

## About My Health

*Learning about the healthcare and communication needs of adults with intellectual and developmental disabilities*

### Introduction

#### IF YOU HAVE A DISABILITY AND WANT TO USE THIS TOOL

This is a worksheet where you can write down important information about yourself before you visit a doctor or hospital. You can write about your own health. You can also write down information such as things you like to do; ways to help you understand things better; names of people that support you; things that help you to feel safe and relaxed; and things that you don't like. Bring this information to the doctor's office or anytime you are seeing a new health care provider to help a visit go well.

#### FOR PROVIDERS AND CAREGIVERS

*About My Health* is a tool for people with intellectual and developmental disabilities to share with health care providers which can be updated on an annual basis, or when there is a significant change in health status or situation. Its focus is on important information that is relevant to any health care issue. Keeping a more extensive health passport is another option to this tool, but this brief form captures some minimal information that would be included in any health passport. Caregivers actively involved in supporting adults with intellectual and developmental disabilities in their health care may find it useful to maintain this brief form in their files. Individuals responsible for their own care or families may prefer a binder or folder that goes with them to appointments. Information like this can be especially useful when seeing a new health care provider. It may be helpful to share it in advance if arranging for a more complex procedure (eg, colonoscopy).

### Supporting materials

i. **Health Passports and Communication Tools**

Health Care Access Research and Developmental Disabilities (H-CARDD), Canada <https://www.porticonetwork.ca/web/hcardd/healthcareresources/people-with-developmental-disabilities-and-caregivers>

ii. **My Healthcare Passport**

NHS, United Kingdom <https://www.england.nhs.uk/6cs/wp-content/uploads/sites/25/2015/03/healthcare-passport.pdf>

iii. **Healthcare Passport**

EasyHealth, United Kingdom  
<http://www.easyhealth.org.uk/sites/default/files/null/Health%20Care%20Passport%20-%202017.pdf>

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.

## 1 My Information

<b>Name</b>		<b>Birthday</b>		<b>I like to be called</b>	
First	Last	Year	Month	Day	<input type="checkbox"/> He <input type="checkbox"/> She <input type="checkbox"/> They

<b>My Address</b>				<b>My phone number</b>	
Apt #	Street	Province	Postal Code		

<b>My health card number</b>	<b>Expiry date:</b>

**I live (check all that apply)**

Alone    With family    With parents    With roommates    Other:  
 With spouse/partner    With friends    In a group home    In supported independent living

## 2 Things I want you to know about me (Note: think about who will be seeing the form when you decide what to include)

<b>My interests and what I like to do</b>	<b>Important people in my life</b>	<b>Difficult life experiences I have had that I want you to know about</b>

## 3 My emergency contact

<b>Name</b>		<b>Relationship to me</b>
First	Last	

<b>Address</b>				<b>Phone number</b>
Apt #	Street	Province	Postal Code	

## 4 Do I have someone who I want to help me make my health care decisions? Yes No

<b>Name</b>		<b>Relationship to me</b>
First	Last	

<b>Address</b>				<b>Phone number</b>
Apt #	Street	Province	Postal Code	

## 5 Is there someone I want to be told about my health care appointments? Yes No

<b>Name</b>		<b>Relationship to me</b>
First	Last	

<b>Address</b>				<b>Phone number</b>
Apt #	Street	Province	Postal Code	

## 6 Important things about my health

### Medical history and conditions

### Things I am allergic to and what happens to me (if known)

## 7 My family doctor (or nurse practitioner)

### Name

First Last

### Phone number

### Address

Unit # Street Province Postal Code

### Fax number

## 8 My pharmacy

### Name

### Phone number

### Address

Unit # Street Province Postal Code

### Fax number

## 9 My medications (please attach or bring medication list)

### Do I have drug coverage?

Yes  No

### My drugs are paid for

Ontario Disability Support Program (ODSP)  Ontario Drug Benefit (ODB)  Other  I don't know

### How do I take my medications?

Whole  Crushed  Mixed with Food  Other

## 10 How can you make my health care visit better?

### What makes me uncomfortable, scared, or nervous about seeing the doctors and nurses?

### If I am...

Scared/nervous

Uncomfortable/overstimulated

In pain/hurting

Sad

Angry

### I show it by:

### You can help me by:

**Try these to help with things like needles, x-rays, or bloodwork**

- |  |   |   |
|--|---|---|
| <input type="checkbox"/> Show and tell me what you are doing | <input type="checkbox"/> I like hearing how well I am doing                 | Get me to look away and do it as quickly as you can |
| <input type="checkbox"/> Let me ask questions                | <input type="checkbox"/> Talk me through each step as you do it             |   |
| <input type="checkbox"/> Use numbing cream for needles       | <input type="checkbox"/> Remind and help me count to ten                    | Other:  |
| <input type="checkbox"/> Be quiet so I can concentrate       | <input type="checkbox"/> I like a little something to look forward to after |   |
| <input type="checkbox"/> I like my hand held                 | <input type="checkbox"/> Let me touch the equipment                         |   |
| <input type="checkbox"/> Remind me to take deep breaths      | <input type="checkbox"/> Play music or sing                                 |   |

**Things that you can do to help me understand:**

- |  |  |  |   |
|--|--|--|---|
| <input type="checkbox"/> Look at me when you speak | <input type="checkbox"/> Write it down | <input type="checkbox"/> Let my caregiver or staff explain | <input type="checkbox"/> Speak directly to me first     |
| <input type="checkbox"/> Speak slowly              | <input type="checkbox"/> Repeat things | <input type="checkbox"/> Use simple language               | <input type="checkbox"/> Speak louder so I can hear you |
| <input type="checkbox"/> Use pictures              | <input type="checkbox"/> Use gestures  | <input type="checkbox"/> Ask me to repeat it back          | because I am hard of hearing                            |

Other

<b>Things I like at health care visits:</b>	<b>Things I don't like at health care visits:</b>
---	---

Blank area for notes on things liked at health care visits.

Blank area for notes on things not liked at health care visits.

**📌 Other helpful information for doctors and nurses**

**Do I have a...**  
*These plans may include information on things you can do to help me calm down or feel better. Ask me or the person supporting me for this information or find it attached.*

<input type="checkbox"/> Health Care Plan	<input type="checkbox"/> Emergency or Crisis Plan	<input type="checkbox"/> Other
---	---	--------------------------------

**More information about my health is attached to this form**  Yes  No

## References

- Boyd K, Diepstra H, Elbard K, Hamdani Y, Lunsky Y. Consumer inclusion: Experience of patients with intellectual and developmental disabilities informs primary care. *Can Fam Physician*. 2018;64(Suppl):8-11.
- Heifetz M, Lunsky Y. Implementation and evaluation of health passport communication tools in emergency departments. *Res Dev Disabil*. 2018;72:23-32.
- Northway R, Rees S, Davies M, Williams S. Hospital passports, patient safety and person-centred care: A review of documents currently used for people with intellectual disabilities in the UK. *J Clin Nurs*. 2017;26(23-24):5160-8.
- Spassiani NA, Sawyer AR, Abou Chacra MS, Koch K, Muñoz YA, Lunsky Y. "Teaches people that I'm more than a disability": Using nominal group technique in patient-oriented research for people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*. 2016;54(2):112-22.
- Author names (2019) The Nuts and Bolts of Healthcare: Training direct support professionals to be effective healthcare advocates. Accessed from: [www.hcadd.ca](http://www.hcadd.ca) DATE

## Copyright and Disclaimer

This document complements the Canadian consensus guidelines on the primary care of adults with developmental disabilities, published by the Developmental Disabilities Primary Program (DDPCP) of Surrey Place and *Canadian Family Physician*, (Volume 64 (4): April 2018, p254-279).

It has been adapted with permission from About My Health, developed through the Nuts and Bolts project, a partnership with the Centre for Addiction and Mental Health and Vita Community Living Services-Mens Sana, Toronto.

The DDPCP supports family physicians and other caregivers to implement clinical practice guidelines and to optimize the health and healthcare of adults with intellectual and developmental disabilities. The DDPCP is funded by the Ontario Ministry of Health and Long-Term Care and The Ministry of Children, Community and Social Services.

Clinical leadership for the development of the tool was provided by Dr. Yona Lunsky, PhD, CPsych, Director of the Azrieli Adult Neurodevelopmental Centre, Senior Scientist in the Adult Neurodevelopment and Geriatric

Psychiatry Division, Centre for Addiction and Mental Health. The content development was subject to review by primary care providers, people with intellectual and developmental disabilities, families, and staff.

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](mailto: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.

**PLEASE USE THIS CITATION WHEN REFERENCING THIS TOOL:** About My Health: Learning about the healthcare and communication needs of adults with intellectual and developmental disabilities. Melhas, M., Hermans, H., Orr, E., Salonia, C., Zaretsky, L., & Lunsky, Y. Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019.