Supporting children with Fragile X syndrome during lockdown: some tips

From Caroline Pringle, Families and Professionals Advisor (Child Enquiries)

Although some children may still be attending school, this might not be every day, and the majority of children will now be at home. I appreciate many will struggle day to day and it’s going to be difficult to keep them occupied. The structure and routine of their day has changed drastically as it has for you too.

There are a lots of tips out there, but I wanted to take the opportunity to bring information together for you to one place.

Activities
Routine is so important for children with fragile X, there is the need to fill their day. The structure of their day has changed so much it will help to have activities to keep things positive and upbeat. Here is a list of some possible activities to help the day pass as smoothly as possible:

- **Gardening** – even if just digging over the soil, perhaps planting some seeds. It’s so good to be out in the fresh air
- **Pets** - Looking after pets, putting out their food, and if your cat or dog could stand it .... a chance for a bit of a brush!!
- **Cooking** – there are only so many cupcakes we can eat - so perhaps making their own lunch and remembering the washing up too.
- **Arts and crafts** - this [link might give you some ideas](#). Cutting up the Argos catalogue or similar is a good activity. Another fun activity is if you have a roll of wallpaper lurking in the loft, roll it out, draw round yourselves and colouring it in.
- **Sensory activities** – messy play such as a tray with shaving foam with small items hidden underneath, a cornflour and water mix to make patterns in. Playing with pasta cooked or raw is another fun activity but appreciate this is in short supply! Make up texture bags with different items inside such as bubble wrap, cotton wool, piece of Lego.
- **Sorting** - perhaps sorting Lego blocks into colours or size, sorting things to help you such as matching the socks etc.
- **Online activities** - I never thought I would say this ......but in the situation we find ourselves in ‘screen time’ takes on an important role. Here are some examples:
  - [David Walliams’ story times](#)
  - or [Joe Wicks‘ weekday keep fit sessions on YouTube](#)
  - [Free downloadable apps such as CBeebies](#)
- **Tasks Around the Home**: There may be tasks you want them to complete such as making their bed, cleaning the breakfast things (if you're lucky!) and having incentives to complete these tasks will help. This could be time on the trampoline or dare I say……. time on the iPad.
- I wanted to put a long walk or bike ride but fully appreciate that this might not be feasible if your child is likely to run off and there is also the factor of social distancing if passing other people on your walk.

**Importantly, sometimes we just need to chill and not do anything in particular.**

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Visuals
Acknowledging the need for routine and structure to the day for most children could mean the use of visual aids to help. This could be in the form of resources such as a schedule, planner or choice board. Often school or a speech and language therapist have supported you with these.

Marcia Braden gives some good tips and templates for visual schedules. There are also some examples of visual schedules from Lisa Martin (Special World Training), featured in Jane’s article last week.

If you need support creating visual aids for your child, please get in touch (caroline@fragilex.org.uk; 01371875100). I will be posting a blog covering visual aids in more detail very soon.

Sensory
I wanted to pay attention to children’s sensory needs and to understand that they will need support to cope at home with the different sounds, smells, light etc. Some children need physical based activities to help them stay focused during the day and cope with all the different sensory experiences they encounter. Activities that help can include:

- jumping on the trampoline
- Wall push ups
- Pushing the wheelie bin out for you
- Digging in the garden
- Sweeping the floor
- Even using the vacuum cleaner on the carpets (if they are ok with the noise)
- If you have a play tunnel; putting some cushions in there so it’s more of a squeeze to get through
- Possibly you have a peanut ball or physio ball they can roll on

They may still need their fidget or sensory bag of small items (ensuring safe and appropriate) such as a stress ball or squishy, piece of blutack, bubble wrap to pop, tangle toy, piece of fabric, soft brush, chew buddy, pot of bubbles to blow etc.

Making an area to escape to may help with perhaps a few sensory toys… this could be a pop-up tent, large golf umbrella or a bedsheet draped over some chairs to make a den.

I hope the information has been of help, remember that children will need time to process the changes around them. If you need any further support then please do contact me and remember I can support you with making visual aids.

It might also be of help to link with other families and share experiences and ideas by joining our closed Facebook group (if you’ve not already done so).