



SECTOR PANDEMIC  
PLANNING INITIATIVE

# COVID-19 Health Monitoring & Supportive Care in Home and/or Developmental Services Residential Care Settings

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## Background

*For this document “person or people” refers to an individual with a developmental disability or intellectual and developmental disability (IDD).*

The following document was developed by senior staff of developmental services agencies that have health care backgrounds and experience. As this group shared information on caring and supporting individuals with IDD who were COVID-19 positive, we were encouraged to develop a document. We gratefully acknowledge Karen Cowan, Director of Health Services, New Visions Toronto, who is the primary author and lead on this project.

We realize that some of the information in this document is clinical in nature. It may be best used by key leads in a developmental services agency. They may wish to interpret and communicate this material to a wider group of supervisors and staff in their organization.

It is important to note that the information in this document is not medical or health care advice— the reader must follow their own agency’s health care practices and protocols.

COVID-19 does not have a specific treatment and the symptoms can be quite common and vary from person to person. Although we have focused on some of the symptoms we have seen in those who are COVID-19 positive with IDD, the monitoring and management are no different than usual. Due to this, ensure that all symptoms are reported to the person’s health care provider (HCP) so that another health issue is not overlooked.

A key focus of this document is to highlight how we need to be prepared and proactive. Our hope is that by increasing awareness and planning, this helps to “flag” issues, enabling a timely and appropriate response.

It is important to recognize that a diagnosis of a COVID-19 illness must be made by the HCP and that the symptoms identified below can also be present in other illnesses. Also, be aware that the person may have a combination of symptoms rather than a single one.

Healthcare providers are mostly using a symptomatic approach, meaning they treat the symptoms rather than target the virus, and provide supportive care, (e.g. oxygen therapy, fluid management) for persons with COVID-19 illness which can be highly effective.

We strongly encourage that you review [Primary Care Guidance Regarding COVID-19 for Those Who Care for Adults with Intellectual and Developmental Disabilities](#); (Dr. William Sullivan, May 19, 2020) [[see bio](#)]

*“This briefing note is for healthcare providers and caregivers of adults with intellectual and developmental disabilities (IDD). It provides primary care guidance regarding the novel coronavirus (SARS-CoV-2) and COVID-19, the disease it causes.”*

Each person with a developmental disability may experience symptoms very differently. This document makes some broad generalizations in order to convey information. However, at any point, no matter what is written here, you are significantly concerned about an individual – you must follow your agency’s emergency policies and procedures. This may include contacting their physician, on-call health services, telehealth or 911 as necessary.

## Disclaimer

This document is meant for a diverse group and we encourage people to review it and forward it on to the appropriate people within the organization

It does not constitute clinical advice. It is a consolidation of experiences to be shared.

People who have IDD must be monitored closely. Should their symptoms worsen, call a HCP or TeleHealth Ontario at 1-866-797-0000, or call 911 as necessary.

## Managing Symptoms

Symptom(s)	Why manage	Monitoring/Management Guidelines	Pre-planning: IE in anticipation
<p>Fever (<a href="#">37.8°C and above</a>), chills and severe body aches.</p> <p>Temperatures above 38°C or 1°C above the person’s usual body temperature indicate a fever, which warrants management with fever-reducing medications. Fever may re-occur over a period of 24-48 hours, but then may occur mostly during evening every few days.</p> <p>May be accompanied by chills, severe body aches and fatigue.</p>	<p>Although a fever is helpful to fight the virus, the accompanying severe aches and chills can be very distressing resulting in the person being dehydrated and not wanting to drink sufficient fluids. The body aches can result in worsening in spasticity, so monitoring for changes in muscle coordination related functions is needed, (e.g. swallowing and mobility changes).</p> <p>Be aware that some persons with IDD may not express pain typically, so be alert for that person’s expression of discomfort.</p> <p>Be aware that some people will ‘hold their breath’ or breathe very shallow when in discomfort</p> <p>Fevers and infection can be accompanied by delirium if not managed especially if the person is older</p> <p>Be aware of Kawasaki-like illness associated with COVID-19 in children. (see <a href="#">Resource page</a> from the Canadian Pediatric Society)</p>	<p>Manage symptomatically and approach proactively once symptoms arise. Offer Acetaminophen or Ibuprofen every 4 -6 hours once a fever develops, around the clock for 24 - 48hours, while awake according the person’s medication order.</p> <p>Providing this over 1-2 days may improve the goal of keeping a person as comfortable as possible, especially for those who may not be able to request pain relief at the earliest sign of it recurring, due to their limited communication abilities.</p> <p>(see <a href="#">Resource page</a> for About Kids Health advising on safe use of Acetaminophen and Ibuprofen.</p> <p>Also note that some children may be unable to take Ibuprofen due to renal failure or heart failure, etc.)</p> <p>Check temperature immediately prior to giving medication and then every hour until it returns to baseline, then every 4 hours for 24</p>	<p>Ensure that the person has a prn ibuprofen, and that the medication is on hand. Review PRN protocol. The HCP should provide specific direction for acetaminophen and ibuprofen use when the person has a compromised immune system, or when either medication must not be used due to other health issues, such as a low immunity. Monitor for effectiveness of medication and keep a log of temperature; contact HCP or pharmacist if not effective. Ensure that you have a working thermometer (Ear temperatures are fairly accurate and least invasive. Current infrared thermometers are not consistently reliable). Avoid oral thermometers if possible to minimize risk of exposure. Ensure there are extra tip covers and replacement batteries. Disinfect health monitoring equipment appropriately.</p>

		<p>- 48 hours, then twice/day until well.</p> <p>Plan to offer fluids while the medication is effective.</p> <p>Track fluid intake.</p> <p><i>Never</i> give a tub bath or shower when the person has a fever.</p> <p>If fever persists after 48 hours, contact the HCP.</p>	
<p>New or Worsening Cough or shortness of breath</p> <p>(usually dry cough)</p> <p>Note: Cough may persist for several weeks.</p>	<p>While productive cough can be helpful to expel secretion, dry cough can cause discomfort in the chest, contribute to decrease appetite and cause (or worsen) fatigue.</p> <p>For some, the dry cough can cause significant distress, impacting their ability to rest and heal.</p>	<p>Avoid lying on back as this can make coughing ineffective.</p> <p>Offer a teaspoon of honey</p> <p>If cough is distressing, discuss with the HCP to consider cough suppressants.</p> <p>For individuals with asthma, COPD or other respiratory disease, discuss with their HCP if additional treatments are needed.</p>	<ol style="list-style-type: none"> <li>1. Identify individuals with respiratory disease who might require additional treatments</li> <li>2. Have honey available at the site</li> </ol> <p>If cough suppressants are needed, discuss OTC options versus codeine preparations (especially in individuals with chronic constipation or other contraindications)</p>
<p>Nausea, vomiting</p> <p>May last for 24 – 48 hours</p>	<p>Important to manage in order to maintain hydration which may prevent the need for a visit to the Emergency department for IV treatment for dehydration.</p> <p>Managing the nausea will ensure that the person may tolerate drinking, and prevent the person from associating drinking/eating with nausea/vomiting.</p>	<p>Provide hydration frequently throughout the day. Ensure fluids are given in appropriate texture for swallowing issues, (e.g. thickened if needed). Consider cold drinks and sipping with a straw which can minimize the nausea, (if safe to use straw with swallowing issues). Provide dry crackers or toast if tolerated to ease nausea.</p>	<p>Adequate household beverages for rehydration such as teas, Gatorade, half-strength apple juice (1:1 water and juice). Have a PRN/as needed order for Gravol (dimenhydrinate), given by mouth/oral or g-tube, or per rectum (suppository). Be aware that oral and g-tube routes can</p>

		<p>Provide anti-nausea medication (e.g. Gravol) on the advice of the HCP, and repeat as ordered for 24 – 48 hours while awake during this period. Monitor for drowsiness and potential falling, especially for people with have compromised mobility</p> <p>Plan to offer fluids after the anti-nausea medication takes effect (approx. 40 minutes)</p> <p>Monitor fluid intake and voiding pattern.</p> <p>Monitor skin turgor/elasticity and other signs of dehydration (see <a href="#">Resource page</a> for About Kids Health outlining signs of dehydration and how to treat it)</p> <p>Hold Domperidone (on the advice of the HCP)</p>	<p>be repeated every 6 hours, PR every 8 hours. Review PRN protocol before administering. Have Gravol/anti-nausea medication easily accessible for use when needed. Offer emotional support/reassurance to the person. Monitor effectiveness. Consult with HCP or pharmacist if Gravol is not effective.</p>
<p><b>Dehydration</b></p> <p>Can present in a variety of the following ways, and if not managed can lead to severe dehydration requiring IV hydration.</p>	<p>Managing nausea/vomiting, fever, and diarrhea, may help with preventing severe dehydration.</p> <p>If the person is already taking diuretic type medication (e.g. furosemide or ‘Lasix’,) this could worsen dehydration, and should be discussed with their HCP.</p> <p>If fluid losses through not drinking or diarrhea, hold “sick day” medications.</p>	<p>Need to be proactive.</p> <p>Track fluid intake and output.</p> <p>You may need to offer fluids every hour, while awake.</p> <p>If the person is awake during the night offer fluids, then as well.</p> <p>(Aim for a daily fluid intake of 1500 – 2000 ml throughout the day.)</p> <p>Contact the HCP (including pharmacist).</p>	<p>Ensure that you have favourite clear fluids/light foods on hand for each person.</p> <p>Ensure adequate household beverages for rehydration such as teas, Gatorade, half-strength apple juice (1:1 water and juice).</p> <p>Replacement electrolyte solutions including liquid and popsicles should be on hand as advised by the HCP.</p>

Some patients who are diabetic may already have orders for this (see [Resource page](#) for guidelines from Canadian Journal on Diabetes).

Boost® Beverage which is a clear meal replacement, can be offered on the advice of an HCP if there is concern of weight loss.

If the person will not typically drink, and is more likely to eat a high fluid fruit (e.g. watermelon).

Ensure easily accessible fluids/formula for anyone who relies on enteral nutrition (g-tubes)

Use a fluid intake/output record.

Severe weakness, worsening of balance

People who have a neuromuscular disorder (e.g. spasticity, ataxia, poor balance,) may be too weak to get out of bed or sit up to drink or take their medications unassisted.

The supported person may not realize that they are weak, which could result in them falling when they do try to get up.

An unexpected fall can result in an injury or fracture, which would then require treatment or hospitalization.

Explain to the person that they might feel weak, that it is only temporary and ask them to call you when they need help. Report concerns about falls risks.

If they are capable, ask them to call you, when they need to get up. If they are non-verbal, may consider bed or floor alarm.

If a person does fall, assess for any injury and treat accordingly and follow your organization's protocol on falls.

Develop a plan to avoid another fall.

Anticipate this for everyone who has a neuromuscular disorder and is ambulatory.

Contact LHIN Home & Community Care for specialized in-home assessments if needed.

**Diarrhea**

Diarrhea can lead to dehydration, which can become severe if unaddressed.

Offer mostly clear fluids, and a very light, bland diet (rice, applesauce, bananas, crackers or dry toast) to help slow diarrhea.

Offer hydration frequently throughout the day to prevent dehydration as well as during the night if the person is awake.

Do not be in a rush to advance the diet, as the lining of the intestines may need a few days to heal.

Track fluid intake and output.

Contact the HCP or pharmacist for medication advice.

Ensure that laxatives are put on hold.

If any blood in the stool, contact the HCP immediately. Monitor for discomfort and consult with the HCP for advice.

Have items for bland diet at hand.

Adequate household beverages for rehydration such as teas, Gatorade, half-strength apple juice (1:1 water and juice).

**Exacerbation of other diagnoses**

Example: an increase in seizures, asthma flare-up.

As COVID-19 will affect people differently due to their other diagnoses, you need to monitor for this

Contact their HCP to inform them as additional medications may be required during this time to manage the exacerbation.

Anticipate the possibility of a worsening of other diagnoses and have necessary prn medications and supplies on hand. Review protocols to ensure they are up to date.



## Emergency Warning Signs

Symptom(s)	Why manage	Monitoring/Management Guidelines	Pre-planning: IE in anticipation
<p>Trouble breathing, persistent pain or pressure on the chest, new confusion, inability to wake or stay awake, bluish lips or face.</p> <p>Low oxygen level (oxygen saturation level below their normal, or below 90%)</p>	<p>This can worsen rapidly (i.e., within 24 hours. )</p> <p>“Covid pneumonia” can develop slowly. The person may develop a low oxygen level or a “silent hypoxia”. This is where blood oxygen saturation levels become low but the person shows no sign of respiratory distress.</p>	<p>If someone is showing any of these signs, seek emergency medical care immediately.</p> <p>Contact 911 and plan to transfer to hospital emergency.</p>	<p>If possible, monitor oxygen saturation levels using an oximeter and obtain a baseline for each person.</p> <p>Be prepared by knowing the specific steps required to take when calling 911 during a pandemic. See <a href="#">Calling 911</a>.</p> <p>(see <a href="#">Resource page</a> for COVID-19 Hospital Transfer Form for Patients with Intellectual and Developmental Disabilities)</p>
<p>Severe dehydration: symptoms can include</p> <p>Fatigue, cramping, muscle weakness, difficulty walking, dizziness, confusion, forgetfulness, headaches, difficulty breathing, dry mouth, nose, or skin, sunken</p>	<p>Severe dehydration is a leading cause of hospitalization especially for older persons.</p>	<p>During the frequent monitoring of the COVID positive person supported, if note any of the signs or symptoms of severe dehydration, notify their Healthcare Practitioner.</p> <p>Discuss arrangements for intravenous fluids either in hospital or in home with the HCP.</p>	<p>Utilize an active monitoring log for symptomatic person supported to monitor for signs and symptoms. Consider monitoring blood pressure and heart rate once or twice daily.</p>

eyes, inability to sweat or produce tears, notable increase in body temperature, elevated heart rate, low blood pressure, low urine output, dark colored urine

<p>Review for potential medications that require being placed on hold or discontinuation during their COVID-19 illness (e.g. Risedronate, furosemide/Lasix, multivitamins)</p>	<p>The person may be less able to take all of their usual medications due to any of the above listed symptoms. It may not be in the person's best interest during an illness of a week or two to insist that they take all medications when feeling unwell</p> <p>Ensure that by giving these medications, that you will not worsen the illness</p>	<p>Holding medications requires direction from the HCP or pharmacist who knows the person.</p>	<p>Discuss with HCP or pharmacist about prioritizing and/or holding medications during the period of being unwell.</p> <p>e.g. Lasix is essential but it is good to ask the HCP to reassess dose if fluid losses or not drinking</p>
<p>Palliative Care Support</p>	<p>Persons with developmental disability may have a pre-existing Advance Care Plan that may need updating in the context of COVID-19 pandemic measures. If the older Advance Care Plan is not updated in this context, there is a risk that the person may not receive appropriate COVID-19 illness supportive care.</p>	<p>Review/update past Advance Care Planning Documents within the context of potentially treatable COVID-19 illness and/or context of the person still possibly benefiting from transfer from home to hospital care for supportive measures.</p>	<p>Ontario-specific Developmental Disability Primary Care Program Advanced Care Plan guidelines and tool (see <a href="#">Resource page</a>)</p>

## Further Suggestions

**Additional monitoring support for the caregiver—** The Coronavirus does not affect everyone the same way. Direct Support staff may be asked to provide health care to a supported person about whom they know very little despite relevant documents being available. In this case, it is especially important that a supervisor or nurse should be checking in with the direct support staff at the beginning and end of each shift. By doing so, you may be able to take proactive measures to address questions that were not previously thought of.

**Staying connected—** with family, friends and favourite staff, virtually, can lessen the anxiety for the person with IDD. Having someone who knows them well, can provide the person the support they need to get through a few days of illness and can help prevent the need to be hospitalized.

**Calling 911—** If a resident/client is going to be taken to a hospital or clinic call ahead. If a resident/client is very ill and requires acute care, call an ambulance and let the 911 operator know that the individual is symptomatic for COVID-19. Follow Dr. William Sullivan's\* recommendations for Transferring a Patient (see [Resource page](#)).

\*Dr. William Sullivan (CCFP (COE), FCFP, PhD) is an Associate Professor in the Department of Family and Community Medicine, University of Toronto. He has a certificate of added competency in Care of the Elderly from the College of Family Physicians of Canada, in which he is also a Fellow. He is the founding director of the [Developmental Disabilities Primary Care Program](#). Dr. Sullivan works as a family physician in Medical Services at Surrey Place (Toronto). In this capacity, he provides primary care assessments of adults with intellectual and developmental disabilities and consults to their family physicians and other healthcare and developmental services providers. He also has a teaching practice in the Academic Family Health Team at St. Michael's Hospital, Toronto.

## Resources

- [COVID-19 Hospital Transfer Form for Patients with Intellectual and Developmental Disabilities](#)
- [Primary Care Guidance Regarding COVID-19 for Those Who Care for Adults with Intellectual and Developmental Disabilities](#)
- [Ontario Ministry of Health. \(2020\). COVID-19 Guidance: \*Congregate Living for Vulnerable Populations\*](#)
- [COVID-19 Guidance for Group Homes and Congregate Settings, Toronto Public Health, Fact Sheet.](#)
- [New York Times. \*The Infection That's Silently Killing Coronavirus Patients, Opinion, Dr Richard Levitan\*](#)
- [Ontario Ministry of Health; Covid-19 Reference Document for Symptoms Version 5.0 – May 25, 2020](#)
- [Public Health Ontario; CHECKLIST Managing COVID-19 Outbreaks in Congregate Living Settings – June 1, 2020](#)
- [How Mild COVID-19 Symptoms Can Quickly Turn Serious](#)
- [Canadian Pediatric Society- A Kawasaki-like illness associated with COVID-19 in kids? What parents need to know](#)
- [Canadian Journal of Diabetes- Appendix 8: Sick-Day Medication List](#)
- [About Kids Health- Article on Dehydration](#)
- [About Kids Health- Article on How to Give Acetaminophen and Ibuprofen for Fever](#)
- [COVID-19 Advance Care Planning: A guide for caregivers of adults with intellectual and developmental disabilities](#)
- [Community Living Burlington- Patient Summary for a Person with a Developmental Disability \(for reference\)](#)