Interim Clinical Guidance for parents and carers on supporting wellness in the autism community during COVID-19

Self-care, Routine, Understanding & Preparation

Compiled by the Autism@UL Special Interest Group at the University of Limerick. This group includes autistic staff and students, parents of children with autism, clinicians, researchers and members of the local community.
**Introduction**

This is a challenging time. For autistic people and their families it may be particularly difficult. Advice can come from many sources. It may feel overwhelming at times. Be kind to yourself. Do what you know works for you and your child to stay safe and well.

For guidance on COVID-19, physical distancing and hand hygiene please see the [Public Information booklet](#) published by the HSE. There is also an [Easy-Read version](#), and a version in [the Irish language](#). There is information in a variety of languages available [here](#).

If you are finding it difficult, we have some ideas that may be helpful for parents and carers of people with autism.

*Please note: Some people prefer to be called an ‘autistic person’, while others prefer ‘person with autism’. In order to respect both views, we use the terms interchangeably throughout this document.*
Self-care

Set realistic expectations

We need to spend more time than usual looking after our loved ones, and looking after ourselves. For those of us who are working, this means that our productivity will be lower than usual. That is OK. Get in touch with your employer and talk about what you can realistically do.

Make time for yourself

If you need to look after others, it is also important to look after yourself. This document focuses on how to support your child with autism, but the advice is relevant for you too. For example, make a routine, exercise and eat well.

Plan at least one nice thing for yourself every day. This helps to us to feel energised.

Try one of these activities to bring a moment of calm:

- Take a breath through your nose, breathe deeply in to your stomach and slowly release the breath
- Slowly press your fingertips together for 10 seconds
- Slowly straighten up your back and spine
- Push your feet hard into the floor.

Reach out

Stay connected to people with whom you have a positive relationship, including support groups and online networks. Reach out for help, advice and support.
Routine

Routine is important for autistic people.

Set up a new routine. Plan the day. It can help to use visuals (written words, pictures, or real items) to explain this new routine.

Begin the day by going through this visual plan. Return to it as many times as is necessary during the day. Using timers or phone alarms can help to remind us when it is time to move onto the next activity.

*Include the following in your daily plan:*

**Physical activity**

Exercise gives us energy. It can be a positive way to start the day. It is nice to go outside for a walk or a run but your child can exercise indoors too. There are online dance and yoga classes, and Sporting Ireland have ideas for how to stay healthy at home, click [here](http://example.com) for more information.

**Activities**

Plan activities to fill the day. These may include schoolwork, household chores, playing, reading and exercising. Many of us have activities from our children’s schools. There are also many activity ideas online, including these resources from [Enable Ireland](http://example.com), and RTÉ2 are providing a ‘home schooling hub’ daily from 11am to 12 noon.

You can go on a virtual visit to the [National Museum of Ireland – Natural History](http://example.com), or further afield, like the [Anne Frank House](http://example.com) or the [San Diego Zoo](http://example.com) and try having a theme for a day, e.g. pirate day, baking day, cinema day etc.

**Interests**

When we do things that interest us, we feel happy, and it can be calming. Include time to engage with interests into the daily routine. Our children have varied interests. If you can, take the opportunity to share your child’s interest. It feels good to share their passion.

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Anxiety-busting activities

Think about the activities that are helpful in managing your child’s anxiety levels (for example, exercise, playing music, meditating, talking about feelings) and build these activities into the daily plan. This can help to reduce anxiety build-up throughout the day.

Sensory Strategies

Everybody experiences sensory information differently. Some sensory inputs can help your child to stay calm and relaxed. Other sensory inputs can cause their system to become stressed. Think of each of the systems and what works, (and does not work) for your child: sight, smell, taste, movement, sounds, touch and body input.

Remember that their response to sensory input may vary depending on the time of day, how they are feeling and what has happened that day. Sensory input is cumulative. This means it builds up in our system. When they are tired or stressed they will be less able to tolerate sensory input that may otherwise only irritate them. They may become overwhelmed. Build in sensory breaks into the daily routine. See this resource from the Middletown Centre for Autism on Sensory Processing.

Daily Living Skills

Daily living skills are so important, pandemic or not. This may be a good time to teach these skills, including dressing your bed, doing laundry, hanging out clothes on the washing line, emptying the dishwasher, sweeping the floor…the list goes on! Include these in the daily plan.

Tip – when teaching these skills it can help to start to include your child at the end of the task, and work backwards. For example, if your child is learning to make the bed, then start with the very last step: putting the pillow on. Next time, they pull up the bedsheets and put the pillow on, and so on. This way, they get to experience the natural success of completing the task every time. We call this backward chaining.
**Time for social connection**

Even though we cannot visit people, there are other ways that we can stay in touch. Support your child to connect with their friends and family. This may be over the phone, or via a video call. This helps us to feel close even though we are physically distant.

**Meal times**

Where possible stick to your usual meal routine. There is no specific food guaranteed to protect you from the coronavirus so general healthy eating guidelines are the best advice for now.

**Strategies for dealing with Selective Eating during isolation:**

Some people do best when meal times are at the same time, place and situation every day. Establish as calm and comfortable an environment as possible. Some people eat more when they have a video or music on, whilst for others this may be distracting.

Use visual timetables and visual schedules. Written timetables or picture symbol schedules detailing when and where eating will happen, what will be eaten and the type of behaviour expected at meal times, makes mealtimes more predictable and a less anxious occasion.

**Quiet space**

Set up a space in your home where your loved one can go if they feel overwhelmed or need a break. Ideally, this place will be quiet and calming. Make sure other people at home know how this space is being used, and how important this is for them.

**Sleep well**

Set a bedtime in your daily plan and do your best to stick to it. See this guide to Managing Sleep from the HSE.

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**Understanding**

**Talk about what is going on**

Talk to your child about what is happening. Social stories™ can help with this. Social stories™ describe a situation, or concept using words and/or pictures. AslAm have produced helpful social stories to explain the current situation, including [Lockdown restrictions explained](#) and [Coping with COVID-19 whilst in residential care](#).

Here is a [link](#) to a social story explaining the current situation for children produced by theautismeducator.ie.

Nosy Crow have published a free information book explaining the coronavirus for children, illustrated by Gruffalo illustrator Axel Sheffler. It is available [here](#).

If someone is asking the same questions repeatedly (even though you keep providing them with the answer), it can indicate that they are feeling overwhelmed and anxious about the situation. It can help to provide them with the answer in a visual format, by writing it down, or by creating a social story.

**Take breaks from the news**

There is so much information available it can be overwhelming. Your child may have a tendency to dwell on news coverage and this can add to anxiety levels. News repeats during the day to perhaps limit yourself and your family to watching one trustworthy news item a day, for example, the news on RTÉ One.

Consider limiting time spent on social media and make sure that the sources on information are trustworthy, such as the HSE social media pages: @HSElive on Twitter, and irishhealthservice on Instagram.
Grocery shopping

Many of us do not have a choice but to bring our child with autism to the supermarket with us. The changes to grocery shopping at present can be challenging. The new queueing system may be stressful. Maintaining social distancing may also be difficult.

Contact your local supermarket or look on their website to find a quiet or protected time to visit the store. Explain that autistic people may need more time to process the new information and instructions to shop safely following social distancing measures.

Many SuperValu stores have autism-friendly shopping times. See information on their website here.

Tesco have a lanyard, which you can pick up from Customer Services. It signifies that the wearer or the person they are with has special needs and may need extra help.
The hospital

It is possible that your child will need to go to hospital. Have their health passport ready. The HSE have developed a [Health Passport template](#). There is also a [guidance document](#) with advice on how to fill in the health passport.

The doctors and nurses are extra busy at this time so it is a good idea to have a short version of your child’s health passport ready with key information:

- What helps to reduce their anxiety
- What makes their anxiety worse
- How best to communicate with them
- Ongoing Medication
- Allergies or food requirements
- Underlying conditions
- Next of kin
- Any specific supports that they have

Also, include something about your child’s interests, or something that is important in their life. It may help to reduce their anxiety if the nurse or doctor talks to them about that.

Prepare a social story about going to the hospital. Hopefully, this will not be needed. However, if it is, then you may not have time to put a resource such as this together. It is better is you are prepared. The following picture-based stories have been produced by the HSE Speech and Language Therapy Team at Dublin North Central:

  - [Getting ready to go to the Test Centre](#)
  - [Getting ready to go to the Test Drive-in Centre](#)

Prepare for you going to hospital

A big worry for many parents is considering who will mind their children should they get sick. Prepare a social story that will explain what will happen if you need to go to the hospital for care during this time.

This is particularly worrying for one-parent families. If you need to talk to someone about this, you can contact the [Askonefamily helpline](#).
Garda checkpoints

The Gardaí are making sure that people follow the current restrictions. They may approach your child on the street, or stop you at a checkpoint. This can be stressful.

Have a document ready that has key information that your child can share with a Garda (see example below). Include your child’s name, address and diagnosis. Include a description of what their behaviour might look like if they feel stressed, and something the Garda can do to help them feel less stressed. Include information about how they communicate, especially, if they do not use verbal language to communicate.

<table>
<thead>
<tr>
<th>MY NAME IS</th>
<th>THIS IS WHAT MY BEHAVIOUR LOOKS LIKE WHEN I AM STRESSED</th>
</tr>
</thead>
<tbody>
<tr>
<td>I LIVE AT</td>
<td></td>
</tr>
<tr>
<td>EMERGENCY CONTACT PERSON (NAME AND CONTACT DETAILS)</td>
<td></td>
</tr>
<tr>
<td>MY DIAGNOSIS IS</td>
<td>THIS CAN HELP TO CALM ME DOWN</td>
</tr>
<tr>
<td>HOW I COMMUNICATE</td>
<td></td>
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Many parents and carers of autistic people are concerned about the legal enforcement of social distancing. Some people need to go for a drive. For some, this is the only opportunity to leave the house each day. Others may need to go to a favourite place. This might be for a visit, or to show that the place is closed, to help the person to understand why they cannot go there.

People are worried that this will mean getting in trouble with the Gardaí.

However, the Minister for Health has clarified that people with autism can go for a drive if needed.

AsIAm have produced a template letter that people can print to show to the Gardaí. It is available here. You also need proof of diagnosis such as an assessment report, or a letter from your local healthcare provider, such as your GP, Disability or CAMHS service.
Resources

COVID-19 related resource links:

The HSE have a website dedicated to supporting our mental health and the Government of Ireland have launched a campaign focused on Getting through COVID-19 together.

See the HSE guide to Coping with Distress during COVID-19.

The HSE have a guide to cocooning available here.

Inclusion Ireland have created a document that explains the current restrictions.

AsIAm have a page dedicated to COVID-19 related resources.

The Illinois Autism Partnership have produced visuals to support daily planning for children with autism here.

St Michael’s House have produced visual support material available here.

Autistica in the UK are organising a series of webinars that you may be interested in. You can see the schedule, and previous webinars here.

Behaviour

If your child are engaged in behaviour that is challenging, then contact your service provider for support. Yvonne Newbold outlines lessons from her experience as a parent here that may be helpful.

Resource links for activities to keep children busy

The National Council for Special Education (NCSE) have shared links and resources – click here.

Family friendly HQ have some ideas for sensory activities at home here.

Ted-Ed have interesting educational video content available for adolescents and adults. View the collection here.

Teachers, Fiona and Lucy have released a free printable activity book for adults “The Great Isolation Activity Book”. The resource is free but they ask that people donate what they can to Cystic Fibrosis Ireland. You can see more here.

Science Foundation Ireland guide you through simple home experiments and resources for children of all ages on their STEM at home webpage.