

COVID-19: Guidance for Prevention and Care

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1. Introduction

This guide is intended for educating care providers of people with IDD. As we learn more about COVID-19, information contained in this guide could change or be supplemented.

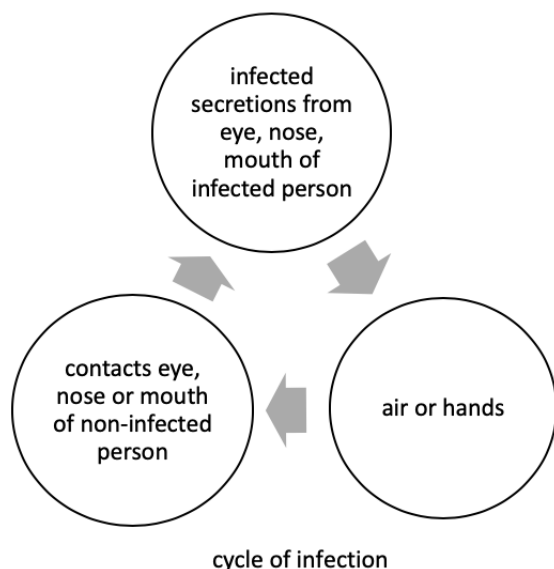
COVID-19 is an illness associated with flu-like, acute respiratory infection (ARI) symptoms. We cannot see the virus that causes it without special instruments. No vaccine has yet been developed to immunize people nor is there any treatment that can cure COVID-19. It is crucial, therefore, to understand how the COVID-19 virus spreads and adopt preventive behaviours to reduce the risks of significant exposures to this virus and of transmitting it. In this way, we can minimize the number of people who will become seriously ill and die from COVID-19.

Most people with COVID-19 experience mild ARI symptoms and will usually fully recover within one week. They are likely not highly contagious if they no longer have ARI symptoms for at least 2 days. Some people with IDD, however, have health conditions that make them physically vulnerable to becoming very sick with COVID-19. Many can also be socially vulnerable when they do not have adequate supports during the pandemic (e.g., lack of accessible health and prevention information, loss of supports due to illness or self-isolation of family caregivers or reduced staffing of care providers, including support workers). There are also specific practical, ethical, and policy issues that relate to care of people with IDD.

2. Patterns of transmission

2(a) Spread

People can become infected when the COVID-19 virus comes into contact with moist surfaces or mucous membranes on their faces (e.g., the lining of their eyes or conjunctiva, the insides of nostrils, and the insides of mouths).



The first possible route is through tiny droplets of nasal mucus or phlegm carried by air that have been expelled by infected people when they sneeze or cough on or near us (within 6 feet or 2 metres). Studies suggest that droplets with viruses can remain in the air for an hour or more, although not at levels high enough to pose a health risk to persons unless they spend a significant amount of time (e.g., 15-30 minutes) in an enclosed space with an infected person with ARI symptoms. It is also possible to be infected by the virus through direct or indirect contact with an infected person's tears, mucus or saliva. When those with COVID-19 have gastro-intestinal symptoms, the virus can also be in their urine and bowel movements.

The second possible route is through contact, when our hands (even gloved hands) touch a surface on which droplets, mucus or saliva from an infected person have landed, and then we touch our faces. The virus can last on surfaces, especially steel and plastic ones, for 1-3 days.

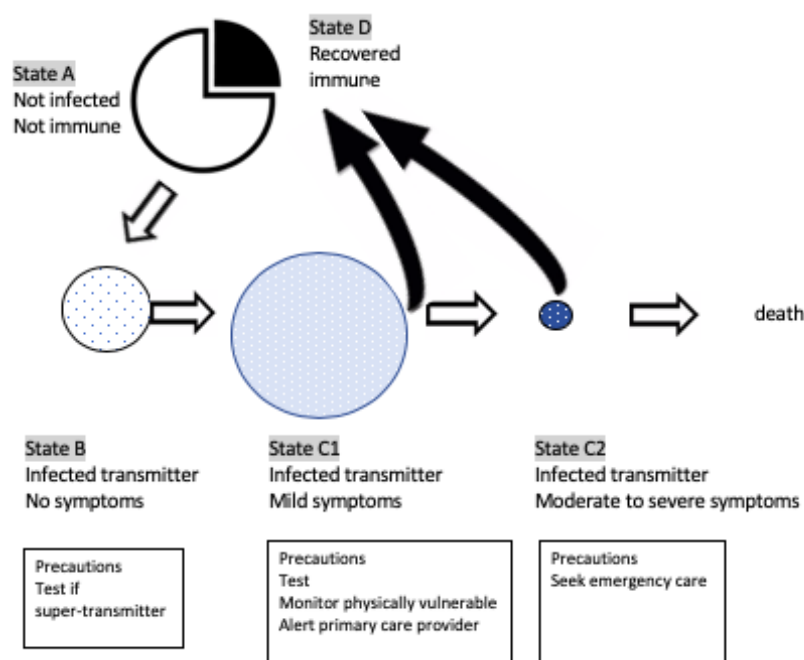
Significant exposure depends on one or more of these factors: close contact with someone who is infected with symptoms (less than 6 feet or 2 metres); shared spaces with someone who is infected, especially those with ARI symptoms, for a prolonged period (e.g., 15-30 minutes); in either of these cases, significant exposure involves not practicing respiratory (coughing or sneezing) etiquette, not adequately sanitizing hands and disinfecting shared objects and surfaces, not physically distancing from others or not wearing appropriate protective equipment (i.e., droplet and contact precautions).

People with IDD often live in homes where physical distancing and the level of hygiene needed to prevent transmission might be difficult to maintain. Care providers entering those homes might be super-transmitters—see section 2(c) below. People with IDD might also need support learning and understanding new preventive behaviours or might have difficulty controlling secretions from eyes, nose or mouth (e.g., drooling).

2(b) States (COVID-19 status of a person with IDD or care provider)

- State A:** **Never infected and not immune:** Many will become infected. *Precautions (e.g., isolation if possible) and monitoring for COVID-19 symptoms are especially vital for those who are vulnerable to developing severe ARI symptoms if infected.*
- State B:** **Infected and without symptoms:** People in state B can still transmit the virus without or before having ARI symptoms by contaminating shared objects and surfaces. *Super-transmitters—see section 2(c) below—who might be in state B following a significant exposure should self-isolate, self-monitor for symptoms of COVID-19, and be tested as soon as possible.*
- State C1:** **Infected with mild symptoms:** People in state C1 should *alert their primary care physician* as soon as symptoms associated with COVID-19 are noticed for advice about testing and management in the community.
- State C2:** **Infected with moderate to severe symptoms (e.g., chest pain, new shortness of breath).** Severe symptoms can be life-threatening. *Follow up with primary care provider or seek emergency care according to the person's advance care plan.*
- State D:** **Recovered and immune.** Based on experiences with other viral infections, those who have fully recovered from COVID-19 are likely immune from re-developing COVID-19 and are no longer sources of the virus. Currently,

state cannot
determined



people in this
be
by testing.

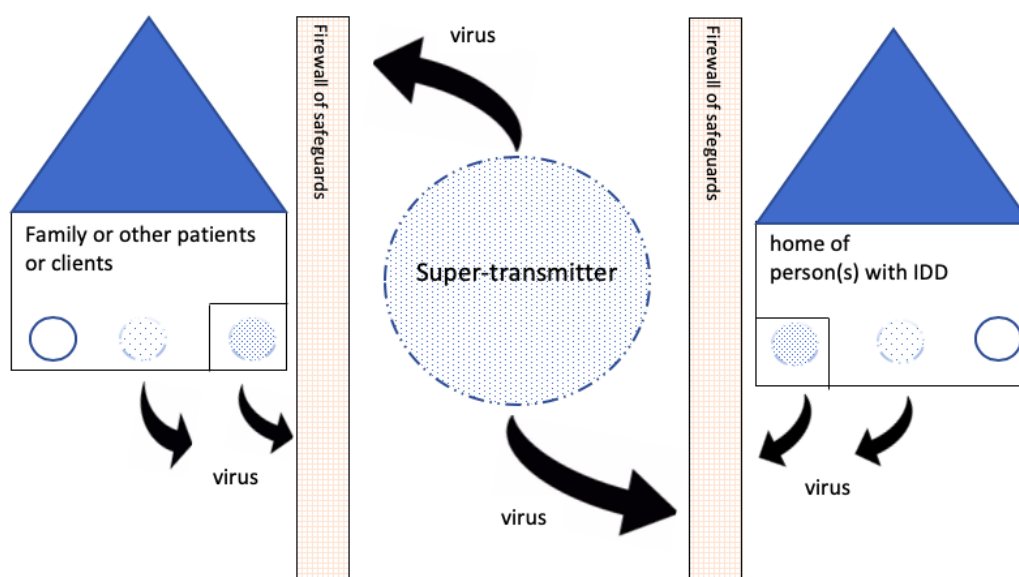
2(c) Super-transmitters

Super-transmitters are people who interact with many other people during the pandemic and are at risk of significant exposures to the virus (e.g., personal or disability support workers, healthcare providers, potentially any member of the public who interacts with many people without physical distancing or isolation).

Persons who have significant exposures from multiple sources of COVID-19 virus are super-transmitters of this virus. They will often not know what state relative to infection with COVID-19 virus they or others with whom they interact are in:

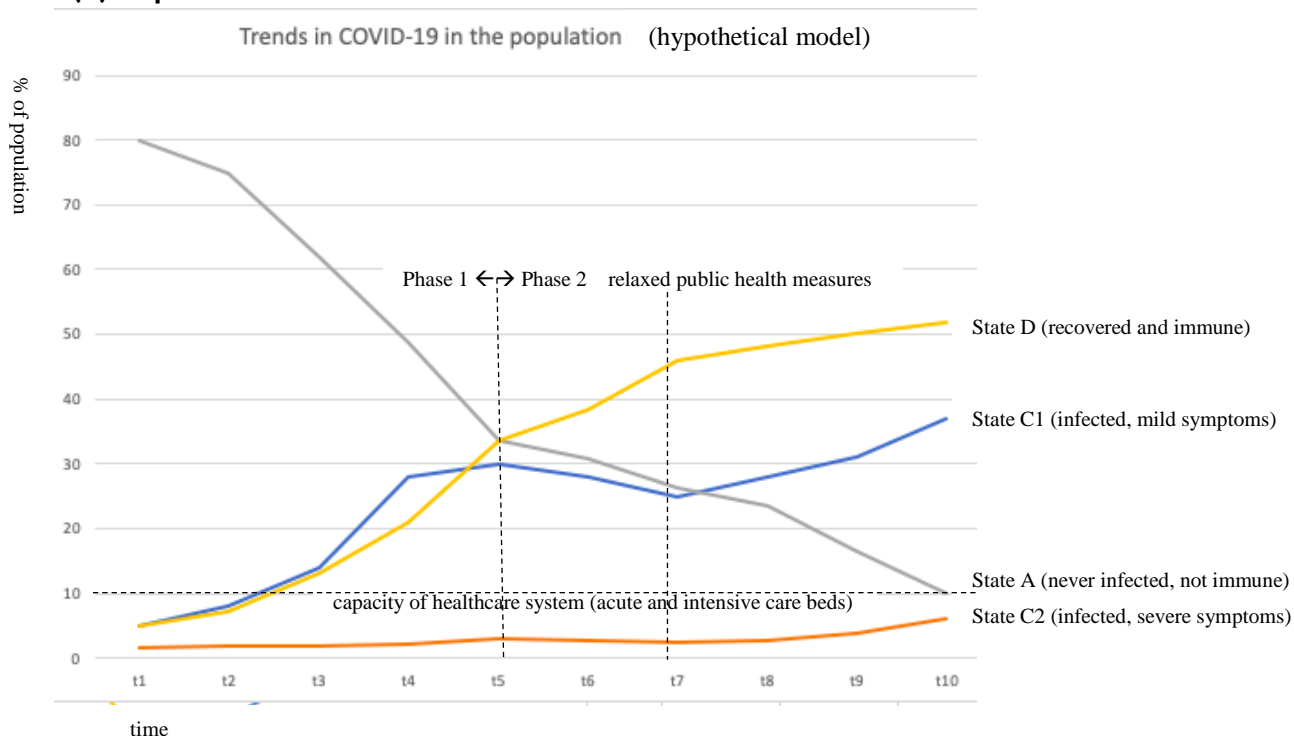
- They or others with whom they interact could be infected with the virus but not yet have developed noticeable symptoms (state B).
- ⊗ They might live or work with persons who have never been infected (state A), some of whom might be physically vulnerable to developing severe ARI symptoms if infected.
- ⊗ They might live or work with persons who have COVID-19 and are in isolation.

In mitigating viral spread in the community, special precautions should be taken in regard to super-transmitters who are healthcare providers or support workers, before and after entering homes of people with IDD. [See Precautions section below.]



Importance of safeguards in regard to super-transmitters who can be a source of infection to/from their family members or other patients or clients and to/from the home of person(s) with IDD during their visit.

2(d) Population trends



During the early phase of a pandemic (Phase 1), there will be decreasing numbers of people in state A (never infected, not immune), represented by the grey line, as new infections rapidly increase (red and blue lines). Over time, the rate of new infections will begin to decrease as public health measures succeed. This is referred to colloquially as “flattening the curve”. In this model, this occurs after t4. The public health goal in Phase 1 is to slow down the rate of increase of people in state C2 who have severe symptoms (red line) so that the capacity of the healthcare system (e.g., numbers of acute and intensive care beds) is sufficient, while gradually increasing the number of those in state D who fully recover from COVID-19 and become immune (orange line). It is uncertain how long Phase 1 will last, but it will likely be several months. Much will depend on observing public health measures, widespread and effective testing and tracking of COVID-19 transmitters, testing for immunity, and effective vaccines and treatments.

In this model, Phase 2 could be presumed to begin at t5 when the percentage of the population in state D (recovered and immune) equals those in state A (never infected, not immune), and the majority of the population is or has been infected. Based on these dynamics, a time will arrive during Phase 2 when restrictive public health measures can be relaxed. If public health measures are relaxed or withdrawn too early in Phase 2, however, there is a risk that the number of new infections and of people in state C2 (severe symptoms) could surge and risk exceeding the capacity of the healthcare system. In this model, this happens after public health measures are relaxed at t7.

There are other factors not considered in this model that could change the dynamics of these trends. These include more effective testing and tracking for the COVID-19 virus, testing for immunity, increased capacity of the healthcare system, development of treatments and a vaccine. The general point is that establishing stringent public health measures can help significantly to slow down spread of the virus so that the healthcare system will have the capacity to address patients' needs. Some measures, however, cause significant hardships for members of the public, and especially for people with IDD and their family caregivers who are vulnerable to becoming even more socially isolated. Others are difficult to enforce. Such measures will eventually need to be relaxed. The challenge in doing so is finding the right balance between accommodating people who are socially vulnerable while optimizing care of those who are physically vulnerable to developing severe symptoms of COVID-19. Often these are the same groups of people.

3. Needs of people with IDD

Public health measures should take into account the specific needs of people with IDD.

- **Accessible information:** Infection prevention, health care, and financial support information relating to COVID-19 should be communicated at a level of understanding or in formats accessible to people with IDD. For example, there should be alternative ways of delivering information to those adults with IDD who do not use or have access to computers and the Internet.
- **Accessible testing and health care:** Specialized testing and care areas for COVID-19 that are set up for the public should be accessible to people with limited mobility and resourced to support people with behaviours that challenge. Remote health care should also be offered in ways that people with IDD can access.
- **Maintaining or replacing supports:** In-home supports and community programs that are essential or beneficial for people with IDD are likely to diminish or stop for several months. Solutions will need to be found to replace these supports. For example, support workers should be included among providers of essential services during the pandemic. Supports should be offered to family caregivers, who might themselves be physically vulnerable, and who need to self-isolate or who fall sick. Creative solutions should be developed to address heightened social exclusion, loneliness, boredom, helplessness, and stress, which already disproportionately affect people with IDD and their family caregivers.
- **Adapting public health measures for risk reduction:** Physical distancing and isolation might be difficult to achieve and maintain in some family and group home settings. Risk reduction strategies should be developed for such settings. For example, people with IDD for whom entirely restricting their engagement with others is unrealistic will need supports (e.g., more frequent monitoring of their health, alerting police and other public officials in charge of enforcing physical distancing measures that they are vulnerable persons).

4. Preventive behaviours

Here are examples of plain-language instructions and suggestions for teaching people with IDD behaviours to reduce risk of infection by the COVID-19 virus. For examples of videos, picture books, and plain-language information that can be used for teaching, see Helpful Resources below.

- **Respiratory (sneezing and coughing) etiquette:** Sneeze, cough or blow your nose into a tissue or into your elbow. Throw used tissues into the garbage right away. (Demonstrate using a lined garbage container.)
- **Washing hands:** Use soap and water to wash your hand for 20 seconds after being outdoors, coughing, sneezing, blowing your nose, or touching food. (Show how to do this or play video.) If you cannot wash your hands, use a hand sanitizer and let dry in the air.
- **Don't share things that you use or another person uses personally** (e.g., toothbrush, towel, cell phone).
- **After touching things that others have touched**, such as tabletops, countertops, door handles, handrails, faucets or shared appliances (this is unavoidable in family households or group homes), remember to wash or sanitize hands.
- **Don't touch your face** (especially eyes, nose, mouth) with unwashed hands. Don't bite nails or pick your nose. These behaviours might be difficult to avoid for some people. Consider teaching an alternative behaviour, e.g., regular face washing with soap and water or using a fidget ball.
- **Only go out when you have to** (e.g., to buy food, pick up medication or exercise once a day). Don't arrange to meet groups of friends or family members (no more than 5 people). Stay in touch using the phone or computer.
- **Physical distancing:** When you go out, keep your distance or leave a space of about three arms' length or 6 feet (2 metres) from people. Avoid touching, shaking hands, high-fives, hugging or kissing. One approach could be to teach positive behaviours instead of or in addition to physical distancing, e.g., how to offer friendly greetings at a distance and other gestures of solidarity like waving.

5. Precautions for providers of home care

Before a home visit:

- **Avoid wearing** jewelry, a watch, nail polish or anything through which the COVID-19 virus could be brought into the home. If you do wear a watch, for example, clean it before and after the home visit.
- **Bring** washable overclothes, e.g., a gown, or bring a change of clothes. Also bring something disposable or washable to cover your shoes or another pair of shoes.

During a home visit:

- **Hygiene routines:** Observe respiratory etiquette and regularly wash and sanitize your hands. Carefully clean belongings such as cell phones and glasses. Avoid touching your face with unprotected hands or gloves.
- **Interact with anyone in self-isolation last.**
- **Personal protective equipment (PPE):** Examples of when to use a procedure or medical mask, disposable gloves, and overclothes include: activities that involve close personal contact, contact with someone in states B or C for 15 minutes or more in an enclosed space, contact with bodily fluids (e.g., washing, bathing or assisting with other personal hygiene routines, doing laundry, and performing a physical assessment as a healthcare provider), situations where proximity to a patient or client who has symptoms of COVID-19 is unavoidable, and where physical distancing of the patient or client from another person at home who is sick is difficult to maintain.
- **Full PPE** (e.g., N95 masks, eye protection, gloves, gowns) is usually reserved for use by healthcare providers and paramedics when assessing or performing certain medical procedures **who has or is likely to have COVID-19**. For PPE to be effective, one needs to use proper techniques when putting it on and removing it. See video under Helpful Resources below.

After a home visit:

- **Hygiene routines:** Wash and sanitize your hands. Carefully clean belongings such as cell phones, watch, and glasses. Take home any overclothes or changed clothes in a disposable paper bag and wash before the next use in hot water. Leave shoes at the door when you return home and clean them.

- **Self-isolation:** Self-isolation means staying at home and separating oneself from other members of the household as much as possible. Healthcare providers and support workers are potentially super-transmitters. If you have symptoms associated with COVID-19 or have had significant contact (e.g., without PPE) with a family member, patient or client who does, even if you yourself do not have those symptoms, you should stay home in self-isolation. Follow public health and organizational policies for the period of self-isolation (e.g., 14 days). Ideally, it is advisable for super-transmitters to be tested for COVID-19 virus before returning to work and be symptom-free for 48 hours.

6. Health monitoring

- The time from exposure to developing ARI symptoms associated with COVID-19 is usually 2-14 days (this is sometimes referred to as the incubation period).
- Watch for new cough, fever, shortness of breath, sore throat, runny nose or any combination of these. **Other less common symptoms** associated with COVID-19 could include muscle aches, nausea, diarrhea, reduced sense of smell or redness of eyes (conjunctivitis). Some infected persons might **only experience diarrhea** without respiratory symptoms, which makes them less infectious through droplets than those with respiratory symptoms (i.e., no droplet precautions are needed).
- Health monitoring is important for some physically vulnerable persons with IDD without symptoms (state A). **They might not be able to communicate new symptoms they are experiencing or might do so in non-typical ways.** Alert their primary care provider when new symptoms are noticed.
- **Check for symptoms that might not be noticed** (e.g., fever). Do so before taking medications such as Tylenol or Advil, by measuring body temperature once or twice a day. Temperatures above 38°C or 1°C above the person's usual body temperature indicate a fever. Look also for the following behaviours in persons who are unable to report feeling unwell: looking flushed or pale, feeling hot or cool to the touch, being atypically fussy or groggy, having "goose bumps", shivers or tremours, diarrhea, excessive sweating and/or being more thirsty than usual.
- **Check for worsening ARI symptoms especially in people with IDD who are physically vulnerable to developing serious symptoms if infected by the COVID-19 virus** (e.g., new continuous coughing and new shortness of breath or rapid breathing with typical activities such as walking up the stairs). For persons with challenges communicating, consider checking oxygen saturation levels if possible (usually a drop of oxygen saturation levels from usual levels of 95-100% to less than 90%, or 5% below typical levels, is significant and a reason to call your primary care provider.

- **Be attentive to changes in behaviour that might communicate heightened stress, intense anxiety, and emotional distress.** Recognize that COVID-19 is bad news, and grieving can be expected. To promote mental health, encourage talking about worries and difficult feelings or expressing feelings with drawings or other forms of art. Encourage exercise at home or once a day outdoors. Encourage continuing spiritual practices.

7. Medically managing symptoms

See also section 6 on Health monitoring above. Alert a primary care provider as soon as new ARI symptoms associated with COVID-19 develop or worsen.

- **In-home care:** In general, isolation and medical care for persons showing new ARI symptoms associated with COVID-19 can be supported at home with guidance from a primary care provider. During this pandemic, most primary care providers have switched from in-person office visits to consultations by phone or Internet.
- **Health Passports** (e.g., About Me—see Helpful Resources below): People with IDD should have a health passport that informs healthcare providers and hospital staff who might not know them well about their medical history, health and support needs.
- **Medical supplies:** Maintain a 2-month stock of medications and other medical supplies (e.g., puffers, oxygen) that the person you care for regularly uses.
- **Advance care plan:** Persons, especially those who are physically vulnerable to developing severe symptoms of COVID-19, should have updated advance care plans. Develop or review these plans with the person and others who know the person well to ensure that the patient’s wishes, goals and values regarding emergency and end-of-life care are known and can be supported.

8. Seeking help from healthcare providers

- **Health information from media, social media or Websites:** Ask for advice from your primary care provider before trying new medications and other therapies still under investigation based on information from such sources.
- **Vaccinations:** There is not yet a vaccine for COVID-19. It is a good idea to get vaccinated for Influenza (“regular” Flu) and Pneumococcal Pneumonia (Pneumovax) to lower the risk of these possible co-infections if one becomes infected with COVID-19.

- **Medical helpline:** Use reliable helplines (e.g., Telehealth Ontario (toll-free 1-8666-797-000) if you cannot reach your primary care provider or team but contact this care provider or team for follow up when new symptoms develop or symptoms worsen.
- **Self-isolation:** In the context of COVID-19, families and group homes should think about their capacity and plan for health care and other supports to address needs of people with IDD who must self-isolate (after significant exposures or after developing symptoms of COVID-19) or who do not wish to go to, or cannot stay in, hospital. This could involve working with your primary care provider to arrange in-home palliative and end-of-life care, as well as bereavement support for family members and persons in the group home.
- **Emergency care:** When someone is experiencing moderate to severe difficulty breathing, chest pains, reduced consciousness or difficulties being roused from sleep, this is an emergency situation. Contact emergency services (911) according to the patient's advance care plan and alert the primary care provider.

9. Testing

Ideally, in managing the pandemic, widespread testing and follow up are optimal strategies if resources are available. With limited resources, however, local regions have established guidelines for who should be tested (e.g., for Ontario, see Helpful Links below for a link to Public Health Ontario).

- When a person with IDD has had a significant exposure to the COVID-19 virus or develops symptoms associated with COVID-19, seek referral for expedited testing when the person is physically vulnerable to developing severe symptoms or is living in a group home setting.
- You will need an assessment (typically by phone) by a healthcare provider for testing for COVID-19.
- At-home testing, if possible, is optimal.
- If being referred to be tested at a hospital or assessment centre, do not use public transportation and use reasonable precautions (e.g., using a mask, sitting in the back seat, keeping the window open).
- Healthcare providers considering the need to test a patient for COVID-19 virus should contact Public Health Ontario's Customer Service Centre at: 416-235-6556 / 1-877-604-4567 for support.

10. Ethics and Policy

- In general, family caregivers and care providers (including support workers) will need to weigh doing good for the patient with avoiding risk of harm to themselves and others for whom they have responsibility. They should continually seek ways to help those who have COVID-19 but also be well-informed regarding risks of infection and take appropriate precautions. To be avoided is refusing to provide care or support when the risk that they and the person with IDD will transmit COVID-19 virus is low with appropriate prevention. Also, to be avoided is failure to observe appropriate precautions when they or the person with IDD to whom they are providing care or support has symptoms of COVID-19.
- Care providers might sometimes be faced with situations where there is incomplete compliance with appropriate preventive measures (e.g., PPE is not available or not optimal; observance of public health directives regarding isolation cannot be managed in the care setting). In such situations, best efforts should still be made to minimize risks of transmitting infections (from patient or client to care provider, and vice versa) while providing care that the person with IDD cannot do without. When the risk of infection falls on the care provider, this might sometimes require a decision to act out of moral courage and compassion that goes beyond professional or legal obligations.
- When a patient or client tests positive for the COVID-19 virus, everyone who is likely to have significant contact with this person at home or elsewhere should be informed regarding their status (usually Public Health officials track prior contacts).
- Public policies addressing the COVID-19 pandemic should be informed by the perspectives of people with disabilities, their family caregivers and care providers. They should take into account the specific needs and barriers to health and palliative care of people with disabilities.
- Guidelines for allocating limited healthcare resources, such as access to intensive or palliative care, should not discriminate solely on the basis of a person living with a disability or on “usefulness” to society. Such discrimination devalues people with disabilities and is unjust. There can be ethical justification for allocating limited resources based on considerations for *any* medical treatment, such as likelihood of benefit to the patient (e.g., recovery from COVID-19 and good prognosis afterwards), risks and burdens of the treatment for the patient and the patient’s caregivers (as determined by the patient’s own goals and values).
- The decision-making capabilities of persons with IDD should be supported to enable them to have equal access to the benefits of participating in trials of new vaccines and treatments.

13. Helpful Resources

13(a). General information about COVID-19

- Government of Canada: <https://www.canada.ca/en/public-health/services/diseases/coronavirus-disease-covid-19.html>
- Ontario Ministry of Health self-assessment for symptoms: <https://covid-19.ontario.ca/self-assessment/#q0>
- Oxford COVID-19 Evidence Service (synthesizes latest research): <https://www.cebm.net/covid-19/>
- Public Health Ontario (news at a glance from major public health agencies): <https://www.publichealthontario.ca/-/media/documents/ncov/ncov-daily-lit.pdf?la=en>
- Toronto Region Assessment Centres: <https://www.toronto.ca/home/covid-19/covid-19-health-advice/covid-19-assessment-centres/>

13(b). IDD-specific information

- Canadian Association on Community Living: <https://cacl.ca/coviddisability/>
- Dr. Chris Hatton, Potential risk factors for the impact of COVID-19 on health: People with learning disabilities: <https://chrishatton.blogspot.com/2020/03/potential-risk-factors-for-impact-of.html>
- Jerome Lejeune Foundation Q&A on COVID-19 and Down syndrome: <https://www.lejeunefoundation.org/wp-content/uploads/2020/03/2020-COVID19-DS-QA-JLF-Expanded-FINAL.pdf>

13(c). Accessible information

- Animation on prevention:
<https://twitter.com/Stanford/status/1242508882993459201?s=20>
- Books Beyond Words: picture book to explain COVID-19
<https://booksbeyondwords.co.uk/downloads-shop/beating-the-virus>
- Handwashing video: <https://youtu.be/O6Y5cK6D8wo>
- HCARDD: <https://www.hcarddcovid.com>
- Keep Safe (UK): <https://www.keepsafe.org.uk>

13(d). Information for professional care providers

- Ontario Ministry of Health guidance for primary care providers:
http://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/2019_primary_care_guidance.pdf
- Ontario Ministry of Health guidance for home and community care providers:
http://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/2019_home_community_care_guidance.pdf

13(d). Information for families

- Information for those in isolation or caring for someone in isolation:
<https://www.gps-can.com.au/covid19-blog/a-guide>
- Surrey Place: <https://www.surreyplace.ca/resources-publications/coronavirus-updates-resources/>

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