The Catatonia Foundation

Advocacy Tips for Caregivers

1 Make sure you have support in place for yourself

Being a caregiver and an advocate can be overwhelming. Out of necessity, you are constantly putting your loved one's needs before yours. You are navigating a system that you may not be familiar with. Seek out emotional support for yourself from friends, family, and professionals with expertise to support you.

It's important that you are not looking to your loved one's healthcare team for your emotional support. You want the team to be focused on your loved one's health and be open to receiving to relevant information and feedback from you. When you look to your to your loved one's healthcare team to support your emotional needs, they may be less likely to take your input into consideration..

2 Build rapport with the healthcare professionals

It's important to build rapport with any healthcare professionals that are involved in the diagnosis or treatment of your loved one. Be friendly and engaging as much as possible. You may want to begin appointments with a moment of small talk to help everyone relax and let their guard down. Remember, you want the healthcare providers invested in your loved one and on their team.

While you may be in an understandably heightened emotional state, do your best to be calm, share from a place of confidence and ask questions from a place of curiosity, all with as little emotion as possible. Stay focused on the facts and getting your questions answered. It's normal to want reassurances; ask the questions in ways that will provide you with as much accurate information as possible (for example, what percentage of people with Catatonia are cured by this particular treatment or what is the likelihood of the Catatonia returning once the patient is cured?)

It may seem obvious but making sure you and your loved one are groomed well is important. Believe it or not, that's often noted in the patient's chart.

3 Be well-informed on Catatonia

If you suspect Catatonia or it's been mentioned by a provider, even in passing, it's important for you to become familiar with the following:

1. The symptoms of Catatonia
2. How Catatonia is diagnosed
3. The various expressions of Catatonia
4. The most effective treatment options for Catatonia

4 Do an inventory of the symptoms

Once you familiarize yourself with the symptoms of Catatonia, do an inventory of the symptoms your loved one exhibits. Make a list and describe in detail what you have observed them doing. It can be what you are currently observing or what you've seen since the onset of the strange behaviors—all are important.

To the extent possible, match up any symptoms you've observed to the symptoms listed on the Bush-Francis Catatonia Rating Scale. The rating scale does a good job describing the symptoms in a way that's easy for the layperson to understand. The rating scale provides a method for determining whether a diagnosis of Catatonia should be considered and also a method for rating the severity of the symptoms on a scale of zero to three. It may be helpful for you to determine the symptoms your loved on is displaying first and then to rate the severity of the symptoms as best you can.

5 Describe your loved one's baseline

At the first appointment, a healthcare provider does not have information to compare how the behaviors they are observing differ from your loved one's behaviors prior to the start of the change in behaviors. They may not understand how dramatically different your loved one's behavior is now.

To assist the healthcare provider, describe your loved one's mental state, physical state and behaviors prior to the onset of the symptoms of Catatonia. Healthcare providers refer to this as "baseline." It will be important for you to use that term when communicating with healthcare providers because they will be more likely to take your description into account since you are speaking their language.

When describing your loved one's baseline, describe the following:

- What the person was capable of doing - job, school, social, activities of daily living (eating, grooming, sleep)
- What a day in their life was like
- How the person dealt with challenges
- Any event(s) that might have precipitated the change in behavior
- Any medical or psychiatric diagnoses

6 Timeline

Create a timeline of the following:

- When symptoms began and what symptoms were observed
- Other symptoms that were observed over time, what they were and when they occurred
- Any treatment provided and response
- What healthcare providers were seen and what they did
- What tests were done and what the tests showed

7 List of key points

Prior to an appointment with a healthcare provider, make a list of the key points you want to make sure you convey. Examples of this may include:

- That the symptoms came on fairly suddenly
- How dramatically different the behaviors are in comparison with their baseline and what the new behaviors are
- That it's important that the healthcare provider has expertise in Catatonia or is at least familiar with it

8 List of questions

It's often challenging to think of questions on the spot when you are at your loved one's healthcare appointment. Spend some time thinking about it in advance and make a list of the questions you would like answers to.

Examples might include:

- Do you have experience or expertise in Catatonia? If not, who can you refer us to who does have expertise in Catatonia?
- Are there any tests that should be done to rule out any other diagnoses or underlying conditions (MRI, bloodwork, spinal tap)?

- Would it be useful to perform the Lorazepam (Ativan) challenge?
- Experts in Catatonia use the Bush-Francis Catatonia Rating Scale. Can you go over how the patient scores on the rating scale and can I provide my input?
- What information do you need from me that would be helpful in making a diagnosis of Catatonia if that's an appropriate diagnosis?
- What treatment options are available and what do you recommend?

9 Relevant medical information

Gather all relevant medical information and make a copy to give to the provider, including the following:

- Reports of healthcare providers from prior appointments
- Lab test results (including spinal taps)
- Reports of CTs, MRIs, ultrasounds or other scans
- Reports of EEGs, EKGs or other tests
- Reports from hospitalizations (ER or inpatient)
- Any other reports

10 Relevant articles

It may be helpful for you to bring relevant articles about Catatonia to your appointment as many healthcare providers are not familiar with Catatonia.

You may want to bring one or more of the following articles or any articles on our resources pages (NOTE - the articles are linked on The Catatonia Foundation Website, Patients and Caregivers, Advocacy page:

- The Many Misconceptions of Catatonia, 2018
- Expanding the Catatonia Tent: Recognizing Electroconvulsive Therapy Response Syndromes, 2020
- Optimizing ECT Technique in Treating Catatonia, 2016
- Electroconvulsive Therapy for Patients with Catatonia: Current Perspectives, 2020
- Catatonia is not Schizophrenia and It is Treatable, 2018
- Catatonia: Clinical Overview of the Diagnosis, Treatment, and Clinical Challenges, 2021

11 Bring someone with you to take notes if possible

When going to a healthcare provider appointment, you may want to bring someone with you to take notes. It's challenging to be dealing with your own emotions and overwhelm while conveying important information and asking questions. You may not be able to process what the provider is saying or recall later what was said. Make sure you introduce the person to the provider and let them know why they are there (for example, to take notes and help you remember your questions).

Go over what you need from the person going with you before you get to the appointment. You may want to give the person who comes with you permission to remind you of what you want to say or ask, and to ask clarifying questions if they feel it would be helpful.

12 Ask for permission to take notes or record the conversation

Always ask the healthcare provider if it's ok with them that you or someone else take notes during the appointment.

If you don't have anyone else to go with you, you may want to ask if you can record the conversation. It is recommended that you do this with caution as you do not want to alienate the provider or put them on the defensive.

13 Other practical issues

Navigating the healthcare system may be challenging enough without having to add more to your plate. You may, however, encounter some practical issues you will need to deal with, including:

1. Insurance

- Your loved one's insurance may not participate with the healthcare providers who are treating them. Exploring other insurance options may be necessary. It may be helpful to explore this with a medical insurance broker and/or the billing department for the provider to understand what your options are.
- Your loved one's medical insurance may require prior authorizations or additional information from providers that you may need to coordinate.

- Your loved one's medical insurance may reject claims for care because of a lack of understanding of the treatment necessary for Catatonia which may require you to coordinate the provision of necessary information to the insurance company.
- It's important not to ignore medical bills. The provider may work with you for amounts that are yours or your loved one's responsibility with payment plans, discounts, and/or write-offs of all or a portion of the bill.

2. Consent

- Consent to ECT may be an issue because your loved one is not competent to consent due to their current illness or due to a developmental disability or other disability or illness. .
- Consent may be an issue because the patient is a minor.
- State laws and hospital policies will need to be considered. You may need to rely on the healthcare provider's guidance and/or engage an attorney to help navigate consent issues.
- In some instances, a court order may be required to proceed with ECT.
- Hospital policies may require the agreement of several specialists regarding ECT.
- You may need to engage an attorney to navigate consent issues.

3. Leave of absence under the Family and Medical Leave Act (FMLA) and access to short or long term disability

- If your loved one is employed, you may need to explore disability and FMLA leave.
- There may be a specific required months or years of service before your loved one is eligible for employer FMLA and/or disability insurance benefits.
- The employer's HR department will help you navigate this process, which will require submitting forms filled out by healthcare providers.
- Individuals who are not eligible for employer provided disability benefits may need to determine whether Social Security Disability is an option. You may need to review the process online, contact the Social Security Disability office, and/or consult with an attorney to navigate the Social Security Disability process.

14 Peer caregivers

- It may be helpful to speak with another caregiver who has been through a similar experience. This may help you to navigate through diagnosis or treatment, or provide hope.
- Contact The Catatonia Foundation at info@thecatatoniafoundation.org if you'd like to be contacted by a peer caregiver who has previously navigated the process.

- Post on our Patient/Caregiver Forum and/or review previous posts.
- Explore Catatonia and/or ECT Facebook Groups, including the following: ECT Support Group, Support for ECT, Friendly ECT Support Group, Catatonia, Catatonia and Autism. NOTE, The Catatonia Foundation has not vetted these groups and is not responsible for anything posted in these groups.
- Seek out peer support at the National Alliance for Caregiving.

Bush-Francis Catatonia Rating Scale

Severity Score (Number of points for items 1 -23) _____
Screening Score (Presence or absence of items 1 – 14) _____
Number of items 1-23 _____

Patient: _____ Date: _____ Time:_____ Examiner: _____

1. Immobility/stupor: Extreme hypoactivity, immobile, minimally responsive to stimuli.
0 - Absent.
1 - Sits abnormally still, may interact briefly.
2 - Virtually no interaction with external world.
3 - Stuporous, non-reactive to painful stimuli.

2. Mutism: Verbally unresponsive or minimally responsive.
0 = Absent.
1 = Verbally unresponsive to majority of questions; incomprehensible whisper.
2 = Speaks less than 20 words/5mins.
3 = No speech.

3. = Staring: Fixed gaze, little or no visual scanning of environment, decreased blinking.
0 = Absent.
1 = Poor eye contact, repeatedly gazes less than 20 s between shifting of attention; decreased blinking.
2 = Gaze held longer than 20 s, occasionally shifts attention.
3 = Fixed gaze, non-reactive.

4. Posturing/catalepsy: Spontaneous maintenance of posture (s), including mundane (e.g. sitting or standing for long periods without reacting).
0 = Absent.
1 = Less than I min.
2 Greater than one minute, less than 15 min.
3 Bizarre posture, or mundane maintained more than 15 min.

5. Grimacing: Maintenance of odd facial expressions.
0 = Absent.
1 = Less than l0seconds.
2 = Less than 1 min.
3 = Bizarre expression(s) or maintained more than 1 min.

6. Echopraxia/echolalia: Mimicking of examiner's movements (echopraxia) or speech (echolalia).
0 = Absent
1 = Occasional.
2 = Frequent.
3 = Constant

7. Stereotypy: Repetitive, non-goal-directed motor activity (e.g. finger-play, repeatedly touching, patting or rubbing self); abnormality not inherent in act but in its frequency.
0 - Absent
1 - Occasional.
2 - Frequent.

3 - Constant.

8. Mannerisms: Odd, purposeful movements (hopping or walking tiptoe, saluting passers-by or
exaggerated caricatures of mundane movements); abnormality inherent in act itself.
0 - Absent
1 - Occasional.
2 - Frequent.
3 - Constant.

9. Stereotyped & meaningless repetition of words & phrases (verbigeration): Repetition of
phrases or sentences (like a scratched records).
0 - Absent.
1 - Occasional.
2 - Frequent, difficult to interrupt.
3 - Constant.

10. Rigidity: Maintenance of a rigid position despite efforts to be moved (exclude if cog-wheeling or tremor present)
0 = Absent.
1 = Mild resistance.
2 = Moderate.
3 = Severe, cannot be repostured.

11. Negativism: Apparently motiveless resistance to instructions or attempts to move/examine patients. Contrary behavior, does exact opposite of instruction.
0 - Absent
1 - Mild resistance and/or occasionally contrary.
2 - Moderate resistance and/or frequently contrary.
3 - Severe resistance and/or continually contrary.

12. Waxy flexibility: During repositioning of patient, patient offers initial resistance before allowing him/herself to be repositioned, similar to that of a bending candle. (also defined as slow resistance to movement as the patient allows the examiner to place his/her extremities in unusual positions. The limb may remain in the position in which they are placed or not)
0 - Absent
3 - Present.

13. Withdrawal: Refusal to eat, drink and/or make eye contact.
0 = Absent.
1 = Minimal oral intake/interaction for less than 1 day.
2 = Minimal oral intake/interaction for more than 1 day.
3 = No oral intake/interaction for 1 day or more.

14. Excitement: Extreme hyperactivity, constant motor unrest which is apparently non-purposeful.
Not to be attributed to akathisia or goal-directed agitation.
1 - Excessive motion, intermittent.
2 - Constant motion, hyperkinetic without rest periods.
3 - Full-blown catatonic excitement, endless frenzied motor activity.

End of Screening Items----------

15. Impulsivity: Patient suddenly engages in inappropriate behavior (e.g. runs down hallway, starts screaming or takes off clothes) without provocation. Afterwards can give no, or only a facile explanation.
0 - Absent.
1 - Occasional.
2 - Frequent.
3 - Constant or not redirectable.

16. Automatic obedience: Exaggerated cooperation with examiner's request or spontaneous continuation of movement requested.
0 = Absent.
1 = Occasional
2 = Frequent
3 = Constant.

17. Passive Obedience (mitgehen): Patient raises arm in response to light pressure of finger, despite instructions to the contrary.
0 = Absent.
3 = Present.

18. Muscle Resistance (gegenhalten): Involuntary resistance to passive movement of a limb to a new position. Resistance increases with the speed of the movement.
0 - Absent
3 - Present.

19. Motorically Stuck (ambitendency): Patient appears stuck in indecisive, hesitant motor movements.
0 - Absent.
3 = Present.

20. Grasp reflex: Striking the patient’s open palm with two extended fingers of the examiner’s hand results in automatic closure of patients hand.
0 = Absent
3 = Present

21. Perseveration: Repeatedly returns to same topic or persists with the same movements.
0 = Absent.
3 = Present.

22. Combativeness: Belligerence or aggression, Usually in an undirected manner, without explanation.
0 = Absent
1 = Occasionally strikes out, low potential for injury.
2 = Frequently strikes out, moderate potential for injury.
3 = Serious danger to others.

23. Autonomic abnormality: Abnormality of body temperature (fever), blood pressure, pulse, respiratory rate, inappropriate sweating, flushing.
0 = Absent
1 = Abnormality of one parameter (exclude pre-existing hypertension).
2 = Abnormality of two parameters.
3 = Abnormality of three or more parameters.