

SARDAA Family Toolkit

If you're assisting a loved one with a serious psychiatric disorder, you'll quickly find that brain disorders are illnesses with no road maps, scattered resources, and confusing information. One way to get better results from the health system when dealing with psychiatric disorders is to have a toolkit. Whether you're just beginning the journey, or a few years down the road, a toolkit can make all the difference in understanding how to proceed and provide your loved ones with the best possible care and assistance on their road to recovery.

What's in a Toolkit?

A toolkit can include anything that helps you manage and assist with an illness. Often they contain ideas, resources, templates, documents—anything that assists with helping your loved one. Here are some ideas for what to include in your kit:

EDUCATION

There is no substitute for educating yourself on your loved one's illness. Psychiatric brain disorders are diagnosed via the DSM, Diagnostic Statistical Manual, now in its fifth version. The DSM identifies brain illnesses (mental illnesses) and their symptoms as experienced over time. You can read portions of the DSM online. One important aspect of the DSM is that diagnosable illnesses have ICD codes, and those codes attributed to an illness are identified on billing from your doctors; this can mean the difference between being reimbursed by insurance or not, and how much is covered. The DSM is a place to start, to help you understand what symptoms are related to which illnesses.

There are many other very good books on brain disorders. Here are some suggestions, which are by no means exhaustive.

I Am Not Sick, I Don't Need Help! How to Help Someone with Mental Illness Accept Treatment. 10th Anniversary Edition, by Dr. Xavier Amador

Surviving Schizophrenia, 7th Edition, by E. Fuller Torrey, founder of the Treatment Advocacy Center in Virginia.

The Complete Family Guide to Schizophrenia: Helping Your Loved One Get the Most Out of Life. by Kim T. Mueser and Susan Gingerich

The Center Cannot Hold: My Journey Through Madness, by Elyn Saks

The Disordered Mind: What Unusual Brains Tell Us About Ourselves, Eric R. Kandel

An Unquiet Mind: A Memoir of Moods and Madness, by Kay Redfield Jamison

A Beautiful Mind, by Sylvia Nasar

MEANINGFUL RECOVERY from Schizophrenia and Serious Mental Illness with Clozapine: Hope & Help, by Dr. Robert S. Laitman MD, and Dr. Lewis A. Opler MD PhD

Recovery from Disability: Manuel Of Psychiatric Rehabilitation, by Robert Paul Liberman

The Gift of Adversity..The Unexpected Benefits of Life's Difficulties, Setbacks, and Imperfections, by Norman E. Rosenthal, M.D., a psychiatrist

Exuberance...The Passion for Life” by Kay Redfield Jamison PhD, a professor of psychiatry at John Hopkins; in recovery with Bipolar and author of related books and other

Miracle Mindset, by J.J.Virgin, a mother who drew on her inner strengths in support of her teenage son who was severely brain injured in an accident. The book resulted from her desire to help others facing catastrophic challenges in life.

Education can come from many other avenues:

- Websites such as SARDAA, NAMI, Treatment Advocacy Center, PsychCentral, and others that focus on brain health
- Documentaries and movies
- Interviewing Doctors and Patients
- Other families and patients
- Support groups such as Schizophrenia Alliance and Families for Care
- Family training, such as NAMI’s Family to Family course
- LEAP Training (Listen, Empathize, Apologize, Partner) by Dr. Xavier Amador

Seeking education can be comforting in that once you know better, you do better. It can help reduce anxiety about the illness you’re facing, and increase understanding of symptoms and behaviors. It can also help families answer hard questions such as, What is Illness, and What is Behavior? Understanding complex brain illnesses doesn’t take a medical degree. Read, ask, learn. It’ll help you build your toolkit.

NOTETAKING

Having a medical journal can be a helpful tool for your toolkit. Use either a Schizophrenia App or written journal documenting appointments, symptoms, medications and doses, therapy instructions, questions for doctors and clinicians, and instructions on what to do when. Dealing with any illness can be daunting and upsetting. Carrying a medical journal to appointments can help you remember later what you may have been too upset to understand at the time.

A journal can also be used to partner with your loved one’s doctors. In the world of brain disease, there is often hostility and negativity toward parents and family members. Keep the meetings professional and show that you are a real partner in your loved one’s journey. Take notes during meetings and reiterate what you’ve been told by clinicians and others professionals. Clinicians appreciate an interested and helpful family member. Repeat what you’ve been told during meetings to show you’re trying to understand your loved one’s issues and are serious about helping. SARDAA has a free Schizophrenia app that assists the diagnosed individual and caregivers with this task.

REACHING OUT TO FAMILY MEMBERS

Psychiatric brain disorders are our best kept secrets. We are conditioned not to talk about them, adding to the isolation of the journey, the stigma and discrimination surrounding brain disorders. Often when you reach out, you find allies and build a support system. While you may find some not willing to understand, what you uncover many times is family history and others who have endured brain health problems, who also felt alone. Be honest about your family member's illness and seek support from those close to you. It can be a great comfort to both you and your loved one. When to tell people about the illness can be daunting. If your child had any other illness, you'd seek support. Remember to do so in this journey as well. You may find they're accepting and understanding and welcome the education. People living with brain disorders deserve family support and a support system. Help your child build that if you're able.

MAKE A PLAN FOR GETTING HELP

Brain health crises are often preceded by periods of turmoil or chaos. Make a plan to get help before a crisis. This can include:

- Introducing your family to local law enforcement and crisis workers
- Meeting your loved one's clinicians and helpers
- Make a list of phone numbers you'll need ahead of time
- Find sitters who can stay with other siblings if needed
- Keep a list of medications you're loved one is taking
- Write a history of the illness to use when you meet new doctors
- Practice for a crises: locate the hospital, line up the resources you need ahead of time
- Know your state's laws on involuntary commitment and psychiatric holds
- Know your HIPAA rights to share information with a treatment team
- Prepare documents you need ahead of time: HIPAA waiver, Power of Attorney, Guardianship

PREPARE WHEN YOUR LOVED ONE IS HEALTHY

What is HIPAA Waiver of Authorization?

It is a legal document that allows an individual's health information to be used or disclosed to a third party. The waiver is part of a series of patient-privacy measures set forth in the Health Insurance Portability and Accountability Act (HIPAA) of 1996.

Breaking Down the HIPAA Waiver of Authorization

The HIPAA waiver of authorization allows doctors to provide information on a patient's health to third parties, such as researchers, attorneys, other doctors or family members. It became necessary because healthcare privacy has come into increased focus in the digital age; it is much easier for doctors to transmit patient health information via the Internet than it was when records had to be mailed or faxed.

Patient information covered under HIPAA, called protected health information (PHI), is information that can be linked to a specific individual, and is held by a covered entity, such as a health insurer, healthcare provider or healthcare clearinghouse.

Get a HIPAA waiver signed while your loved one is healthy! They very often (due to paranoia and anosognosia) refuse to allow communication with families, especially if coming to care involuntarily. HIPAA **does not prevent** families from communicating helpful information on symptoms and recent events to doctors and clinicians.

What is Advanced Medical Directive?

An advance medical directive is a legal document that provides medical direction for a patient who may be unable to make medical decisions for him or herself. It can cover anything from who can ride in an ambulance to what medications they will allow you to let the doctor prescribe.

Complete an advance directive, downloadable via **your state's department of health and human services**, while your loved one is healthy. Keep it handy and know where it is. You can find your state's particular advanced medical directive via caringinfo.org. Provide the advance directive to be included in his/her medical record.

SEEKING GUARDIANSHIP

Consulting a disability or mental health attorney can help you answer questions you may have about seeking guardianship for your loved one. The requirements and legal filings are different for each state, and it has different names in each state. Guardianship can cost money and time, so prepare for this by gathering documentation before crises that will help your case. Guardianships can be temporary or permanent. If your loved one is able, discuss the possibility with him or her and ways this can help protect them medically and financially.

DISABILITY and SSDI

Disability is a federal benefit for citizens who are unable to work or care for themselves at a level appropriate to their age. There is a federal disability application that is fast tracked to assist brain disorder patients from becoming homeless. This application is called **SOAR**. Having a social worker or lawyer help you complete the application ensures it has the pertinent information required for disability. Schizophrenia and related disorders are the largest cause of disability in the United States. It can be an arduous process, and the process becomes more difficult as your loved one ages. Select a representative payee ahead of time (someone willing to help with the financial aspects for your loved one). The SOAR application is a federal application, meaning it's used for all states. It also comes with Medicaid or Medicare, providing free or low cost invaluable help with access to medical care for patients disabled by psychosis.

The SOAR application is available via SAMHSA, the Substance Abuse and Mental Health Services Administration. <https://soarworks.prainc.com/>

L.E.A.P. APPROACH

L.E.A.P. is the leading methodology to partner with your loved one on his illness, helping to gain his trust and bring him to care when needed. The L.E.A.P. method was invented by Dr. Xavier Amador over time as he assisted his own brother who had schizophrenia, and suffered from anosognosia (lack of awareness of illness). As many families know, their loved one often says that they aren't sick and don't need help. L.E.A.P. is a method that teaches families, friends, health professionals and criminal justice personnel how to build trust and partner with someone experiencing psychosis to help them to be involved in their care. Dr. Amador's method is available via personal training sessions, through his many YouTube videos, and via his acclaimed book, "I'm Not Sick, I Don't Need Help." The tools you learn in L.E.A.P. can be used in any relationship, but are particularly useful when your loved one cannot perceive that he is in need of medical assistance or medication. L.E.A.P. is in use across the nation. If you cannot attend a training session, find the books and videos and begin learning how to sincerely partner with your loved one with psychosis on healthy goals.

REACT APPROPRIATELY IN A CRISIS

Below are some general guidelines for handling a psychiatric crisis or responding to someone in the grips of psychosis. You may want to add your own tips to this list.

Your goal in a brain health emergency is to stabilize the situation and get the person to professional help as quickly as possible.

- Do not try to manage the situation alone – Sometimes just having another party present or on the phone with your loved one will defuse a situation.
- Start at the top of your Emergency Contacts list and work your way down. If it is an evening or weekend and you cannot reach providers or agencies, call the most appropriate hot-line.
- Speak to your loved one in a calm, quiet voice – If it seems he/she isn't listening or can't hear you, it is possible that auditory hallucinations ("voices") may be interfering. Don't shout; raising your voice won't help and may escalate tensions.
- Keep instructions and explanations simple and clear – Say, "We're going to the car now," not, "After we get in the car, we'll drive to your doctor's office so she can examine you."
- Respond to delusions by talking about the person's feelings, not about the delusions – Say, "This must be frightening," not "You shouldn't be frightened – nobody's going to hurt you."
- Don't stare – Direct eye contact may be perceived as confrontational or threatening.
- Don't touch unless absolutely necessary – Touch may be perceived as a threat and trigger a violent reaction. Ask permission of the person before you touch him.
- Don't stand over the person – If the person is seated, seat yourself to avoid being perceived as trying to control or intimidate.
- Don't give multiple choices or ask multi-part questions – Choices will increase confusion. Say, "Would you like me to call your psychiatrist?" not "Would you rather I called your psychiatrist or your therapist?"
- Don't threaten or criticize – Acute brain illness is a medical emergency. Suggesting that the person has chosen to be in this condition won't help and may escalate tension.
- Don't argue with others on the scene – Conduct all discussion of the situation with third parties quietly and out of the person's hearing.

- Don't whisper, joke or laugh – This may increase agitation and/or trigger paranoia.
- Print a copy of this list to keep with your list of essential telephone numbers.

IF THERE IS A SUICIDE THREAT

It is a myth that people who threaten to kill themselves don't do it. ASSUME that any suicide threat is serious and treat it as a danger to the person's life. A previous suicide attempt increases the likelihood that the person will act on the threat.

ASK in a private, calm setting whether the person is thinking about suicide. Your questions can be indirect...

"Do you ever think you should never have been born?" or Direct..."Do you feel like you want to die?"

FOLLOW UP if the answer to these general questions is Yes and ask about specific suicide plans. When does the person plan to commit suicide? How? Has the person already acquired the means, e.g., pills, gun, etc.

DETERMINE the imminence of the danger based on the answers to the questions. A college freshman who describes a suicide plan for graduation day in four years is probably not in imminent danger. A college senior who is graduating the next day is. Act accordingly.

CONTACT the person's mental health or medical providers and repeat exactly what the person has told you.

HIDE all vehicle keys and any means that could be used for self-harm, e.g., medications (including over-the-counter drugs), knives including kitchen knives, guns, ropes.

KEEP the person sober. Suicide completers have high rates of positive blood alcohol. Intoxicated people are more likely to attempt suicide using more lethal methods. Be aware that the combination of alcohol and Tylenol can be lethal. Be sure there is no Tylenol available if the person is drinking.

DO YOUR BEST to persuade the person to get help voluntarily. Dial the hotline number, drive to the clinic, take a taxi to the ER. Do whatever is necessary to get them to help.

Call 911 if the suicide attempt appears imminent.

GET PERSONAL WEEKLY HELP VIA SARDAA'S CONFERENCE CALLS FOR FAMILIES/FRIENDS

SARDAA hosts free weekly teleconference calls to support family members and loved ones of those with serious psychosis brain illnesses. Keep this phone number handy! You can call in every Tuesday and find a host of people willing to listen and share. Here are the details.

Families For Care Support Group (FFC) (Not For Diagnosed Individuals)

Every Tuesday – 7 pm Eastern Time

Call 240-423-9432 to register for the call

Preparing a Psychiatric Advance Directive

Caveat: Do not encourage a person to create a PAD when they are not stable and/or they are experiencing anosognosia, both of which will adversely inform their decision-making abilities.

People with disabilities who exercise greater self-determination have a better quality of life

Better employment situations, less physical and sexual abuse, more successful community integration. (Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003)

Advance directives support principles of recovery: person-driven; based on respect; and involving individual, family and community strengths and responsibilities. (SAMHSA “10 Guiding Principles of Recovery”)

1990 Patient Self-determination Act added weight to the authority of Psychiatric Advanced Directives

Medicaid/Medicare providers must ask if a person has a directive and note this in the medical record (including a copy of the directive if it is provided).

Providers must summarize health care decision-making rights and facility’s policies about health care directives; cannot require or prohibit PAD.

Must also educate staff and community about patient rights

Why have a Psychiatric Advance Directive?

Self-determination: PAD operationalizes an individual’s choices regarding treatment and services—a crisis prevention plan with teeth.

Good vehicle to discuss planning and recovery with family, friends and providers.

Gives providers who may not know you, information which will help them provide you with good care.

Opportunity to authorize in advance who can receive/release medical information.

Can incorporate legal arrangements for care of children, finances, pets at a time of crisis

Informed decision-making aka “informed consent”

Caveat: Do not encourage a person to create a PAD when they are not stable and/or they are experiencing anosognosia, both of which will adversely inform their decision-making abilities.

Understanding the psychiatric/medical condition

Understanding the risks and benefits

Understanding treatment options

Understanding the possible consequences of agreeing or disagreeing with certain treatments

Factoring in one’s values, beliefs, preferences

Weighing these together.

Making and communicating a reasoned decision, which is not per se a “best interest” decision

Basic legal components of a PAD

Instructions:

A legally recognized document with instructions (directives) on psychiatric/medical care, written in advance of the anticipated need:

‘Now, for later’.

and/or:

Agent:

In most states a person may name a decision

-making agent (‘health care power of attorney’, “proxy”) to carry out instructions.

In some states the PAD is primarily the appointment of an agent.

Executed:

The PAD is executed by an adult (age 18) with capacity to do so (usually legal presumption of capacity in law) in writing, signed and dated, usually two witnesses and/or notarize

Different States; Different Requirements

Instructions commonly used in PAD

When to treat/hospitalize

I authorize my agent to get me mental health help if I start to... order lots of stuff from TV ads... if I start hearing voices telling me to hurt myself...

Alternatives to hospitals

I want to go to a crisis bed but not a hospital if I am feeling self-destructive.

Preferences for care

Take me to X hospital, where I trust the staff.

Knowledge of medication effects

I will take this antipsychotic but have learned from past experience not to have a dosage over XYZ

Adverse actions

I do not want injections because I am afraid of shots but I am OK with pills.

Trauma concerns

Because of past sexual abuse, I cannot be put into restraints. This would worsen my condition. Do this instead...

Setting treatment parameters for providers and agents

I authorize my agent/provider to treat with anti-psychotics they decide on, but if I start exhibiting the following side effects, I want the medication reduced or stopped.

CAVEAT: A PAD is not a wish list. It does not give a person more rights or services than they are **reasonably and otherwise entitled to as a competent per**

Reference:

https://www.samhsa.gov/sites/default/files/programs_campaigns/recovery_to_practice/pad-webinar-ppt.pdf

Early Intervention to Prevent Relapse in Schizophrenia by Dr Steven Lambert

Presentation: <https://www.youtube.com/watch?v=NS9iKBH5row>

SEVEN KEYS TO RELAPSE PREVENTION IN SCHIZOPHRENIA

Appendix. Early Signs Questionnaire, Short Form		
NAME _____	DATE _____	
Compared to last week, has there been an increase in any of the following symptoms?		
	YES	NO
1. Problems with sleep	_____	_____
2. Problems with appetite	_____	_____
3. Depression	_____	_____
4. Problems with concentration	_____	_____
5. Restlessness	_____	_____
6. Tension or nervousness	_____	_____
7. Use of alcohol	_____	_____
8. Use of street drugs (includes marijuana)	_____	_____
9. Hearing voices or seeing things that others can't hear or see	_____	_____
10. Less pleasure gained from things you usually enjoy	_____	_____
11. Feeling people were watching you, were against you, or were talking about you	_____	_____
12. Preference for being alone and/or been spending less time with other people	_____	_____
13. Arguments with others	_____	_____
14. Inability to get your mind off of one or two things	_____	_____
Have any other symptoms appeared or increased?	_____	_____
If so, what were they? _____		

Did anything specific happen last week which upset you?	_____	_____
If so, what was it? _____		

Have you been taking your medication as it is prescribed for you?	_____	_____
<p><i>Reprinted with permission from Marvin Herz, MD. Clinicians may reproduce this scale for use in their clinical practice. Researchers who wish to use the Early Signs Questionnaire in multi-patient studies should contact Dr. Herz at University of Rochester Medical Center, Strong Ties Community Support Program, 1650 Elmwood Avenue, Rochester, NY 14620, (716)275-0300, x2337, marvin_herz@urmc.rochester.edu</i></p>		

Tips and Tricks to Help Your Loved One with Severe Neuro-Psychiatric Brain Illness

Tips derived from Mental Illness Policy Org's Facebook and SARDAA communities' responses to the question "what tips and tricks do you have to help their neuropsychiatrically [mentally] brain ill loved ones"

- Have an account at the local cab company for transportation. If well enough an account with Uber or Lyft on a smart phone. Their own account provides less reliance on caregiver and provides more autonomy to loved one.
- Hire a weekly visitor to friend, take shopping, out for a walk, to the movies etc. Search by advertising through Craigslist, a local college, perhaps one that has a social work program.
- Provide gift certificates to local chain restaurants, grocery stores, general stores in lieu of extra cash. To ensure meals and purchases are available without the risk misappropriating cash and running out of food. Some grocery stores sell cards that are only redeemable for food.
- Send care packages from smile.Amazon.com (select schizophrenia and related disorders alliance of America as charity) include Items needed (like new sheets and toiletries)
- Purchase groceries on line, for loved one to pick-up or for delivery.
- Pay loved one's bills & rent online.
- Utilize Grub Hub, Uber Eats or other food deliver to deliver nightly dinners.
- Utilize a True Link Visa® debit card. This debit card lets you control expenses. You can designate where it is allowed and not allowed to be used, and how much that can be withdrawn per day. Cash withdrawals can be prevented. By using a debit card, rather than cash, you can often prevent them racking up needless ATM fees and have greater control over where the money is spent.
- Never argue and always reassure your loved one. Stay positive, but empathize with their sadness and paranoia ("It must feel awful to feel like the FBI put a transmitter in your head). Listen without

judgement.

- Be content to listen. "My niece calls me 4 times a day basically to describe a random train of thought or minutiae of her day (who said what to who). It used to upset me because when I tried to engage in a conversation she just babbled on. Then I realized she was not calling to talk to me, she was calling to talk at me. It made her comfortable to express the thoughts that were crowding in her brain. So now I let her talk, and just interject reassurances occasionally.
- Don't take it personally when they want to be alone.
- Give your loved one's phone number to relatives and friends who live father away (or even not so far away) and asked them to call or text occasionally. Request that they will visit once a month and take your loved one for walks or to lunch. You can volunteer to reimburse their parking and cost of lunch.
- Include their cell phone on your plan so you can track him if needed.
- Check with cell phone companies with special cell phone plans for those who are on Medicaid, disabled or elderly.
- The six steps of the SARDAA support groups are tools/instruments, drawn from family experience, for self-support and change.
- Encouragement to connect with others in phone and/or FB support groups, to listen and share as able, with hope of learning and growing.
- Seek out reading resources, as one's time allows, which deal with the illness as educational, and 'very importantly' self-care, as supportive for one's challenges. Also, readings which put things in a positive light, thus giving hope.

Examples:

- Search for coping strategies for those inevitable challenging times which are overwhelming and put hope in doubt.
- Emphasis on 'daily' self-care, important in maintaining strength. Practices

such as meditation, yoga, Qigong, healthy eating, physical activity/exercise, nature connection and anything which lifts one up!

- Involvement in volunteer activities, as time allows. “When one is helping another both are strong...” a German proverb. If volunteering in a mental health capacity it would put one in touch with knowledgeable and ‘unconditionally understanding and accepting people’.
- To the extent of one’s ability to ‘move beyond the way things were with wish to return, to view one’s loved one’s situation realistically, enabling the family member to lend support; related, to be tuned, alert, to things in life which put things in a positive light, e.g. quotes, articles, etc.
- In terms of supporting one's family member, next to the importance of medications, to learn the value of peer support for the family member, and attempt to introduce him/her to the opportunities of support groups either via phone, FB or face to face if available in one's community. From the personal experience of people in recovery, this can be a very important step forward, as demonstrated in other support communities of AA, NA, veterans, etc. There exists an inherent trust in one's peers who have 'been there', even over that of professionals, family, friends.