



COVID-19 Coronavirus Testing Toolkit

Testing for COVID-19 coronavirus currently requires a **nasopharyngeal** (through the nose) test and/or **oropharyngeal** (through the mouth to the throat) test using a cotton swab. For many people with autism spectrum disorder and/or intellectual/developmental disorders (ASD/IDD) this test may be hard because it can feel uncomfortable and is unfamiliar.

This COVID-19 Coronavirus Testing Toolkit includes two social stories with the goal to prepare people with ASD/IDD for nasopharyngeal and oropharyngeal testing:

- A **detailed** version for people who need specific instructions, explanations and pictures to understand what to expect during the test.
- A **simple** version for people who need simple instructions and one picture on each page. The simple version can also be broken into shorter stories for people who need extra time to understand each step.
- Both versions have “fill-in-the-blank” portions so the social stories can be personalized.

SPECIAL CONSIDERATIONS

Symptoms of COVID-19 Coronavirus

The US Center for Disease Control (CDC) states the most common symptoms of COVID-19 coronavirus are fever, cough and shortness of breath (see www.cdc.gov/coronavirus). If a person with ASD/IDD does not reliably communicate about pain or symptoms, it is very important to tell this person’s primary care physician or pediatrician. Ask the primary care physician or pediatrician to explain what signs and symptoms would be important to watch for that would indicate need to seek medical care.

Test Location

- **Preparation:** COVID-19 coronavirus testing is occurring in different places. Therefore, information and pictures related to “where” the test will happen are not included in these social stories. It is recommended this information is written in and visuals such as photographs or videos be reviewed.
- **Consider Options for Best Testing Site Scenario:** Discuss local testing site options with the primary care physician or pediatrician to determine the best testing site scenario for the person with ASD/IDD. For example, some people will do best testing with an indoor medical clinic because they can relate to previous medical experiences. Others may do best with an outdoor “drive thru” testing site because they will feel more comfortable waiting in the car or would be able to hold a comfort object that may not be allowed into an indoor clinic for infection control reasons.

When Testing Isn’t Possible

Some people with ASD/IDD may not be able tolerate a COVID-19 coronavirus test even when preparation such as social stories is tried. In these cases, it is very important to continue to speak with the primary care physician or pediatrician about the person’s symptoms and when to seek additional care.

ADDITIONAL RESOURCES AND SUPPORT

Social Stories

The following social stories explain the COVID-19 coronavirus pandemic. Reviewing them along with this toolkit may help individuals better understand concepts such as coronavirus and germs.

- **My Story About Pandemics and the Coronavirus by Carol Gray**
www.carolgraysocialstories.com/wp-content/uploads/2020/03/Pandemics-and-the-Coronavirus-1.pdf
- **What's COVID-19? by the National Autism Association**
www.nationalautismassociation.org/wp-content/uploads/2020/03/WhatsCOVID-19.pdf
- **Don't Share Your Germs! A Social Story About Staying Healthy by the Autism Society of North Carolina**
www.autismsociety-nc.org/wp-content/uploads/Germs-Social-Story.pdf

Videos

Some people with ASD/IDD will benefit from watching a video prior to their testing. Search the internet using the words "nasopharyngeal test" or "oropharyngeal test" to find videos.

- **The New England Journal of Medicine's nasopharyngeal test video includes simple video and illustration:**
www.youtube.com/watch?v=DVJNWefmHjE
- **The photographs in these social stories are from the following MGH Coronavirus NP OP Swab video:**
www.youtube.com/watch?v=tSASmeAYZs4&feature=youtu.be

Questions

Contact the person with ASD/IDD's primary care physician or pediatrician with any medical questions or concerns. Specialists in the person's community, such as special education teachers, board certified behavior analysts, occupational therapists or speech therapists may be able to provide additional suggestions for preparing a person with ASD/IDD for COVID-19 coronavirus testing.

Acknowledgements

A special thank you to the individuals, parents and professionals who reviewed and provided feedback on these social stories. Thank you also to the Ruderman Family Foundation for their support of the Healthcare Inclusion Program for Developmental Disorders at Massachusetts General Hospital.

Creation of this COVID-19 Coronavirus Testing Toolkit was led by Karen Turner, MS, OTR/L, Occupational Therapist Patient Navigator for Autism and Developmental Disorders, Healthcare Inclusion Program for Developmental Disorders at Massachusetts General Hospital. Permission is granted to download, copy, re-send, share and translate with credit to Massachusetts General Hospital.

Rev. 4/2020. Mass General Hospital for Children and Massachusetts General Hospital do not endorse any of the brands listed on this handout. This handout is intended to provide health information so that you can be better informed. It is not a substitute for medical advice and should not be used to treatment of any medical conditions.

**Healthcare Inclusion Program for
Developmental Disorders**

Mass General Hospital for Children
55 Fruit Street
Boston, MA 02114

www.massgeneralforchildren.org

For more information please call

888-644-3248