

COMMUNICATION 101 FOR EASA FAMILIES

A NEWSLETTER FROM EASA'S FAMILY AND FRIENDS LEADERSHIP COUNCIL



What EASA parents say

"My son graduated from EASA years ago, and he has been doing really well. Still, when he recently told me he was going to talk to his doctor about reducing his medication, I could feel myself get really tense inside. I flashed back right away to how things were when he first got sick and we hadn't figured out his medication yet. That was such a hard time. I realize now that I am going to need to remember how to use the communication skills I learned back then and apply them to this new life situation."

FFLC Mom

"I really wish when my son first got sick somebody had told me about anosognosia. I had no idea that he didn't really grasp how bad things were, or that he maybe didn't even realize that he was sick at all. So, I kept trying to get him to see the light and take his medication, but to him, I was just trying to control him when there wasn't anything wrong that he couldn't handle himself. I was beating my head against a wall, and I didn't even realize it."

FFLC Mom

The ultimate communication challenge: Anosognosia

What is anosognosia (sometimes also referred to as 'lack of insight')?

The National Institute of Health uses the analogy of your brain as a computer that constantly runs diagnostic checks on your body and mind. When someone has anosognosia, that internal "monitoring system" is broken. [1, 2, 3]

(Note: To access these links go to <https://easacommunity.org/family-resource/fflc-newsletters/>)

Consequently, someone with anosognosia is unable to even perceive their own illness or limitations.

How common is it?

Medical conditions that can include anosognosia are strokes, dementia and Alzheimer's. Anosognosia is also highly common in people experiencing psychosis. An estimated 57% to 98% of individuals with schizophrenia, and roughly 40% of people with bipolar disorder with psychotic episodes have anosognosia

What are the consequences of anosognosia?

Because the neurological networks responsible for self-awareness are impaired, people with anosognosia are unable to recognize that their hallucinations, delusions, or disorganized thoughts are symptoms of an illness. This creates profound challenges, making anosognosia the leading reason people with severe mental illnesses refuse or discontinue medication.

Trying to argue with someone who has anosognosia or showing them medical proof of their illness usually won't work, because their brain simply cannot process that they are sick.

So, What DO You Do???

Communication tips for EASA families

There is so much that could be said about communicating with your young person who is going through psychosis. Here's what our group decided on as our top four:

1. Keep it simple

Psychosis can cause processing delays, thought confusion, difficulties understanding and coming up with language, along with competing inner conversations.

- Use short, direct statements.
- Share one idea at a time.
- Pause and wait between ideas.
- Avoid offering too many choices, which can feel overwhelming.

2. Radiate calm (Ha!)

With everything going on, this is a big ask. Try to remember, though, that even if your son or daughter comes across as being disconnected from what is happening, people experiencing psychosis are often highly sensitive to the emotions around them, and they may react strongly to the messages they are getting from your body language and tone.

3. Above everything else, protect your relationship

It's not unusual for someone with psychosis to start seeing those who used to be closest to them as adversaries. Thinking back to anosognosia, that's not surprising. From their point of view, you may constantly be trying to get them to take medication that they don't need for an illness they don't believe they have. You might even be trying to get them 'locked up for no reason'. You may know exactly what the other person needs to do to get better, but this doesn't matter one bit if the person you're trying to help sees you as the enemy.

4. Learn new ways to communicate

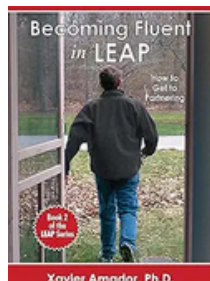
Trying to argue someone with anosognosia out of their beliefs won't work and will cause a lot of conflict. There are some great books (see below) and free classes (see next column) that can help you find ways to communicate more effectively, even when anosognosia is in play.



Parent Picks

The author of these books developed the LEAP method, as a way to communicate better with his brother who had schizophrenia.

<https://leapinstitute.org/>



This recent article about the challenges of being a caregiver for someone with psychosis gives a good overview of the LEAP method.

<https://www.aarp.org/caregiving/medical/schizophrenia-care/>

Where to learn new skills

Talk to your EASA Team. EASA uses a 'shared decision-making' approach that puts the young person experiencing psychosis in the driver's seat. There's a reason for this: For better or worse, they ARE the person in charge of making the decisions about their life, so look for ways to empower them and to partner with them in reaching their life goals.

The University of Washington offers a free online class developed by families for families. It's called Psychosis REACH, and it is GREAT! The next class is in early September. You can find out more and sign up here:

<https://www.psychosisreach.org>



The School of Hard Talks: Free, short interactive video lessons that can help you learn new ways to talk to your son or daughter effectively in difficult circumstances.

<https://www.cbhknowledge.center/training/schtalks/>

NAMI offers free **'Family to Family'** classes taught by people who have been in challenging situations like yours.

<https://www.nami.org/programs/nami-family-to-family/>



OPEN PHONE LINE

Want to talk to another caregiver who understands what you're going through?

Call EASA's Open Phone Line:

971-610-1529

Mondays, 5 - 6 PM Fridays, 9 - 10 AM

Or email Karma at clarkejung@ohsu.edu to schedule a time that works for you.

