

Preparing for Your Fragile X Specialist Healthcare Visit

Every individual is unique, and the priority should be partnering with a healthcare team to address symptoms and develop a personalized treatment plan based on individual needs. The presence of an expansion of the FMR1 gene may identify an increased risk for certain conditions. However, treatment decisions should be based on an individual's symptoms, health history, clinical findings, and individual needs.

Knowing that you have an FMR1 premutation can provide important information about potential health risks and may help you and your healthcare provider determine what concerns may need further evaluation.

Sharing your symptoms, health history, and Fragile X status with your healthcare provider can help support a focused conversation about your health and the concerns you are currently experiencing.

You do not need to complete every section of this worksheet. Focus on the concerns that are most important to you and that you want to discuss during your visit. *This checklist is a tool for discussion with a healthcare professional and is not a substitute for medical evaluation.*

My Fragile X Specialist Visit Worksheet

Why am I seeing my provider today?	Answer:
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What are the most important things I want to discuss?	
1	
2	
3	
4	
5	

What changed or prompted me to seek care?	Answer:
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What would I like help with today?	
	Understanding what may be causing my symptoms
	Evaluating a new or changing symptom
	Discussing treatment or management options
	Discussing whether additional testing or evaluation is needed
	Discussing whether I should see a specialist
	Other:

My Fragile X Information

I have been diagnosed with an FMR1 premutation	☐ Yes ☐ No ☐ Unsure
FMR1 CGG repeat number, if known:	Answer:
What else should my provider know about my Fragile X or family history?	Answer:

My Symptoms and Health Concerns

Check the symptoms or concerns you are currently experiencing, have experienced recently, or would like to discuss with your healthcare provider. You do not need to check everything. Focus on the symptoms or concerns that are most important to you.

Thinking, Memory, Movement & Neurological		
	Memory changes	
	Difficulty concentrating	

Thinking, Memory, Movement & Neurological		
	Difficulty planning, organizing, or completing tasks	
	Tremor or shaking	
	Balance or coordination problems	
	Changes in walking or increased stumbling	
	Falls	
	Numbness or tingling	
	Weakness	
	Changes in speech	
	Dizziness or vertigo	
	Headaches	
	Seizures	
	Other _____	

Mental Health, Sleep & Energy		
	Anxiety	
	Excessive worry	
	Panic attacks	
	Depression or low mood	
	Irritability	
	Mood changes	
	Difficulty sleeping	
	Fatigue or low energy	
	Other _____	

Reproductive & Hormonal Health		
	Changes in menstrual cycle	
	Periods becoming irregular or stopping	
	Hot flashes or night sweats	
	Fertility concerns	
	Pelvic pain	
	Other reproductive or sexual health concerns	
	Other _____	

Pain, Muscles, Joints & Physical Function		
	Joint pain	
	Joint swelling	
	Muscle pain	
	Muscle cramps	
	Back pain	
	Neck pain	
	Stiffness	
	Limited movement	
	Changes in physical function	
	Other _____	

My Top Concerns

You may have checked several symptoms above. Now narrow your list to the three concerns that are most important for you to discuss with your provider at this visit. You may only have one or two concerns.

Think about:

- Which concern is affecting me the most?
- Which concern has changed recently?
- Which concern do I most want help understanding?
- Which concern do I want my provider to evaluate or address?

Concern #1:	
When did I first notice this?	Answer:
How often does it happen?	☐ Occasionally ☐ Weekly ☐ Daily ☐ Other:
Has it changed over time?	☐ Improving ☐ Worsening ☐ About the same ☐ Unsure
What does this concern look or feel like for me?	Answer:
How does it affect my daily life or activities?	Answer:

Concern #2:	
When did I first notice this?	Answer:
How often does it happen?	☐ Occasionally ☐ Weekly ☐ Daily ☐ Other:
Has it changed over time?	☐ Improving ☐ Worsening ☐ About the same ☐ Unsure
What does this concern look or feel like for me?	Answer:
How does it affect my daily life or activities?	Answer:

Concern #3:	
When did I first notice this?	Answer:
How often does it happen?	☐ Occasionally ☐ Weekly ☐ Daily ☐ Other:
Has it changed over time?	☐ Improving ☐ Worsening ☐ About the same ☐ Unsure
What does this concern look or feel like for me?	Answer:
How does it affect my daily life or activities?	Answer:

My Current Health Information

Current medications, over-the-counter products, and supplements. Include everything you currently take or use, even if it does not require a prescription.

This may include vitamins, minerals, herbal products, natural or "wellness" products, CBD products, or other products you take or use for your health.

Medication or product	How much / how often?	Why do I take or use it?

Tip: If you are unsure whether something is a medication or supplement, include it anyway and bring the product or a photo of the label to your appointment

Medication, environmental, or other allergies	Answer:
Other diagnosed health conditions	Answer:
Other diagnosed health conditions	Answer:

Questions for My Provider

The most important question I want answered today:	Answer:
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Other questions I want to ask:	
1	
2	
3	
4	
5	

Is there anything I want to make sure I discuss before my visit ends?	Answer:
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Before I Leave My Appointment

Additional or recommended testing or evaluation:	Answer:
Treatment or management recommendations:	Answer:
Referrals or specialist evaluation	Answer:

Follow-up recommendations:	Answer:
Other next steps:	Answer: