

“ABOUT ME” TEMPLATE FOR SUCCESS

FOR WORK OR SCHOOL ENVIRONMENTS

Here is a template to help you talk to teachers, educators, aides, and supervisors about Fragile X syndrome.

Let's set your loved one up for success!

Tips:

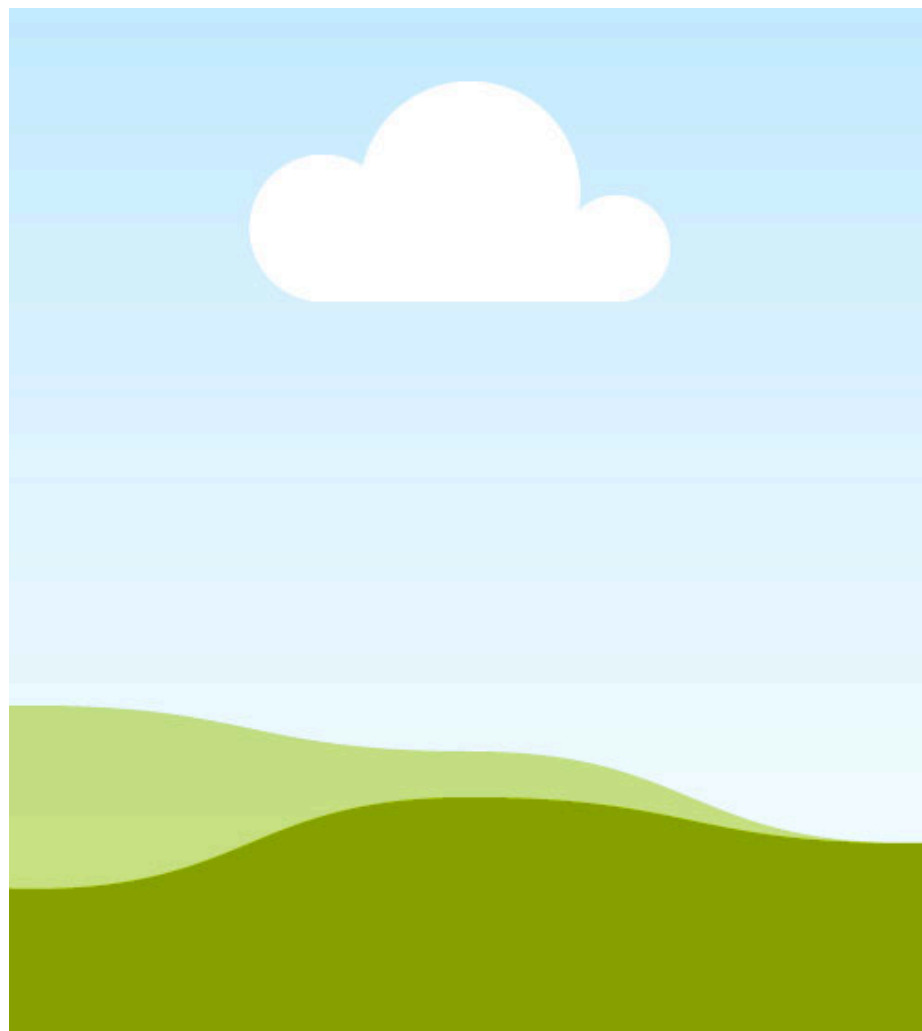
- Use lots of pictures to personalize the template
- Include helpful tips that are specific to your loved one; share things that motivate them, things they prefer, and things that may trigger negative behaviors
- Use only the pages that apply. For example, you may choose not to include the page with information about autism, that's OK! You may want to pick either the 10 Things for Teachers or the 10 Things Everyone Should Know article, not include both.
- Share additional NFXF resources! QR codes to corresponding resources are included within the template pages.



Meet



Our
who lives with
Fragile X Syndrome



About

is ____ years old and lives with

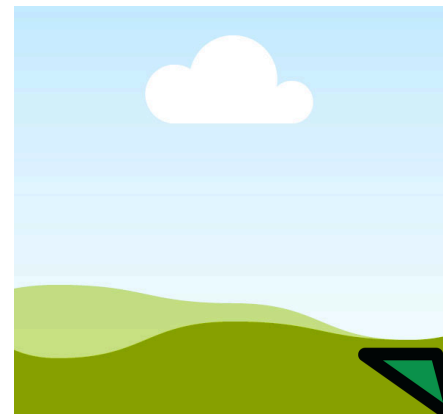
They are ...

-
-

They like ...

-
-

also has Fragile X syndrome (FXS).



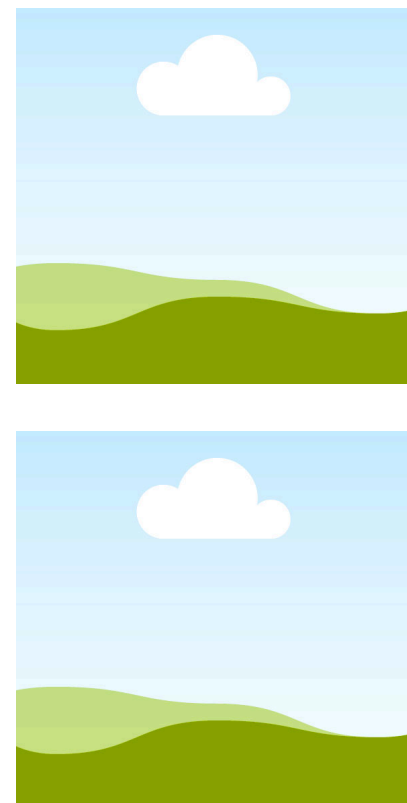
What is Fragile X syndrome?

FXS is a rare genetic condition caused by a mutation of a single gene — FMR1 — on the X chromosome.

Everyone has the FMR1 gene on their X chromosome, but when a mutation occurs, it can cause intellectual disability, behavioral and learning challenges, and various physical characteristics.

There are no specific treatments or a cure, but therapies, interventions, and medications are often prescribed to treat behavioral symptoms like anxiety, challenging behavior, and ADHD.

People with FXS may have challenges, but they also commonly have a great sense of humor, are loyal friends and have a fantastic memory.



*Learn more about Fragile
X syndrome here:*



FXS and Autism

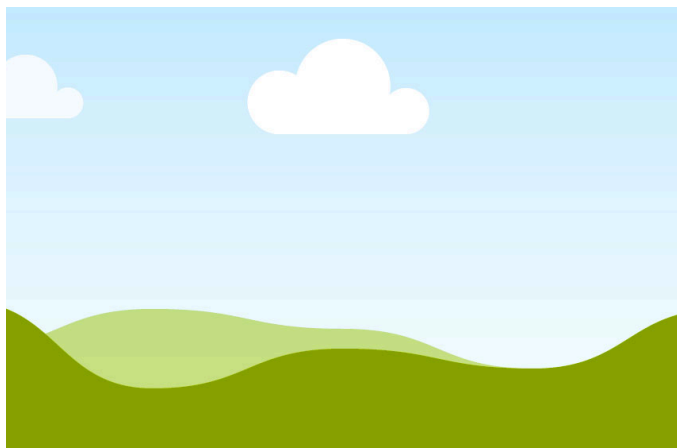
FXS is the most common single gene condition associated with autism/autism spectrum disorder (ASD).

Not everyone with FXS has ASD; some do, some do not, and others may exhibit features of ASD but do not qualify for a diagnosis.

Individuals with ASD may commonly have social communication and social interaction challenges and restricted, repetitive behaviors. These can also be seen in people with FXS.

Just because someone with FXS has ASD-like characteristics, it does not mean they have ASD or common interventions used for individuals with ASD will be successful.

does/does not have a co-occurring diagnosis of ASD.



How will FXS affect at school?

Cognition

-
-
-

Behaviors

-
-
-

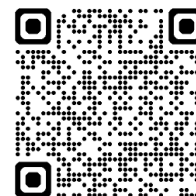
Receiving Instructions/Feedback

-
-
-

Social situations

-
-
-

*Learn more on the NFXF's
School & Education page:*



10 Things Teachers Should Know About Fragile X Syndrome: Strengths, Challenges, and How They Learn

One of our most popular resources!

1. Don't force eye contact.

Eye contact will come naturally as the student becomes more comfortable with you.

2. Expect inconsistency.

Engagement and performance are likely to vary. To avoid frustration, it's best to try and accept that there will be inconsistency. Otherwise, your student will pick up on frustrated energy, which can add to their anxiety.

3. Students with Fragile X syndrome are simultaneous — not sequential — learners.

They are good sight word learners, but have a terrible time with phonetics. They're motivated by the end result, but impatient with the process. Use backward rather than forward chaining, e.g., checklists to show progress toward an end result.

4. Allow and encourage frequent breaks.

Accommodate attention deficits by keeping tasks brief. Keep up a good pace — power breaks are short breaks.

5. Verbal expression is cognitively taxing.

Provide some non-verbal alternatives for students to show what they know, such as following directions and pointing to visual representations.



10 Things Teachers Should Know About Fragile X Syndrome: Strengths, Challenges, and How They Learn -- (cont.)

6. Think and be “indirect.”

There are times when students with Fragile X syndrome enjoy attention, but most often they prefer to avoid the limelight.

- Give compliments in the third person about the student to others within earshot.
- Use incidental learning.
- Include the student in a small group while directing instruction to a peer.
- Avoid direct, open-ended questioning. Use prompts like “The President of the United States is _____” rather than “Who is the President of the United States?”

7. Prepare for transitions.

- Give 10- and 5-minute prompts.
- Allow them to be at the head or back of a line.
- Use social stories about routine transitions.
- Provide a purposeful errand so the focus is on the outcome (e.g., delivering an envelope) rather than moving from one place to another.

8. Embed sensory integration strategies into their day.

Because hyperarousal and anxiety undermine their ability to focus, work with an occupational therapist knowledgeable in sensory integration to learn which supplemental instruction techniques are the most calming for your student. Then integrate associated activities into their day to sustain a calm, regulated nervous system.



10 Things Teachers Should Know About Fragile X Syndrome: Strengths, Challenges, and How They Learn -- (cont.)

Examples:

- Heavy work, like rearranging desks, cleaning windows, or moving stacks of books.
- Vestibular input, like going for a walk, doing wall push-ups, swinging, or using a skateboard.

9. Notice (and resolve) environmental triggers.

Students with Fragile X syndrome often have sensory sensitivities to sound, light, textures, taste, and smell that provoke hyperarousal. Make adjustments as needed, such as dimming lights or allowing use of muting headphones as much as possible.

10. Recognize 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 their strengths by using visual cues, make learning fun, provide opportunities for them to be of assistance, encourage them to provide emotional support to their peers, and use modeling as a primary teaching technique, e.g., embedding academics into useful and practical tasks such as taking attendance (counting) or ordering from a menu (reading).

But mostly, ENJOY YOUR STUDENT WITH FRAGILE X SYNDROME!

Link to web version:



10 Things Everyone Should Know About Fragile X Syndrome: Strengths, Challenges, and How They Learn

Adapted from one of the NFXF's most popular resources, this version is more widely applicable across settings and experiences. Consider these your top 10 strategies for success

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.).



10 Things Everyone Should Know About Fragile X Syndrome: Strengths, Challenges, and How They Learn

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!



10 Things Everyone Should Know About Fragile X Syndrome: Strengths, Challenges, and How They Learn

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:
 - Support individual – Sometimes my work is hard, and I get frustrated.
 - Support individual – When I get frustrated, I get mad and sometimes say words I shouldn’t.
 - Support individual – Maybe when I get frustrated, I could say “This is hard, I need help” or “I’m mad, this is hard.”
 - Support individual – 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



10 Things Everyone Should Know About Fragile X Syndrome: Strengths, Challenges, and How They Learn

(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 noise-reducing 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!

Link to web version:

