



Resource eBlast *April 2020*

for families of children and youth with special health care needs

COVID-19 SERIES, Part 1: *Put On Your Own Oxygen Mask First*

This is the first of a three-part series. Coming soon: *Telehealth and Parenting and Ideas for Kiddos.*

Put on your own oxygen mask first!

Rather than being confined to our homes in an effort to flatten the COVID-19 curve, how many of us wish we were in another time, on a plane to a dream vacation? Can you hear the safety instructions? *“If the oxygen mask drops down, put your own mask on first, before helping others.”* Unfortunately we are not on that dream vacation, but we can still use what the flight attendants have taught us to take great care of ourselves during the pandemic.

As family and primary caregivers for our children with special health care needs, we are given (a lot of) advice and expected to comply. We are really good at following advice and implementing orders for our children...but maybe not for ourselves.

This eBlast shares **resources for self-care** and asks us to consider **what happens if we get sick**, with related types of emergency planning to consider in order to be prepared.

A Plan for Self-Care: Day by Day

Families and caregivers of children with special health care needs have been part of making MANY plans—IEP, 504, treatment, plan of care, etc.

Now it is time for YOU to make a plan for your own SELF CARE! This may feel awkward or cheesy—but lean into it. Pandemics make us stretch and grow in new ways—and putting that oxygen mask on first every day is more important than ever. Explore the links below for ideas. Make it unique to you, of course, but take some time to create it—it’s worth the investment.

- [Make a self-care plan](#)
- [Cook your way out of stress- quarantine baking and cooking](#)
- [Laugh and find hope by watching some good news](#)
- [Exercise](#)



What If I Get Sick...Where Do I Start?

One way we can help manage life’s unknowns is to prepare by talking openly about what matters to us and what we’d want most if we became seriously ill with COVID-19.

Explore this site:

[The Conversation Project](#) conversation starter kits.

Conversations about things we can’t control can actually help to give us a sense of control. We may not be able to predict every choice we’ll have to make, but we can give those we love the guiding principles to confidently make decisions for us. *If we don’t say it, they won’t know.*



Your Conversation Starter Kit

When it comes to end-of-life care, talking matters.

Who Speaks For Me If I Can't Speak?

Pick Your Person And Make It Official

- [Explore, document and share all your health, legal, funeral and legacy decisions in an end-of-life plan](#)
- [Download Your State's Advance Directive](#)

Even if it will hopefully not be needed in this pandemic, it's always a good time to be prepared for the unexpected. Choose a friend, family member or other trusted person to make medical decisions on your behalf. Talk to this person about becoming your medical care decision-maker if you can't make decisions for yourself. *Make sure the person you choose knows what is important to you first and foremost.*

Then, *document that person in an official state health care proxy/agent/power of attorney form or an Advance Directive*, a term for any written health care instruction that specifies your wishes and names your proxy.

What If I Get Sick and Can't Take Care of My Child(ren)? Where Do I Start?

Try these two resources to move towards figuring this out and getting it documented:

- [Child Care Options](#) - in [English](#) and [Spanish](#) - Family Voices created this resource to help families plan for childcare if they are deported. Getting sick is different, but the need for pre-planning is similar.
- [Basic information about estate planning and health care laws in your state](#)



Although this is a painful question, it is part of putting your oxygen mask on first. This planning may help alleviate some worry, allow you to focus on staying healthy, and enjoy the goodness of family time that shelter-in-place provides.

Document and Share All About Your Child

Finally, make sure to document and share all of the things another caretaker needs to know about your child(ren). For example: *What makes your children their spunky, unique selves? What gives your child with special health care needs life? Think about medical care, nutrition, education, therapy, supplies, nuances of equipment function or use, best position to sleep in, easiest way to give a complete bath, how to ensure all medication is completely taken, etc.*

Many of you have some sort of care binder and/or care map, and although you may not have thought of these tools in that way, you have already started planning by collecting and organizing this information.

- **Consider using this Family Voices checklist** ([English](#), [Spanish](#)), created to help families plan what information to share about their CYSHCN if deported, to help you organize what you might need to share with a designated caregiver for your child if you get sick.
- [American Academy of Pediatrics' Medical Home pages](#) have suggestions for forms that you can use to record and share this information about your child.

Caring for Others: Know Where Your Loved Ones Stand

We are very familiar with speaking up for and caring for our children. But consider the other people closest to you—friends, spouses, parents, or grandparents—*what would your loved one would want if they became very ill*/with COVID-19? It is more important than ever that you **talk** with your loved one to learn and understand what matters most to them in the event that the person becomes seriously ill. The tools above can help you understand how to care for others as their healthcare agents, and also consider [this resource from Respecting Choices](#).

Final Thought:



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