The Struggle is Real! How to Interface with Healthcare Professionals from an AuDHD Psychiatrist who is a Patient Herself.

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Insight Tip:

When a doctor dismisses or invalidates you, usually this is not because you came off weird or did something wrong. It is about the doctor, not you. Most doctors are traumatized in some form by their medical training and feel powerless, inadequate, and scared when they can't make sense of or fix their patient's suffering. Doctors may then defensively disavow the reality of that which they do not understand. This is not ok and this is not your fault as a patient. However, it is not because your doctor doesn't care about you usually, but instead because they can't tolerate not being able to fix your suffering.

- 1. Ideal doctor/patient relationship is like two explorers together (one explorer is more familiar with the terrain and one explorer has superior technology)
  - a. Patient is expert in:
    - i. Their subjective experience.
    - ii. Their symptoms.
    - iii. Decision to take medication.
    - iv. Their values.
    - v. Their side effects.
    - vi. The positive effects of medication.
    - vii. Their story/history.
    - viii. Their goals.
  - b. Doctor is expert in:
    - i. Medication selection.
    - ii. Medication dosage.
    - iii. Diagnosis.
    - iv. Treatment plan.
    - v. Frequency of visits.
    - vi. Method of communication outside of appointments.
- 2. Preparing for an appointment:
  - a. Imagine the best possible outcome you get from treatment, 6 mo down the road you are doing much better, what does that look like?
  - b. Report specific examples and behavioral data and avoid jargon/medical terms.
    - i. Instead of "I felt manic"
      - 1. "I was so angry, I felt out of control. I threw my clothes all over the floor and screamed."
      - "I had this sped up feeling, my thoughts were racing, I was so full of energy, I just felt invincible, like who needs to sleep. I was up for 3 nights in a row."

- c. When requesting medication, it is often more effective to report specific symptoms you need help with instead of requesting a specific medication.....
  - i. Instead of "I need a mood stabilizer, Abilify worked well for my friend, my therapist said I should ask you about Lexapro"-
    - 1. I really need more help with my anxiety. I wake up with a feeling of dread and nervousness. I just feel tense all the time.
    - 2. Sometimes I feel fine and other times, I am stuck in this pit of deep despair.
- d. Bring a list of past medications,
  - i. maximum dosages you tried
  - ii. how long you were on them
  - iii. benefits
  - iv. side effects
- e. request a release of info to sign for your therapist and previous psychiatric professional
- f. Take notes! Don't expect to keep everything in your memory.
- g. Bring a friend to help you if it is emotionally charged for note-taking and processing.
- 3. Communication and Information Processing Challenges!
  - a. Make a written list of the symptoms that are most important for you to communicate.
  - b. On this website you can download symptom report sheets or make a healthcare passport expressing your needs to bring to doctor's appointments.
    - i. <u>https://autismandhealth.org/?a=pt&p=main&t=pt\_frm&theme=ltlc&size=sm</u> <u>all</u>
  - c. Most doctors are not going to be comfortable with you audio-recording an appointment because they will be concerned about getting sued. That is sad.
  - d. Many doctors will welcome you having a supportive friend on speaker phone or with you in person to help process information.
  - e. Ask for written instructions to bring with you from the appointment.
  - f. Ask if your doctor will give you a list of questions you can fill out ahead of time before your next appointment instead of having to answer their questions on the spot.
  - g. Ask your doctor what the best way to reach them is if you remember something that you forgot to ask or tell them about during your appointment.
  - h. Ask to schedule more frequent appointments with your doctor to alleviate the pressure to cover everything in one appointment, especially if you have difficulty reaching your doctor outside of appointments.
- 4. Questions to ask your doctor

pro tip –if your doctor is defensive, you can preface your questions with reassurance that you think your doctor is a good doctor to avoid inciting a defensive response from them

- a. "You are the expert, thank you for taking all this time with me"....
  - i. What do you think my diagnosis is? Did you consider any other diagnoses?
- b. "You're so knowledgeable and I feel really good that you're my doctor. I want to understand as much as possible and do my part..."

- i. Why are you picking this particular medication for me? Did you consider other medications?
- c. "I trust you the most and really want your opinion on...."
  - i. Show them the NY time article that has you afraid to take medication, etc
  - ii. What is your opinion on this ..... treatment/medication?
- 5. Questions that will impress your doctor
  - a. What can I do to make my medication work better?
  - b. Any books I can read or websites or podcasts I can use to inform myself about my diagnosis?
  - c. What is the best way to reach you if I have an issue?
  - d. What tools can I use besides medication?
- 6. How do you know you have a good psychiatrist?
  - a. Feeling understood like "my doctor gets me"
  - b. Feeling challenged to grow, "They push me, "I leave thinking a little differently"
  - c. Never hurts to get a second opinion. A confident doctor will be OK with you getting a second opinion from another doctor and will not be offended by this.
- 7. Medical Invalidation
  - a. Sadly, you are not alone in experiencing invalidation or dismissal from medical professionals. In an ideal world, you should change to a medical professional who can be curious about unexplained/uncommon symptoms and diagnoses without getting defensive or dismissive. Sometimes due to limitations such as insurance, limited number of specialists, etc this is not possible however.
  - b. Remember, just because your medical professional doesn't understand or have an explanation for your symptoms, does NOT mean that your symptoms do not exist or are not real!
- 8. Why do so many psychiatrists not take insurance?
  - a. Insurance is financially rewarding to the doctor only if visits are very short so many psychiatrists don't take insurance so they can spend more time with people and do actual psychiatry instead of a conveyer belt but then less people can afford them if they don't take insurance, so it is a really tough decision
  - b. If your doctor takes insurance, plan on shorter visits and try to schedule multiple visits ahead of time to allow you to cover more information
- 9. What are the most common reasons that psychiatrists might discharge you from their practice?
  - a. Not allowing communication with your therapist or other treatment professionals
  - b. Getting medications from two different doctors without telling them about each other, especially controlled substances
  - c. not showing up to appointments
- 10. Doctors are human and struggle with their own mental health needs more than you realize. Being a psychiatrist does not offer me immunity against psychiatric issues myself.
  - a. The doctor in front of you is also a patient themselves. Maybe they too have struggled with substance abuse or sexual dysfunction or any number of things that feel embarrassing to talk about.
  - b. If a doctor is getting defensive or judgmental, that is their problem, not yours.

- 11. Handling a difficult situation with a doctor
  - a. "you can be right or you can be happy/healthy," try to leave your pride outside
  - b. Focus on getting your needs met instead of proving a point
  - c. Don't engage in a power struggle
  - d. Plan to vent to an empathic nonjudgmental friend after a challenging appointment
  - e. Always be extra nice to office staff and pharmacists because you rely on them for your care.
- 12. Stimulants can never be refilled. It is a "prescription on file" not a refill. Call your doctor if you are out of medicine. Your doctor has a vested interest in you staying on the medication so PLEASE call your doctor if you are out of medication.
- 13. When in doubt just call your doctor. Ask your doctor if they are glad you called or if you should have waited till the next appointment if you are unsure.
- 14. Doctors are very vulnerable to their front desk staff and don't intend for mistakes to happen. Usually your doctor has nothing to do with what is happening at the front desk and isn't even aware of it.
- 15. Doctors are usually scheduled back to back and sometimes over booked and we wish we had time to get on the phone and answer phone calls but usually it is just physically impossible and that is sad.
  - a. For myself personally, I listen to voicemail while driving and while peeing to try to keep on top of it. Just know that most of us are doing the best we can in a crummy situation.