This is dedicated to all of our friends with neuromuscular disabilities who broke our rule. We fight, advocate, and keep on keepin' on because of you.
COVID-19 (Novel Coronavirus) Plan and Preparation Guide for Adults Living with Neuromuscular Disabilities

A 2020 publication by NMD United Volunteers

Contributors:

- Emily Wolinsky, President of NMD United/Project Lead
- T.K. Small, Vice President of NMD United/Project Advisor
- Brooklyn Marx, NMD United Board Member/Social Media Director
- Ali Ramos, NMD United Board Member/Art Director
- Elizabette Guéçamburu, Copy-Writer/Meme Maker
- Delphine Andrews, Copy-Writer
- Rachel Markley, Copy-Writer
- Jessica Maloney, Copy-Writer
- Allegra Keys, Meme Maker
- Melissa Young, Meme Maker
- Alana Theriault, Copy-Editor
- Kristen Elaine Smith, Copy-Editor
- Katelyn Orler, Copy-Editor
“If you know how to fight, you know how to survive.”
~Dan Darkow, Board Member of NMD United

About This Guide

During the weekend of March 7 & 8th 2020, NMD United volunteers came together to design a COVID-19 (novel coronavirus) guide for adults living with neuromuscular disabilities. The goal of this guide is to provide our readers with fact-based, reliable resources that educate our community on how to reduce and prevent the spread of COVID-19, while also providing practical coping tools and life-management strategies that can be used not just for this specific situation, but for addressing any viral or bacterial infection risk.

Please understand that this guide does not replace medical direction by a qualified doctor or clinical professional. NMD United is a peer-led and run organization composed of adults living with neuromuscular disabilities (NMDs). We are not doctors, pulmonologists, nurses, infectious disease specialists, etc. We are simply peers who can offer our perspectives on coping and life-management with NMDs. We understand that every individual’s situation is unique to them and that even if fifty of us do X, some in our community may choose to do Y. And that’s absolutely okay. You do you. In the meantime, here’s what some of your peers are doing, saying, thinking, asking, and preparing for in the wake of a pandemic.
# Table of Contents

- **Resources, Readings, and Media**
  - Evaluating Source Materials ................................................................. Page 6
  - Links to Bookmark .................................................................................. Pages 7-8

- **Anxiety Management and Coping Strategies**
  - How to Avoid Going Down the Rabbit Hole ........................................ Page 9
  - Mantras with Thought and Listing Exercises ....................................... Pages 10-11
  - Ways to Avoid Going Stir Crazy .......................................................... Page 12
  - Regain Your Calm .................................................................................. Pages 13-16
  - Look at the Bright Side ......................................................................... Page 17

- **Managing Your Personal Care**
  - Scenarios with Issues and Questions to Consider ................................ Pages 18-21
  - Letter to Personal Care Attendants ...................................................... Pages 22-23
  - Assertive Communication Resources .................................................... Page 24
  - Practice Your Assertive Communication Skills ...................................... Page 25

- **Emergency Preparation Checklists**
  - Home Supplies ........................................................................................ Pages 26-28
  - Go-Bag Supplies .................................................................................... Pages 29-31
Resources, Readings and Media

NMD United assumes that anyone following along with this guide is able to research basic information on COVID-19 (novel coronavirus) via the internet. Since time is of the essence, we do not want to reinvent the wheel. Here are a few great resources, readings, and media links on the virus and tools for if you get sick, its current outbreak status around the world, and recommendations from qualified sources on what to do to prevent getting up close and personal with this virus.

Evaluating Source Material

There’s a lot of bad or confusing information being spread about COVID-19 and sometimes it’s hard to know what to believe or not to believe. NMD United chose sources based on specific criteria that we recommend you also apply to your research and information gathering. This article gives great tips on how to evaluate online resources.
Emerging respiratory viruses, including COVID-19: methods for detection, prevention, response and control — A three-hour, free, online course by World Health Organization (WHO) for healthcare professionals.

People at Higher Risk for COVID-19 Complications — The Center for Disease Control (CDC) and Prevention’s guidance.

https://ncov2019.live/data — “Along with his concern for the spread of the COVID-19 coronavirus, Avi Schiffmann was concerned about the spread of misinformation. So the 17-year-old from just outside Seattle set out to make a website that pulls together the latest and most accurate data about the epidemic — and he’s heard from people around the world about how useful his effort has been.” — GeekWire (2020)

What I think about COVID-19 this morning — An essay written by Malia Jones, PhD, MPH and scholar on epidemics.

What Actually Happens If You Get Coronavirus? — A video with over eight million views on YouTube that explains how the virus works in your body.

Taking Care of Your Behavioral Health: TIPS FOR SOCIAL DISTANCING, QUARANTINE, AND ISOLATION DURING AN INFECTIOUS DISEASE OUTBREAK — This guide was published by the Substance Abuse and Mental Health Services Administration in 2014, but it has some decent tips.

Cluster, COVID-19 and all the coronavirus terms you need to know — Learn the most important terms and definitions that apply to this virus, like “social distancing,” “N95 respirator,” and “community spread,” “symptomatic,” etc.
Nursing 101: Caring for your loved ones at home — A Reddit post provided by Living with MD member, Jonathan Marchand. It’s got some great suggestions for respiratory protocols.

Creating Your Advance Directive — Please note that every state has different laws pertaining to Advance Directives. This source just provides some general guidance as you draft your own.

The WHO sent 25 international experts to China and here are their main findings after 9 days — Another interesting Reddit post from Jonathan Marchand with some data that puts things into perspective.
Anxiety Management & Coping Strategies
How to Avoid Going Down the Rabbit Hole

Limit screen time

- Avoid 24/7 news channels in favor of enjoying Netflix, podcasts, your DVD collection, or a book.
- Google Chrome offers a free Facebook Newsfeed Eradicator app that will put a motivational quote as the only thing you see when you go to your newsfeed. 
- Set personal challenges to reduce your screen-time day by day until you hit a goal.

Download the Calm app

- This app is mostly guided meditation with a background sound of your choosing. Calm has different themes to choose from, as well as sleep stories and courses on managing pain, anxiety, and stress.

Approach news and media this way

- If you feel an obligation to stay informed about COVID-19, dedicate a limited amount of time every day to read up on any coronavirus updates.
- Know the facts and stick to the facts as much as possible. Try not to spiral down into the “what ifs,” which can be stressful when you take in dramatic media information. Select news sources that are low key with less or no sensationalism or hyperbole.

Realize you are not alone in how you’re feeling

- Lose yourself in some music - sing along, dance, tap your finger to the beat, create a choreographed dance or produce a music video in your head.
Mantras with Thought and Listing Exercises

When your anxiety gets especially ramped-up, tryout some or all of these exercises:

**I have survived and I will continue to survive**
- Write about a time when you survived a crisis or succeeded in doing a difficult task. What were some of the lessons that you learned?

**Other people feel this way too**
- Create a mini virtual support group of like-minded folks to talk or chat with during high anxiety times. Who do you talk with when you get stressed? You could also go online to Facebook and join or connect with a support group for adults living with neuromuscular disabilities or other similar disabilities.

**Anxiety is just a feeling**
- Focus on feelings that relieve anxiety. What are some things you think about or do that make you happy, smile, relax? Make a list of those things and refer to it during highly anxious times.

**Release all worry and celebrate what could go right**
- List all the parts of your body that feel good right now and all the stuff that’s going right for you. Reflect on that list.
Just keep swimming
   ● List three goals that have nothing to do with your NMD and try to accomplish at least one today.

I will release what I cannot change
   ● Set a timer for five minutes. In that time, list all of your fears, anxieties, negative thoughts, worries, and worst case scenarios. When the timer goes off, stop making your list. Now, imagine or physically erase each fear one by one.

Breathing in “I calm my body”, breathing out “I smile”
   ● Check out these cool [yoga breathing exercises](#) for relaxation.

Don’t go in your mind where your body is not
   ● Think about the immediate present and stay in this moment for a set amount of time.

“I am fine. I am going to continue doing what I am doing.”
   ● List things you do that make you really happy and then do something from that list for waaaaay longer than you normally do (i.e. snuggling a pet, having coffee, SEX (with a non-contagious person of course)).

“I will calm my mind and overcome this feeling.”
   ● Close your eyes and count backwards from 100 when your mind goes 100 miles an hour.

Anxiety is not dangerous; it’s just uncomfortable
   ● Do you agree or disagree with this statement? Explain.

OK, next point. (good if you find yourself spiraling for a mind shift)
   ● List 25 specific things you are grateful for or that have gone well today or this week.

**Coronavirus: Last Week Tonight with John Oliver (HBO)**
(This is pretty funny and is good for a laugh during unfunny times.)
Ways to Avoid Going Stir Crazy

Whether you are staying inside because your area is on lockdown, or you are just limiting your exposure to the outside world as much as possible, here are some tips, ideas, and activities to keep you from going stir crazy and feeling trapped. Please note that these are just general ideas, and they may not be appropriate for every person in every situation.

- Knitting ([loom knitting](https://en.wikipedia.org/wiki/Loom_knitting) is often more accessible for those with weak hands and limited range of motion)
- **Beadwork/Jewelry making**
- **Cooking/Meal Prepping/Finding NMD-Friendly Recipe Ideas**
- **Coloring** (digital coloring is an excellent alternative if paper coloring is too difficult, and watercolor pencils are softer than regular colored pencils)
- **Take a free, online, course** on a topic you want to learn more about
- Start a [blog](https://en.wikipedia.org/wiki/Blogging) or [podcast](https://en.wikipedia.org/wiki/Podcast)
- **Write a business plan**
- **Design your dream house**
- Go through your “To Watch” list, start tackling the list
- **Practice meditating**
- **Read a book** or listen to an audiobook (Goodreads.com is a good way to keep track of your reading list)
- **Organize** your medical supplies and/or household items
- Work on a **puzzle**, whether it be jigsaw, crossword, sudoku, etc.
- **Study a new language** (many public libraries offer free access to on-line language courses)
- Plan an accessible future vacation or **road trip**
- Apply for disability related grants and scholarships, such as **NMD United's ALEF grants**
- Do virtual volunteer work (one example is through the **United Nations**)
- Play an addictive video game
- **Start building a wish list**
- Play board/card games (**BoardGameGeek** has a great database and sharing/trading/buying/selling forums)
- Listen to and/or create music
- Learn about everything **Alexa can do** for you
- Reach out to someone you haven't chatted or wrote to in a while
- Enter a poetry, short story, or essay **contest**
Regain Your Calm

The following essay is adapted to fit the lives of NMDers from the article Pandemic Panic? These 5 Tips Can Help You Regain Your Calm.

Living with a NMD can be stressful at the best of times, let alone when an infectious disease turns into a pandemic. It can be difficult to find a balance between staying prepared and responsible, and falling down a rabbit hole of anxiety and panic. We believe that a happy medium can be achieved. Here are some tips to stay prepared and calm:

Prepare before you need to.
As NMDers, we are already very well-versed in the arts of preparation and planning. Most of us do it every day without a second thought. These skills are extremely valuable when preparing for the coronavirus. If you already have an emergency go-bag (see the end of this guide for a supply list), make sure to look through it and update it if necessary. You'll want to make sure to have an adequate amount of medications, medical supplies, and general household items that you would need if your area gets locked down or you need to self-quarantine. The CDC recommends having a two week supply of these items on hand. Talk to your PCAs, nurses, and other caregivers about how you will handle things if someone gets sick or your area gets locked down. Having things prepared ahead of time is a good way to keep yourself safe and to feel more in control.
Stay educated on the virus and any updates in your area, but try to avoid obsessing over the news.

There are thousands of blogs, news sites, groups, etc. with information on the virus. It is very important to be certain that you are getting information from reliable and reputable sources. We recommend the CDC, the WHO, and your state and county health departments. Avoid spending too much time reading news articles and blogs, as that can just make anxiety worse.

Give yourself a set amount of time each day to check on updates, or sign up to get notifications from your local health agency. Have distractions ready in case you begin to fall down the news “rabbit hole” such as a favorite show to watch, music to listen to, or a book to read.

Continue to take care of your health.

This does not just include your physical health, but your mental health as well. Being proactive is important with any potential illness. The stronger and healthier you are, the better chance you will have in quickly and successfully fighting off an illness. Keep up with any respiratory treatments, such as using a cough assist, nebulizer, inhaler, bipap/ventilator, chest PT, etc. Not all of this will apply for every person, it is just meant to be a general guide. Try to eat healthy and stay hydrated when possible. Try to get enough sleep. Give yourself time each day to feel whatever you are feeling, whether it’s anxiety, frustration, fear, etc. Acknowledge those feelings because they are valid, but don’t let them consume you. Instead, redirect your mind, and focus on the things you can control.
Do your best to not let fear control your actions, while still staying responsible.

Talk to your healthcare teams about whether you should be limiting your exposure to the outside world. Currently, the CDC recommends those of us with pre-existing conditions, especially when the respiratory system is involved, stay home when possible and avoid large crowds. Many employers, especially in tech, are already having some or all employees work remotely. Discuss the option of working remotely with your employer. This may qualify as a “reasonable accommodation.”

Some states are not currently canceling events that will have large crowds, or telling people to stay home (unless they are sick or have been in contact with a sick person, of course). Despite this, we each have to decide what is the best course of action for our specific situation. We recommend that this be done in conjunction with your medical team and the recommendations from your local health department. It is important to be safe and responsible, of course, but it is also important to continue to live your life. Luckily, we NMDers are excellent at adapting to our environment and new situations. Even if you need to or choose to stay home, there are many ways to remain connected to the outside world, thanks to technology. Consider having your groceries and prescriptions delivered when possible rather than going out to buy them, though, be aware that, depending on where you live, it might be prudent to wipe down packages that are handled by shoppers you don’t know. Instead of going to the movies with friends, have a virtual movie night. Join an online book club. Technology is amazing, utilize it as much as possible.

We’re going to say what you have said to every PCA and caregiver your whole life: wash your hands!

This is by far one of the best ways to prevent the spread of COVID-19, as well as countless other viruses and bacteria. Since sinks are often not accessible to those
of us with mobility devices, hand sanitizer is a viable option. **Per the CDC**, make sure the hand sanitizer you are using is a minimum of 60% alcohol or else it will not be effective. When you are at home, another option to wash your hands is to have someone fill a bowl or another similar container with water that you can wash your hands in. Be sure whoever is helping you disinfects their hands before and after washing yours. The bowl method or using a washcloth with soap and water may not be 100% effective, because it is recommended to wash your hands for a minimum of 20 seconds each time to kill all the germs, so using hand sanitizer in conjunction with these methods is a good idea. Use alcohol to disinfect commonly touched surfaces, and don’t forget about your joystick and any other buttons on your wheelchair. Do not be afraid to constantly remind caregivers to wash their hands. If you go out in public, consider bringing a [CDC approved cleaner](https://www.cdc.gov) to wipe down anything you need to touch, as well as hand sanitizer.

---

**Your store sold-out of hand sanitizer? Make your own!**

Here’s what you’ll need:

- 2/3 cup Isopropyl Alcohol 91% (rubbing alcohol)
- 1/3 cup aloe vera gel
- essential oil in your choice of fragrance (optional!)
- mixing bowl & spoon
- empty container for storage
Look at the Brightside

As fears about COVID-19 (novel coronavirus) spread, looking at this crisis as not just a crisis, but an opportunity to show off our resilience, positive thinking, and problem solving skills becomes key to overcoming and surviving this crisis.

- We have been preparing for these moments all our lives.
- Many of us have already faced death and have lived to see another day.
- People will start paying attention to their personal hygiene practices (hopefully) and reduce our risk to get future common colds and flus.
- We are expert problem solvers and we are part of a community of problem solvers.
- Many of us already have respiratory support and protocols in place, like traches, and technology, like a Cough Assist or suction machine.
- This is one of the times in our lives when we can seize the moment and use it to prepare for future emergencies.
- We do not take our health for granted and know full well how to appreciate all the healthy days and moments that we have. We can model this for others.
- This is a great time to write essays and tell stories about how people of the world, including people with disabilities, can learn to adapt to new situations with the right societal support, like funding home and community-based services over institutionalization, or paying Personal Care Attendants more, or providing people with affordable health insurance.
Managing Your Personal Care

The following are different types of scenarios that could or may have already come up. Read and think about how you would respond to each scenario as you prepare for an potential outbreak affecting your life:

SCENARIO 1: PCA FEARS SAFETY

Madonna doesn’t live with family or roommates and only has outside personal care attendants (PCAs) who come in from outside to work in her home. Today, one of Madonna’s PCAs said she didn’t think it was safe to work during the outbreak. Her PCA explained that if a case shows up in their county she will have to miss work for at least three weeks. Madonna obviously doesn’t want to seem unempathetic (her PCA doesn’t have health insurance and makes $10.50/hour), but without this PCA on the team, she will not have enough coverage to get her basic care needs met.

Issues:
Attendance Policy - Sick Leave Policy - Communicating Needs - Empathy - Definition of “Emergency” - Fear of Neglect

Questions:
Do you have a sick leave policy? Can you require a doctor’s note? Can you get guidance from your own doctor for staff to follow?

How does Madonna handle this situation?

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________
SCENARIO 2: PCA PARTICIPATES IN HIGH RISK BEHAVIORS

J-Zee has a great team of PCAs, but they are young, and a few of them have active social lives that involve them going out on a regular basis to clubs, bars, and crowded venues. With the COVID-19 outbreak, J-Zee assumed that his partier PCAs would listen to the advice of the CDC and stay home, but at least two of the three have stated that they think the news is a bunch of hype used to get ratings up and scare people.

Issues:
Trust - Communication - Empathy - Education - Professional Responsibility - Accountability

Questions:
How do you deal with PCAs who don't follow protocols in their personal lives?
Should you hold a team meeting or meet with each PCA individually? Can you require PCAs to follow If-Then-Do protocols to keep you safe after they engage in high risk behaviors in their off time?

How does J-Zee handle this situation?
SCENARIO 3: PCA WASTES A LOT OF SUPPLIES
The stores are selling out of important consumable medical supplies that you need to use at home, like masks, hand sanitizer, and paper products. Despite this, Beebonsay, has spent a lot of money stocking up for at least three weeks of potential scarcity. Beebonsay's PCA is especially germaphobic and in an eight-hour shift, used an entire bottle of hand sanitizer, a roll of paper towels, and a half a box of latex gloves. Beebonsay is all about personal protection, but feels this is a bit ridiculous.

**Issues:**
Communication - Empathy - Education - Professional Responsibility - Inventory - Fear

**Questions:**
Have you discussed with your PCA the scarcity issue as it pertains to your specific situation? Can you look into ways to get cheaper supplies or reimbursed for the supplies you have already bought (like with a [NMD United ALEF grant for consumable medical supplies](#))? Have you asked your PCA directly to monitor their use of supplies?

**How does Beebonsay handle this situation?**

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
SCENARIO 4: PCA IS WAY TOO OVERPROTECTIVE/PARANOID
Prance usually gets sick once a year in the spring when the flowers and grasses are in full bloom. Last year, he was hospitalized for a number of weeks with the flu and pneumonia. This morning he woke up with some slight congestion and a headache. His PCA is demanding he go to the Emergency Room ASAP for COVID-19 testing. When Prance explains that he feels this is an overreaction, his PCA gets angry and states that he doesn’t want to be held responsible for Prance’s death and therefore, may have to quit.

Issues:
Communication - Empathy - Paranoia/Past Trauma - Personal and Professional Responsibility - Autonomy

Questions:
Have you discussed with your PCA your personal criteria for deciding to go to the Emergency Room? Does your PCA understand that you are the boss of your own body? Is your PCA prone to overreaction? Is there something you could write down in official format to absolve the PCA of the feeling of responsibility?

How does Prance handle this situation?
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
Letter To Personal Care Attendants

Below is an example of an email that you can copy-change and send to your team of Personal Care Attendants, which address illness prevention in the event of a public health crisis.

Dear Team,

As you’re all aware, the novel coronavirus or COVID-19, is something our community/city/country, is preparing for, and as your employer, I feel that it’s also important that we address how a public health crisis such as this could possibly affect our small team in the coming months.

Because I am an adult living with a neuromuscular disability, I am in a high-risk category for death with any illness that impacts respiratory function. Understandably, I’m concerned about my health and safety. I am also concerned for each individual on this team. I want you to know what I’m doing to prepare for a possible personal health crisis. I have:

1. Regularly visited the Center for Disease Control & Prevention and World Health Organization websites for updates.
2. Called my doctors and re-upped my stock of respiratory supplies and prescription meds.
3. Stocked my house with sanitizing cleaners, masks, gloves, etc. for you to use.
4. Consulted with my medical team to review protocols if I become symptomatic.
5. Updated my Power of Attorney and Living Will, providing the necessary copies to people who will take over if I cannot speak or advocate for myself.
6. Created a phone tree for extra support and have friends on hand to reach out to in the event that you, as a member of my personal care team, cannot assist me.
7. Talked to my employer about accommodations I will need in order to continue working remotely.
8. Established a private fund to pay each of you for up to five days of sick leave if absolutely necessary.

My goal is to prevent a major disruption to your work and my life. With that, I am going to need your help to keep us all healthy. Until further notice, when on duty I will need you to:

1. Call me as soon as possible if you have any sign or symptom of illness and stay in regular contact. Make sure you take your temperature and if you have a fever, please refer to the
Substitute Phone Tree so you can help me find your back-up. You will need to be fever-free for 24 hours before you come back to work.

2. If you’re sick for more than three days, I will need you to provide me with a doctor’s note to activate your sick leave.

3. Wash your hands immediately upon coming into the house and regularly throughout your shift.

4. Wear and change your gloves regularly throughout your shift.

5. Wipe down and clean surface areas, door knobs, medical equipment and tubing, and other bacteria/viral-ridden areas during your shift. Please use cleaning supplies per my instructions.

6. Monitor your use of supplies and prevent waste as much as possible, while also protecting yourself and me.

7. Notify me immediately if members of your household are symptomatic and/or have a fever even if you yourself are not feeling sick.

8. Leave an extra set of clean clothes to change into while working. I will launder those clothes in your absence.

Please let me know if you have any questions or concerns about what you’ve read above. Thank you for all you do to keep me healthy, safe, and independent.
Assertive Communication Resources

Below are some resources focusing on assertive communication techniques that you can use with any of your care providers.

What is assertive communication?

Assertive communication is the ability to express positive and negative ideas and feelings in an open, honest and direct way. It considers our rights while still respecting the rights of others. It allows us to take responsibility for ourselves and our actions without judging or blaming other people. It falls in the middle of Aggressive and Passive Communication.

NMD United hosted a webinar on having tough conversations with Personal Care Attendants and using assertive communication. Check it out!

Being assertive: Reduce stress, communicate better - Here is a great article from the Mayo Clinic that offers some great tips in learning assertive communication techniques.
Here’s another great tool that discusses how to implement **assertive communication**.

### Practice Your Assertive Communication Skills

<table>
<thead>
<tr>
<th>I feel X</th>
<th>When you do Y</th>
<th>In situation Z</th>
<th>And I would like X</th>
</tr>
</thead>
<tbody>
<tr>
<td>I FELT FRIUTRATED</td>
<td>WHEN YOU REFUSED TO WASH YOUR HANDS AFTER I ASKED YOU TO</td>
<td>THIS MORNING</td>
<td>AND I WOULD LIKE YOU TO UNDERSTAND THAT WASHING YOUR HANDS IS IMPORTANT RIGHT NOW.</td>
</tr>
<tr>
<td>I FEEL UNHEARD</td>
<td>WHEN I ASK YOU TO CALL IN WHEN YOU’RE NOT FEELING WELL</td>
<td>AND YOU COME TO WORK ANYWAY</td>
<td>AND I WOULD LIKE YOU TO PLEASE BE RESPECTFUL OF MY HEALTH AND GO HOME ONCE WE FIND SOMEONE TO COVER.</td>
</tr>
<tr>
<td>I FEEL RESPECTED</td>
<td>WHEN YOU SANITIZED THOSE TWO SURFACES THAT I FORGOT TO ASK TO SANITIZE</td>
<td>YESTERDAY</td>
<td>AND I HOPE YOU KNOW THAT IT MEANT A LOT TO ME.</td>
</tr>
<tr>
<td>I FELT APPRECIATED</td>
<td>WHEN YOU REMEMBERED TO RESTOCK MY MEDICAL SUPPLIES WITHOUT ME REMINDING YOU</td>
<td>BEFORE YOU LEFT FOR THE DAY</td>
<td>AND I JUST WANTED YOU TO KNOW HOW MUCH I APPRECIATE YOUR EXTRA EFFORT.</td>
</tr>
</tbody>
</table>
Emergency Preparation Checklists

It is always important to be prepared, especially when you are someone with extensive medical needs. Many of us already have a “go bag” on hand for natural disasters and other emergencies. For COVID-19, it is unlikely that you will need to evacuate quickly. The more likely scenario is that you will need to quarantine in your home for a period of time. We do not recommend “panic buying”—you don’t need a year’s supply of toilet paper. The CDC recommends having enough supplies to be able to stay in your home without leaving for two weeks. There are thousands of preparation lists available, but we wanted to make one that focuses on our specific needs as NMDers. If you need financial assistance in order to purchase medical supplies, we encourage you to apply for NMD United's ALEF Consumable Medical Supplies grant.

Please note: this is a general list and all items do not necessarily apply to all. Feel free to download this list for personal use and adapt it to your specific needs.

Home Supplies

- BiPAP/CPAP/ventilator
  - Masks/mouthpieces
  - Tubing and adapters
  - Filters
  - AC & DC Power cables
  - Extension cords
  - Batteries
  - Chargers
- Suction machine
  - Yankaeurs/catheters
  - Tubing
  - Canisters
  - Filters
  - Power cord
- Cough assist
- Masks/mouthpiece
- Tubing/adapters
- Filters
- Power cord
- Nebulizer
  - Mask/mouthpiece
  - Tubing/adapters
  - Medicine cup
  - Medicine
  - Power cord
- Gtube supplies
  - Feeding bags
  - Extension sets
  - Syringes
  - Gauze/tape/tubie pads
  - Blended food/formula
  - Backup button change kit
  - Power cord
  - Batteries
- Catheter supplies
  - Overnight/leg bags
  - Extension/connector tubings
  - Flip flo valves
  - Catheter change kit
  - Alcohol swabs
  - Gauze/tape
  - Flush syringes
  - Gloves
- Prescription medications
- Over the counter medications
  - Acetaminophen
  - Ibuprofen
  - Tums
  - Gas-x
- Stool softener
- Benadryl
- Creams/ointments
  - Antibiotic cream
  - Vick's vapor rub
  - Steroid cream
  - Barrier cream
- Supplements/Vitamins
- Toiletries
  - Hand sanitizer with at least 60% alcohol
  - Wet wipes
  - Shampoo/conditioner/body wash
  - Toothpaste
  - Mouthwash
  - Tissues
  - Toilet paper
  - Hydrogen peroxide
- First aid kit
- Flashlight
- Batteries
- Wheelchair/scooter battery charger
- DME temporary repair kit
  - Duct tape
  - Pliers
  - Screwdriver
  - Wire cutter
  - Measuring tape
  - Zip ties
  - Scissors
- Cleaning supplies
  - Bleach
  - Rubbing Alcohol
  - CDC approved disinfectants
  - Multi-surface cleaners
- Dish soap
- Laundry detergent
- Service animal/pet supplies
- Two weeks’ worth of NMD-friendly foods
  - Hummus
  - Nut/seed butter
  - Applesauce
  - Yogurt
  - Potatoes
  - Fruit/veggie smoothies
- Two weeks worth of water if unable to drink from the tap
- Important papers/documents
  - Birth certificate
  - ID/passport
  - A list of all your current medications and allergies
  - Health insurance cards
  - Medical records/any kind of protocols
  - Advanced Directive/Living Will

**Hospital “Go-Bag” Checklist**

- Clothing
  - Comfortable pajamas
  - A light robe, oversized shirt, or warm cardigan
  - If ambulatory, slippers with rubber soles (to prevent slipping)
  - Plenty of socks and underwear
  - Outfit to wear home
- Toiletries
  - Toothbrush, toothpaste, and deodorant
  - Hairbrush or comb
- Soap, skin care products, and hair care products, if you prefer your own
- Personal care products like tampons, sanitary pads, or denture cream
- Glasses and/or contacts
- Adaptive hair washing tray or tub
- Wheelchair/scOOTer battery charger
- A cell phone charger for your cell phone
- Your laptop charger if you intend to bring one
- Extension cord
- Earplugs if you are a light sleeper
- An eye mask if you have trouble sleeping in lighter rooms
- Entertainment such as books, a portable DVD player, puzzles, or magazines
- Earbuds or earphones for your phone or portable electronics
- Non-perishable snacks, especially if you have dietary concerns
- Important papers/documents
  - ID/passport
  - Copies of prescription medications
  - Health insurance cards
  - Medical records/any kind of protocols
  - List of treating physicians
  - List of contacts for DMEs, medical supply companies, pharmacies
  - List of settings for BiPap/ventilator, feeding pump, and Cough Assist (emphasize settings for illness if they differ)
  - Emergency contacts
  - Advanced Directive/Living Will
- Cough assist (Many hospitals do not have one)
  - Masks/mouthpiece
  - Tubing/adapters
  - Filters
- Bipap/ventilator (bring your items so you are as comfortable as possible)
  - Masks/mouthpieces
  - Humidifier
  - Tubing and adapters
  - Filters
- Label all your medical equipment and supplies with your name.