

## **The Fragile X Society**

### **Helping your child to make sense of their world**

Paper prepared by Claire Wolstencroft for her Workshop at Fragile X Society Conference in June 2004

Claire, is a teacher and mother of two teenage boys, one of whom is 21 years old and has fragile X. She is also a contributing author of the book “Educating Children with Fragile X Syndrome”. The aim of the workshop is to explain how sensory processing problems may affect a person’s view of the world and to identify strategies that may help them to deal better with their world. A further reading list is given at the end.

#### **Sensory Processing Problems**

We have five senses: sight, hearing, smell, taste, touch. Messages are sent to our brain by our eyes, ears, nose, mouth and skin. Our brain then has to make sense of these messages. When you think how many messages your brain is getting all the time it is amazing that it can sort it out and make sense of it all. It seems that in some people, especially those affected by fragile X syndrome, the brain finds it quite difficult to sort all these messages out – it has a “sensory processing” problem. We can call this a “sensory integration dysfunction”.

#### **Sensory Defensiveness**

If a person has sensory processing problems then the world can become a very scary place as they are trying to make sense of everything going on. All of us, when we are scared, become defensive. It is an essential and healthy survival strategy. (Sometimes the best form of defence seems to be attack!) People affected by fragile X may get overwhelmed by busy environments much more easily than others and this affects their behaviour. They become “sensory defensive”.

#### **Tactile Defensiveness**

This is very common in those affected by fragile X. It means that a person finds it difficult to respond in the right way to touch. They often don’t enjoy being touched, and can have extreme reactions. However, they will quite often instigate a hug; somehow, when they are in control and know what’s going on, they can deal with it better.

#### **Olfactory Defensiveness**

A reaction to strong perfumes and smells.

#### **Auditory Defensiveness**

Over-sensitivity to sounds. Sometimes a child or person can react to this by making more noise, for example: by screaming, banging something, humming etc. This may be an attempt to gain control of the sounds around them.

#### **Oral Defensiveness**

An aversive response to taste, texture and temperature, which often shows up as “faddy eating”. Mouth stuffing can also be another way that this is dealt with.

Just as our bodies get overwhelmed when we eat too much and we suffer from a fat explosion, our brains get overwhelmed by too much information and feel like they are going to explode!

We need to try to control the amount and type of sensory information that a fragile X affected child or person is given. We also need to make sure that they (and us!) get plenty of the right type of “brain food”.

### **Promoting a healthy “Sensory Diet”**

Push for a referral to an Occupational Therapist who has knowledge of Sensory Integration Therapy. It may be possible to get an out of area referral.

Watch for your child’s response to sensory stimuli. Fast movement may make one child more alert and communicative; another child may be scared and withdraw. See how your child responds and alter the activity appropriately.

With a young baby vary the positions you put them in for sleeping, sitting, playing, cuddling. They learn more about body control this way.

Light touch can be irritating. Deep pressure is often more calming. Hands, tummy, face and soles of feet are the most sensitive parts of the body so tickling and touch may be particularly irritating here. Back rubbing may be more calming than hand-holding.

Children (and adults) often seek the sensory experience that their nervous systems need. If a child is looking for a particular sensory input – touch, smell, sight, movement etc then this is the type of stimulus that might be needed. Try to provide these in normal play. For example, if a child needs a lot of hugging and pressure input try games or activities like a tug-of-war, hiking carrying a back-pack, rolling games, hide and seek under large cushions.

If a child is humming or wailing try a piece of favourite music in a quiet corner, or play with simple musical instruments.

A child seeking movement may enjoy running games, swinging on a swing or riding a bike.

When a child is actively involved in a situation they have more control over it. Active involvement also provides the best opportunity of changes in the brain that lead to growth, learning and better organisation of behaviour.

If your child is an addicted “chewer”, a discrete piece of silicon aquarium tubing (tie a knot in one end), or a piece of beef jerky to chew on may be a better alternative to fingers or a piece of clothing.

Drinking through straws, especially bendy ones, exercises mouth muscles and provides a new sensation.

Heavy bed-clothes, for example: old fashioned blankets may be more calming than a light-weight duvet.

A qualified occupational therapist, trained in sensory integration therapy, will give you lots more ideas.

## **Strategies that may help to calm a child**

### Do a “Heavy” Task

It is often helpful to do these before a stressful event, or before school. They are all essential life skills to learn as well!

Digging in the garden	Playing with clay or playdough
Pushing a wheeled toy or a wheelbarrow	Mopping the floor
Carrying some books around (useful in school!)	Making beds
Press ups against a wall or off the floor	Kneading dough
Beating all the cushions in the house!	Mowing the lawn

### A “Quiet Retreat”

Provide the child/person with a quiet place to withdraw to with favourite toys or books. A large cardboard box is a favourite!

A dark bathroom, with a lovely warm bubble bath and candles is relaxing for parents as well as children!

### Jumping

Hug your child tight and jump up and down with him ten times. This is useful in Supermarket Paddies. Take your child out and have a jump!

A good bounce on a trampoline or re-bouncer (also de-stressing for parents and carers!)

### Swinging

Local swings in a park  
Swing seat in the garden for older children/adults  
Rocking chair

### **Further Reading** (available from The Fragile X Society)

“Occupational therapy and sensory integrative therapy for individuals with fragile X syndrome” by Dido Green – chapter 15 in “Educating Children with Fragile X Syndrome edited by Denise Dew-Hughes, published by Routledge Falmer

“Living with Fragile X : Sensory Integration Therapy”  
Report of two talks given at Fragile X Society Conferences June 1999 & April 2000

“Occupation therapy strategies at home for individuals with fragile X syndrome”  
by Dido Green, Fragile X Society Newsletter No 27 Winter 2002

“Education Ideas for Home and School”  
by Claire Wolstencroft, Fragile X Society Conference and Workshop 1993

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