



COVID-19 Materials for People Living with Spina Bifida: Guidance During a Global Pandemic

Introduction:

Global pandemics recognize no national borders, language, or creeds. Globally we are all facing an unprecedented scene with COVID-19. In this setting individuals living with Spina Bifida, a chronic condition that presents unique medical and neurodevelopmental challenges, deserve special attention and warrant adaptation of current guidance. In this spirit, we offer the following materials. Specific information relevant to your geographical area can be sought from your local state health department. Additionally continually [updated information](#) can be also found at the Centers for Disease Control and Prevention (CDC) website.

General Guidance:

- COVID-19 is spread via **aerosol**, which means particles can be inhaled from the air when a person coughs or sneezes. It is also shed in other body fluids, **such as urine and stool**, as well as nasal secretions and saliva. Therefore, it can be spread through poor sanitation before and after catheterization or toileting procedures, by poor secretion control, or by touching kitchen or bathroom surfaces.
- The CDC reports that relatively few children with COVID-19 are hospitalized, and fewer children than adults experience fever, cough, or shortness of breath. Parents and caregivers should ensure that they and their children follow everyday preventive behaviors and physical distancing, because patients with less serious illness and those without symptoms likely play an important role in disease transmission.
- In general, individuals with Spina Bifida are NOT at increased risk of being infected by COVID-19 or increased risk of severe illness. However, people with Spina Bifida or a loved one may fall into a high-risk category. These would include:
 - Adults over the age of 60
 - People with heart disease
 - People with chronic respiratory issues
 - People with diabetes
 - People with medical conditions or taking medications which may make them immune-suppressed.



- There is no medication to treat or prevent COVID-19 infection at present, though medications to treat symptoms of fever, cough or congestion maybe recommended.
- Remember that stigma will not help fight illness. The risk of COVID-19 is not connected with income level, race, ethnicity, or nationality.

Infection Prevention:

- Wash your hands with soap and water or alcohol-based sanitizer frequently. Soap and water are as effective as hand sanitizer if it is used properly. To do this, lather up your hands and scrub for at least 20 seconds. This is the length of time to sing the “ABC Song.”
- Wash or sanitize after the following situations:
 - After coughing or sneezing, even if you have covered your cough.
 - **Before and after** catheterizations, bowel routines or any toileting procedures, even if you have used gloves.
 - Touching potentially contaminated surfaces.
- Avoid touching your face, nose, or mouth unnecessarily. Wash your hands after touching your face.
- Avoid touching surfaces in public places (elevator buttons, door handles, etc.) as much as possible. Consider using a tissue to touch those things. Wash or sanitize after touching if possible.
- Clean and disinfect counters and equipment at work.
- Clean and disinfect your home to remove germs: practice routine cleaning of frequently touched surfaces (for example: tables, countertops, doorknobs, light switches, handles, desks, toilets, faucets, cell phones, etc.).
- Check with your home medical supply companies and /or providers that sign for supplies, for any questions regarding the delivery of supplies.
- Cover your mouth and nose with a cloth face cover when around others
- Practice “social distancing”: avoid close contact by maintaining distance with other people.
- Avoid tightly crowded spaces with unknown individuals, if possible.

Self-Management and Learning:

Utilize this time to maximize at-home learning which may not be achievable when school is in session. For example, if you have been wanting to work on a self-management, cooking, cleaning skill, etc., use this time to break down the task into steps to maximize the learning at home. Since we all have more concentrated time at home, take the next steps towards self-management. As a parent, if your child has expressed interest in self-catheterization or self-bowel management use this time to problem solve together and come up with ways to enhance independence in any area.



Also, use this time to fine-tune bowel and bladder management programs. Take advantage of available *telehealth* visits and time at home to improve your bowel and bladder care.

- Call your physicians and nurses who may have ideas for next steps that could be helpful to improve continence or self-management.
- Do not be afraid of telehealth, this may be an optimal time to make changes with so much family time in the home.

Take this time to learn together by having fun.

- Go outside and play a game in the yard or play a board game. These activities not only promote healthy family relationships but can also provide opportunities to strengthen executive functioning skills.
- Creative learning will be beneficial in many ways and are wonderful alternatives to “screen/TV time.”
- Engage in physical activity as a family -- this can be accomplished by learning a new online workout together.

Secondary to social distancing measures implemented by school districts, students with Spina Bifida may be completing most of their schooling at home. Although we are all different from each other; there are some common characteristics in individuals with Spina Bifida that may have adverse impact on learning, in particular on on-line and independent learning: Deficits in attention and focus-exacerbated by a more “passive” learning environment, and varying relative strengths in verbal and social learning. Additionally, deficits in executive function skills can substantially compromise independent learning.

- Executive function skills include:
 - Planning Tasks
 - Initiating Tasks
 - Managing Time
 - Organizing Space
 - Evaluating Self-efficacy
 - Problem-solving and flexibility

It is important to consider special education services related student rights in this time of obligatory remote learning. **Individualized Educational Plans** and **504 Plans** remain in force, and schools are required to maintain the related services. Although accommodations and related services may look different in this environment, do communicate with your school’s special education coordinator if you have concerns (please see *Supplemental Resources* section below).

Creating a schedule for daily activities and stick to it will help the student at home. Give yourself (or your student) grace, do not over schedule your time. Set yourself up for success by scheduling regular breaks, snacks and shift in activities.

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Expectations should be clearly articulated, and then let your student be as independent as possible. Do not “hover,” encourage and support independence.

Amount of academically engaged time should be age appropriate:

- No more than 2-3 hours per day in 20 minute blocks for elementary students.
- 3-4 hours per day in 30 minute blocs for middle school students.
- 5-6 hours in per day 30-45 minute blocks for high school students.
- 6-8 hours per day in 45-60 minute blocks for college students (full time students should be “working” at college as though it was a full time job).

- It is also important to designate space for schoolwork and consider the following:
 - Comfortable seating and proper desk height.
 - Proper lighting.
 - Minimize distractions.
 - Maintain all needed academic materials readily at hand.
 - As is age appropriate, together clear and organize the space every night to prep for the next day.

Mental Health:

- Furthermore, Spina Bifida may already affect how we think and feel and COVID-19 has dramatically changed how we live. Unprecedented changes are valid reasons to feel uncertain and anxious.
- We should also recognize that people with Spina Bifida might already be predisposed to specific issues such as depression, executive dysfunction, and isolation.
- Many people with disabilities are concerned about their needs, such as:
 - Not being heard by their health care providers
 - Home health aides are not being available
 - Accessible transit services postponed or cancelled
 - Availability of supplies

- We must recognize that COVID-19 poses a real threat to our lives and the lives of our friends and families, as well as our livelihood. However, we are still in control of some aspects of our lives and we are able to remain positive. Part of taking control involves developing a plan.

Steps to take which may support your mental health:

- Seek safe ways to connect with your friends, neighbors, church, and maintain sense of community. Connecting with other people helps yourself and helps others.
- Remember that, how we think affects how we feel.
- Control your intake of COVID-19 news.

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- Seek information from CDC and WHO, and do not rely on unverified sources.
- Do what you can to stay healthy.
- Control what you eat.
- Look for ways to exercise and stay physically active.
- Questions to ask yourself:
 - What would you be doing if COVID-19 were not happening? In addition, try to keep your daily routine (that does not include staying in your pajamas)
 - If you think, you are sick: whom can you call on to help?
 - Who can you reach out to if you have a mental/emotional health crisis?
 - Whom can you call if you are feeling sick?

Medical Transition:

During the COVID-19 pandemic, the clock does not stop, and your young adult may be even closer to the Transition point to adult medical care. Learn more on this *Got Transition* portal (<https://gottransition.org/resourceGet.cfm?id=540>).

- As a young adult you must remember that: **When you take charge of your health, you take charge of your life!**
- Use a calendar to plan the transition. You have to know where you are before you can plan where you are going! Find out where you are on the journey to adult health care.
- Find out what you already know about your health and health care by completing the *Transition Readiness Assessment*. The other family members can and should do it on the same website and then you can compare their answers!
- Setting goals is an important part of helping you achieve independence in your health care. On this website, you can fill out an outline to establish your health goals.
- A smartphone is a great place to store important information about your health. Complete a medical identification (mini-record) on your smartphone, which can be accessed by anyone in an emergency.

Frequently asked questions:

- *What if you rely on a home-health nurse that also work with other clients?*

If individuals have health aides coming in to their homes, those aides should self-screen for symptoms of COVID-19. In addition, they should wear a mask and wash their hands with soap and water for 20 seconds before and after assisting their clients with Spina Bifida.

- *If our adult child has to be hospitalized, could he have a family member stay with him? He cannot make medical decisions on his own.*

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Caregivers of adults with Spina Bifida should have legal documentation of power of attorney or legal guardianship that indicates a need for the adult with Spina Bifida to have assistance for medical decision-making, and they should provide that documentation to the hospital. A family member staying with the adult would need to be discussed individually with hospital providers as each hospital is able to set its own rules and restrictions, and special situations such as yours may need to be made on an individual basis.

- ***If you are on a prophylactic antibiotic due to catheterization, are you at greater risk?***

SBA does not believe that being on a prophylactic antibiotic places you at increased risk.

- ***I have seen people wearing latex gloves in grocery stores, banks or gas stations. This puts us with latex allergy at severe risk of developing an allergic reaction, and we are terrified of going to a store to buy food that has been handled by someone wearing latex gloves. What can we do?***

While many people are using latex gloves as a protective measure, we have also seen people wearing vinyl or nitrile gloves, which do not pose a risk to people with latex allergy. One option is to contact the establishment in advance of your visit to ask if they are using latex or non-latex gloves. Parents who have a child with latex sensitivity or allergy should not take them to places where they may be at risk of exposure.

If an adult with Spina Bifida has latex sensitivity or allergy, they could ask friend or family member to shop for them, and ask them to wipe items down before they are brought into the home. Additionally, people with allergy or sensitivity to latex can protect themselves by wearing a mask and non-latex gloves when they enter establishments that could have been exposed to latex. For more information, visit [SBA's information about latex allergy](#) website and the [Asthma and Allergy Foundation](#).

- ***Do frequent UTIs increase risk of getting COVID-19?***

Frequent UTIs are not considered an increased risk factor for COVID-19. However, it is recommended that you wash your hands before and after each toileting and bowel procedure.

- ***Does being a full-time manual wheelchair user put you in a high-risk group?***

This is a challenge, and it depends much on your level of mobility. People who are able to do some walking may have a decreased risk of lung disease compared to those who are full-time wheelchair users. Regardless of your level of mobility, practice six feet of social distancing: six feet from side to side and six feet in front and back of you. This will reduce the potential spread from coughs, sneezes, and secretions.



- ***Does having Spina Bifida and epilepsy put a person at a higher risk of getting COVID-19?***

The Epilepsy Foundation states that having epilepsy alone does not put people at higher risk of getting COVID-19. For more information, visit the [Epilepsy Foundation](#).

- ***Wet Ones® wipes are said to be antibacterial, but do they work for COVID-19? Many of us use those for clean up, but what should we use instead, since it's impossible to find our usual wipes in the store and we can't use soap and water when we are away from home?***

You may want to try keeping a travel-size bar of soap in a plastic bag or plastic travel soap container, as well as paper towel, in your bladder/bowel supply bag. That way you will always be able to use soap and water to keep yourself clean.

Also, ask yourself: Do I have to be out of the house? Is it possible to work remotely? Additionally, try to time your outings with your bowel/bladder routine so that you can avoid having to void and clean yourself in an environment outside of your home.

- ***When we receive packages, supplies, groceries, and other materials through the mail or by delivery, should they be handled in a special way? Does the CDC have a list of personal hygiene and household cleaning products that they recommend?***

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Whether you go shopping for groceries or have them delivered, follow the CDC's current guidance for cleaning and disinfecting items in your house. [Visit the CDC's website](#) for general recommendations on cleaning and disinfecting.

- ***Are people with Spina Bifida and sleep apnea (both central and obstructive); ones who have never had a productive cough; people with shorter torsos (with a smaller chest and lungs); and those with reduced lung function at more risk from COVID-19?***

People with Spina Bifida who have thoracic-level lesions or who have severe scoliosis may be at increased risk of having more severe complications from COVID-19 because it causes significant respiratory issues.

People with a thoracic-level lesion are at increased risk in general because they don't have full lung expansion or the ability to clear their airways of secretions. People with thoracic-level defects are usually also more likely to have scoliosis, and have restrictive lung disease. Restrictive lung disease happens when the lungs are not able to fully expand. Even if someone has not been formally diagnosed with restrictive lung disease or does not have significant

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scoliosis, it is still wise to take the extra precautions and presume that they are at a high-risk group.

- ***Do people with Spina Bifida and a chronic lung diagnosis have to make a greater effort to wipe down items brought into the home?***

People with chronic respiratory issues (the CDC includes moderate to severe asthma in this category) are at greater risk of experiencing severe symptoms of COVID-19. We suggest following the [CDC's guidance on cleaning household items](#).

- ***I have Spina Bifida and am in my late 40's. I have borderline hypertension and no other underlining condition. Besides the usual precautions from the CDC, are there any other precautions I should take?***

The best option is to follow the CDC's hygiene recommendations. People with hypertension are not at increased risk of catching COVID-19, but they may be at increased risk of facing more severe symptoms of the disease if the hypertension has caused their heart to work harder than normal.

- ***Does reduced kidney function, chronic kidney disease, or chronic liver disease affect the immune system's ability to fight the virus?***

Both chronic kidney disease and chronic liver disease may impair immune function. People who have these conditions may be at increased risk of getting the disease due to a weakened immune system, and face an increased risk of the disease being more severe. They should speak with a health care provider who knows their individual situation and circumstances. Everyone should [follow all recommendations from the CDC on how to protect themselves](#).

- ***Does having lymphedema heighten my risk of getting COVID-19?***

We don't know with certainty. The lymphatic system plays a significant role in immune function. Lymphedema is frequently accompanied by obesity, poor circulation, or heart disease. As such, SBA would consider a person with lymphedema to be at increased risk of contracting COVID-19, and suggest that they speak with their health care provider for more specific information. We also cannot overemphasize the importance of hygiene: [follow the CDC recommendations for protecting yourself](#).

- ***Does having a Mitrofinoff or ACE/MACE procedure and cathing several times a day lower your immune system and expose you to a greater risk of contracting COVID-19?***





People who have a Mitrofanoff procedure, Antegrade Colonic Enema surgery (ACE) or Malone Antegrade Colonic Enema (MACE) procedure, or who catheterize, could contract the infection by spread from secretions. They should maintain good hand hygiene before and after doing any kind of procedure.

The virus spreads by secretions we make, so you would not necessarily be at risk if you don't have COVID-19. But, if you require assistance to perform these procedures, there could be a greater likelihood of spread as a result of being in close contact with the person assisting you, and possible exposure to aerosolized particles spread through cough. However, washing hands before and after procedures, particularly if people assist you with a MACE or catheterization, will protect you.

- ***If you have SB and MRSA, are you at increased risk?***

Not necessarily. A number of people are colonized with MRSA, meaning that MRSA is on their skin and body. However, they are not getting sick from it. We do not know that having MRSA colonized as opposed to being actively ill with MRSA would be any more of a risk factor in contracting COVID-19.

- ***Does COVID-19 affect people with shunts?***

Having a shunt does not place you at increased risk of getting COVID-19. We don't know if having a ventriculo-atrial (VA) shunt or ventriculo-pleural (VPL) shunt versus a ventriculo-peritoneal (VP) shunt would be an issue if you got a COVID infection. Contact your health care providers if you suspect that you have COVID-19 so that they may monitor you closely, and review the guidance from the [Hydrocephalus Association](#) for patients with hydrocephalus.

- ***Are people with a suprapubic catheter at a higher risk from having that opening in our bodies?***

Having the suprapubic catheter in place does not automatically place you at higher risk. But it is imperative that you follow good hygiene techniques and the CDC's recommendations for staying at home, social distancing, and cleaning your home.

- ***If you contract the novel coronavirus and recover, can you get it again?***

The full answer to this is unknown. However, doctors and researchers believe that if you have had COVID-19 you are less likely to get it again. It is believed that you will develop immunity to this current virus. That hope is the basis for work on developing a vaccine.



- ***If a caregiver gets symptoms and can't fully isolate, what should they do — besides follow usual hygiene procedures — to avoid transmitting COVID-19 to children with Spina Bifida while assisting them with tasks that require direct contact such as catheterizing, administering enemas, and lifting them?***

If someone in the household is sick, that person should isolate themselves as much as possible and stay in a single room. If possible, the person should use a separate bathroom and wear a mask when other family members or caregivers are nearby. Every day, clean all surfaces that are touched frequently by family members. Caregivers should wash their hands appropriately after providing ANY care to a person with COVID-19. Everyone in the home should avoid touching their face.

- ***Should I wear a mask and gloves out in public?***

The CDC is now recommending that people who are out in public both practice social distancing as well as wear a cloth face covering. It is hoped that wearing a face covering will decrease the risk of COVID-19 being spread by aerosol by people who are asymptomatic or mildly symptomatic. Gloves themselves won't prevent people from getting COVID-19 unless they strictly follow all the general hygiene recommendations.

- ***Are newborn babies at a higher risk due to their decreased immune system?***

At present, we simply do not know. There is little information about COVID-19 in babies. The CDC will learn and gather more information as the pandemic continues. [Follow the CDC's recommendations](#) on how to protect yourself and your baby from getting COVID-19.

- ***What options do I have to stay active during this time when we are mostly stuck at home?***

View SBA's SB-You webinar, [Get Fit and Stay Healthy!](#) It has many great ideas for staying active if you cannot visit the gym or leave your house.

- ***I am adult with Spina Bifida, and I have a few lung issues. I was invited to a gathering at a friend's house. I have not been out unless necessary. Is it okay for me to go?***

Please follow the social distancing guidelines recommended for your area. Err on the side of safety. The recommendation from the CDC would be to not attend gatherings for now; consider organizing or attending a virtual gathering instead.



- *How long will the virus live on a wheelchair? Could a wheelchair bring it into the home?*

We believe that the risk of spread from this kind of contact is less common, but it certainly may occur. We don't know for sure how long the virus will survive on different surfaces, including wheelchairs. It may vary depending on the amount of virus a person is exposed to or how much exists in the environment. It likely also depends on the type of material a surface is made from. In laboratories, the virus has been detected for up to 72 hours.

Supplemental Reading and Resources:

Educational sites for younger students:

<https://www.prodigygame.com/>

<https://www.getepic.com/>

<https://www.splashlearn.com/>

<https://www.teachervision.com/lesson-planning/essential-resources>

Educational sites for middle school/junior high students:

<https://www.commonensemedia.org/>

<https://www.etutorworld.com/middle-school-tutoring.html>

<https://www.teachervision.com/lesson-planning/essential-resources>

Resources for adult learners learning at home:

<https://www.beyondbooksmart.com/>

<https://blog.edx.org/tips-for-successful-online-learning/>

Learning platform support:

<https://help.blackboard.com/>

https://docs.moodle.org/22/en/Moodle_video_tutorials

<https://support.google.com/edu/classroom/?hl=en#topic=6020277>

<https://support.zoom.us/hc/en-us>

<https://support.office.com/en-us/teams>

Enrichment activities:

<https://artsandculture.google.com/>

<https://www.boredteachers.com/resources/50-online-art-and-music-resources-to-help-kids-learn-and-create-from-home>





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