

Easy
Read

The FragileX Society



I Have Fragile X Syndrome

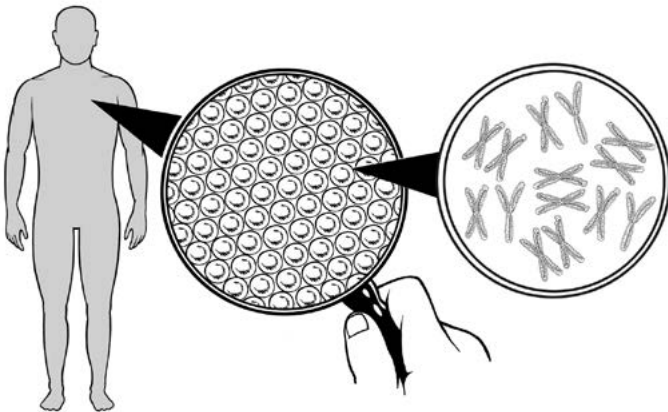
What is fragile X syndrome?



Fragile X syndrome is a genetic condition. This means people are born with it.



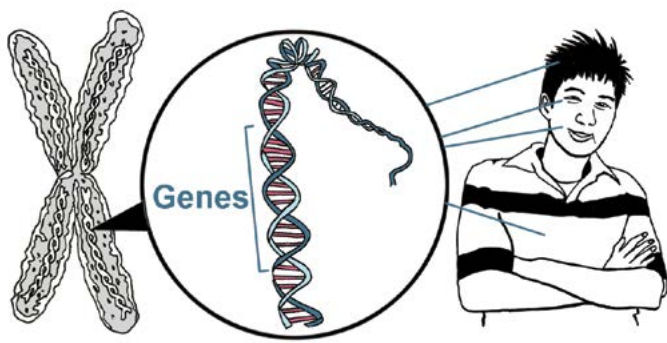
Fragile X syndrome is passed down through families.



Our bodies are made up of millions of cells. Each cell has pairs of chromosomes.



We all have a pair of sex chromosomes. A man has an X and a Y chromosome. A woman has 2 X chromosomes.



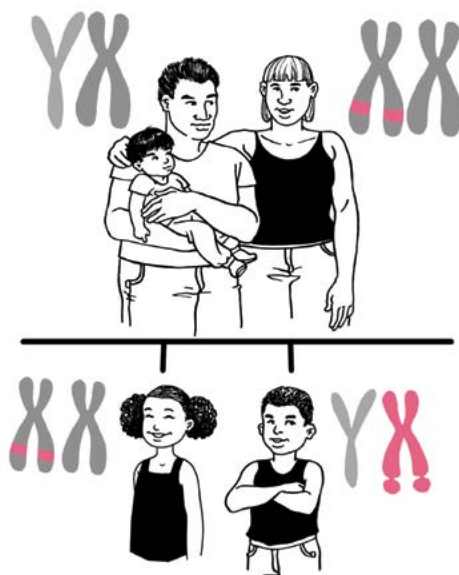
Genes are carried on the chromosomes. Genes are tiny pieces of information about how our body grows.



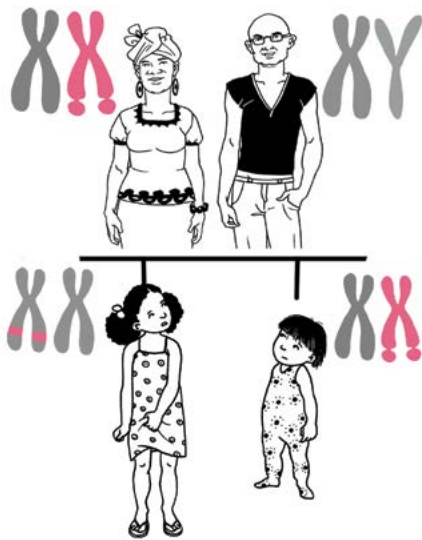
The fragile X gene is on the X chromosome. So men and women can have fragile X.



Everyone has a fragile X gene. Sometimes the gene can change. It is when the fragile X gene changes that a person can have fragile X syndrome.



If the change in a person's fragile X gene is small they are carriers. Men and women can be carriers of fragile X. This means they can pass the gene to their children.



A person who has fragile X syndrome has a larger change in their fragile X gene. People with fragile X syndrome can also pass the gene to their children.



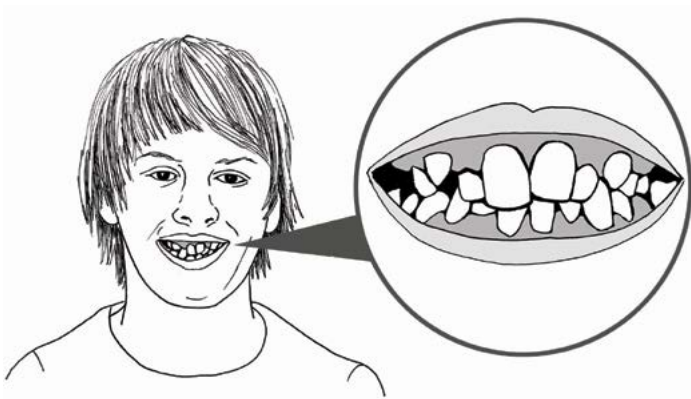
A blood test can tell if a person is a carrier of fragile X or has fragile X syndrome.

Do people with fragile X syndrome look different?



They might have:

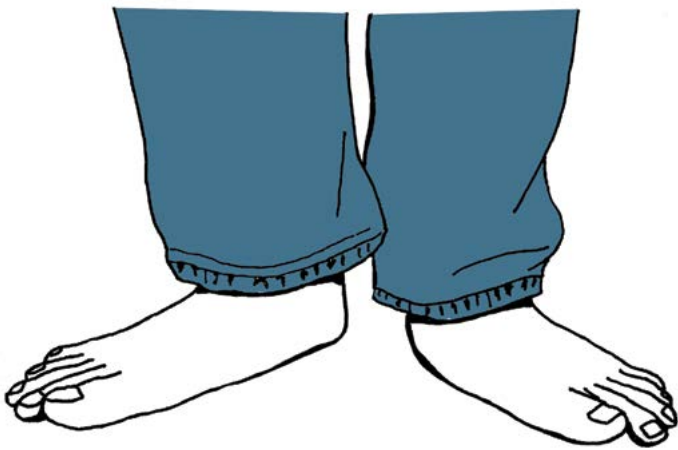
- Longer faces
- Bigger ears



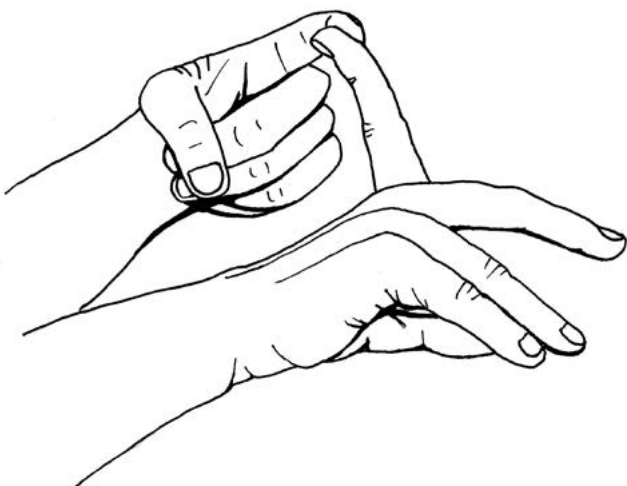
- Overcrowded teeth



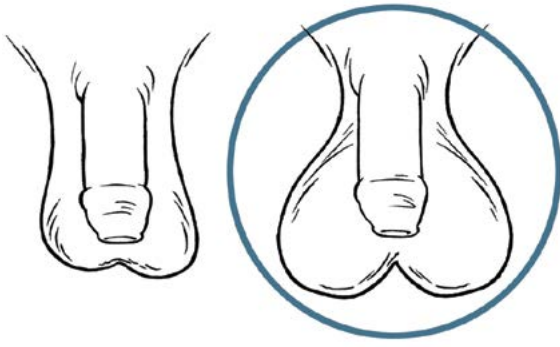
- Soft skin



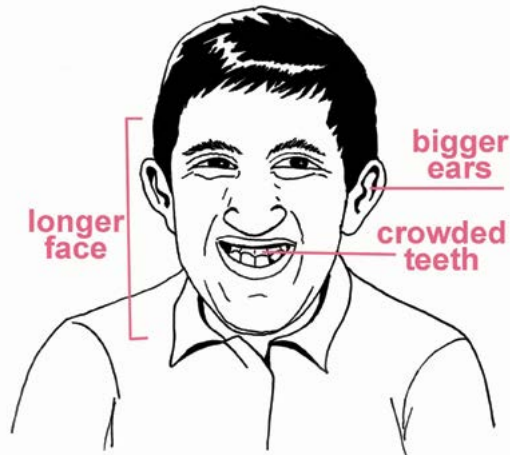
- Flat feet



- Some joints that go backwards and forwards and are more bendy. This is often the joints in the fingers. This is called double jointedness.



- Some men have larger testes or balls.



Some people with fragile X syndrome have a few of these features. People do not usually have all of them.



Many people with fragile X syndrome do not look any different than anyone else.

Do people with fragile X syndrome have health problems?



Some people have fits or seizures. Medication can help with this.



People should have regular checks at their doctors.



Regular eye checks are also important.



Mostly people are healthy but they may need help to eat a balanced diet.

How does fragile X syndrome affect me?



People who have fragile X syndrome are individuals with likes and dislikes just like anyone else. But they may share some things with each other. These are called characteristics.



This means fragile X syndrome can affect you in the following ways;

- How you talk and listen to people.
- How you learn.
- How you behave sometimes.
- How you react to noise, lights and what is happening around you.



- Feeling anxious.

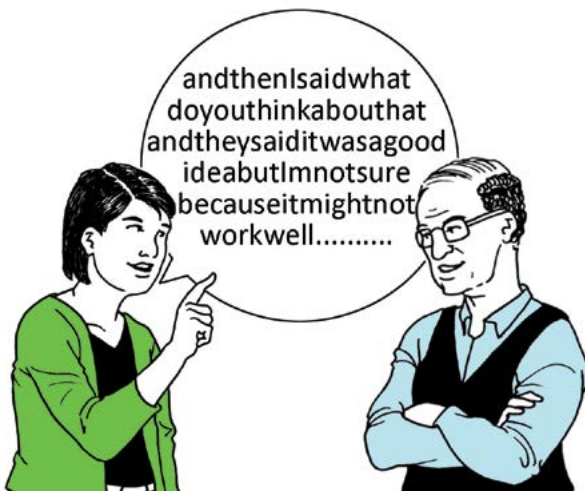
Let us look at each of these.

Talking and Listening

People with fragile X syndrome usually speak quickly.

You may also;

- Say the same thing over and over again.
- You may talk to yourself to help you understand what's been said.





- You may find it hard to say what you are feeling or make choices.



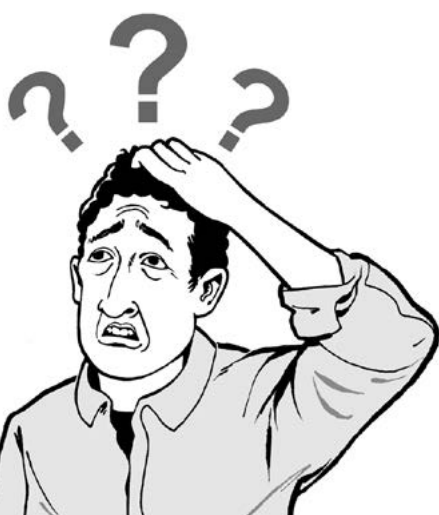
Some people with fragile X syndrome do not talk and have other ways of communicating like gestures, photo cards and signs.



Usually people with fragile X syndrome do understand what is being said to them. People who care and support you should know this.



Many people with fragile X syndrome are shy. Sometimes this is called social anxiety. They don't like being the centre of attention.



What can help?

Use photos, symbols or pictures to help you when you are feeling anxious.

Try to keep calm. This will help to slow your speech down.

A speech and language therapist may need to work with you. This can be helpful.

Learning

Most men with fragile X syndrome have learning disabilities. This means you may find some things harder to understand.



You may take longer to do things and need some support from family, friends or paid workers in your daily life.



You may also have problems staying on one task. You may get easily distracted or interested in something else.

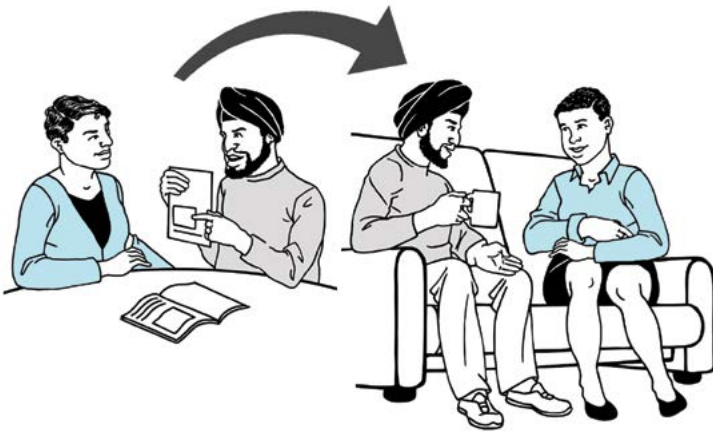


You may need more time to learn new tasks.



What can help?

It is better to learn things all in one go. This is because it is hard to learn one thing then another.



Taking lots of breaks and doing tasks over again can help.



Ask someone to make you a visual diary or timetable so you can follow what you need to do next. This is because people with fragile X are good visual learners. This means they learn better when they see things.



People usually like to copy other people too.



It can help if someone works with you for a while. These are good tips for the workplace.



Behaviour

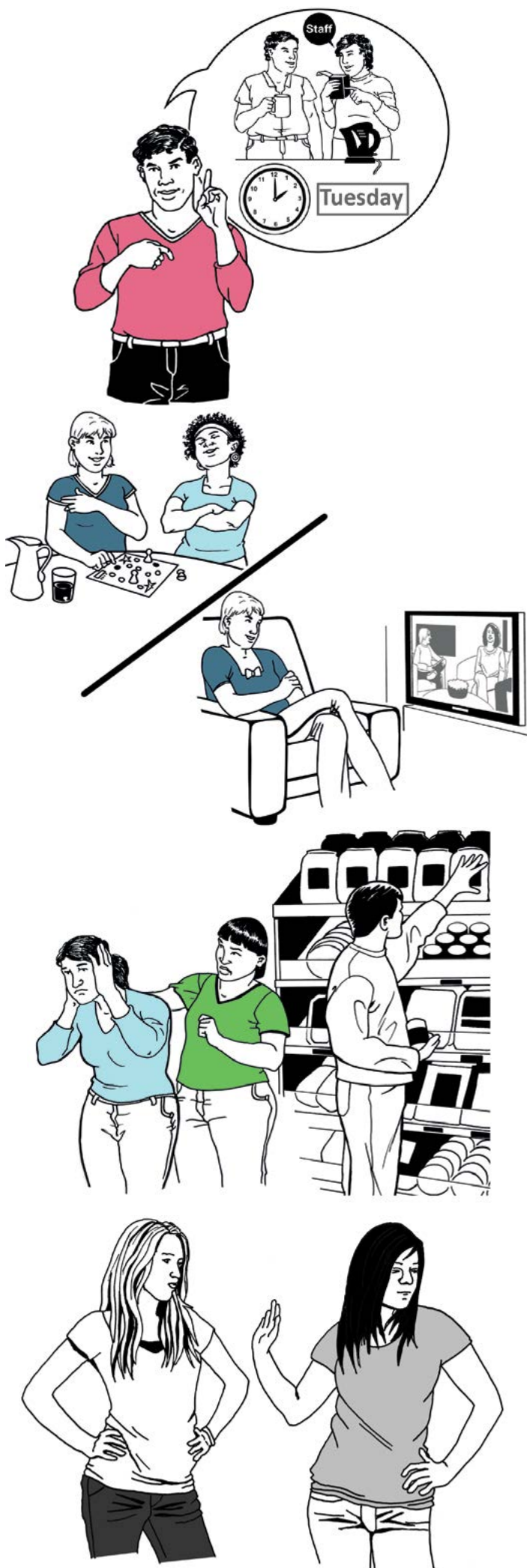
People with fragile X syndrome can do some things or act without thinking. They may hit out or shout if they are upset or not happy in a situation.

You may find it difficult to wait your turn and find it hard to sit and relax. You may like to be very active a lot of the time.

Changes in your day like different staff and routines can be very hard sometimes to cope with. This may make you upset and unsure. Trying new things might also worry you.

What can help?

Having changes explained to you using pictures or photos can help.



Making sure you know your routine can help as well. You like to know what you are doing and who with.

You like to have fun but you also like some calm around you.

Sensory problems

Most people with fragile X syndrome do not like noisy and loud places. So you might need some support in busy shopping centres or canteens.

You may not like people being too close to you.



You might like to know how to get out of a place quickly.



You might need lots of support until you get used to a place.



What can help?

Learning ways to calm yourself and relax can be helpful.



Only spend a short time in busy places because you can always come back.



Give yourself a task when you go shopping so you know what you are going to do.

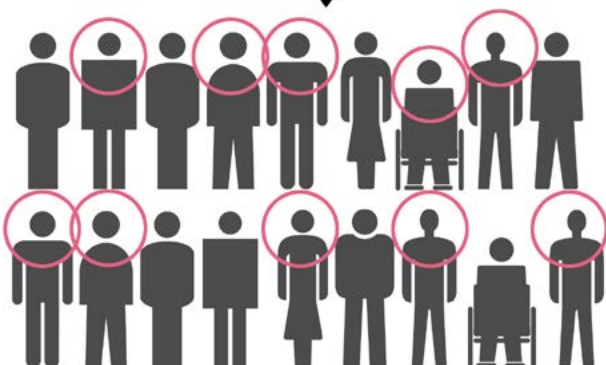


Have a way of telling the person you are with that you want to leave - a card or photo might help.



Anxiety

Many people with fragile X can feel very anxious. Signs of being anxious include changes in your body like sweating, heart beating fast and not sitting still.



This is very common in fragile X syndrome

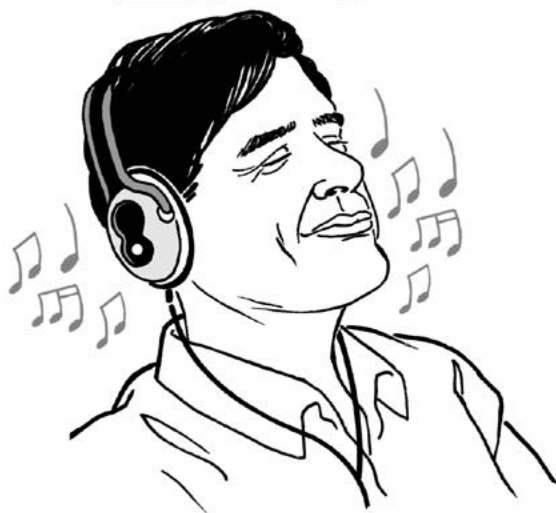


You may feel angry and upset. You cannot talk and listen to other people because of the way you are feeling.

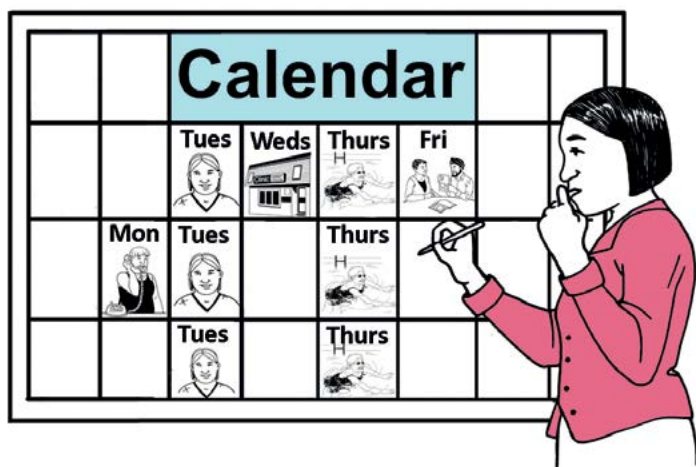


What can help?

Learning ways to calm yourself can help a lot. This can mean learning breathing exercises.



Knowing when you need time to yourself. You might want to watch a DVD or listen to music.



Keeping to a routine can be helpful. Knowing what is going to happen next. Using visual diaries as well are good.



Everyone can have a bad day.

Other people who can help.

Occupational Therapists or OTs can help with anxiety. They can teach you ways to calm down by using exercises and deep breathing.



Learning disability nurses can also help. You may see a community psychiatric nurse or CPN instead.



These people will need to meet you and think about ways of helping you manage your anxiety. It can be very useful.

Making friends and meeting people

This is often easier to do in a small group.

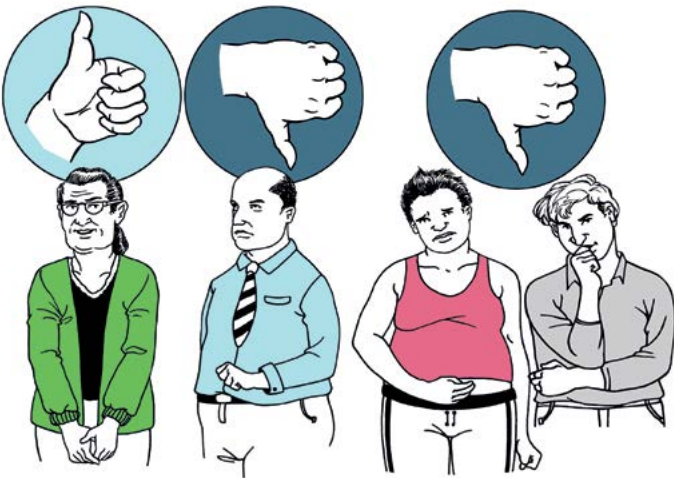


People with fragile X can be very shy. They do not like to look directly at people.



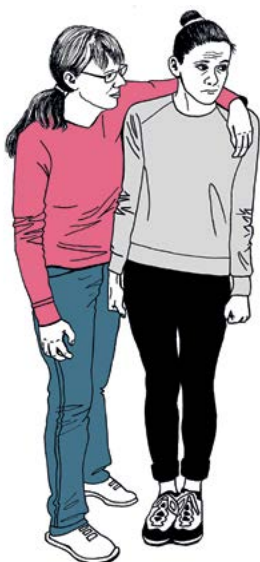
Women with fragile X syndrome

Usually women have fewer difficulties than men with fragile X. Some women can have the same difficulties though.



Women can feel very anxious and shy - especially in social situations. They may find it difficult to make friends.





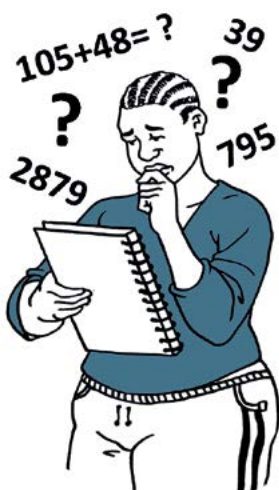
Some women can have problems understanding social boundaries. For example think someone is their best friend when they have only just met them.



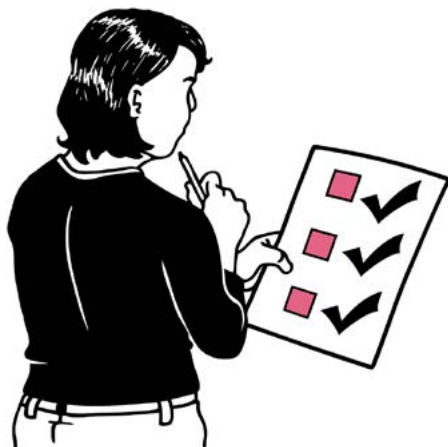
Women with fragile X can become withdrawn.



Women can have problems following a plan or changing their plans if they need to.



Women usually have problems with maths and numbers.



What can help?

Practice talking to people you trust and know you well, for example a member of your family or key worker.

Try to think about things before you say them. This might help to build up your confidence.

Use lists or other ways to help you remember what you need to do next.

You may need some help managing your money.



Finally

Many people with fragile X have a good sense of humour.

They understand other people's moods and emotions. They want to make friends and spend time with people.



They feel anger, grief and loss the same as everyone else.



You may have fragile X but you are a person first.



The Fragile X Society

Contact us:



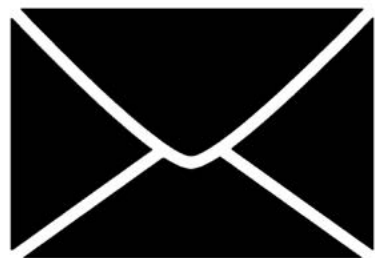
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