



COVID-19

CORONAVIRUS DISEASE 2019

Prepare, **P**rioritize, **E**xpectations

PPE for Families with
Medically Fragile Children

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Prepare

“In preparing for battle I have always found that plans are useless, but planning is indispensable”

~Dwight D Eisenhower

Preparing for the worst: either someone in your family catching this virus or being forced into this healthcare system through an unrelated crisis.

- Who will care for who if your child gets critically sick? if you get critically sick? Make a plan for all contingencies.
- If hospitalization is necessary,
 - What will you bring for your child? Bring all medications and specialized equipment (VNS magnetic, g-tube supplies, diapering for older children, ...). Comfort items (iPad, stuffed animals, slippers, ...)
 - What will you bring for you? Make a list so you can throw a bag together quickly.
- Do you have a list readily available of all current medications and a plan of care for you child (seizure plan, feeding schedule, ...), so that information can be quickly and reliably passed on to others? If not, consider starting one.

Prioritize

“It does not do to leave a live dragon out of your calculations, if you live by one.”

~J.R. Tolken

Good crisis management requires the ability to prioritize needs and tasks.

- Medical experts agree that during this pandemic:
 - We should prioritize staying at home
 - Utilize Telemedicine whenever possible
- But if you have a medically fragile child,
 - you and your doctor may have to weigh the medical needs of your child against the risks of seeking medical help in this environment
 - certain medical conditions may require in-house assessment and care

Always trust yourself to appropriately prioritize medical emergencies such as acute respiratory distress, status epilepticus, trauma,

Expectations

“If you align expectations with reality,
you will never be disappointed.”

~Terrell Owens

Manage your expectations, because no matter how many times your child has been hospitalized in the past, hospitalization in the current environment will be different.

- Respiratory infections will likely be treated as COVID-19, until proved otherwise.
- Isolation is real and hard on whole family.
 - Adult COVID-19 patients are required to do this alone.
 - Pediatric patients are generally allowed only one caregiver – there is no come and go.
- You may be required to handle more of your child’s care in the hospital.
- Doctors and nurses may become mentally and physically exhausted.

Treat healthcare providers with gratitude and grace. Anticipate good care but be ready to advocate on your child’s behalf if the need arises.