

HOW YOU CAN WORK WELL WITH JANE OR JOHN

Provided in confidence

Jane and John have a genetic condition called Fragile X Syndrome (FXS), which is the most common cause of inherited intellectual disability and affects the DNA relevant to information processing. It causes varying degrees of learning difficulties and symptoms comparable with people on the autistic spectrum, including the Asberger's syndrome.

It is called Fragile X because X chromosomes affected by the condition are missing part of their DNA. Girls are less affected than boys because they have two X chromosomes and only one is affected whereas boys having only one X chromosome are more severely affected.

Girls can inherit the defective X chromosome from either mother or father as they take an X chromosome from each. Boys can only inherit through their mothers from whom they take their X chromosome - fathers do not pass on FXS to their sons as they contribute only their Y chromosome to sons.

The defect becomes more marked as it is 'carried' from one generation to the next until the degree of damage increases to the point where a child is detrimentally 'affected' by the state of the X chromosome.

While Jane and John are considered mild, their condition still affects them in many ways. More than anything in the world Jane and John want to be treated like any other young person with warmth and friendship. You can help them by understanding their particular areas of difficulty.

STRENGTHS

Jane is very trusting of people she likes and admires. She is warm and loyal and will return friendship to those who extend it. She has a bright, sunny personality for much of the time. She has a great sense of humour and can be very funny.

Jane responds very well to:

- genuinely friendly approaches
- being included and involved
- joking as long as it is not sarcastic and jokes are said with a friendly smile.

John is similar in that he has a great sense of fun but takes a while to warm up to people. He is very quick to detect who is genuine and kind, but not patronising, and very intuitive in assessing those who are not so nice. He is usually spot on in his assessments. He warms quickly to people who show an interest that is not condescending and who treat him as an equal individual.

GETTING ON WITH OTHERS

The condition means that people like Jane find it more difficult to understand some of the subtle ways people communicate. They do not pick up the 'rules' of conversation and are very literal in their understanding of words. She speaks quite loudly at times

and can be 'perseverative' that is stuck on a subject. As a result she may sometimes seem a bit different. A common characteristic is the avoidance of eye contact which obviously reduces the ability to understand non-verbal signals. We have had some success over the years helping her work on this. John has the same tendencies but has learnt to look at people he is speaking to.

However this can cause people, particularly young people, to tease or otherwise be unkind and adults to think the person is being deliberately rude. Jane finds it hard to understand how she is to others, or why people get annoyed with her. She is extremely sensitive and suffers a great deal from angry reactions.

They may:

- speak too loudly.
- not look you in the face.
- talk a great deal and not leave adequate speaking spaces for others.
- say things where you can't follow the logic or get lost in telling a story.
- find it hard to understand a situation from your point of view.
- become upset if you criticise or ridicule something they value - the most frequent problem flows from their love of pop stars to whom they are fiercely loyal.
- misunderstand a situation, like thinking you are serious when you were joking.
- be unable to reconstruct a series of events. It is therefore very difficult to get 'the full story' when Jane has been upset about an incident. This also makes it very hard for her to defend herself after the event.

You can help by:

- being friendly and kind – she will always listen best to people she likes and trusts.
- *keeping criticism or correction gentle, friendly and calm- please never shout* as she will respond very autistically. This is very important
- not teasing about her icons – in fact don't tease at all
- find subjects that Jane or John are interested in talking about (ask family members or others discreetly) and engage them in conversation about these things. They want to talk but are often shy unless someone shows a strong interest.
- being careful with your expressions and avoiding sarcasm - she may think you mean it if you use a joking expression like 'you are mad!' or 'I told you 1000 times'
- gently reminding her if she is off track– 'Hey Jane we were talking about cooking..''.
- being respectful and not patronising her.
- avoiding long arguments trying to prove you are right - she will not manage the interchange – it is often better to leave the situation alone for a while and you may find later that you can try again or she/he realises the situation.
- *asking her to speak more softly in a friendly and pleasant way*
- not trying to talk or reason her out of being upset. It is better to divert her by involving her in a task if the situation is getting difficult or remove her from the situation and give her time out – a drink etc. In a work situation this may amount to allowing the person to take time out for a short walk or to have an unscheduled short break.

SENSITIVITIES

People like Jane have acute hearing and other senses. They also have an obsessive tendency and dislike the idea of contamination. As a result Jane gets agitated by:

- any clicking noise, pens, clicking tongues, tapping, sometimes humming or singing, particularly when out of tune.
- chewing nails or sucking fingers, chewing loudly.
- mouth noises, eg sucking teeth in particular cause her difficulty.
- dirtiness or messiness, anything that is unhygienic, like not washing hands or sharing lip balm or other cosmetics.
- food hygiene such as someone picking at food with fingers or 'double dipping'.
- smoking or other strong unpleasant smells.

You can help by:

- sitting her near a sensitive person, not for example someone who chews gum or is poorly groomed
- explaining quietly to someone how difficult it is for Jane to cope and asking for their cooperation
- keeping the noise and confusion level to a minimum in the surrounding environment

ORGANISATION

Jane can get very confused if people fire off a whole lot of instructions or give instructions in a confused, noisy environment. She can find it difficult to organise her time and to understand and conclude new tasks. She has to work very hard at concentrating and can become tired and frustrated; but she is fine once she understands a task.

Jane will often:

- need help to commence a task
- avoid doing something if she has not understood
- become distracted and divert to another task
- need help to meet important deadlines
- not follow multiple verbal instructions - you cannot presume it will happen because you told Jane to do something
- find it hard to make arrangements which involve planning ahead
- not be realistic or thorough about the task eg thinking a few sweeps is a swept floor

John is the same and needs a workplace where he does routine macro tasks that do not require a great deal of finesse. He likes to be active and move around a lot so jobs that involve standing in the one spot (packing) are not suitable. He can operate simple machines will do this reliably and safely.

You can help by:

- avoiding lots of instructions in a row
- keeping your expectations fair and realistic
- keeping instructions simple or writing them down for Jane
- being extra careful with important instructions like meeting places or travel plans – write it down for her
- assisting in her forward planning , especially managing time

- finding a quiet place to explain something in a quiet voice
- giving her a bit more time to complete things

LEARNING DIFFICULTIES

All FXS children and adults have learning difficulties, especially with abstract or conceptual areas like Maths and Science. Jane has some difficulties, while she has strengths in other areas. She reads easily and well and has a good memory for factual matters that capture her interest. In all areas she needs assistance in understanding the task and completing work. John is the same and has an extraordinary knowledge and recall of things that interest him – cricket, football, movies, TV shows, etc.

You can help by:

- helping them to understand a task by breaking it into small chunks and helping them to get started
- avoid giving tasks which are beyond their understanding, especially conceptual, rather than concrete tasks,

Some FXS people, once they hit onto something that they really like they will stick with and persevere for a long time. This can enable them to develop a great interest in a particular activity or subject. Encouraging this can be of great benefit to FXS people.

If there is one key factor that will assist Jane and John manage a new learning environment it is for *no-one to get angry with her/him*. They will respond immediately by withdrawing.

Thank you for your effort to assist Jane and John.

Please feel free to ask for further information (leaflets and booklets are available from the Fragile X Association of Australia website: www.fragilex.org.au)