

COVID-19: Caring For Children and Youth With Special Health Care Needs

As COVID-19 continues to spread, children and youth with special health care needs may be at increased risk for complications. This includes children with chronic conditions, disabilities, and those with medically complex conditions. School, supports, activities and routines may also be disrupted on an ongoing basis.

Here are some ways parents and caregivers can help themselves, their families, and their children with special health care needs meet their safety, growth and health care needs during the COVID-19 outbreak:

Using layers of protection to reduce risk

Especially for children and teens with special health needs, it is important to use different layers of protection to reduce the risk of spreading SARS-CoV-2, the virus that causes COVID-19:

Hands & surfaces. Hand washing and cleaning surfaces, especially in shared spaces and with shared objects, are two important ways to help protect your child from COVID-19. Put signs on your front door or on the door to your child's room to remind family members and caregivers to wash their hands often, for at least 20 seconds. Keep plenty of hand soap, tissues, wipes, and hand sanitizer on hand for everyone in your home to use. Make kits or hand washing stations, if needed. If your child is returning to school or a location for therapies or other activities, have conversations to make sure surface cleaning and handwashing are part of the process.

Safer space. Avoid the 3 Cs: **closed spaces**, especially those with poor air flow where physical distancing alone may not be enough; **crowded places**, inside and outside, and **close contact**, especially while exercising, singing and other activities that increase the spread of respiratory droplets that can carry SARS-CoV-2.

Cloth face coverings. Nearly all children with special health needs, age 2 and older, can safely wear cloth face coverings that securely cover the nose and mouth. There are very few medical conditions that would prevent a child from safely wearing them. Face coverings should be used in public, indoor spaces at all times, and outside when it is hard to keep a 6-foot distance from others.

Anyone providing care or therapy for your child should wear a cloth face covering, too, especially in closed or crowded spaces. Family members may also want to consider wearing face coverings at home to help protect a child or adult who has increased risk of severe illness from SARS-CoV-2 infection, especially if their jobs, return to school and activities, or other responsibilities put them at increased risk of exposure. This could be extra important if a family member's job puts them at higher risk for exposure to the virus.

Screening. Where a good supply of COVID-19 tests is available, periodically screening care providers in close contact with children with special health needs can offer an additional layer of protection. Examples include home care providers, child care providers, teachers and therapists.

Clinic & therapy appointments

If your child with special health care needs has regular and multiple provider visits, talk to your pediatrician and specialists to plan out a schedule. Ask which visits can be done virtually and which need to be in person, as well as what is covered by insurance.

The right fit & type of cloth face covering

Getting good coverage from a mask or cloth face covering may take extra attention for children with special health care needs who have craniofacial conditions. See here for tips on helping your child get used to wearing a cloth face covering, and how to get it to fit correctly.

Some children with developmental, emotional or mental health diagnoses may also need intentional time and creative planning to help them get used to wearing a mask or cloth face covering. Families can use social stories to help their children become familiar with masks, for example. Slowly building tolerance over time with a wearing schedule may also help.

For children who rely on lip reading, people in close contact can use face coverings with transparent windows. Additional ways of communicating, such as voice-to-text mobile apps, may also be helpful. Face shields are not a substitute for cloth face coverings, but they may provide some extra protection.

Certain children with special health needs who have conditions known to put them at higher risk of severe illness with SARS-CoV-2 infection, as well as their families and caregivers, may need the type of personal protective equipment used by health care workers. This may include N95 respirators and eye protection, for example. Talk with your pediatrician about whether special protective gear may be needed.

Virtual visits. Your pediatrician, specialists, therapists, and others who care for your child may offer appointments by phone, Skype, FaceTime, or another telehealth option. Home-based lab draws and diagnostic imaging tests may also be available.

In-person appointments. When in-person appointments are necessary, you and your child (if over the age of 2) should wear cloth face coverings, with rare exceptions for medical reasons, and be screened for fever and symptoms of COVID-19.

Among other changes to help keep children with special health needs safe, there may be a separate waiting area for your child to be seen. Early appointments, before other patients arrive, may also be an option.

Supplies

Talk to your pediatrician about getting extra medicines or supplies that your child needs, including any medical technology and nutrition support. If your child is on a special diet or requires a specific type of food (like infant formula, for example) be sure you have enough on hand. Some insurance companies may require special approval to allow you to get a supply of medication beyond 30 days. If this is not possible, see if you can get refills for your child's medications by phone or delivered to your home.

Try to have enough cloth face coverings and other personal protective equipment to last a few weeks, without stockpiling. Be sure you have enough nebulizers and airway suctioning, as well. Consider the necessary supplies for school if your child has returned to in-person

learning. If you need help with ordering extra supplies, or are having trouble finding what you need, talk with your pediatrician or care coordinator.

Returning to school with special health needs

Discuss the best and safest school options and needed accommodations with your child's health care providers and educators. Your pediatrician can help explain the known benefits and risks of attending school in-person, virtual learning and various combinations schools may be using. Even if your child's school has already "re-opened," there is always time to work with your doctor and school to develop creative, flexible and responsive accommodations as a way to implement or update IEP and 504 plans.

If virtual school is the best option for a child at increased risk for severe COVID-19 illness, consider whether siblings should also utilize a remote option. If attending school virtually, children should have the chance to participate in some in-person activities such as outdoor events, if possible.

Changes in school routines can be stressful, so be sure to talk with your child about why they are staying home and what your daily structure will be during this time.

Coping & staying strong

Families, parents, and caregivers who take care of children with special health care needs are strong and resilient. But it's hard not to feel stressed or anxious in this unprecedented time. It helps to:

- remember to take time for yourself, doing activities and hobbies you enjoy.
- recognize when you may need a break.
- connect with other families virtually, through video chats, social media or texting.
- take deep breaths, meditate, and get some exercise.

As a family, try to come up with creative ideas for how to stay active and healthy. Encourage children to suggest their ideas.

Monitor your child's emotional health during this time, too. Talk with your child about their fears, and let them express their feelings. It is important to note that these emotions and reactions are likely affecting children with cognitive disabilities, as well.

Not every child or adult will react in the same way to the stress of COVID-19, but it is likely that everyone is reacting in some way. Extended time at home and restrictions away from school may cause anxiety and concern. Maintain routines, connect with friends virtually, and build family time into the schedule.

Community supports & services

During this time of change and uncertainty, it's even more important to stay connected. Reach out to peer support organizations, such as Family to Family Health Information Centers, for local information specific to children with special health care needs and disabilities.

Remember, social distancing does not mean that you are alone! But it may mean you'll need help with basic needs such as food or food delivery, ride shares, and getting medications. Reach out to a trusted case manager, friend, family-led or community-based organization, or your pediatrician for help.

Work with your child's school to make sure IEPs and 504s are addressed and arrange for home therapies or teletherapies if available. School meals may be able to be picked up in batches. Work with community partners for delivery to your home, if needed.

Stay informed

Families are encouraged to stay up to date about this situation as we learn more about how to prevent this virus from spreading in homes and in communities.

For more parenting information from the AAP, visit www.HealthyChildren.org.

For the latest developments from the CDC, including travel warnings, new cases, and prevention advice, visit www.cdc.gov.

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