

SMI Caregiver

Bill of Rights and Responsibilities

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As SMI Caregivers, we often feel we have -no- rights and the -only- “right” our Loved Ones have is to “die with their ‘rights’ on”. Society most often leaves SMI Caregivers to struggle on our own without the needed help afforded to other medical problems. Just imagine if there was no dialysis for those with kidney disease or chemotherapy for cancer patients or insulin for diabetics. Yet, Loved Ones with SMIs are ignored, if not blamed or incarcerated. SMIs -are- cruel illnesses and society is cruel to SMI caregivers and families.

While advocacy groups such as The Treatment Advocacy Center, Shattering Silence Coalition, Schizophrenia and Psychosis Action Alliance, and a growing number of “Mad Moms” organizations on Facebook, and others are actively lobbying legislators, SMI Caregivers and families are largely left to struggle in desperation and silence. (see links at end of article)

Responsibilities Follow Rights

Normally, we think that “responsibilities” follow from their associated “rights”. We have, for example, the right of free speech but a responsibility flowing from that right to NOT falsely yell “fire” in a crowded theatre. For SMI Caregivers, however, **responsibilities precede rights** and the rights do not naturally flow from those responsibilities - SMI Caregivers must fight for them. And ironically, our fight starts at home with ourselves and our Loved Ones – the very souls we are trying to help.

Fighting With Ourselves and Our Loved Ones

When we SMI Caregivers bring our Loved Ones from the hospital we are not given an SMI Playbook. We are hardly given any information at all! As SMIs are neurodevelopmental illnesses (which typically develop in teens and early twenties), we are completely unprepared when our sweet, loving young children morph into people we still love but do not recognize.

Serious Mental Illnesses are unlike many other disabilities – there can be a -very large- degree of behavioral and symptom unpredictability which is not characteristic of other chronic illnesses. Extreme but stable stresses are easier to handle than erratic ones. This is one reason why parents of people with Down syndrome, for example, have an easier time than parents of Loved Ones who have schizophrenia, bipolar, or autism. With Down syndrome you know with whom you are dealing from day to day and the demands on you change relatively little. With schizophrenia, bipolar, or autism, one never knows what’s around the next corner or when the next meltdown moment may occur. This is why so many SMI caregivers have CPTSD (Complex PTSD).

This is why constructing and sticking to “guardrails” are so very important for SMI Caregivers and their Loved Ones. Along a highway, “guardrails” are proactively placed along potentially dangerous stretches of road. The time to erect guardrails is -before- they are needed, not after. Yet, SMI Caregivers are often reluctant to proactively put guardrails in place in their homes, for their Loved Ones for a variety of reasons:

- **Most of us try to avoid conflict.** Conflict is unpleasant. We postpone either because we are unaware of potential problems -or- we are in denial that our Loved One(s) would need them or even that they have a brain neurological illness. Postponing guardrails is tantamount to the proverbial ostrich burying its head in the sand but yet we find that warm sand at least temporarily comforting.
- **They feel “unnatural”.** While the lessons we modeled and taught our young children have not been “forgotten” by our Loved Ones, they are often buried under gathering storm winds carrying clouds of sand and dirt through the air - overwhelming both memory and judgment.
- **We fear guardrails will feel “disrespectful” and even condescending** to our Loved Ones, especially when they are adults. Yet, if we postpone erecting guardrails, life becomes even more difficult when our Loved Ones run into a metaphorical ditch.

The following “Feels Like” chart (from the “Love Can’t Fix SMIs” Caregiver Class taught by the SMI Caregiver Academy) captures many of the effects experienced by those who have an SMI:

SMIs: More than Mood Swings ... More than Psychosis						Feels Like Chart
						
Emotional	Behavioral	Physical	Trauma	Insight	Cognitive	
• Anger • Depression • Overwhelmed • Isolation • Shame • Paranoia • Anhedonia	• Rage / Mania • Impulsivity • Excitability • Hyper-sexuality • Promiscuity • Self-sabotage • Criminality	• Exhaustion • Digestion • Insomnia • Low energy • “frozen” • Texture-sensitive	Events can feel: • Extraordinary to our LO .. But ... • Ordinary to us • Psychosis can cause PTSD	Lacking insight to others’ • reactions • feelings • body language • Narcissist? Lacking insight to their own: • feelings • behavior • symptoms • Judgment	Impairment • Working memory • Processing Speed • ADHD (Attention) • OCD (Thoughts) • Poor Adaptability • Finding words for thoughts, feelings • Time Perception* • Cognition • Psychosis • Hallucinations • Delusion, Paranoia	

SMI Caregivers should erect proactive guardrails at home to save both our Loved Ones and ourselves from serious consequences – foreseen or not.

A Short List of Proactive Guardrails We Should Erect

- **Substances:** Remove all alcohol, MJ, and substances from the home. Any/all use ends for everyone.
- **Meds:** Lock up all prescription and OTC (over-the-counter) meds in lockable file cabinet.
- **Weapons:** Remove all guns, sharp knives, hunting paraphernalia, ammunition, etc. from the home.
- **Money**
 - **Under lock-and-key:** money, credit cards, debit cards, checkbooks, wallets, purses
 - **Credit Cards:** No access because of impulsiveness and impaired judgment
 - **Debit Card:** Loved One -can- have ONE with \$0 maximum withdrawal from ATM (no cash) Parent(s) load weekly allowance onto Loved One’s debit card
 - **Payment Apps:** remove from phones, tablets.
- **Keys**
 - **Parents’** – keep on their person at ALL times. Kept under parents’ bed mattress at night.
 - **Car:** Loved Ones should not be driving. Remember: Parents are LEGALLY LIABLE.
 - **House:** No keys for Loved One to ensure no sneaking in/out past bedtime. Change locks if needed
 - **Never Leave Alone in House:** Loved One
- **Devices:**
 - **Passwords:** Strengthen passwords / passkeys on all computers, phones
 - **Passwords:** on Loved One’s devices – remove. Devices should be unlocked so parents can inspect at any/all times. If Loved One places password on device – take device away.
 - **Paswords:** online shopping sites – strengthen, keep private
 - **TV & Computers:** Remove any/all access to dark web / illegal / immoral sites
 - **Parental Controls:** placed on all devices in the home as well as internet
- **Contacts**
 - **Subscribe to MEDICALERT.ORG** – to keep list of meds, doctors, emergency contacts
 - **Proactively meet (in person):** Crisis Team Lead / Police Chief. Brief them about situation

- **Social Benefits**

- **Social Security Disability** – file application with first diagnosis – BEFORE 22nd birthday.
Get SS attorney. [National Organization of Social Security Claimants' Representatives \(NOSSCR\)](#)
- **Caregiver** – should be Social Security Payee (when application is approved)
- **IEP plan at School:** work with school counselor as appropriate

A Short List of Expectations (Rights) Caregivers Should Set

- **Caregiver Personal Boundaries**

- **What We Need:** to be comfortable in a relationship with our Loved One
- **No verbal abuse:** directed at Caregivers, Loved One, or other family members
- **Respect / Protection of Property**

- **Medical**

- **Caregivers attend appts with Loved One:** psychiatrist, family doctor, (but not therapist)
- **Administer Meds:** Caregiver administer meds and keep daily track
- **Caregiver Daily Journal:** keep daily records of symptoms, moods, sleep, behaviors
- **Random Drug Tests:** non-negotiable

Links:

Treatment Advocacy Center - tac.org

Shattering Silence Coalition (<https://www.nationalshatteringsilencecoalition.org>)

Schizophrenia and Psychosis Action Alliance - sczaction.org

“Mad Moms” organizations on FB:

- [Heart of America Serious Mental Illness \(SMI\) Advocacy](#)
- [Arizona Mad Moms](#)
- [Colorado Mad Moms](#)