

Managing the current 'stay at home' situation for youngsters with Autism Spectrum Disorder (ASD)

The current situation that we are experiencing with the COVID 19 pandemic has brought sudden and unprecedented disruption and changes in every aspect of our daily life. Changes like schools suddenly closing and parents being at home cause anxiety, possibly even distress; as all these changes in our daily routine have happened so quickly, there has been no time to prepare or plan for them. People with ASD (of all ages) are particularly sensitive and vulnerable to both such abrupt, unexpected changes, but also to the uncertainty and insecurity that this pandemic presents for all of us.

Below is a list of ideas and tips to maintain structure, manage uncertainty and anxiety, some of which may be helpful. They are aimed for parents of youngsters with ASD, but some can also be used by adults with ASD. They need to be adapted to the developmental level and functioning of each child.

First and foremost, parents have to do their best to keep well and maintain composure. Children absorb and are affected by what they see, so if they see anxiety, worry and panic, that is what they will feel and manifest themselves. Moreover, parents should reduce expectations and standards at this time; for example, it is sensible to be flexible about screen time, but ensure to clarify that this flexibility in expectations is only due to the current exceptional circumstances. Parents need to be empathic towards their children and what they may be feeling. Prepare children that inevitably things will be different for an indefinite period of time.

- **Maintain normalcy:** using basic TEACCH (**) principles, establish a **home-based daily schedule** (with words on a calendar/whiteboard or pictures), Monday to Friday, prescribing activities that need to be done (eg school tasks/lessons) as well as activities that are chosen (eg time for a walk/ free time). The programme should include school commitments, exercise and fun activities. Time should be specified for fun and exercise activities, as well as school work. Leave 1-2 times per day blank, for a youngster to choose what to do without needing direction from an adult (see below for an example, to be completed).

Monday	Tuesday	Wednesday	Thursday	Friday
9-12pm school lessons	9-12pm school lessons			
12-1pm FREE ++				
1.30pm Lunch				
2.30pm Homework				
4-5pm FREE ++				
5pm Exercise (walk/dance etc)				
6pm Fun time +				
8pm Dinner				
9pm prepare for sleep				
9.30pm Bedtime				

+ Bake cookies/bread/cake, cook a new recipe, art & crafts, play a game with others, talk with a friend, occupy yourself with a special interest etc.
++ Free time is a time the youngster can do whatever he/she likes and chooses that activity with no need to seek input from an adult.

Enable your youngsters to do any of the following:

- **Do 1 thing every day that's fun/ makes you laugh!**
- **Use the phone, Skype, FaceTime etc. to connect with loved ones:** Touch base with people. Call someone and say, "I'm lonely/bored. Want to chat?" Most likely that person will want to chat too.
- **Reassure others-**ensure you give others comfort and information that is reliable and valid, with encouragement and optimism.
- **Keep a daily journal** (with thoughts & feelings, ideas, drawings, sketches, photos etc).
- **Find a new joke every day and tell it others.**
- **Do things you have never had time to do beforehand** (eg sort out & organize your folders/files on your computer/ classify paper files/paperwork in your room/ read a book/blog etc.)
- **Use this opportunity to develop in some way:** Find out something new about a topic that you don't know about and interests you (eg marsupials/ historical figures/ a music genre or a musician/ the galaxy/ capital cities of the world/ sports players/a new computer programme etc).
- **Limit your news consumption to certain times of day & to reliable sources:** Reading every news notification that comes in all day long is unnecessary. Set some healthy limits (eg once per day, every evening).
- **Is home overstimulating on the senses?** If this is the case, try to create an area within the home where the youngster can retreat for peace and quiet. Use cushions or a floor mat to mark out the space, ensure this space contains relaxing activities (eg music/ nature sounds that can be heard with earphones, books/ scrapbooks with relaxing photos, a fleece blanket that the youngster can wrap him/her self in...anything the young person finds soothing.)
- **Rediscover games:** Do a jigsaw puzzle or play a game on your own or with others (eg Sudoku, Monopoly, Scrabble, UNO, chess, backgammon).
- **Put notes around the house with positive messages-**add one every day (eg home is safe; time stretches out; challenges make us stronger etc).
- **Pay attention to self-talk:** Our self-talk (the chatter in our mind) can be very anxiety-producing, worrisome and pessimistic, especially at times like the ones we are currently experiencing. Negative self-talk will inevitably adversely affect our mood, our behaviour and our feelings. As self talk can work in a very latent but powerful way, it is up to us to notice those thoughts in our minds and when we notice destructive and disheartening messages, we must try to challenge them and replace them with more rational coping self-statements. [For example, catastrophizing thoughts can be replaced with more realistic thoughts using evidence from other viruses humanity has experienced].

- **Make time to pay attention to your feelings and allow yourself to feel them:** We march through all of the sudden changes and anxiety these produce, often without paying due attention to how we are actually feeling. It is important to pause, focus on your feelings and talk about them. Are you feeling frightened? Worried? Sad? Disappointed? Lost? Alone? Fearful? Helpless? Hopeless? Model calm behaviour, use practical and thinking coping strategies to maximise well-being. Ensure some physical exercise every day as a practical anxiety-reducing intervention.

If negative feelings are overwhelming for the youngster, establish a “worry time”, a daily 10 minutes to allow him/her to discuss any worries. This must occur during a specified time in the day (which a young person knows) when he/she can talk about worries with a loved one freely and openly. It is, however, important that worry times should not last more than 10 minutes and should be followed with something fun. Should a young person want to talk about a worry time at other times during the day, he/she needs to be redirected and reminded that worries will be discussed during worry time only.

- **Limit compulsive behaviour:** Ensure limits are put in place for compulsive behaviour and let the youngster know that this is the case- ie where, when, how much, for how long the behaviour happens (eg reassurance-seeking questions; hand washing or similar behaviours).
- **Worry about others:** youngsters often worry about other people/ loved ones. They need to be reassured about other people with sensitivity and honesty. If the worry is over-the-top, it can be voiced during worry time.
- **Worry about the coronavirus-**be reassuring, but honest and ensure the information you give is developmentally appropriate. Take any concerns seriously, use social stories (****) to explain specific information and what to expect (eg *‘a lot of people might get sick, but normally it is like a cold or flu and they get better’*) and include positive coping strategies (see below a worksheet on coronavirus for children, Mindhearts.kids, Molina).
- **Write 2 positive things at the end of every day:** it can be something simple like enjoying a movie, drawing something beautiful, mastering a piece on the piano, talking to someone that you have not talked to for a long time etc.

Appendix

- ** TEACCH (Treatment and Education of Autistic and related Communication handicapped children).
- **** Social stories (Carol Gray) are educational stories aiming to help children gain a better understanding of real-life events.
- Mindhearts.kids (Manuela Molina)
- [Freddy, the coronavirus and school](#) – written by Lucy Sanctuary, Specialist Speech & Language Therapist and Cognitive Behaviour Practitioner (see attached).
- [When anxiety feels overwhelming](#) – written by Professor Jacqui Rodgers, Newcastle University (see attached).