertive Community Treatment (ACT)

• Multidisciplinary, round the clock community care.
• Strict admission criteria
• Goal is to:
  • prevent or minimize crises
  • meet basic needs
  • enhance quality of life
  • improve functioning
  • enhance ability to live independently
  • encourage engagement
  • Lessen family’s role of providing care
How to Support Your Loved One

- Be prepared - don’t wait for a crisis
- Know the options available in your community
- Participate in treatment planning
- Notify treatment team of concerns
- Understand HIPAA
- Recognize improvement and celebrate it
- Let monitors monitor
Resources for Your Loved One

• NAMI Peer to Peer
• NAMI Connections
• MHA Schizophrenics Anonymous
• Depression Bipolar Support Alliance
• Peer Run Organizations/Consumer Operated Services
• Clubhouses
• Peer Support Specialists
• Peer Support Specialist Training
Resources for You

• NAMI
  • Family to Family
  • Home Front
  • Friends and Family
  • Family and Caregiver Support Groups

• MHA
  • Families in Touch Support Group
NAMI Family-to-Family Class

Free, 12 week class covers:
• How to solve problems and communicate effectively
• Taking care of yourself and managing stress
• Supporting your loved one with compassion
• Finding and using local supports and services
• Up-to-date information on mental health conditions and how they affect the brain
• How to handle a crisis
• Current treatments and therapies
• Impact of mental health conditions on the entire family
Resources for You

“I know of no other book even in the same league.”
Gary Squire, Author of the NY Times Bestseller How to Argue and Win Every Time

I AM NOT SICK
I Don’t Need Help!
How to Help Someone with Mental Illness Accept Treatment

Xavier Amador, Ph.D.

A Father’s Search Through America’s Mental Health Madness

"Crazy is a godsend."
—Patty Duke

"A magnificent gift... a clarion call for change and justice, and an enthralling portrait of a father who refused to surrender." —Bobo Moore Campbell

Pete Earley
New York Times Bestselling Author of The Hot House

SEVENTH EDITION
NEWLY REVISED AND UPDATED

SURVIVING SCHIZOPHRENIA
A FAMILY MANUAL

"E. Fuller Torrey is a brilliant writer. There is no one writing on psychology today whom I would rather read." —LOS ANGELES TIMES

THE INDISPENSABLE GUIDE TO TODAY’S MOST MISUNDERSTOOD ILLNESS

E. FULLER TORREY, M.D.
Tips for Taking Care of Yourself

• Understand how stress affects you
• Protect your physical health
• Notice the positive
• Build a support network
• Gather strength from Others
• Know your limits and don’t be afraid to set boundaries
• Let go of guilt
• Recharge yourself
  • Inquire about respite
• Advocate for system improvement!!
Contact Information

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