# SURREY

## Getting Ready for My Shot Accommodation request and preparation form for people with intellectual and developmental disabilities

#### **Tips for caregivers**

People with developmental disabilities (e.g., Down syndrome, Autism) might be uncomfortable with injections or reject medical procedures based on previous negative experiences, fear, or limited understanding. Good preparation can help to make sure that vaccination causes minimal distress. People have unique needs. Think of strategies that might work best for the person you care for.

Prepare the attached **Getting Ready For My Shot** form together and use it when you need to inform staff at the vaccination site about any special needs or accommodations.

#### Making a decision

- All vaccines are scientifically tested, effective, and safe. Adverse reactions are extremely rare and there are no higher risks of side effects for people with intellectual and developmental disabilities than for other people.
- Contact the person's family physician if you have questions about vaccine options and certain health conditions or medications.
- Weigh the benefits of protection against serious illness, hospitalization, or death, over the risks and challenges of getting the vaccine.

#### **Getting consent**

- Vaccines are not mandatory, and no-one can make a person take a vaccine if they do not want to.
- Involve the person you support as much as possible in making the decision. Use accessible materials, social stories, or videos to explain vaccination. Talk about the benefits of getting a vaccine, side effects, and consequences of not taking it.
- Consent to receive a vaccine is required at each vaccination appointment. If the person you care for does not have capacity to give consent, bring a consent form signed by their substitute decision maker. A consent form might be shared upon appointment booking or it might be available for

download at public health websites or the doctor's office.

#### Preparing while you wait

- Be prepared to answer some medical screening questions at the vaccination site. This includes information about medical history (e.g., allergies, immune or blood disorders) and medications.
- Know which documents you must bring, such as identification, consent form, or a health card. Collect all documents in one folder.
- Discuss who the person would like to bring for support and comfort.
- Think about what will motivate the person and choose a reward together. For example, think of a fun activity you will do after the vaccination.
- There will be a waiting time after the vaccination. This may vary from 15-30 minutes. Plan for some distractions (e.g., favourite book, music, video, or an iPad game). Use a cellphone timer to help with counting down waiting time.
- If the person you support is very anxious, consider pre-medication. Always discuss this with the person's family doctor. If this is a first-time use, try the medication at least once before the vaccination date to make sure it has the right effect.
- Use a topical numbing cream to address fear of pain and needles. Buy the cream at your pharmacy.
- Practice as much as possible. Repeat social stories, Easy Read materials, or videos often.
- Practice relaxation and desensitization strategies, such as breathing techniques, sitting still, rolling up the sleeve, massaging the area of the arm where the vaccine is administered, putting on band-aids, seeing masks and gowns.
- If needed, get familiar with the vaccination site. Consider driving or walking by the building. Ask if you can arrange a pre-visit.

#### Asking for accommodations

- People with developmental disabilities have a right to accommodations in health care. This means they should not face any barriers to accessing a vaccine because of their disability. Accommodation needs are unique for each person. Fill out the Getting Ready For My Shot form and bring it to the vaccination appointment.
- Contact the vaccination site ahead of time to discuss specific accommodations. Ask if there will be someone available who can support the person you care for. Types of accommodations that you might ask for:
  - > Exemption from special measures like wearing a mask or physical distancing.
  - > Being moved to the front of check-in line.
  - > A quiet room, away from other people, for the vaccination and/or for waiting times.
  - Permission to bring in certain items that offer comfort and distraction during waiting times (e.g., iPad for watching a video).
  - > Rescheduling the appointment to the quietest time of day to avoid crowds or noisy environments.

#### On the day of vaccination

- Make sure the person you care for is dressed in comfortable clothing, with easy to roll up sleeves or a t-shirt.
- Collect everything to bring in one bag: forms, documents, distractions, comfort items and rewards.
- Repeat social stories, Easy Read materials, or other visuals.
- Plan for enough time to travel to the vaccination site but estimate to arrive close to the appointment time to avoid waiting.
- Consider how the person is feeling on the day of the appointment. If necessary, rebook the appointment. Avoid traumatic experiences that might negatively affect future vaccinations.

#### At the vaccination site

- When you arrive, ask if there is a staff member that can offer support throughout the entire process. If needed, share the Getting Ready For My Shot form, and explain any accommodations needed.
- Each vaccination site looks different. Some vaccinations take place at the doctors office.

Mass-vaccinations often take place in a large hall or gym with rows of vaccination stations. Consider any challenging sensory inputs like noises, bright lights, open spaces, people, visual markings on floors, medical products (e.g., needles, band-aids), staff wearing masks and gowns.

 Celebrate the completion of the vaccination. For example, use a vaccination "diploma" that marks the vaccination date(s). Note the date for upcoming appointments.

#### After the vaccination

- Follow up on the reward after vaccination.
- Read and explain any after-care instructions provided. Explain normal side effects: a sore arm, headaches, feeling tired or low fever. Explain that these symptoms mean the vaccine is working to protect the person from future disease. Typical side effects should disappear within three days.
- If, at any time, the person you care for shows abnormal symptoms (e.g., seizures), immediately contact a doctor.

#### Next appointments

- Some type of vaccines (e.g., COVID-19) require a second dose or "booster", within a specific timeframe for optimal effect. Set a reminder for the follow-up appointment.
- Repeat this preparation process and update the Getting Ready For My Shot form, including getting consent, each time the person you care for has a vaccination appointment.

## **Getting ready for my shot** Accommodation request form

# Complete this form together with someone who supports you. Bring this form to your vaccine appointment.

My Name	
First	Last
I have a vaccination appointment for	Location
day/month/year time	
Name of the person coming with me	
First	Last
Things that I find difficult	How you can help me
Waiting in line	Bring me to the front of the check-in line
Wearing a facial mask	Allow me to wear my own mask*
Keeping physical distance	Let me walk around
Seeing other people getting needles	Bring me to a separate quiet area
Holding still	Let my support person(s) help me stay still
Keeping quiet	Use simple language
Noises	Repeat questions or information if needed
Bright lights	Show and tell me what you will be doing
Large open spaces	Let me look away
Talking with people	Give the shot as quickly as you can
Understanding information	Remind and help me to count down
Seeing needles	Massage my arm before administering the vaccine
Band-aids	Let someone hold my hand
Pain	Tell me how well I am doing
Other:	Ask if I feel faint and let me lie down
	Other:

\*entering a vaccination site without wearing a facial mask might not be possible. Call the clinic before the appointment date to ask about specific accommodations.

Overall, you can help me by

## **Getting ready for my shot** A form to prepare for vaccination

A vaccine protects you from getting sick. Doctors and nurses give people vaccines by using a needle. This is also called "getting a shot". Fill out this form before getting your shot. Bring the form with you.

MYAPPOINTMENT				
My name				
First			Last	
I will get my shot	: on		Place where I will go to get my shot	
day/month/year		time	Location	
	1			
I will go there by				
car	taxi	bike	public transit walk	
Name of the person I will bring with me				
First			Last	
I want to get the	shot because			

#### WHAT I NEED TO BRING WITH ME

My health-card OR My passport

A form with my written name or signature that shows that I say yes to getting the shot (the consent form). \*This form can also be signed by someone who helps you make health care decisions. You can also get this form at the place where you are getting your shot.

Something to do while I am waiting

Something that makes me feel good

Other things I want to bring

#### WHAT THE DOCTOR OR NURSES NEED TO KNOW

Answer these questions before you go to get your shot.

My doctor's name	
First	Last
I already got another shot in the past two weeks yes	no

#### My medication

Other important things about my health

The doctor or nurse will ask how you are feeling on the day of your shot. Answer these questions on the day that you are getting your shot.

Have any of these been bothering me in the last 2 weeks	
fever or chills	headache
new cough	feeling tired
runny nose or stuffy nose	stomach pain
sore throat or hoarse voice	diarrhea
hard to breathe	problems smelling or tasting things

Was anyone I live with sick in the past week yes no

#### **AFTER THE SHOT**

After getting your shot you may have a sore arm, a headache, feel tired or like you have a fever. This is normal. It means it is working and will protect you from getting sick later. This should go away in 3 days after getting your shot. If you feel very sick, get help right away and call your doctor or nurse.

#### **MY NEXT SHOT**

You may get an email or a phone call about your next shot. Write down the day and time and keep it with your health papers.

Fill out this form again when you go for a next shot.

My next shot is on	
day/month/year	time

Things I liked about getting the shot

Things I did not like about getting the shot

Ideas to make my next shot easier

# **SURREY** PLACE

### **Supporting material**

## Accessible information about COVID-19 vaccines and how to prepare

For accessible resources on the COVID-19 vaccine, social stories, videos and practical tips on how to prepare, see:

### COVID-19 Resources for Healthcare Providers and Caregivers

Developmental Disabilities Primary Care Program (DDPCP), Surrey Place, Toronto https://ddprimarycare.surreyplace.ca/covid-19/covid-19-tools-and-resources/

#### How to Stay Safe, Well and Connected: COVID-19 Resources

Health Care Access Research and Developmental Disabilities (H-CARDD), Centre for Addiction and Mental Health, Toronto https://www.hcarddcovid.com/info

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.

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This document is developed by the Developmental Disabilities Primary Care Program (DDPCP) at Surrey Place, Toronto in collaboration with the Azrieli Adult Neurodevelopmental Centre, CAMH, Toronto. The DDPCP supports family physicians and other caregivers to optimize the health and healthcare of adults with intellectual and developmental disabilities. The content of this tool was subject to review by primary care providers and other relevant stakeholders. All rights reserved. The content of this tool may not be reproduced or stored in a retrieval system in any form or by any means without the prior written permission of the copyright owner, Surrey Place. Permission to use, copy, and distribute the tool is granted with proper citation as outlined below. Contact ddpcp@ surreyplace.ca for permission to adapt this tool to your local practice setting. This tool is developed as a guide only. While great effort has been taken to assure the accuracy of the information provided, Surrey Place, the Developmental Disabilities Primary Care Program, the reviewers, printer and others contributing to the preparation of this document cannot accept liability for errors, omissions or any consequences arising from the use of the information. Primary care providers and other healthcare professionals are required to exercise their own clinical judgement in using this tool.

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