

# The International Journal for Direct Support Professionals

## My COVID Check-in: A new tool to support people with developmental disabilities to live their best and healthiest lives during a pandemic

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Several years ago, we wrote an [article about the annual Health Check](#) and why proactive, comprehensive primary health care is important for people with developmental disabilities. Now that we are beginning the third year of this pandemic, there is even more risk that preventive care has been sidelined. To counteract this, our team at CAMH, H-CARDD, and Surrey Place, together with partners from across Canada are doing a project to promote a new tool, “My COVID Check-In” ([Coming Soon!](#)). Has it been a while since the people you support have seen their doctor and have had a chance to talk about everything going on now? This tool can help.

In this newsletter, we explain the “My COVID Check-In” and all the things it needs to cover. These areas are particularly important to review for people with developmental disabilities, but they are actually important for all of us to think about. You can talk about these issues and complete the “My COVID Check-In” together with the people you support before the check-in appointment. When you call to make the appointment, you can offer to share a copy of this article or the “My COVID Check-In” form with the doctor to help explain why you are doing this.

Depending on what is going on personally or in your community, this appointment might be over the phone, on video, or in person. It might be one discussion, or it might be a few meetings. The important thing is not to wait until something goes very wrong, but to make an appointment soon and start the conversation.

Here, we outline all the areas that should be discussed. This is also a chance to give the doctor a sense of how things have been going over the past two years. What is a typical day like now and how is that different from how things used to be?

### My COVID Check-In

1. **My Shot** – One of the best strategies we have to be safe from severe illness from COVID-19 infection is to get vaccinated. Being fully vaccinated for most people means having three doses or shots of the vaccine. In Canada, most adults have had at least two shots, and many have had three. There are some people who have compromised immune systems, and they have had four. It is likely that a time will come later this year

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when all adults may be asked to get a fourth vaccine. The vaccine works to protect our bodies for a while, and then after some time, they don't work as well, so we need to get another one, just like how we get a flu shot each year. There are some people with and without developmental disabilities who are afraid of any kind of needle, or who just don't know where to go to get a vaccine. Some people think vaccines are not important, or they worry about vaccine side effects. Everyone needs clear information about how vaccines work and why they matter, and a chance to talk with their doctor about what worries them. If getting a vaccine has been hard for any reason with the people you support, this is important to discuss with the doctor. A plan can be made to get the vaccine in a way that is safe and less stressful. The [Getting Ready for My Shot tool](#) has many suggestions to help with this.

2. **My Mask** – Masks are one of a few ways we can work together to reduce the spread of COVID-19 and keep others and ourselves safe. These days, we are all required to wear masks at least some of the time, unless unable to do so for medical reasons. Everyone needs to understand why masks are important, and as Direct Support Professionals (DSP's), you have to know how to support those who are unable to wear one. It is especially important to have the right kind of mask that fits well. There are a number of resources available to help people wear masks the right way. For some people with developmental disabilities, they have not had as much practice wearing a mask because they have not been outside very much. A conversation with the doctor about the best mask to wear, and what to do if wearing masks is hard is very important. (Remember, sometimes it helps to talk to a doctor about these things, instead of just speaking to staff or family, especially if the rules seem confusing, or there is disagreement about what to do).
3. **My Medications** – It is important to monitor how medications are working, especially when someone takes more than one medication at the same time. About 20% of adults with developmental disabilities takes at least five medications at once, and even before the pandemic started, they did not always have regular appointments to discuss how their medications were working. [This earlier article gives a lot of information about why these things are important.](#) Medication monitoring matters because all medications can have side effects, which can be missed when it is hard to describe or recognize them. Since COVID-19 began, most people have been getting medications renewed by phone instead of seeing a doctor in person; sometimes, new medications are started without seeing the doctor. Although health care visits may look different during the pandemic, it is still important to check in with a doctor on how well daily medications are working. It is also important to have a list of medications to share when visiting any health care provider to make sure prescriptions get refilled before running out, and that there are no problems taking medications regularly or interactions between already prescribed medications and new ones that may be started. Some people with developmental disabilities may get confused about which medications to take or may only take them sometimes. Others may have a medication that is PRN, which means only take it when needed, but they are taking that medication almost every day. That is also something important to talk to the doctor about.
4. **My Physical Health** (this includes **dental health, vision screening, cancer screening, and chronic health issues**) – Even though medical appointments may look different these days, it is still important to pay attention to the physical health of adults with developmental disabilities. Depending on the health issues that the people you support may have, it may be helpful to have some equipment available in their home that you know how to use (such as a thermometer, an automated blood pressure cuff, a scale, a pulse oximeter, or a blood glucose monitor), especially when it is difficult to go to the doctor's office. There may not be time at the COVID Health Check-In appointment to look at everything going on in terms of physical health, but it is an opportunity to flag any new issues that have come up, or any aches or pains that have become worse since the pandemic. As people age, certain types of health screening become important, including cancer screening, which may have been

missed due to disruptions related to the pandemic. It is also important to check for other health problems, which can be more common for people with developmental disabilities (e.g., breathing problems, constipation, or skin problems). The [Nuts and Bolts of Health Care Toolkit](#) includes information on a number of these concerns and also has links to different tracking sheets to help describe health problems, which can be completed at home before seeing a doctor. It may be worthwhile to review when and how to test for COVID-19, how to isolate if positive and monitor symptoms.

5. **My Movement** – With colder weather and pandemic-related restrictions in place, we can expect many people with developmental disabilities to be staying indoors this winter. One of the risks of being indoors more is that we move less and can become increasingly sedentary. If muscles are not used over time, they become “deconditioned” which is linked to a number of serious health problems. Movement is important not only for exercise and maintaining our physical health, but also for our mental health. Getting dressed and going outside, enjoying fresh air, and watching the world go by is something we all should do and probably took for granted before the pandemic. This should not stop because of COVID-19. Remember that spending time outdoors is more enjoyable when we dress the part (warm clothes in winter, rain gear, sun protection in summer). If moving around outdoors is not an option, even ten minutes sitting on a porch or balcony when there is daylight can make a difference. And moving around inside is always an option. You can move around when you do household chores, you can do exercise to a video or as a challenge with other people. To stay healthy, people should do at least 150 minutes of activity per week. If that is not happening for people you support, and you are having trouble making it happen, this is something to discuss with the doctor.
6. **My Habits (sleeping, eating, alcohol, drugs)** – Some things are really important to do every day, while other things are really important not to do. Examples of things that are good for everyone’s health include eating a balanced diet, spending time outdoors, exercising, and getting a good night’s sleep. Under stress, bad habits can also develop. This can include overeating, too much screen time, drinking too much alcohol, or using too much cannabis/weed or other drugs that are not healthy. It is important that people with developmental disabilities be able to talk to their doctors about unhealthy habits that have developed during the pandemic. Not everyone will think that what they are doing is a problem, and depending on how often it is happening, it may not be a concern. Doctors have a good sense of how much is too much, and how to start these difficult conversations. A first step to getting help is having an honest discussion of what happens day-to-day.
7. **My Mood** – A good health check-in with a doctor includes looking at how well people with developmental disabilities are handling their stress and anxiety. It is to be expected that people with developmental disabilities, like all of us, may feel scared about getting sick, and sad or frustrated about not being able to see people they love or do their favourite activities. Sometimes these feelings can be so overwhelming that just getting out of bed and getting dressed is a challenge. If someone is not acting like themselves, it may be a good time to check in on them and address any issues. [These self-help booklets](#) developed for people with developmental disabilities during COVID-19 can be a helpful resource to deal with difficult emotions. Having an anxious moment or a day where you don’t feel like doing a whole lot happens to many of us. But if there has been a change from how someone you support used to feel or act, this is important to discuss with a doctor.
8. **My Family and Friends** – There have been many difficult choices to make around how people with developmental disabilities connect with family and friends over the past two years, made harder when there is a lockdown or other restrictions. Outdoor visits, which can be safer, are harder in the cold and with fewer hours of daylight. It is important to evaluate how the people you support can best stay connected with loved ones; it may be necessary to

connect face-to-face when virtual meetings are not an option. There are [a number of things we can do to make visits safe](#). That said, after relationships being different for so long, it might be hard to figure out how to be with family and friends now. The family doctor may not realize just how much things have changed for people with developmental disabilities. Some people have found that, even when things “open up” or there are fewer restrictions, interactions don’t happen the way they used to. Some of the people you support may have forgotten some of the rules of social interactions, or they have problems adjusting to the new rules of less close physical contact. And some people may have less tolerance for being with other people than they used to. It is important to update the doctor about relationships that have changed because of the pandemic.

9. **My Meaning** – What we do each and every day matters. Having something meaningful to do gives us purpose and contributes to our sense of well-being, which is especially important in times of uncertainty and change. What can you do to build opportunities for meaningful activity and connection with the people you support? It may be tidying a room, doing an activity that brings joy, or helping someone else. Remember that it has to be meaningful to the person for it to be of benefit (and that might not be the same as what is meaningful to you). Check out the [Do-Live-Well framework for more information](#) on meaningful activity and the connection to our health and well-being. If there is not enough support to do these activities, or you can’t figure out how to do this, it is an important topic to flag with the doctor. In health care, there is recognition that just as people need prescriptions for medications, they also need prescriptions to do things with members of their community, called [“social prescribing.”](#) This is particularly important now after so many things have been closed for so long, and people with developmental disabilities have felt so isolated. If this is a concern for the people you are supporting, be sure to discuss it with the doctor and consider including the doctor in discussions or meetings with other members of your support team such as service coordinators or therapists. It helps to be able to talk about what things are happening now, and what is no longer happening but used to be enjoyable.
10. **My Technology** – Whether it is for seeing health care providers, taking a class, connecting with friends and family, or just entertainment, so many of our activities are now online and require not only the right equipment, but also the right skills. What can be done to facilitate online connections with the people you support? [Check out this blog for some ideas](#). One of the most interesting lessons from this pandemic is that many people with developmental disabilities who did not have the chance to benefit from technology in the past, have learned to use it well. However, some people do not have Wi-Fi that works, or still have problems with using a computer or tablet. Some people may get upset with the technology that has been shared with them because they associate it with something negative, or it reminds them of something they cannot do. Don’t forget that a telephone is also a kind of technology, and it still works great! Don’t underestimate the value of a phone call (or lots of phone calls) even when there is not that much to say. Hearing other people’s voices is important and, for some people, the phone is more familiar and less stressful than other types of technology. Other people may enjoy using technology so much that they are less motivated to do other types of activities, or making the transition away from technology is very difficult. How the people you support are using technology or not using it is an important topic to review with a doctor, especially if there are concerns.
11. **My Money** – The majority of people with developmental disabilities live in poverty. Winter (and the pandemic) brings additional challenges, with extra costs related to heating our homes, buying winter clothing, buying the right kind of mask, and getting groceries delivered if going out is too difficult. It is important to know if there is enough money for all these basics, as well as having extra money to do something fun. Not everyone can pay for things with a credit card or bankcard, so planning is also about figuring out how to pay for things and where to get financial help if needed. Sometimes, people with developmental disabilities

may not get the help they need because they cannot afford it. This is something that it is important to make the doctor aware of.

12. **My Plan** – Make an emergency plan! Hospital emergency department (ED) visits are more common for people with developmental disabilities. With pandemic restrictions in place, it is not always possible for an essential support person to enter the hospital. And in some hospitals, support people must be fully vaccinated against Covid-19. Even if a support person is ready to help, an emergency plan will help to answer important questions quickly: How are health care decisions made and who supports decision-making? It is helpful to have health care communication tools ready before an emergency, such as the COVID-19 [Hospital Transfer Form](#), and the [Advance Care Planning Tool](#) along with [other resources to take to hospital](#).



## Q and A about “My COVID Check-In”

### **What if the person I support doesn’t really talk? Why would we use a form like this if they can’t say anything?**

In every health care interaction, we want to prepare and involve the patient as much as possible. My COVID Check-In, just by the way it is written, reminds us of who is at the center of care. It is one tool to help bring the focus on the person and can give them more ownership of the discussion.

### **I was told that doctors are not seeing patients right now because of COVID. How am I supposed to book a COVID Check-In appointment if appointments are not happening?**

Most doctors are still doing some in-person care. The first step is to call or email (whatever you normally do) the doctor’s office to find out what type of appointments they are offering. Just like so many other aspects of our lives during the past few years, things continue to change at doctor’s offices. It is reasonable to connect with them to see what types of appointments are currently available. Many of the aspects of the “My COVID Check-In” can be done virtually. The person you are supporting, you, and the doctor can go over the different parts of the check-in and then make a decision if a follow-up call/video appointment or in-person appointment is needed. If the doctor’s office does not have any appointments at this time, ask if the person can be put on a waitlist for an appointment when things open up again, or when it would be reasonable to call again for an appointment.

### **The doctor that we see is always in a hurry. To be honest, I would be scared to show them a new form.**

This tool is a way for you and the person you support to organize your thoughts about the topics you think are most important to check in about. Remember: Not all the topics on this list need to be discussed with the doctor in one visit; pick the ones you think are the biggest concerns right now. You don’t even have to show the doctor the specific form – just mention to the doctor that these are the topics you want to discuss and realize that it may take multiple appointments to address all the concerns.

### **Does the doctor have to take the form and fill it out? What if they refuse?**

The actions or next steps on the “My COVID Check-In” do not have to be filled out by the doctor. You can be the one to take notes about what was discussed at the visit and what you have decided as a team to do next. This form is your record or reminder of what happened at the visit and what needs to happen next. This sort of record is good to refer back to with the person you support. It can also be a helpful update or reminder for other people who work with that person. It is something to look at before the next appointment with the doctor, or it might lead to organizing a [Health Check program](#), which was described at the start of this article. These periodic (this means they happen regularly, e.g., every year), proactive (this means they address issues before they become a big problem), and comprehensive (this means they look at everything, head-to-toe) health assessments have been adopted internationally to improve the health of people with developmental disabilities. [Resources](#) are available to explain Health Check’s to your doctor or other primary care provider.

**COVID Caregiver Check-In:** Remember that you have to take care of yourself to help support others. Part of the check-in is also checking in with family and staff who are involved in caregiving and supporting people with developmental disabilities. The pandemic has been difficult for everyone including caregivers. What has changed for you and what are you worried about now? This may be something you want to discuss at the COVID Health Check-In, or it may be important to flag this concern at the meeting and set up a separate meeting to talk about it more. If there are caregiver concerns, the COVID Health Check-In form can be a place to list that there are concerns.

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## Answers to FAQ's about the journal

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