

# Complex Child

<https://complexchild.org/articles/covid/covid-preparations/>

## Ten COVID-19 Preparations To Do RIGHT NOW for Medically Complex Families

As more states are shutting down and even issuing shelter-in-place orders, it is critical for families of children who are medically complex to prepare as much as possible. The following ten tips are things you can — and should — do right now in order to survive the next few months.

### **1. FILL OUT AN EMERGENCY PLAN FOR YOUR CHILD**

An Emergency Plan is critical in case your child becomes ill, and [these forms from the American College of Emergency Physicians](#) are the best option to help prepare Emergency Department staff.

Download the [Blank Interactive Form](#) and fill it out. Especially important is to document your child's normal vital signs, particularly if your child has autonomic dysfunction and has a temperature that runs low or a heartrate that runs high or low.

### **2. ORDER AS MANY SUPPLIES AS POSSIBLE AND REUSE NON-STERILE SUPPLIES**

We expect that certain items may experience shortages, especially those made in China, since factories were shut down for several months. In addition, other supplies that are being used to treat COVID-19 patients may become more difficult to get. We aren't sure exactly what these will be, but we expect respiratory supplies like vent circuits, suction catheters, as well as items like syringes may become more difficult to get.

Try to reuse non-sterile supplies such as tube feeding extension sets or oxygen cannulas for as long as possible so you preserve more of your stock. Do not reuse sterile supplies.

The federal government and individual states are trying to ease restrictions that may allow easier ordering and potentially greater quantities, though how and when this may be implemented is not entirely clear yet.

### **3. TRAIN OTHERS IN YOUR CHILD'S CARE**

Do you have a plan if YOU get sick? Who will take care of your child? What if your nurses or aides are quarantined or get sick? Try to train at least one additional person to care for your child if you become sick or hospitalized. This could be another family member, a teenage sibling, or a friend.

One good option is to find another local family with a similar child and cross-train on each other's child just in case. Another option may be to work with one or more of your home care nurses to take your child if you become sick.

Train as many people as you possible. It is possible that both you and your spouse, as well as other family members, may all be sick at the same time. Have backups for your backups.

### **4. CREATE A CARE PLAN OR MANUAL FOR YOUR CHILD**

If you become sick, someone else may end up caring for your child. You need to make sure that every aspect of your child's care is well documented so that someone can step into your shoes if needed. This plan might be one page or as long as 20 or more pages. It should include all information to care for your child throughout the day, lists of your child's doctors, emergency plans, and other such information.

There are lots of templates online to help you get started. Here are just a few:

- [Care Plans from the National Center for Patient/Family-Centered Medical Home](#)
- [The Center for Children with Special Needs](#)

### **5. PREPARE FOR QUARANTINE OR SHELTER-IN-PLACE**

If someone in your family is sick or your area has issued a shelter-in-place order, you may be unable to leave your home for 14 days or longer. In addition to the normal recommendations, such as stocking up on food, make sure you have two weeks worth of all supplies, medications, over-the-counter products, and other items your child uses on a daily basis.

### **6. STOCK UP ON MEDICATIONS AND HAVE A PHARMACY PLAN**

Many medications are made in China, and some may go into shortage since factories were closed down for awhile. While insurance and Medicaid usually make it hard to get prescriptions in advance, some states and plans are loosening requirements to allow

earlier refills or greater quantities. In some cases, this may require you to sign up for mail-order medications.

In addition, make sure you have a plan if you are unable to get to the pharmacy. Sign up for mail order delivery, switch to a pharmacy that delivers, or arrange for a family member or friend to help you out. Also make sure that none of your prescriptions are about to expire or run out of refills.

Finally, make sure to stock up on Tylenol in case your child does get sick. The current recommendation is to use Tylenol only to reduce a fever, as there is some limited evidence that Ibuprofen or Motrin may increase risks in COVID-19.

## **7. KEEP YOUR CHILD IN HIS OR HER BEST HEALTH**

If your child does get sick, you want him or her to be in the most ideal health possible. Make sure your child is getting nutritious food or tube feedings, is always well-hydrated, is not deficient in any vitamins, and is using the best possible respiratory hygiene.

Children with asthma and other respiratory conditions should continue with their regular daily medications and respiratory regimens, such as oscillating vest treatments, chest PT, or cough assist devices. This will keep their lungs in the best health possible. Note that the process of giving nebulized medications will spread COVID-19 droplets, so switch to inhalers if possible.

Of course, keeping your child home and away from germs as much possible. Don't go the ER or even the doctor's office unless it is an actual emergency.

## **8. SET UP TELEMEDICINE VISITS**

In many locations, clinics are cancelling routine visits. For many kids, these visits really make a difference in their plan of care, especially children with ongoing complications or who have recently had procedures. In many cases, these visits may be able to occur using telemedicine, on the phone or virtually using typical video-conferencing programs and apps. The federal government has loosened requirements so care can be delivered remotely in this fashion.

Contact your medical teams and ask if telemedicine visits are an option. If they are, find out what you might need to have one. Typically, you will need an internet connection or phone minutes, and you may need a computer. There are several internet providers currently offering free services to families who don't have internet access.

## **9. REST UP NOW AND EVALUATE YOUR HOME CARE**

Due to quarantines, illnesses, and other orders, you may not have any home nursing, aide services, or respite for an extended period of time. In addition, your children likely will not be attending school. For many families, this means 24-hour hands on care, day after day, which can be overwhelming, and in some cases near impossible.

Rest as much as possible now while you can. If you currently have home nursing, keep it going for as long as possible if you think it is safe.

How do you decide whether having a nurse is safe? Here are a few recommendations:

1. Nurses who are also working in hospitals or nursing homes should not be used in the home environment. They are much more likely to have exposure to infected patients.
2. Try to convince your nursing agency to send just one or two nurses to your home, preferably not shared with any other families.
3. Nurses who have traveled recently should wait 14 days before working.
4. Nurses who are not isolating themselves or social distancing in their personal lives should not be used.

## **10. BE KIND AND HELP ONE ANOTHER**

This is going to be hard on everyone, whether they have a child who is medically complex or not. In fact, in some ways, parents of children who are medically complex may be in a better position to handle these situations, as we are much more used to isolation, quarantines, and infection prevention.

We are going to need to help each other out a lot. Identify similar families in your area so you can share extra supplies if available. Provide food or financial assistance to another family who is struggling. We will only get through this by working together — from a six-foot minimum distance, of course.

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