

10 Things Everyone Should Know About Fragile X Syndrome

Strengths, Challenges, and How to Make the Most of Any Experience

One of the most important things for anyone to know who interacts with individuals living with FXS is ...

People living with Fragile X syndrome are prone to hyperarousal and anxiety. It's how their nervous systems are wired.

The most effective way to support someone living with FXS in any setting is to maximize their focus, cooperation, and enjoyment of your interaction. Applying the strategies shared below can minimize the likelihood of behaviors that are products of the biologic impact of FXS, including hyperarousal and anxiety.

1. Find common interests.

Identifying common interests can be helpful in making meaningful connections with anyone we interact with. Sharing an interest of yours first (favorite sports, fictional character, food, movie, television show, etc.) is a great way to initiate, connect and learn about their interest. "I like eating tacos! I see that you are wearing a shirt that has tacos on it."

2. Begin with the end in mind.

People living with FXS are motivated by the result, which means going through the steps from the beginning without a clear understanding of the end can be taxing. Use backward (sharing the expected end result and demonstrating the steps in reverse order) rather than forward chaining, e.g., checklists to show progress toward the desired result.

3. Prepare for transitions.

- Give 10- and 5-minute prompts. Some individuals may prefer visual timers/prompts, while others may prefer verbal, and some may prefer a combination of verbal and visual prompts.
- Use social stories about transitions.
- Provide a purposeful errand so the focus is on the outcome (e.g., getting the cart at the grocery store) rather than moving from one place to another.
- Some individuals may prefer to be the first or last person to complete a transition (entering the store, restaurant, work, home, etc.).

4. Take breaks.

Any activity, even ones that are preferred by the person living with FXS, can demand a lot of energy. Pace yourselves through the activity

and take breaks as needed. Keep the steps brief with short breaks between tasks to help keep up a good pace.

5. Don't force eye contact.

Don't worry if there is not a lot of eye contact in your interactions. Eye contact will come naturally as the person living with FXS becomes more comfortable with you! Just because someone is not making eye contact does not mean they aren't listening to you.

6. Be flexible.

Engagement is likely to vary. To avoid frustration, it's best to try and understand that there may be inconsistencies in behaviors or interactions. Allow for time between activities, take breaks from conversations, and keep up a positive attitude! People living with FXS are perceptive and may pick up on any frustrated energy, which can add to their anxiety.

7. Verbal expression can be taxing.

Provide some non-verbal alternatives to a conversation, like participating in an activity together, watching a show, or going for a walk. Consider the person's interests and find an activity that is fun for both of you!

8. Think and be "indirect."

There are times when people living with Fragile X syndrome enjoy attention, but most often they prefer to avoid being the sole focus.

- Praise the positive! Give compliments in the third person, "Joe did a great job on his morning work!"
- Have a "side dialogue" conversation to identify a situation and define options for behavior in that activity. Essentially, talking out loud about ideas and strategies to support the individual living with FXS. For example, the support individual could say:
 - Sometimes my work is hard, and I get frustrated.
 - When I get frustrated, I get mad and sometimes say words I shouldn't.
 - Maybe when I get frustrated, I could say "This is hard, I need help" or "I'm mad, this is hard."
 - That is a good idea. I will try to say, "This is hard, I need help" or "I'm mad, this is hard."
- Avoid direct, open-ended questioning. Use prompts like "It's time to get ready to go to the park! The first thing we do to get ready for the park is _____" rather than "What do you need to do to leave for the park?"
- Visual supports, schedules, lists, and timers can be especially helpful when prompting through an activity!

9. Embed sensory integration strategies into your plans.

Hyperarousal and anxiety can be ever-present for people living with FXS, even when they may not be showing outward signs. It's important to think about sensory integration (involves detecting sensory stimuli in the environment, processing this information, and integrating it into meaningful information, action and adaptation (Baranak et al. 2008)) strategies and how they can be safely integrated into activities to support success. Examples:

- Heavy work, like moving sports equipment, lifting something heavy, moving furniture around, or carrying a heavy backpack.
- Vestibular input, like going for a walk, doing wall push-ups, swinging, or using a skateboard.

10. Notice (and resolve) environmental triggers.

People living with FXS often have sensory sensitivities to sound, light, textures, taste, and smell that provoke hyperarousal. Adjust as needed, such as dimming lights or allowing the use of noisereducing headphones as much as possible.

Bonus Tip: Most importantly, recognize the individual living with Fragile X syndrome's strengths.

Common strengths associated with Fragile X syndrome are good visual memory, a sense of humor, the desire to be helpful, an empathic nature, and a gift for mimicry. Take advantage of the person's strengths when considering an activity. Examples:

- Are you going to an event? Stand at the entrance and greet people as they enter, but take breaks as needed.
- Does the person love sports? Go to a local sports game outdoors where you can cheer the team on and walk around as needed. Don't forget to bring noise-reducing headphones!

But mostly, ENJOY YOUR TIME TOGETHER!

National Fragile X Foundation

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