



***"IT'S ESPECIALLY GOOD JUST TO KNOW THAT  
YOU'RE NOT THE ONLY ONE"***

EXPLORING EXPERIENCES WITH ONLINE PEER  
SUPPORT PROGRAMS FOR THE FRAGILE X  
COMMUNITY

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# WHY DID WE DO THIS STUDY?

Fragile X syndrome is a genetic disorder caused by a change to a gene on the X chromosome. The syndrome is the most common inherited cause of intellectual disability and causes a wide range of physical, developmental, behavioural, and emotional difficulties in those who are affected. Carriers for Fragile X (known as 'Fragile X premutation carriers') can also be affected by Fragile-X associated conditions, which may include a range of physical, psychosocial and emotional symptoms.

Information about Fragile X disorders can be complex, requiring an understanding of genetics and various associated health issues. As such, education for people and families affected by Fragile X disorders is important and can help increase knowledge in managing the disorders, improve quality of life, and ensure the needs of all family members are met. Access to peer support networks and contact with other families affected by Fragile X disorders is also important. Families of those with Fragile X disorders can face a lifetime of caretaking challenges, and peer support can help facilitate the sharing of resources and ideas, and provide emotional support.

Although education and peer support are important for the Fragile X community, many people do not have easy access to such networks. Since COVID-19, the Fragile X Association of Australia has introduced a number of online peer support group programs for its members and the wider Australian Fragile X community to complement an existing online discussion group. To better understand the experiences of community members who participated in these programs, and whether they are of value or not, we undertook a qualitative research project.

**The aim of this study was to explore experiences of people with Fragile X syndrome, Fragile X premutation carriers, and their families/carers with Fragile X-specific online peer support programs.**







## WHAT DID WE DO?

We interviewed 16 people from the Fragile X community. Most (75%) were parents/carers of a child or adult with a Fragile X disorder, the remaining 25% were adult carriers for Fragile X.

We asked people about their experiences with three online peer support programs offered by the Fragile X Association of Australia:

**Educational webinars:** The Association runs informative webinars approximately once per month for their members and the public to learn more about Fragile X disorders or other relevant topics. Webinars are presented by invited speakers (eg experts in the field) and are facilitated by Association staff. Webinars are designed to be interactive and facilitate discussion among attendees.

**Facebook discussion group:** The Association runs a private Facebook peer discussion group for those affected by Fragile X disorders and their family members. The group has ~1,000 members (75% Australians) and is moderated daily by staff from, and volunteers of, the Association. It predominantly involves peer-to-peer sharing of information and resources relating to Fragile X disorders or issues relevant to the Fragile X community (e.g. discussions around social or health supports, service referrals, NDIS etc.).

**Zoom group peer support sessions:** Sessions are facilitated and curated by a staff member of the Association who is a qualified counsellor, and involve a small number of attendees with a shared experience or interest who meet regularly (frequency as needed) to share information and experiences, and provide emotional support to one another.





# WHAT DID WE FIND?

## OVERALL THEMES

### ***Uncertainty and value of shared experiences***

The opportunity to participate in online support programs was highly valued. The support and information that participants received helped address feelings of uncertainty about the future - for themselves and/or for their child/relative with a Fragile X disorder. In addition, the ability to share experiences with others in similar situations was invaluable.

***"For doctors, it's easy to say, "This is how it is," but then when you live it it's different...I didn't know anything, and it was just amazing to be able to feel connected, and I got a lot of valuable information and resources."*** 21-30 year old carrier for Fragile X

### ***Support to navigate healthcare***

Participants found it difficult to access care. Participating in online support programs enhanced their confidence and knowledge, particularly regarding how to navigate healthcare services. Participants used this knowledge to identify and connect with clinicians who have expertise in managing Fragile X disorders.

***"It gave me a framework to try and see what's happening, so it made me actually sit down and think about behaviours or communication strategies or what I might need to do differently"*** Parent/carer of 21-30 year old

### ***Advantages being online, but still a place for in-person events***

Overall, participants had very positive experiences with the online support programs, valuing their convenience and accessibility. Some felt that participating online was particularly beneficial when they felt anxious or reluctant to contribute (eg they could turn their camera off or leave the session if needed). However, collectively, there was still a desire for in-person programs as many felt it was difficult to create informal personal connections or interpret important non-verbal cues when online.

***"They can turn up, even if they're feeling anxious, with that in the back of their mind if they're not quite sure if they can cope - you can always put your camera off if you want to be quiet for a while and just listen."*** 41-50 year old carrier for Fragile X

***"There's something really valuable about being with people in person, that it's kind irreplaceable. So I'd like that, and so it'd be really nice actually if you could just have more of them as well, be able to have greater local people."*** Parent/carer of 0-10 year old



# WHAT DID WE FIND?

## EXPERIENCES WITH EDUCATIONAL WEBINARS

### ***Valuable source of information about, and strategies to support, living with Fragile X***

Participants believed the webinars were a highly valuable source of information, providing advice about a range of support strategies. Many believed that most healthcare clinicians, and the general public, typically knew very little about the Fragile X disorders. As such, the webinars were an important method of educating clinicians, support workers, and extended family members. Participants also appreciated the fact that the webinars were recorded and could be replayed at any time.

***"They've been fantastic. The topics have been, like, really bang on. The experts that they've brought in have been really, really good. And so informative. So yeah, fantastic experience"*** Parent/carer of 11-20 year old

### ***Variable content***

Some found that the content of some webinars did not always meet their needs or was unrelated to them or their situation. Some also found that the content was, at times, difficult to understand or follow (eg too much information, information that is too dense/complex).

***"Webinars are difficult for me to focus and concentrate and maintain focus. I find it really hard to ask questions, or to approach things."*** 41-50 year old carrier for Fragile X

***"Because there has been such a lack of focus and interest in the girls, that that's really hard, and being a mum of a Fragile X child is really hard because I don't feel I have a lot of support or help around that. I did do the webinar recently that was on girls, but even then, it was still quite limited as to what they'd done and where things are up to"*** 41-50 year old carrier for Fragile X





# WHAT DID WE FIND?

## EXPERIENCES WITH FACEBOOK DISCUSSION GROUP

### **Connecting with others**

The Facebook group was perceived to be a valuable way to connect with other families affected by Fragile X disorders and share lived experiences. Often, this included providing, or receiving, advice about navigating healthcare (eg recommendations for clinicians, information about available supports and services), understanding behaviours of those affected, and developing support networks with other families.

***"I think my experience, because my son's a bit older, some people have benefited from my experience - now people are asking really the same questions I did as my son was growing up... it's not only answers to your question, but it's also feeling like you're not alone, that other people have gone through it."*** Parent/carer of 21-30 year old

***"It's useful to see what other parents are doing when they're asking questions about certain things. But because my son's younger, he was quite young when he was diagnosed, so a lot of the content wasn't necessarily relevant for him in this point in time."*** Parent/carer of 0-10 year old

### **Different needs**

Although most believed the Facebook group provided support and valuable information, some had different experiences. For example, some participants did not use Facebook or were concerned about privacy and were therefore reluctant to share personal information online. Although the Facebook page was very well moderated, some believed that the page felt formal, making it difficult to develop relationships or ask personal questions.

***"Some groups have an "ask anonymously" type question sort of thing. So - because I do feel that privacy issue is a big one at the moment with Facebook and just sharing too much of my information, my daughter's information, my family situation"*** 41-50 year old carrier for Fragile X

***"I'm part of a [different] group - in those forums, people will actually get on there and ask really personal questions like, "I am having this problem. Has anyone else had this problem, what sort of things have you done?" And so it really gets into that community nitty gritty, and we don't really have that kind of forum in the Fragile X Association"*** 41-50 year old carrier for Fragile X



## WHAT DID WE FIND?

### EXPERIENCES WITH ZOOM GROUP PEER SUPPORT SESSIONS

#### ***Being supported by, and supporting, others***

Participants had very positive experiences with Zoom support groups, finding the facilitator was excellent at encouraging conversation and ensuring group members had the opportunity to speak. Groups were well-organised, with participants being matched well according to their individual needs or circumstances (eg carers of children of a similar age being matched). Participants found it helpful to share their own experiences while also learning from others in the group. Many valued meeting parents online who had children with Fragile X that were older than their own, which helped them learn support strategies for the future.

***"Just feeling like somebody actually understands and even just those "me too" moments where other parents would be like "oh my kid does this" or whatever and you are like "oh yes," all the time. Or just feeling like other parents understand and there is that solidarity and you're not as alone."*** Parent/carer of 0-10 year old

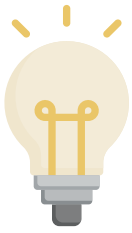
***"Initially I would just have thought it's about support network and that commonality of shared experiences, but I guess when I walked away from that was learning unexpected things. Because that shared experience is shared ideas, some of it you're like, "that's my shared experience," and actually having to see how that's working really well for us and I'm glad that we're doing that - that's a great way of doing it."*** Parent/carer of 11-20 year old

#### ***Consistency and organisation is important***

Although participants had positive experiences, there were suggestions for improvements in the future. Participants felt that sessions were infrequent and that maintaining a consistent schedule (eg monthly) would be preferable. In addition, some felt that a clearer process around the organisation of the sessions was important, including providing the Zoom invitation ahead of time, and providing clear information about how to join such groups.

***"It might be nice to have a once-a-month mums catch-up or something, rather than a one-off, because I think it's nice if things are organised - and we're reminded to catch up. And even if it's only two people that attend, it would still be nice, because it can be quite isolating"*** Parent/carer of 11-20 year old





## WHAT DID WE CONCLUDE?

The aim of this study was to explore experiences with online peer support programs for the Fragile X community in Australia. Overall, findings suggest that participants had positive experiences, and all were intending to continue using these services. However, there were also some opportunities for future improvements.

### **Online peer support programs are valuable**

Participants found all three peer support programs to be helpful in terms of providing information about Fragile X disorders, support services, and different management strategies. Being able to share lived experiences and connect with others in similar situations was perceived to be invaluable. A key advantage of these programs being online was the ease and convenience of attending. Collectively, findings highlight how beneficial such online programs are to populations like the Fragile X community. Further, harnessing online delivery modes has enabled small organisations like the Fragile X Association of Australia to deliver information and peer support nation-wide, and reach those who otherwise may not have access to such services.

### **Opportunities for future design and delivery**

Although participants had very positive experiences overall, they still acknowledged the value of having the opportunity to attend activities in-person. In addition, the usefulness or relevance of information delivered depended on individual circumstances/needs (eg the age of their child/family member with a Fragile X disorder, whether they were a parent/carer or were affected themselves). This highlights the challenges of designing content/activities that meet the diverse needs and personal preferences of the community. In general, participants also felt that better awareness of how to access or sign up to various activities, such as the Zoom support groups, would be beneficial.





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The Fragile X Association of Australia is a member-based organisation and registered charity (<https://www.fragilex.org.au/>).

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