My COVID Check-In: Conversation guide for caregivers

The **My COVID Check-In** form helps you to check in with the person you support and talk about how they are managing related to the COVID pandemic. It helps to identify concerns and can support the person in bringing these concerns forward to their family doctor.

Use the form as a conversation guide and involve the person you support as much as possible by using supporting materials (e.g., videos, Easy Read, social stories, pictures). This guide explains why it is important to check-in on the topics listed in the **My COVID Check-In** form and provides tips for how to approach the conversation

Conversation tips:

- Talk about what has changed during the pandemic.
- Talk about something positive or neutral to introduce a topic, before asking more sensitive questions.
- Not all topics are relevant to every person; you don't have to talk about everything.
- You don't have to talk about everything at once. Consider spreading the conversation over time.
- Identify concerns and ask the person you support whether they want to talk with their doctor about these concerns, either together or alone. Explain that this could also be a phone call or a video visit with the doctor.

1. My shot

People with developmental disabilities, especially those with Down syndrome, are more likely to get very sick with COVID-19. This is because of reasons like underlying health issues or a compromised immune system. Thus, it is important that they get the COVID-19 vaccine and any booster shot when it becomes available.

Some people with developmental disabilities are hesitant to get the vaccine because they are afraid of needles, worry about side effects, or do not trust how vaccines work. Others do not know how or where to get the vaccine. If getting a vaccine has been hard for any reason with the person you support, it is important to discuss this with the doctor. A plan can be made to get a vaccine in a way that is safe and less stressful.

Questions you could ask

Have you already had a COVID-19 vaccine? Do you know why you need the vaccine? How many shots have you had? Do you have any questions about how the vaccine works? Was it difficult/easy to get the vaccine? Why did you find it difficult/easy? What would make it easier for you to get a vaccine next time? What questions do you still have about the COVID vaccine?

Materials you could use

- Things to know about the vaccine, an Easy Read guide
- What happens when I get the vaccine, an Easy Read guide
- COVID-19, Ready, Set, Go!, a social story
- Having a vaccine for coronavirus, a wordless picture story
- Amanda gets a COVID vaccine, a video journal
- Getting ready for my shot, an accommodation request form
- Steffi explains booster vaccines, e-learning
- Steffi explains self-tests, e-learning
- Steffi explains fake news, e-learning

2. My mask

The COVID-19 virus spreads through the air. Wearing a mask is one way to reduce the virus spread. Some people are not able to wear masks because of medical reasons (e.g., asthma). Some people with developmental disabilities have difficulty wearing a mask due to sensitivities. They also might not fully understand why it is necessary or have difficulty remembering when and where to wear it. Masks only work if they fit well. It might be difficult to know which masks protects best and how to wear a mask properly. Some people with developmental disabilities have had little practice with wearing a mask because they have not spent much time out in public during the pandemic.

Questions you could ask

Do you know why you must wear a mask sometimes? When do you wear your mask? Does your mask fit well on your face? Do you know where to get masks? What can you do if you can't wear a mask? What questions do you have about the mask?

Materials you could use

- How-to guide: Putting on a surgical mask, a video guide

3. My medications

About 1 in 5 adults with developmental disabilities takes at least 5 medications at once. It is important to monitor how medications are working, especially when someone takes more than one medication at the same time. Medication side effects can be easily missed for people who have difficulty communicating or recognizing them. Already prescribed and new medications can interact, with harmful effects. Some people with developmental disabilities get confused about which medications to take, or do not take them regularly or as prescribed (e.g., taking a medication every day instead of only when needed).

During the pandemic, many people renewed their medication by phone instead of seeing a doctor in person; sometimes, new medications were started without seeing the doctor. Together, make a list of current medications. You can also get this list printed from the pharmacy. Talk about what has changed during the pandemic and if the medication is working well or not. Talk about remembering how to take the medication and about refilling it in time.

Questions you could ask

Do you have a list of all your medications? Do you know why you are taking this medication? Did you get any new medications? How have you been feeling since the new medication? How are you remembering what medication to take and when? What questions do you have about the medication?

Materials you could use

- Daily medication routine (1), a template
- Daily medication routine (2), a template

4. My physical health

Preventative health care is important for people with developmental disabilities. This includes dental health, hearing and vision screening, cancer screening, and monitoring of chronic health issues. Because they may not recognize symptoms or are less likely to communicate these, it is important to pro-actively review their health.

During the pandemic, many people postponed seeing their doctor in-person and important screenings may have been missed (e.g., cancer screening, vision, and hearing). Chronic health issues may not have been attended to properly for a while (e.g., breathing problems, skin issues, constipation), and new health issues may have emerged but not checked on by a doctor. Talk with the person you support about new or worsened issues. Collect information about any overlooked issues before going to the doctor (e.g., blood pressure, glucose measures, weight, or sleep patterns).

It may also be worthwhile to review when and how to test for COVID-19, how to isolate if positive and monitor symptoms. If the person has experienced COVID-19, check for ongoing health problems, including "Long COVID".

Questions you could ask

Have you got any new aches or pains? Did any aches or pains get worse? Did you have COVID? How have you been feeling since you had COVID? Do you know what to do when you fall ill with COVID? Do you know about health screenings that you are supposed to do at certain ages, like for cancer, or diabetes when you get older?

Materials you could use

- Health monitoring charts, symptom tracking sheets
- Pain scale, visual support
- If you get sick with coronavirus, an Easy Read
- Beating the virus, a wordless picture story
- Steffi explains self-tests, e-learning
- Steffie explains booster vaccines, e-learning

5. My movement

Moving around and being physically active are important for our physical and mental health. To stay healthy, people should be physically active at least 150 minutes each week. There are many options to move our bodies indoors (e.g., doing chores, exercise to a video, walking the stairs) and outdoors (e.g., walking, cycling).

Due to public health measures during the pandemic, typical activities might have changed for the person you support. Exercise classes have been cancelled, group activities have been restricted, and people might have experienced an overall anxiety to go outside. One of the risks of being indoors more is an increasingly sedentary lifestyle, potentially leading to health problems. If someone does not get enough physical activity, this is something to discuss with the doctor.

Questions you could ask

Talk about physical activities the person you supports likes doing and whether these have been happening during the pandemic or not. How much movement are you getting each week? Would you like help with exercising more? What type of movement are you getting indoors and outdoors? Do you enjoy spending time outside? What do you like about it or not? What questions do you have about staying fit?

Materials you could use

- You can do it, a self-help booklet and guide

6. My habits

A pandemic is a stressful time for everyone. Under stress, bad habits can develop, for example: sleeping too much or too little, eating too much or too little, consuming too much alcohol, drugs, cannabis/weed, or too much screen time. People with developmental disabilities are as likely or more likely to have addictions as everyone else and for some people these problems have gotten worse 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.

Questions you could ask

What are things you do that are good for your health? Have you developed any new habits since the start of the pandemic? Has there been any change in how much you sleep, drink alcohol, eat, smoke? How much time would you say you are spending on a screen each day? What questions do you have about healthy habits?

Materials you could use

- A good night's sleep, self-help booklet and guide
- Alcohol and you, an Easy Read
- Alcohol, an Easy Read

7. My mood

It is to be expected that people with developmental disabilities, like all of us during a pandemic, 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. Some people with developmental disabilities may not be able to explain what they are feeling, but people around them can tell that they are acting differently. "All behavior is communication" and sometimes what looks like a behavior problem to someone else is the only way someone can communicate their distress. If you have noticed a clear change from how the person you support used to feel or act, discuss it with a doctor.

Questions you could ask

Do you feel more worried or sad or angry during the pandemic? Do these feelings happen only sometimes? Or are they not going away?

Materials you could use

- Feeling anxious, a self-help booklet and guide
- Sort it out, a self-help booklet and guide
- Feeling down, a self-help booklet and guide
- Feeling angry and staying calm, a self-help booklet and guide
- Good days and bad days during lockdown, a wordless picture story
- Know your normal, a toolkit
- Steffi explains grief, e-learning

8. My family and friends

During the pandemic, public health measures made connections with family and friends harder. Outdoor visits, which can be safer, are harder in the cold and with fewer hours of daylight. It is important to evaluate how people are staying connected with their loved ones. Virtual meetings may work for some, while for others face-to-face and in-person is the only way to connect.

Due to the duration the pandemic, relationships may have changed, and it might be hard to figure out how to be with family and friends again. Even when public health measures are lifted, some feel that interactions don't happen the way they used to. Some people may have forgotten social interaction rules, or they have difficulty adjusting to physical distancing rules. Others may have less tolerance for being with other people than they used to.

Finally, friends and family members may have been severely ill or died because of COVID. People may have experienced significant grief. It is important to update the doctor about relationships that have changed because of the pandemic.

Questions you could ask

Who do you enjoy spending time with? Are you able to see them as often as you like? Do you sometimes feel stressed during a visit? Are you feeling lonely? Has anything sad happened to your family or friends because of the coronavirus? What questions do you have about seeing your friends and family now?

Materials you could use

- When someone is ill or dies from coronavirus, a wordless story
- When someone dies from coronavirus, a wordless story
- When it's not safe to stay at home, a wordless story
- Love in lockdown, a wordless story
- Steffi explains grief and breavement, e-learning
- Steffi explains the importance of family and friends, e-learning

9. My activities and interests

Having something meaningful to do gives people purpose and contributes to a sense of well-being. This is especially important in times of uncertainty and change. A meaningful activity may be tidying a room, doing an activity that brings joy, or helping someone else.

Find out what are meaningful activities for the person you support. This is particularly important during a pandemic when many people with developmental disabilities have felt isolated or excluded from activities (e.g., school, work, or day programs). If there is not enough support to do these activities, flag it with the doctor and other members of the support team such as service coordinators or therapists.

Questions you could ask

What are things you like to do? What fun activities are you doing now? What activities have stopped? What would you like to do again that makes you feel good? Is it hard to find things to do during the day that are important and special to you? What questions do you have about finding things to do?

Materials you could use

- You can do it, a self-help booklet

10. My technology

The COVID pandemic has moved many activities online, whether it is seeing health care providers, taking a class, connecting with friends and family, or entertainment. This requires not only the right equipment, but also the right skills. Many people with developmental disabilities who did not have the chance to benefit from technology before, have now learned to use it well.

However, some people do not have Wi-Fi, or have problems with using devices. Some people may get upset with the technology because they associate it with something negative, or it reminds them of something they cannot do.

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 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. Making the transition away from technology may be difficult. Review how the person you support uses technology.

Questions you could ask

What devices are you using? What do you use it for most? Is it hard to use a phone, laptop, or tablet? What do you find difficult? How much time do you spend on your phone or computer every day? Do you have questions about using the internet? Are there some people you are talking to on the internet that ask you for money or to do things that make you uncomfortable?

Materials you could use

- I can be safe online, a toolkit

11. My money

Many people with developmental disabilities live in poverty. Paying for basics like rent, clothing, food, transportation can be a challenge. A pandemic can bring extra costs like having to buy masks, cleaning products, getting groceries delivered when going out is difficult, or higher internet or phone bills. It is important to know if there is enough money for all these basics, as well as having extra money to do something fun.

For in-store shopping, payment in cash might no longer be accepted. Not everyone can pay for things with a credit card or bank card. If relevant, find out if the person you care for knows 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 is important to make the doctor aware of.

Questions you could ask

Do you have money to pay for important things like food, rent, transportation, phone, internet or getting help? Do you buy things on the internet? Do you need help using the bank on the internet? What questions do you have about money?

12. My plan

Hospital emergency department visits are more common for people with developmental disabilities than those without. With pandemic restrictions in place, it is not always possible for an essential support person to enter the hospital. In some hospitals, support people must be fully vaccinated against COVID.

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? Talk about preparedness for the event of a visit to the hospital or falling ill at home with COVID-19.

Questions you could ask

Do you have a plan in case you need to visit a hospital for an emergency? If you had to go to the hospital, do you know what to take with you? If you had to go to the hospital who would come along to help you?

Materials you could use

- COVID-19 hospital transfer form, an accommodation request form
- COVID-19 advance care planning, a guide for caregivers

Questions and Answers about My COVID Check-In

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

In every healthcare 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 who is at the centre of care. It helps bring the focus on the person and can give them more ownership of the discussion.

I was told that the doctors are not seeing patients right now because of COVID. How am I supposed to book an appointment like this if appointments are not happening?

Most doctors are still doing some in-person care. The first step is to call or email 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 doctors' offices.

Many of the aspects of the **My COVID Check-In** form 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 decide if a follow up call/video appointment or in-person appointment is needed. If the doctor’s office does not have any appointments available, ask if the person can be put on a waitlist for an appointment when things open again or when it would be reasonable to call again.

Our doctor is always in a hurry. To be honest, I would be scared to show her a new form.

My COVID Check-In 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. 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 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 of the identified concerns.

Does the doctor have to take the form and fill it out? What if they don’t?

The actions or next steps on the **My COVID Check-In** form do not have to be filled out by the doctor. You can be the one who takes notes about what you have decided as a team to do next because of the things you discussed at the visit. 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 to with the person you support.

It can also be a helpful update or reminder for other people who work with the person. It is something to look at before the next appointment with the doctor, or it might lead to organizing a comprehensive health check. Regular, proactive, comprehensive health assessments are recommended internationally to improve the health of people with developmental disabilities.

My family member does not live with me and he goes to his medical appointments with staff. What if they don't know how to use a form like this?

The **My COVID Check-In** form is one way to help remind all of us about issues that can be impacted by the pandemic. Sharing it with your family member and other people active in his or her life is a way to build a team approach and improve healthcare communication. Reviewing this form prior to the healthcare visit helps to include different perspectives and feel prepared. It can facilitate conversations about health.

I support someone who take a lot of pride in doing this sort of thing on their own. How can this form help if they do not think they need help?

The **My COVID Check-In** helps someone to think about their health and feel prepared to talk about any concerns. Review the form with other people before an appointment. It might appear that having a family member or staff person present at the conversation with the doctor would be helpful. It also helps to get everyone on the same page. People can get nervous about a healthcare visit and forget to mention certain things to the doctor. Taking some time to prepare can make a difference. Sharing the form with healthcare providers helps them focus on relevant matters in the brief thealthcare visit.

How else can I support the COVID Check-In?

Tracking changes in physical health over time can help identify problems. Consider using Health Monitoring Charts[v] to track weight, sleep, bowel movements, or responses to medication when appropriate.

Finally, the pandemic has been difficult for everyone. Check in with yourself and others who are involved in the person’s care, for example family and staff. The COVID check-in may be a way to flag caregiver concerns and ask for a separate caregiver appointment.

Supporting materials

i. **COVID-19 Self Help Booklets**
Adapted by the Centre for Addiction and Mental Healt (CAMH), Toronto, from COVID-19 Guided Self-help Booklet Series, The University of Glasgow.

ii. **Getting Ready For My Shot**
Developmental Disabilities Primary Care Program, Surrey Place, Toronto

iii. **COVID-19 Hospital Transfer Form**
Developmental Disabilities Primary Care Program, Surrey Place, Toronto

iv. **COVID-19 Advance Care Planning: A Guide for Caregivers of Adults with Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program, Surrey Place, Toronto

v. **Health Monitoring Charts**
Developmental Disabilities Primary Care Program, Surrey Place, Toronto

vi. **How to Stay Safe, Well and Connected**
Health Care Access Research and Developmental Disabilities, CAMH, Toronto [website]

vii. **COVID-19 Resources: Supporting Individuals, Families and Caregivers**
ConnectAbility, Community Living Toronto, Ontario [website]

Online information about COVID and other health topics can be difficult to understand. Everybody has a right to clear information. That is why avatar Steffi explains things in an easy-to-understand way. She does this by using animated pictures, text and audio. Steffi was originally developed in the Netherlands. We are testing how Steffi would do her work in Canada. Have a look at her website at steffihelps.ca.

Let us know how you like it! You can send us an email at ddpcp@surreyplace.ca.

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Some of these supporting materials are hosted by external organizations and the accessibility of these links cannot be guaranteed. The DDPCP will make every effort to keep these links up-to-date.