



Family Matters Toolkit

**Tools and Resources to Help Adults with
Intellectual and Developmental Disabilities
Manage their Health and Health Care**



Health Care Access Research
and Developmental Disabilities

camh | Azrieli Adult
Neurodevelopmental Centre

About this Toolkit



The Family Matters Toolkit is an opportunity to share tools and resources with caregivers who are interested in improving the health and health care of a family member with intellectual and developmental disabilities (IDD). The resources included in this toolkit can be used together, or as stand-alone materials, depending on your needs, goals and existing resources. We encourage you to use whichever pieces of this toolkit you feel are helpful. There are electronic versions of all materials available at <http://familymatters.ddtoolkits.com>. Where available, we have included a modifiable version (usually in Microsoft Word), that can be downloaded and further adapted as required.

Why do we need a toolkit?

This toolkit is for caregivers to better support their family members with IDD regarding their health care.

We know that adults with IDD have worse mental and physical health than adults without these disabilities and that their health problems can lead to the use of many medications, some with very serious side effects. In addition, research shows that people with IDD visit their doctors more frequently, go to the emergency department more often and have more hospitalizations than the general population. They also experience unnecessary long hospital admissions, and even death. Many things can be done to improve the health of adults with IDD and caregivers play a very important role.

To make changes, individuals and caregivers need information about how to: 1) manage common health issues; 2) talk about health issues and health care; and 3) navigate the health care system. This toolkit has information and tools that can be helpful.

The toolkit is divided into five sections:



Tools and Tips for Health Care Visits: Information to help caregivers and their family member to prepare and participate in health care visits.



Enhancing Communication: Tips and information on fostering improved communication for the individual with IDD and their families, and role modelling it to others (including health care providers).



Health Care Information: Information and resources on health care conditions that commonly affect people with IDD.



Monitoring Charts: Monitoring charts on various health issues and conditions that you can use to collect data and health information.



Health Care Handouts and Other Resources: Information sheets and other resources on common health care conditions and procedures for reference and to review with your family member to better understand health care issues and prepare for medical procedures.

About the H-CARDD Program

This toolkit is an adaptation of the [Nuts and Bolts of Health Care for DSPs Toolkit](#), developed by the [Health Care Access Research and Developmental Disabilities Program](#) (H-CARDD) at the Centre for Addiction and Mental Health (CAMH), in partnership with Vita Community Living Services. H-CARDD is a research program based in Ontario, Canada, studying the health and health care outcomes of adults with IDD. Vita CLS is a non-profit community organization that provides services for adults with developmental disabilities and dual diagnosis (developmental disability accompanied by a mental health or addiction support need). The original toolkit was the product of a two-year effort, informed by speaking with direct support professionals, supervisors, directors, and self-advocates from Vita CLS as well as with health care providers.

Who worked on this toolkit?

- Lee Steel, Family Support Worker, CAMH
- Irfan Jiwa, Research Analyst, CAMH
- Mahrukh Nisar, Research Student, CAMH
- Andrea Perry, Research Consultant
- Megan Abou-Chacra, Research Analyst, CAMH
- Tiziana Volpe, Research Coordinator, CAMH
- Yona Lunsky, Director, H-CARDD Program

With special thanks to:

- Developmental Disabilities Primary Care Program at Surrey Place.
- Vita Community Living Services implementation team, trainers, and all staff and members who worked on the original Nuts and Bolts of Health Care project.
- Special Olympics Ontario for supporting a student to work on this project.

How to cite this publication:

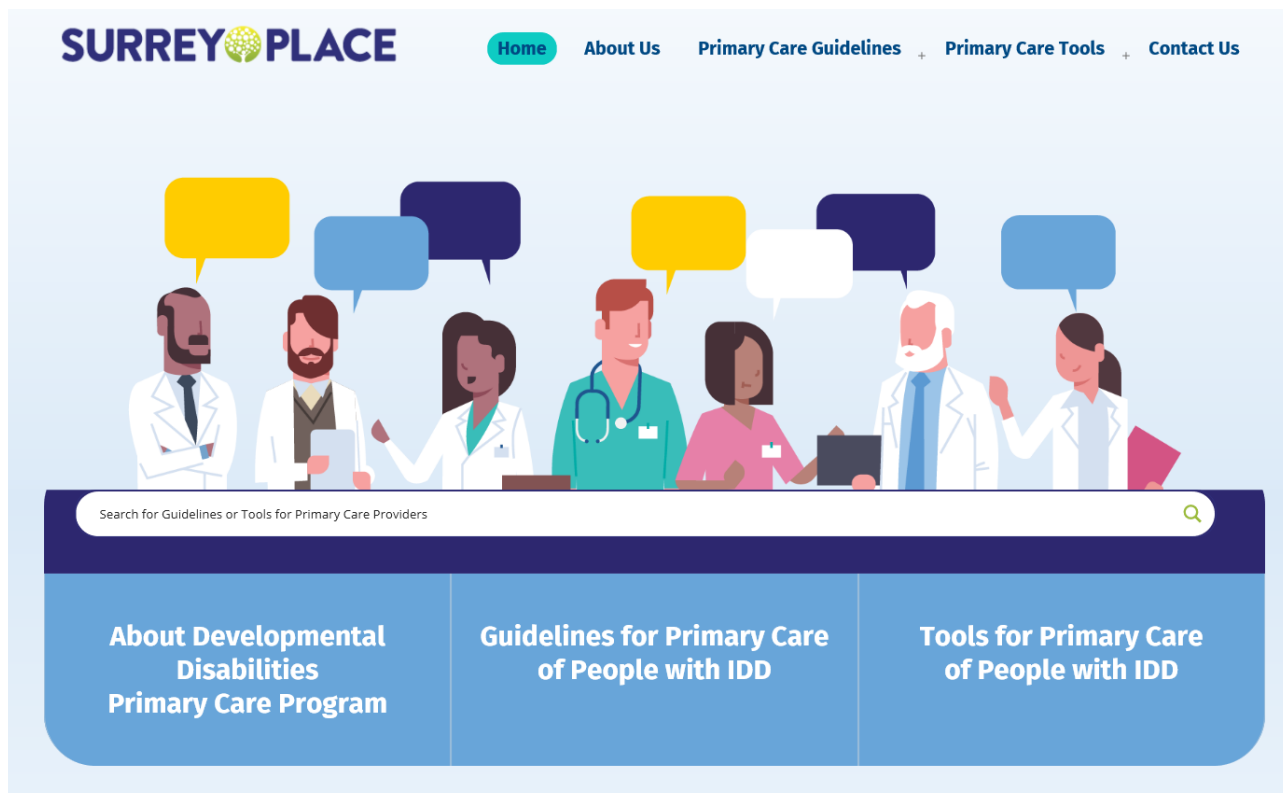
Steel, L., Irfan, J., Nisar, M., Perry, A., Abou-Chacra, M., Volpe, T., & Lunsky, Y. (2020). *Family Matters Toolkit: Tools and Resources to Help Adults with Intellectual and Developmental Disabilities Manage their Health and Health Care*. Toronto, ON: Health Care Access Research and Developmental Disabilities Program.

The Developmental Disabilities Primary Care Program

The [Developmental Disabilities Primary Care Program \(DDPCP\)](#) is a program of Surrey Place that collaborates with primary care providers (family doctors, nurses, health care providers) throughout Canada, researchers and knowledge translation professionals to publish guidelines and corresponding clinical practice tools and educational materials to assist primary care providers in their care of patients with intellectual and developmental disabilities (IDD).

The H-CARDD program partnered with the DDPCP to publish two new tools to help make health care visits a success: [About My Health](#) and [My Health Care Visit](#). You can find these in *Chapter 1: Tools and Tips for Health Care Visits* of this toolkit. Caregivers can support their family member to complete these tools when preparing for and attending health care visits, to enhance comfort, communication and effectiveness during the visit.

In this toolkit, you will also find other tools published by the DDPCP, including physical health monitoring charts (see *Chapter 4: Monitoring Charts*), and information on seizures (see *Chapter 3: Health Care Information*). The DDPCP updated many of their tools in 2019; for the most up-to-date versions of their tools, we encourage you to visit their website: www.ddprimarycare.surreyplace.ca.



To read the most recent Canadian consensus guidelines, *Primary Care of Adults with Intellectual and Developmental Disabilities*, please visit: <http://www.cfp.ca/content/64/4/254>.

Table of Contents



Tools and Tips for Health Care Visits

Tool: “About My Health”	2
Sample: “About My Health”	5
Tips for Filling out the “About My Health” Tool	8
Tool: “My Health Care Visit”	10
Sample: “My Health Care Visit”	12
Tips for Filling out the “My Health Care Visit” Tool	14
Preparing for Future Emergencies: A Checklist	16



Enhancing Communication

Who’s Who in Health Care: A Glossary	18
Finding a Family Doctor	21
Empowerment	23
Communicating with Health Care Providers	25
Health Care Decision Making	27
Supporting Someone who has a Catastrophic Illness	29





Health Care Information

Seizures: General Information	33	Aging	40
Seizures: Tips for Caregivers	35	Dementia	46
Seizure Action Plan	36	Urinary Tract Infections	48
Seizures: First Aid	38	Medications	51
Pain Assessment	39	Mental Health and IDD	55



Monitoring Charts

Direct Observation System	59	Seizure Record	65
Bowel Movement	60	Sleep (24-hour sleep record)	66
Menstrual Cycle	61	Weight (Adults)	68
Food Diary (Daily)	62	Diabetes Blood Sugar Diary	69
Food Diary (Weekly)	63		
Seizures Yearly	64	Pain Assessment	70



Health Care Handouts and Other Resources

Fecal Occult Blood Test (FOBT)	73	Glossary of Terms	81
Pap Test & Exam	74	IDD: Frequently Asked Questions	82
Mammogram	77	Genetic and Neurodevelopmental Conditions Linked to IDD	83
MRI Scan	79		
Other Resources	80		

Section 1:



Tools and Tips for Health Care Visits

- **Tool: “About My Health”**
- **Sample: “About My Health”**
- **Tips for Filling out the “About My Health” Tool**
- **Tool: “My Health Care Visit”**
- **Sample: “My Health Care Visit”**
- **Tips for Filling out the “My Health Care Visit” Tool**
- **Preparing for Future Emergencies: A Checklist**



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>

About My Health

1 My Information

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

My Address				My phone number	
Apt #	Street	Province	Postal Code		

My health card number	Expiry date:

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)

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

3 My emergency contact

Name		Relationship to me
First	Last	

My Address				Phone number	
Apt #	Street	Province	Postal Code		

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

Name		Relationship to me
First	Last	

My Address				Phone number	
Apt #	Street	Province	Postal Code		

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

Name		Relationship to me
First	Last	

My Address				Phone number	
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		Phone number
First	Last	

My Address				Fax number
Apt #	Street	Province	Postal Code	

8 My pharmacy

Name		Phone number
First	Last	

My Address				Fax number
Apt #	Street	Province	Postal Code	

9 My medications

Do I have drug coverage?		My drugs are paid for			
Yes	No	<input type="checkbox"/> Ontario Disability Support Program (ODSP)	<input type="checkbox"/> Ontario Drug Benefit (ODB)	<input type="checkbox"/> Other	<input type="checkbox"/> I don't know

How do I take my medications?				
<input type="checkbox"/> Whole	<input type="checkbox"/> Crushed	<input type="checkbox"/> Mixed with Food	<input type="checkbox"/> 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...	I show it by:	You can help me by:
Scared/nervous		
Uncomfortable/overstimulated		
In pain/hurting		
Sad		
Angry		

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

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

Things that you can do to help me understand:

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

Other

Things I like at health care visits:

Blank area for writing things liked at health care visits.

Things I don't like at health care visits:

Blank area for writing 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.

Health Care Plan Emergency or Crisis Plan 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.hcardd.ca DATE

Copyright and Disclaimer

This document complements "Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines" published by the Developmental Disabilities Primary Care Program (DDPCP) of Surrey Place and the College of Family Physicians of Canada, in *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 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.

Tips for Filling out the About My Health Tool

The About My Health tool was created to help people with IDD share key health information with new health care providers to help appointments run more smoothly. This tool provides a brief summary of a person's health that will help health care providers understand their strengths and needs more easily.

Here are some tips to help you fill out and use the About My Health tool:

- When filling out the tool with your family member, consider the person's level of independence:
 - If they require greater support, you may want to try to involve other family members or staff who know the person well to get their input as you are filling it out.
 - If your family member is more independent, you can invite them to fill it out with support or to fill it out on their own.
- This tool should be updated on a yearly basis to ensure that the information listed is up-to-date.
- This tool was not designed to be taken to every health care visit. Instead, this tool can be photocopied and used to:
 - Provide a summary of a person's health to a new health care provider (e.g., family doctor, specialist, walk-in clinic, emergency room visit, hospital visit, dentist, eye doctor, etc.).
 - Provide health information to a health care provider you are seeing again after there has been a change in the health of your family member.
 - Orient staff who may accompany your family member to a health care appointment. This is especially important in cases of emergency where a non-family member may accompany the individual.
- This tool is not meant to provide an individual's full and detailed medical history. Instead, its purpose is to highlight key aspects of an individual's medical record that are important for health care providers to know.

Here are some tips to help you fill out specific sections of the About My Health tool:

About My Health
Surrey Place Centre Developmental Disabilities Primary Care Program

My Information

Name: [First Name] [Last Name] Birthday: [Month] [Day] [Year] I like to be called: He She They

My Address: [Street] [City] [Province] [Postal Code] My phone number: [Area Code] [Number]

My health card number: [Number] Expiry date: [Month] [Year]

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

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

My interests and what I like to do: [Text Box]

Important people in my life: [Text Box]

Difficult life experiences I have had that I want you to know about: [Text Box]

My emergency contact

Name: [First Name] [Last Name] Relationship to me: [Text Box]

My Address: [Street] [City] [Province] [Postal Code] Phone number: [Area Code] [Number]

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

Name: [First Name] [Last Name] Relationship to me: [Text Box]

My Address: [Street] [City] [Province] [Postal Code] Phone number: [Area Code] [Number]

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

Name: [First Name] [Last Name] Relationship to me: [Text Box]

My Address: [Street] [City] [Province] [Postal Code] Phone number: [Area Code] [Number]

DEVELOPED BY: Surrey Place Centre Developmental Disabilities Primary Care Program PAGE 1 of 3

“Things I want you to know about me” section:

- Make sure that your family member is comfortable with the information that is listed in this section (e.g. specific difficult life experiences) as there may be some information that the person you are supporting may not want to share with health care providers.
- If they are able, it is important that your family member is given the opportunity to approve the information that is provided.

“My Emergency Contact” section:

Difference between “My emergency contact”, “Individual who helps make health care decisions”, and “Individual who should be told about health care appointments”:

The image shows a screenshot of a web form titled "About My Health" from Surrey Place Centre Developmental Disabilities Primary Care Program. The form is divided into several sections. The "My emergency contact" section is highlighted with a red border. This section includes fields for Name, Relationship to me, My Address, and Phone number. Below this, there are two questions: "Do I have someone who I want to help me make my health care decisions?" and "Is there someone I want to be told about my health care appointments?", each with Yes/No radio buttons. The form also includes sections for "My Information" (Name, Birthday, I like to be called, My Address, My phone number, My health card number, Expiry date, I live) and "Things I want you to know about me" (My interests and what I like to do, Important people in my life, Difficult life experiences I have had that I want you to know about).

- These three types of contacts may be the same person in some circumstances but it is important to be clear what exactly each contact means so the right individuals are listed:
 - **Emergency contact:** This is the person who your family member would like to call first in the event of an emergency. This may be a family member or friend.
 - **Individual who helps make health care decisions:** The person listed here could be the individual’s substitute decision maker (i.e., the individual whose responsibility it is to make decisions for a person who is not able to make his or her own health care decisions) if they have one, or someone else the person likes to be involved in decisions about their health. *Note: A substitute decision maker cannot be a staff/paid caregiver.*
 - **Individual who should be told about health care appointments:** This is a person that your family member would like to be notified when a health care appointment is needed and/or scheduled. This may be a family member or friend.

- It is important to include all of the contact information of the person’s family doctor/nurse practitioner and pharmacy because these contacts will be important to have available when health care decisions (e.g., medication changes) are made.
- Remember to notify the health care provider if your family member has a crisis plan.
- If there is not enough room on the page to include all of the necessary information, remember that additional information can always be attached to this tool.

My Health Care Visit

Understanding Today's Visit and Follow-up

Introduction

FOR PERSONS WITH AN INTELLECTUAL OR DEVELOPMENTAL DISABILITY

This is a worksheet to help prepare for your medical appointment, and to help understand and remember what happened. Bring this to every health care visit, even if you already know the doctor. There are 3 sections on the form:

1 ABOUT MY HEALTH CARE VISIT: this is for you to write out the reasons why you are seeing the doctor. You should fill this out before you go.

2 DURING MY HEALTH CARE VISIT: this section is for you, the doctor and anyone else who is supporting you to fill out during the visit, to help remember what was done, and what you have to do after you leave.

3 AFTER MY HEALTH CARE VISIT: this section can be completed when you are back home. It is a chance for you and people who support you to discuss the appointment, and review what you liked, and what might make it better next time.

FOR PROVIDERS AND CAREGIBERS

My Health Care Visit is a tool for people with intellectual and developmental disabilities to complete with health care providers to foster understanding of the purpose, and outcome of today's health care visit. The first section is to summarize why the person is coming in today; the second section is intended to be completed as a summary of what was discussed, to help the person understand the information, and what follow up steps will occur, if any. The third section is optional, and is intended as a 'debrief' back home, after the appointment to reflect on what went well, and if any ideas for to improve future appointments. This could ideally serve as documentation of a health care visit for the person's record, if needed.

Supporting materials

Going to the Doctor?

Health Care Access Research and Developmental Disabilities (H-CARDD), Centre for Addition and Mental Health, Toronto [video] <https://www.porticonetwork.ca/web/hcardd/resources/videos/idd>

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.

Preparing for My Health Care Visit

FILL OUT BEFORE GOING TO THE VISIT BY ME AND PERSON SUPPORTING ME

1 Appointment information

My Name

First

Last

Name of person supporting me

First

Last

Appointment type

- Family Doctor
 Walk-in Clinic
 Other (e.g., dentist, eye doctor, specialist, X-ray, etc.):
 Hospital Visit
 Emergency Room Visit

Things to bring with me

- OHIP card
 Comfort items (eg., snacks, books, games, etc.)
 ODSP card (if going to the dentist or eye doctor)
 Any medications I need to bring with me

2 Why am I going to the appointment? (Note: let the doctor know if you've already had an appointment for this reason)

EXAMPLES: Feeling sick, I got hurt, I need a check up, something hurts in my body, illness, injury, need more medication, medication changes or concerns, stress with family or friends, need forms filled out, etc.

3 Have any of these been bothering me in the last week (or longer)?

Health Concern:	Is there a problem?	What is the issue?	Is tracking sheet(s) attached?
Pain	<input type="checkbox"/>		<input type="checkbox"/>
Eating	<input type="checkbox"/>		<input type="checkbox"/>
Bathroom or toileting	<input type="checkbox"/>		<input type="checkbox"/>
Energy or tired or sleep	<input type="checkbox"/>		<input type="checkbox"/>
Emotions or feelings	<input type="checkbox"/>		<input type="checkbox"/>
Relationships	<input type="checkbox"/>		<input type="checkbox"/>
Sexual health	<input type="checkbox"/>		<input type="checkbox"/>
Other (eg., falls, hearing, vision)	<input type="checkbox"/>		<input type="checkbox"/>
Medication	<input type="checkbox"/>		<input type="checkbox"/>

During My Health Care Visit

FILL OUT WITH A HEALTH CARE PROVIDER

1 Appointment summary (*If the health care provider does not fill out this section, a copy of their note from the appointment or a letter summarizing the required information can be attached. If attaching a document, please check this box:)

What did we talk about and do?

Next steps (Things like: tests or exams I need to do like X-ray or blood work, appointments to see a different doctor or health professional, need to come back to see the doctor I saw today, things I or the people supporting me can do to be healthier at home)

2 Medications (Were there changes to my medications?)

Yes No

New Medications (if any)

Medication Name	Why do I need to take this medication?
1.	
2.	
3.	

Things to remember to do before I leave

Don't forget to:

- Make sure this page is completed
- Schedule any upcoming appointments with the front desk Appointment date:
- If there is a referral, make sure I know whether I need to call to follow up Referral:

Doctors Name:

Signature:

Date:

After My Health Care Visit

FILL OUT AFTER THE VISIT WITH THE PERSON SUPPORTING ME

Comments about the visit:

Things like: How did the visit go? What do I need to do now? What could we do differently next time?

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). This document is an updated version of *Today's Visit*, published in Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. Tools for the primary care of people with developmental disabilities. Toronto: MUMS Guideline Clearing House; 2011, p. 24-25.

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 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: My Health Care Visit: Understanding Today's Visit and Follow-up. Malhas, M., Hermans, H., Orr, E., Salonia, C., Zaretsky, L., & Lunsky, Y., Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019.

Tips for Filling out the My Health Care Visit Tool

The My Health Care Visit tool was created to help your family member be more involved in their own health care. Specifically, this tool is designed to help people with disabilities to be more actively involved in the health care visit and in preparing for the visit.

Here are some tips to help you fill out and use the My Health Care Visit tool:

- When filling out the tool with your family member, consider the person’s level of independence:
 - If they require greater support, you may want to try to involve family members or staff who know the person well to get their input as you are filling it out.
 - If your family member is more independent, you can invite them to fill it out with support or to fill it out on their own.
- This tool was designed to be used for any health care visit (e.g., with a family doctor, specialist, walk-in clinic, emergency room visit, hospital visit, dentist, eye doctor, etc.).

My Health Care Visit: Preparing for the Visit

- The first page of the tool should be filled out as soon as the health care visit is booked (this could be days or weeks in advance).
- The person helping your family member fill out the tool does not have to be the same person who attends the appointment.
- It can be helpful to read this section aloud or to show it to the health care provider at the beginning of the visit so that any health questions/concerns can be discussed and are not forgotten.
- For the section called “Have any of these been bothering me in the last week (or longer?)” when trying to decide whether to mark issues as possible “problems” for the health care provider to look into, think about whether each issue represents a change that has made your family member different from their usual self. If it is a change, it should be checked off.
- A monitoring chart should be completed for any health concern your family member is having.
 - Begin monitoring once you recognize your family member is experiencing a problem. This will allow you to begin collecting information leading up to the appointment that will be helpful for the health care provider to know.
- Monitoring charts can be found in Section 4 of this Toolkit.

Preparing for My Health Care Visit

Surrey Place Developmental Disabilities Primary Care Program

FILL OUT BEFORE GOING TO THE VISIT BY ME AND PERSON SUPPORTING ME

1 Appointment information

My Name

Name of person supporting me

Appointment type

Family Doctor
 Walk-in Clinic
 Other (e.g., dentist, eye doctor, specialist, X-ray, etc.)

Hospital Visit
 Emergency Room Visit

Things to bring with me

OHIP card
 Comfort items (eg., snacks, books, games, etc.)

ODSIP card (if going to the dentist or eye doctor)
 Any medications I need to bring with me

2 Why am I going to the appointment? (Note: let the doctor know if you've already had an appointment for this reason)

EXAMPLES: Feeling sick, I got hurt, I need a check up, something hurts in my body, illness, injury, need more medication, medication changes or concerns, stress with family or friends, need forms filled out, etc.

3 Have any of these been bothering me in the last week (or longer)?

Health Concerns:	Is there a problem?	What is the issue?	Is tracking sheet(s) attached?
Pain	<input type="checkbox"/>		<input type="checkbox"/>
Eating	<input type="checkbox"/>		<input type="checkbox"/>
Bathroom or toileting	<input type="checkbox"/>		<input type="checkbox"/>
Energy or tired or sleep	<input type="checkbox"/>		<input type="checkbox"/>
Emotions or feelings	<input type="checkbox"/>		<input type="checkbox"/>
Relationships	<input type="checkbox"/>		<input type="checkbox"/>
Sexual health	<input type="checkbox"/>		<input type="checkbox"/>
Other (eg., falls, hearing, vision)	<input type="checkbox"/>		<input type="checkbox"/>
Medication	<input type="checkbox"/>		<input type="checkbox"/>

My Health Care Visit: *During the Visit*

How do you fill out the second page of the tool when you are in the appointment?

Option 1: Invite the health care provider to fill out this page of the tool with you and your family member during the visit, as you discuss different issues that come up.

Option 2: If the health care provider does not want to fill out the tool, ask them if they would be willing to print a copy of their notes from the appointment or a letter summarizing the required information and attach it.

Option 3: If the health care provider does not wish to do either option 1 or 2, summarize what the health care provider tells you, ask them to confirm that what you summarized is correct, and write it down on the tool while you are still in the appointment.

Surrey Place Developmental
Disabilities Primary Care Program

During My Health Care Visit

FILL OUT WITH A HEALTH CARE PROVIDER

Appointment summary (If the health care provider does not fill out this section, a copy of their note from the appointment or a letter summarizing the required information can be attached. If attaching a document, please check this box)

What did we talk about and do?

Next steps (Things like: tests or exams I need to do like: X-ray or blood work, appointments to see a different doctor or health professional, need to come back to see the doctor I saw today, things I or the people supporting me can do to be healthier at home)

Medications (Were there changes to my medications?) Yes No

New Medications (if any)

Medication Name	Why do I need to take this medication?
1. _____	_____
2. _____	_____
3. _____	_____

Things to remember to do before I leave

Don't forget to:

- Make sure this page is completed
- Schedule any upcoming appointments with the front desk Appointment date: _____
- If there is a referral, make sure I know whether I need to call to follow up Referral: _____

Doctors Name: _____ Signature: _____ Date: _____

After My Health Care Visit

FILL OUT AFTER THE VISIT WITH THE PERSON SUPPORTING ME

Comments about the visit:

Things like: I saw did the visit go? What do I need to do now? What could we do differently next time?

DEVELOPED BY: Surrey Place, Developmental Disabilities Primary Care Program

PAGE 2 of 2



Preparing for Future Emergencies:

A Checklist

- ❑ **About My Health tool:** Don't forget to bring the tool with you — it has a lot of important information that will be helpful for the doctor.
- ❑ **Identification or health card:** The hospital will need to know your name, address, how old you are and where you live.
- ❑ **Crisis plan:** If you already have a crisis plan, bring this with you to the hospital. This will have information that you can give to the hospital staff that will tell them how they can help you in an emergency.
 - If you don't have a crisis plan, you can still tell the hospital about ways that they can help you. You can also tell them things you do NOT like, or what you are afraid of. The hospital might not remember to ask you this, so it is important that you remember to tell them.
- ❑ **List of medications:** What medications are you taking and how much of it? You can print this off from your pharmacist. Or, if you get ODSP money, let the hospital know. They can then look up your list of medications in the computer.
- ❑ **Name of your family doctor:** Write down the name of your family doctor and anyone else that helps you.
- ❑ **List of all your health problems:** This information will help the doctors understand what is wrong and how to make you feel better.
- ❑ **Food and drink:** You may have to wait for a very long time. Take your favourite food and a drink so you can eat it if you get hungry.
- ❑ **Activities to do while you wait:** You may have to wait for a very long time, take activities to keep you comfortable while you wait (your favourite music, pictures, books).
- ❑ **Comforters:** Bring something that makes you feel safe and comfortable. Things like a favourite blanket, shoes, stuffed animal, etc.



Check out the **Tools and Tips for Health Care Visits** in this section for examples of what you can bring to a hospital or medical appointment.



Section 2: Enhancing Communication



- **Who's Who in Health Care: A Glossary**
- **Finding a Family Doctor**
- **Empowerment**
- **Communicating with Health Care Providers**
- **Health Care Decision Making**
- **Supporting Someone who has a Catastrophic Illness**





Who's Who in Health Care: A Glossary

Part of empowering all of us to be equal partners in health care is understanding who does what and how we can all work together.

Health care provider: People who work in health care and who give health care. It includes the doctor, but it can also include other parts of the team like a nurse or social worker, a psychologist, or an x-ray technician.

General practitioner (GP) or “family doctor”: A GP is a doctor that you can go to first for any health problems. They do routine checkups and screening tests, give you flu and immunization shots, and manage diabetes and other ongoing medical conditions.

Some people have built a relationship with their GP over time, which can be helpful as the doctor gets to understand that person's particular needs and medical history. GPs work in many types of health services including family health teams and community health centres. See the “*Finding a Family Doctor*” tip sheet in this section for more information on these different types of clinics. Your GP may refer you to other health care providers when necessary, such as:

Allergist: A doctor who diagnoses and treats asthma and allergies (asthma and allergies typically go hand-in-hand).

Anesthesiologist: A doctor who works with patients who are having surgery or need relief from pain. This doctor is responsible for keeping patients safe and free of pain during and after surgery.

Audiologist: A health care professional who diagnoses and treats hearing problems and issues with balance. They can assess whether someone has trouble with hearing and give recommendations to help deal with this.

Behaviour therapist: Someone whose job is to help people learn new or change behaviours that are causing problems in their daily lives, often using an approach like Applied Behavioural Analysis (ABA).

Cardiologist: A doctor who diagnoses and treats issues with the heart and blood vessels.

Chiropractor: A health care provider who works with people to prevent and treat issues such as back and neck pain, headaches, whiplash, strains and sprains, work and sports injuries, arthritis, and difficulty moving your back, shoulders, neck, or limbs.

Counsellor: A professional that you can discuss your difficulties with and who can help you learn ways to cope with stress and sadness.

Dental hygienist: A health care provider who cleans teeth, examines patients' mouths for signs of disease and helps patients keep their mouth and teeth healthy.

Dentist: A health care provider who deals with oral health to make sure that a patient's teeth and jaws are healthy. They also help to prevent and treat oral diseases and conditions.

Dermatologist: A doctor who identifies, treats and prevents diseases of the skin, hair and nails.

Dietitian: A Registered Dietitian (RD) is a food and nutrition expert. They are trained to give advice and counselling about diet, food and nutrition.

Endocrinologist: A doctor who diagnoses and treats hormone problems and conditions (including diabetes).

Gastroenterologist: A doctor who diagnoses and treats issues with the gastrointestinal (GI) tract (which is a part of the body that is involved in digestion, absorbing nutrients and removing waste from the body).

General surgeon: A doctor who cares for patients before, during and after a surgery on any part of the body.

Hematologist: A doctor who deals with the diagnosis, treatment and prevention of blood-related disorders.

Immunologist: A doctor who diagnoses, treats and prevents disorders of the immune system (a system in the body that protects the body from infection). Immunologists are involved in treating health conditions such as allergies, pneumonia and sinus issues.

Infectious disease specialist: A doctor who deals with the diagnosis, control and treatment of infections in any part of the body.

Nephrologist: A doctor who specializes in kidney care and treating diseases of the kidneys.

Neurologist: A doctor who treats disorders (such as strokes) that affect the brain, spinal cord, and nerves.

Nurse: A health care provider who is trained to help people who are sick or injured. Nurses work with doctors and other health care workers to care for patients when they are sick and to keep them fit and healthy.

Nurse practitioner: An advanced practice registered nurse who is trained to assess patient needs, order and interpret laboratory tests, diagnose illness and disease, and formulate treatment plans. Nurse practitioners can also prescribe medication.

Nutritionist: A health care provider who is trained to give advice and counseling about diet, food, and nutrition. Nutritionists can have varying degrees of education in nutrition.

Obstetrician/gynecologist: A doctor who specializes in the care of women who are pregnant or are going through childbirth, and in some cases, helps women with their general medical care. They can also diagnose, treat and help prevent diseases of the reproductive system.

Occupational therapist: A health care provider who helps to solve problems that prevent a person from being able to do things that are important to them (things like: caring for themselves, playing sports, doing activities with others, or doing things at school or work).

Oncologist: A doctor who specializes in diagnosing and treating cancer.

Optometrist: A health care provider who diagnoses, treats and helps prevent any issues related to a person's eyes. They also provide eyewear products like glasses or contact lenses.



Ophthalmologist: A doctor and surgeon who specializes in eye diseases.

Orthopedic specialist: A doctor who specializes in issues and diseases with a person's bones. These doctors are involved in everything from treating things like sprained ankles or broken bones to complex procedures and surgeries like hip replacements.

Otolaryngologist (ear, nose and throat doctor): A doctor who specializes in disorders of the head and neck, particularly those related to the ears, nose and throat.

Pharmacist: A health care provider who gives patients the medications that were prescribed by their doctor and helps them understand more about the medications and any side effects or things to keep in mind about the medications. Pharmacists are a great resource if you have questions about medications you are taking.

Physiatrist: A doctor who treats and rehabilitates physical disabilities and pain caused by injury or illness.

Physical therapist (physiotherapist): A health care provider who works with patients to help them regain movement and manage pain caused by physical disabilities or injuries.

Psychiatrist: A doctor who diagnoses, treats and works to prevent mental, emotional and behavioural disorders. They can also prescribe medications related to mental health disorders.

Psychologist: A health care provider who assesses, diagnoses and treats psychological and behavioural problems. They work to promote healthy behaviour and improve patients' quality of life.

Psychotherapist: A mental health professional who specializes in providing psychotherapy (i.e., the treatment of mental disorders or other psychological problems).

Pulmonary disease specialist (respirologist): A doctor who diagnoses and treats lung conditions and diseases.

Radiologist: A doctor who diagnoses and treats disease and injury by using medical imaging equipment such as x-rays, CT, MRI, and PET scans and ultrasounds.

Rheumatologist: A doctor who diagnoses and treats pain and other symptoms related to joints and other parts of the musculoskeletal system, like arthritis.

Social worker: A health care provider who is responsible for helping individuals, families and groups of people to cope with problems they are facing to improve their lives.

Speech and language pathologist: A health care provider who assesses and manages disorders related to speaking and swallowing.

Urologist: A health care provider who treats conditions relating to the urinary tract as well as disorders of the male reproductive system.



Finding a Family Doctor

Value of a family doctor

Having a family doctor, or primary care nurse practitioner, is important to help with everyday health care. They can help keep people healthy, help manage chronic illnesses and help people get connected with specialists if they need them.

Not all family doctors or nurse practitioners are the same. Some doctors work independently, while others are part of larger teams including other providers like nurses, dietitians, pharmacists and social workers. For some people with disabilities who have a lot of health issues, it can be helpful to see a doctor who is part of a team such as a Community Health Centre or a Family Health Team.

When choosing a family doctor, there are a number of different things to consider. What is most important for one person might be different for another person.

When trying to find a family doctor, it can be helpful to:

- Review the questions listed below with your family member and discuss what is important to them.
- Learn more about the different models of care that family doctors belong to (see next page) and why this might make a difference. Ask doctors about the model of care they belong to and consider which one makes the most sense for your family member.

Here are some questions to ask when trying to find a family doctor:

- How comfortable/familiar is the doctor with intellectual and developmental disabilities (IDD)?
- Can appointment times accommodate a person's schedule? (e.g., evening hours if they work during day)
- How quickly can you get an appointment?
- How important is distance from home?
- How important is accessibility to public transportation?
- How important are hours of operation? Are evening or weekend visits needed?
- Does it matter if the doctor is male or female?
- Is it important to be part of a larger kind of team with different types of health care providers?



To speak with someone about finding a family doctor in Ontario, contact Health Care Connect:
1-800-445-1822

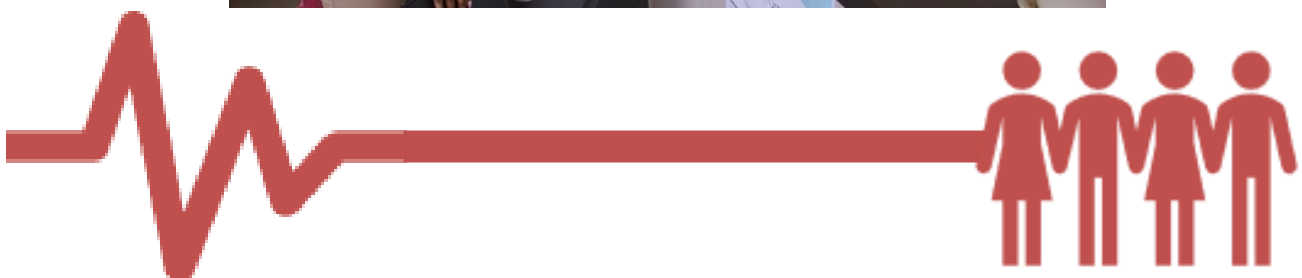
Different types of family doctors

Not all family doctors or nurse practitioners are the same. Some have extra services available that can be important for people with disabilities. One thing to think about when choosing a new doctor is their delivery model. There are three main types of primary care models:

Solo practitioners – Some doctors may work in a practice by themselves or share a practice with other primary care providers. Doctors in these practices do not tend to have extended hours (e.g., evenings and weekends). Typically, there are no other health care providers from other disciplines at these practices.

Groups of doctors – Some doctors work in groups with other doctors. In Ontario, these would include Family Health Organizations and Family Health Networks. If your doctor is not available, another doctor from the team can take the appointment. The doctors may have after hour clinics that you can go to when the doctor's office is closed. There may be a nurse or other kind of allied health professional but it is not a big part of how care is provided. The different doctors who work there do most of the work. It can be helpful that these groups have after hour clinics and they can share information with each other, but if you need to see other types of health care providers, you would have to go somewhere else for that care.

Primary care teams – Some doctors or nurse practitioners work as part of a larger team including other types of health care providers like nurses, social workers, dietitians, psychologists, occupational therapists, pharmacists and health educators. These include Family Health Teams and Community Health Centres. Each team is a little bit different so not all types of health care providers are on each team. What is the same about each primary care team is that the services offered by the team are free to the patient, and are under one roof. So you can see your doctor and also see the other people on the team if that is what the team thinks would be best. Community Health Centres are especially focused on helping patients with complex health care needs. *These practices can be really helpful for patients with disabilities who have multiple health conditions or need some extra support from their doctors.*



Empowerment

“Our job is not to silence.”

Facilitating Voice and Personal Power

As you know, people with disabilities may need a lot of support and encouragement to speak up for themselves and to be seen as an important partner in the process of receiving medical care. Many people feel intimidated when visiting their doctor and this can be especially true when you have an intellectual disability. The words that are used, the speed of a visit and the assumption that others know better how you experience your life and your disability can lead to compliance rather than collaboration.



As a caregiver, it's tempting to want to simply step in and 'be the voice' of your family member. But as appealing as that may be, it's important to remember that your goal is to support, not to silence. Helping your family member present their issues and use their way of communicating is one of the most powerful ways of being a supportive caregiver.

You will notice as a theme throughout this toolkit that the involvement of people with disabilities in the health care process is paramount in the approach taken. What we need to look at is the everyday kind of approaches to 'voice' and 'choice' that one can take when supporting people with disabilities.

**Your goal is to support,
not silence the individual.**

It's important to be mindful of your role as a caregiver: helping your family member find their voice and ensure that they get the best of service because they have learned to ask for it and expect it.

Keep reading to learn more about how YOU can facilitate the voice of your loved one, through targeted approaches and strategies. Then, review some ideas about how to promote positive communication during health care appointments and foster positive outcomes before, during and after appointments.



Tips on facilitating assertion and self advocacy

- 1 Use active listening skills when your family member needs to speak to you about something.** Active listening involves giving your family member your undivided attention when they have something to say, and eliminating distractions (e.g. silencing your phone). By doing so, your family member learns that you are saying, 'I value you and I value what you have to say.' It's important that people with disabilities learn, from how they interact with you, that they have importance and that their voice is welcome.
- 2 Be there to listen and to help your family member discover their own path and their own way.** Despite our good intentions, we don't know best how someone should live their life and our advice could be seen as judgmental. It is important to know where you end and where the person you support begins. When you listen, try hard not to immediately put on the 'problem solver' or 'advice giver' or 'opinion sharer' hat.
- 3 Offer opportunities for your loved one to express their opinion.** Watching the news or seeing a movie provides an opportunity for them to express their opinions. Allow room for respectful disagreement – if they change their opinion to match yours, understand that this is often done out of fear of disapproval; so it's important to foster opportunities for them to feel safe to express alternative and different opinions.
- 4 Sometimes you just need to let people make their own choices.** Just like anyone else, your family member will have their own preferences and opinions, for example, the music they listen to or movies they want to see. It is important to remember not to judge or try to change their preferences, but to encourage their own individuality.
- 5 Support your family member to be assertive in situations where *they* need to speak up.** As much as possible, help them to express themselves, rather than speaking for them. For example, if they need to complain about rude treatment at a store, work with them so they can assert themselves to the manager, with your support and help if needed. Knowing their voice matters and should be taken seriously is an important step towards self-advocacy.
- 6 Discover strategies to support your family member to learn about speaking up and speaking out.** Use techniques such as role plays, social stories, and practical try outs; tailored to the supports they need.
- 7 Don't be afraid of innovation and adaptation.** Explore different ways to facilitate communication. For example, a person may find it easier to make a video on their phone and play it for someone as a way to express themselves. What matters most is that you help your loved one express themselves in the way they are most comfortable.
- 8 Make a language dictionary.** For people with significant disabilities who don't communicate by words, a language dictionary of their communication strategies is helpful - how they say 'yes' or 'no' or 'more' or 'stop' along with their way of showing sadness or anger or fear or happiness, and any other words they communicate non- traditionally. Make sure that all who work with your family member know of these strategies. Take this with you to health care appointments or other places where it may be needed.
- 9 If a person uses alternative communication like a communication board USE IT.** It takes time but it's important. Otherwise, it's like leaving their ability to communicate at home, and you can imagine what that would feel like.

Communicating with Health Care Providers

How you can be a health care communication champion for your family member

Before the appointment:

Explore and understand any worries the person has about the appointment:

- Ask about their fears - don't avoid this topic. Validate how important their feelings are to you.
- Help them to overcome their fears and worries. Discuss and review strategies that might be helpful:
Preparing a social story? Doing a site tour? Watching a demonstration video? Role playing and practicing? Making note of a favourite item to bring?
- Record information in the **About My Health** tool, and bring it to the appointment.

Did you know?
[Easyhealth.org.uk](https://www.easyhealth.org.uk)
has loads of health care videos made with and for people with IDD.

Help the person to understand what will happen at the health care appointment:

- Be truthful, *but supportive*. (*'I'm sorry this might hurt. We will try to be quick.'*)
- If you minimize what will happen (for example, saying *'it won't hurt much'* to have blood taken), this tells a person that you can't be trusted, or that they are weak because it did hurt for them, but not you. This may impact your relationship, while also making your family member even *more* afraid about health care visits in the future. This may seem helpful for a moment, but when we think about it, it is not helpful at all.
- Review with the provider if there are ways to make things more comfortable.
- When booking the health care appointment, ask if it's possible to have extra time booked for the appointment.

During the appointment:

Help promote positive communication with the provider:

- Encourage and support the person to express their feelings: any questions, pains, worries. You may need to initiate this during the appointment. Ask your loved one's permission before you share any sensitive information.

Role model ideal communication to the provider:

- As a caregiver, you have expert knowledge about how to enhance communication. Techniques you can demonstrate to the health care provider may include:
 - If a question is posed to you, redirect it to your loved one: make eye contact, ask the person directly, modify your language if needed.
 - Pause and give enough time for a response before repeating or trying again.
 - Rephrase difficult concepts or medical jargon (and don't be afraid to ask the health care provider to explain it to you too).
 - Use the **My Health Care Visit tool** to record information.
 - Suggest concrete wording instead of abstract/open ended questions.(e.g. "Are you happy? Mad? Sad?" - instead of "How's your mood?").
 - Use visual aids, gestures or written information if that will foster understanding.

After the appointment:

Reflect and Review

*See the [Health Care Decision Making tool](#) for more information.

- Review how the visit went.
- If it went well reinforce your family member's great efforts at being their own self advocate.
- If there were problems debrief about what can be done next time.

Appointment Preparation

Summary Checklist

The following is a summary of the things to discuss to help increase the success of the medical appointment.



Stages of the appointment to plan for:

Before

- Practice running through the appointment and what can be expected
- Track the health care issue/symptoms using a tracking sheet.
- Bring preferred items to help with waiting.
- Have “**About My Health**” and “**My Health Care Visit**” tools and any other data you were tracking, ready to show the doctor.
- Arrive on time.
- Ask about a quiet waiting space.
- Have up-to-date contact information for yourself as a caregiver and the substitute decision maker (see “**About My Health**”) in case the doctor needs to contact them for any health care decisions.
- Other ideas:
 - Ask your family member before sharing information.
 - Give the health care provider the “**About My Health**” tool and “**My Health Care Visit**” tool and any other data you were tracking.
 - Model the best way to communicate.
 - Involve your family member.
 - Support the communication process.
 - Other ideas:

Start

- Check in with your family member during the appointment.
- Ask the health care provider to explain what will happen before they start.
- Ask for a demonstration when possible.
- Ask the health care provider to deliver one instruction at a time and to slow down.
- Other ideas:

Exam

Summary

- Ask if your family member wants you to be present to hear what the doctor says.
- If health care decisions require a substitute decision maker, have their contact information available.
- Make sure the information is understood as best as possible
- Other ideas:

Wrap up

- Make a note of what happened and what was decided in the “**My Health Care Visit**” tool.
- Make sure instructions are understood.
- Other ideas:



“Be my microphone, not my voice.”

- Dave Hingsburger

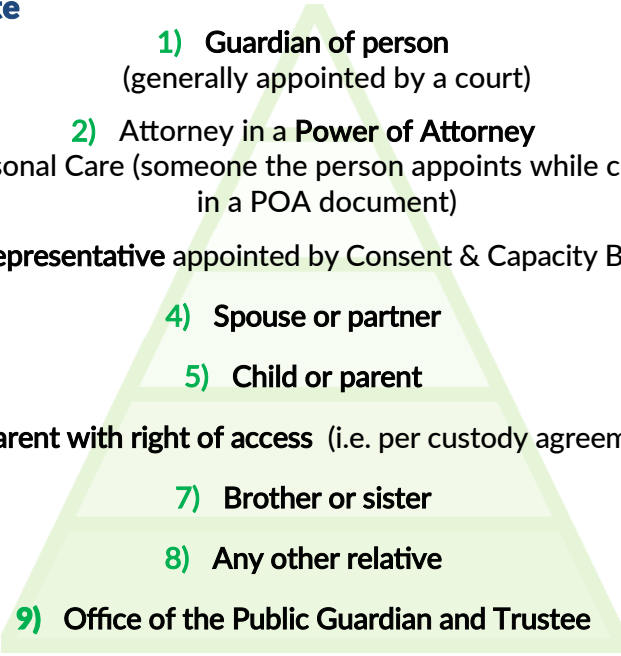
Health Care Decision Making

The ability to make decisions for ourselves is a human right. This is part of the ethical principle known as autonomy. When it comes to making a health care decision, current laws state that people can make their own decisions—unless there are grounds to think a person does not have the capacity or mental ability to do so. This can happen if a person is temporarily incapacitated (e.g. in a coma), or if someone has a more chronic disability that affects decision making.

People with intellectual and developmental disabilities (IDD) can participate in decision making and planning, even if they might need some extra support and accommodations from family, caregivers, and health care professionals. This person-centred approach puts the person with IDD at the centre of communication, planning, and decisions regarding their care.

There may be times when, even if information is explained clearly or repeated, the decision may be too complex given the person's abilities, and someone else is needed to make the decision. This follows the current laws in Ontario which are based around a concept known as *substitute decision making*. When a person is found to be incapable of making decisions, a substitute decision maker (SDM) is appointed to make the decision. The SDM is guided by knowledge of the person, gained from those closest to her or him. The laws in Ontario are very specific on who can be a SDM. In order, they are:

The “hierarchy” of substitute decision making in Ontario

- 
- 1) **Guardian of person**
(generally appointed by a court)
 - 2) **Attorney in a Power of Attorney**
for Personal Care (someone the person appoints while competent,
in a POA document)
 - 3) **Representative** appointed by Consent & Capacity Board
 - 4) **Spouse or partner**
 - 5) **Child or parent**
 - 6) **Parent with right of access** (i.e. per custody agreement)
 - 7) **Brother or sister**
 - 8) **Any other relative**
 - 9) **Office of the Public Guardian and Trustee**

Health Care Consent Act (1996)

When the SDM does not know the person well, trusted family members and other caregivers can help to inform decision making. You can also be helpful by ensuring that up-to-date contact information for the SDM is shared with the health care provider, in case this is needed. You can also discuss with your loved one the benefit of keeping their SDM informed of any health care appointments, in the event there is a decision the health care provider will call upon them to make.

What does capacity mean?

Legal capacity means having the ability to **understand the information** that is being presented (for example, knowing the risks and benefits of the decision), and to **appreciate how it relates to you** (for example, being able to explain what happens if you agree to treatment, but also understand the consequences if you refuse treatment). If a person understands and appreciates the information, they have the right to say no, or to make a bad or foolish decision. In fact, people do this all the time!

What health care decisions are included?

In Ontario, the law specifies that health care decisions include **medical treatment**. This is anything done for a *“therapeutic, preventive, palliative, diagnostic, cosmetic or health related purpose and includes a course of treatment”*. Examples could include things like having a pap test, starting new medications, having a biopsy, going for surgery, or getting physiotherapy. It also includes decisions about going into a long-term care home and personal support services. It does not include asking questions about your health history.

Who determines if a person is capable to make the health care decision?

The person proposing the treatment (the doctor, therapist, etc.) is the one to determine a person’s capacity to decide whether or not they wish to proceed. Usually, capacity is presumed – meaning, it is only questioned if the health care provider feels there are significant grounds to think a person can’t make the decision. Having an intellectual or developmental disability (IDD) may be a situation where the health care provider takes some extra time to explain and assess the person’s decision making abilities. Capacity needs to be assessed for each decision. This means that people may be able to make some decisions, but not other decisions AND that people may be able to make a decision at one point in time, but not at another time.

What is your role as a caregiver?

As a caregiver, whether you are the SDM or not, your role could include:

- Role modelling and encouraging effective communication and accommodations, so that your family member can be provided with the best opportunity to participate in the decision making process. If there are any specialist reports (e.g. psychology or speech and language pathology) that provide strategies for how best to communicate with the person, encourage that these be shared and reviewed by the health care provider.
- Ensuring that your family member has familiar, positive faces around them who can be trusted allies and support them through any big decisions.
- Make sure the SDM’s contact information is up-to-date and clear at every appointment, and on hospital information sheets in emergencies.
- The SDM needs to know about every appointment before it happens, so they are aware that they may be contacted, if the doctor feels it is necessary (i.e. if the doctor feels the patient is not capable to make a health care decision).
- If you are the SDM, be prepared and available to help the care team know about decisions being made. Help your loved one understand what is happening and involve them to get their input (“assent”).



SURREY PLACE

If you would like more resources on this topic, please visit the Developmental Disabilities Primary Care Program at Surrey Place:

- [Capacity for Decision Making Guidelines](#)
- [Communicate CARE: Guidance for person-centred care of adults with IDD](#)
- [Decision Making in Health Care Tool](#)

Supporting Someone who has a Catastrophic Illness

Receiving a diagnosis of a catastrophic illness is difficult. It's difficult for the person who receives it, and it's difficult for the family and for all those that support the individual. The diagnosis affects everyone differently but everyone needs to create time and space for the person most affected.

Shock, grief, and a sense of being out of control are common responses after hearing about a catastrophic illness and dealing with shortened time, and the expectation of loss. However, there are some things that can be done to bring everyone together and focus on what happens next.

Here are 5 tips for social and emotional support:

1

Look at what kind of care and support your loved one wants from friends and family:

- Ask how they want to spend time with family and/or friends. What are some of the things they want to do? What are the things they don't want to do anymore?
- If possible, create a week by week calendar that schedules in time for your loved one to be with family and friends, either at home, at a special event, or just having a coffee together.
- There can be a sense of aloneness, even by people who are well loved, when facing a catastrophic diagnosis, so knowing that people can and will be there matters. It is also important to find out what is bothersome and what your loved one would like others to avoid doing when they are around them.

2

Now is not the time for you to talk about your health experiences, the experiences of your friends, or of people who have it worse. These are often brought up as 'sharing' but in fact they can make the person feel that their experiences are not of importance. **Right now the only story that matters is the one that your loved one has to tell.** Don't shy away from talking about the diagnosis but don't force it either. "Talking doesn't always make it better." Let things happen naturally and take their lead. When they want to talk, they will tell you.

If you are interested in learning more about this, check out this video, Brené Brown on Empathy. It describes the difference between sympathy and empathy:

<https://www.youtube.com/watch?v=1Evwgu369Jw>



5 tips for social and emotional support (continued)

3 Don't overwhelm the person with sympathy. This can be both burdensome and frightening. Try to get back to a normal style of communication. Let them feel comfortable to joke about themselves or the situation – this can ease the tension they are feeling. Doing ordinary stuff, as long as that is possible, can be therapeutic. Watch a television series or go for a drive to somewhere they like. Do things that they normally do, bring back a sense that while life may not be long, life still goes on with its ups and downs.

4 Beware of false hope. “Everything will work out, you’ll see,” “It’s all going to be just fine,” are lies. You don’t have to be blunt with the truth but you also don’t need to provide false hope. People with disabilities don’t need to be persuaded into happiness. Some things are sad, or scary, or frustrating, they just are. Let them figure out for themselves how they will view what’s happening.

5 Bring as much choice and control back to your loved one’s life as possible. One of the scary things about having a catastrophic illness is that you feel out of control. Ensuring that the person can make choices and take control of their time and their needs can calm the panic. Being out of control is terrifying; re-establishing it can be as good as any medication.



Here are tips for working with the health care system:

- 1) Read this toolkit very carefully. You will find advice about preparing for a health care visit, ensuring that you have the necessary information, and that your family member will have their voice heard in the process. Study those sections and use them well.
- 2) Be sure to communicate with health care providers about your role as a caregiver. Ask them what information they want from you and what observations need to be made. Ensure that your role on this team is included. Ensure that your family member is as involved as they want to be.
- 3) The health care provider may have information about how to support someone with a particular diagnosis. Seek that out. If it isn't offered, ask. Find out if there are places where you and/or your family member can find information and resources. Help contact those places and find out what is offered. No matter how good something may sound, and how much you think they may benefit, it is your family member's choice to attend or not.

Here are some tips for taking care of yourself:

- 1) Make sure you have some time to yourself. You will need time to process what's happening and to recharge your physical and emotional batteries.
- 2) Make time for the things that help you feel relaxed. Purposefully and intentionally care for yourself.

This is a difficult role for caregivers. Focus on how you can best support your family member, while you are providing the best support for yourself. The needs of your family member are valid, so are your needs, don't ignore them.



If you would like more resources on this topic, please visit:

<http://www.breakingbadnews.org/>

To learn more about palliative care, please visit:

<https://www.caresearch.com.au/caresearch/Default.aspx>

Section 3: Health Care Information



- **Seizures: General Information**
- **Seizures: Tips for Caregivers**
- **Seizure Action Plan**
- **Seizures: First Aid**
- **Pain Assessment**
- **Aging**
- **Dementia**
- **Urinary Tract Infections**
- **Medications**
- **Mental Health and IDD**



What are seizures?

- ▶ Seizures are the physical effects of unusual bursts of electrical energy in the brain. This electrical hyperactivity in the brain produces "seizures".
- ▶ Seizures are not the same in everyone who has them – they can be different in how they appear, how long they last (a few seconds to a few minutes) and how often they occur.
- ▶ Seizures may appear as a brief stare, a change of awareness, or convulsions that include muscle spasms, loss of consciousness, uncontrolled body movement, incontinence and/or vomiting.

What is epilepsy?

- ▶ Epilepsy is a condition where an individual has recurrent seizures secondary to unknown or uncorrectable causes.
- ▶ Anyone can develop epilepsy, but it is normally diagnosed in childhood.
- ▶ The most common cause of epilepsy is injury to the brain (e.g., birth trauma, infections, a head injury, low blood sugar, or stroke). However, often no cause can be found.
- ▶ If someone has seizure-like behaviour, it does not always mean they have epilepsy.

Can people tell that they are going to have a seizure?

- ▶ Some (but not all) people can tell, because they have a strange sensation before a seizure, called an "aura".
 - ▶ Common seizure warning signs to look for are:
 - » periods of forgetfulness or memory lapses
 - » feeling spacey, 'fuzzy', or confused
 - » jerking movements of an arm, leg, or body
 - » tingling, numbness or feelings of electricity in parts of the body
 - » odd feelings
 - » unusual smells or tastes
 - » daydreaming episodes
 - » headaches
 - » losing control of urine or stool unexpectedly.

Are there triggers that might make a person's seizures more likely to happen?

- Yes. It is important to know what might trigger a seizure in an individual person, and to help them avoid the triggers, when possible. Some possible triggers to be aware of are:
- ▶ Stress:
 - » Emotional stress, eg, over-excitement, emotional upset, being startled.
 - » Physical stress, eg, illness, lack of sleep, low blood sugar (hypoglycemia), hormone changes, alcohol, or drugs.
 - » Environmental stress, eg, televisions, flashing lights (including flickering overhead lights), heat and/or humidity.
 - ▶ Change in medication.
 - ▶ Missed seizure medication.

Check with the person's doctor about how to respond when a seizure happens.

- ▶ If you are living with or caring for someone with a seizure disorder:
 - » Complete a Seizure Action Plan.
 - » Find out whether the doctor wants to be notified every time the person has a seizure, or just in certain specific situations.
 - » Ask if there are any special warning signals that you should look for. Ask whether or when you should call an ambulance.
- ▶ Ensure the individual has a medical alert device (e.g., MedicAlert bracelet or ID).

How is epilepsy diagnosed?

- ▶ The doctor takes a detailed history, takes into account eyewitness reports of events thought to be seizures, usually does an EEG (electroencephalogram – a test that measures electrical activity in the brain), and may do further tests.

Misdiagnosis of seizures/epilepsy

- ▶ Epilepsy is difficult to diagnose and may be wrongly diagnosed some of the time, especially in people with IDD – behaviours may be wrongly given the diagnosis of a seizure.
- ▶ Behaviours that are caused by seizure activity may not be recognized and treatment not given.
- ▶ The role of caregivers in accurately recording and describing any event that may be a seizure is extremely important for the doctor's assessment.

Types of Seizures

People with a seizure disorder can have just one type of seizure or more than one type. This makes diagnosis and management more complicated.

There are more than 40 types of seizures, but most are grouped into two main types:

- 1) **GENERALIZED** – the seizure (electrical discharge) affects the whole brain.
- 2) **PARTIAL** – the seizure affects only part of the brain.

GENERALIZED OR PARTIAL	Status Epilepticus	<ul style="list-style-type: none"> ▶ A state of prolonged seizure activity or repeated seizures without time for recovery. ▶ May exist for any seizure type. <p><i>Status epilepticus is a medical emergency that can lead to severe brain damage and even death. This is a medical emergency. Call 9-1-1.</i></p>
	Myoclonic	<ul style="list-style-type: none"> ▶ Involves a sudden, shocking jerk of the muscles in the arms, legs, neck and trunk. ▶ Tends to involve both sides of the body at the same time and the person may fall over.
GENERALIZED	Tonic-clonic Seizures “Grand Mal”	<ul style="list-style-type: none"> ▶ General convulsions with two phases. <ul style="list-style-type: none"> » First phase: Tonic. The person may vocalize (e.g., cry or groan), lose consciousness, and then the person’s body grows stiff. » Second phase: Clonic. It involves jerking/twitching, sometimes with the whole body or just the face and arms. The person could have shallow breathing, bluish skin or lips, drooling and/or loss of bladder or bowel control. ▶ Normally lasts one to three minutes. ▶ Consciousness returns slowly and the person may look very tired or want to sleep.
	Absence “Petit Mal”	<ul style="list-style-type: none"> ▶ Brief periods of complete loss of awareness, e.g., staring into space completely unaware of surroundings and unresponsive. Rapid blinking, mouth or arm movement may occur. ▶ These seizures start and end suddenly without warning. Lasts only a few seconds but happens many times a day.
	Atypical Absence	<ul style="list-style-type: none"> ▶ Jerking or automatic movements lasting longer than 20 seconds with partial loss of awareness.
PARTIAL	Atonic	<ul style="list-style-type: none"> ▶ Lasts a few seconds and involves sudden loss of tone in the muscles of the neck, arms, legs or trunk muscles. ▶ The person may fall to the ground suddenly. ▶ People with atonic seizures may have to wear a helmet to protect their head from injury during a fall.
	Simple Partial “Focal”	<ul style="list-style-type: none"> ▶ Causes strange and unusual sensations, changing the way things look, sound, taste or smell. ▶ The person remains conscious but cannot control sudden, jerky movements or a part of the body.
	Complex Partial “Psychomotor or Temporal Lobe”	<ul style="list-style-type: none"> ▶ Changes the person’s awareness of what is going on during the seizure, so the person may seem dazed, confused or trance-like. ▶ The person may repeat simple actions over and over, e.g. head turning, mumbling, pulling at clothing, smacking lips, making random arm or leg movements or walking randomly. ▶ Lasts a minute or two.

References

1. Epilepsy Ontario. Types of Seizures. Ontario: Epilepsy Ontario. Retrieved June 10 2019 from <https://www.epilepsy.com/learn/types-seizures>
2. The Nemours Foundation. United States: Kids Health from Nemours. Retrieved June 10 2019 from http://kidshealth.org/parent/firstaid_safe/emergencies/seizure.html.
3. Schachter S.C., Shafer P.O. Warning Signs of Seizures. United States: epilepsy.com; Retrieved June 10 2019 from www.epilepsy.com/epilepsy/warning_signs.
4. Chapman M, Iddon P, Atkinson K, Brodie C, Mitchell D, Parvin G, et al. (2011). The misdiagnosis of epilepsy in people with intellectual disabilities: A systematic review. *Seizure*, 20(2), 101-6.
5. International League Against Epilepsy 2017 New Classification of Seizure Types. Retrieved June 10 2019 from <http://www.canadianepilepsyalliance.org/wp-content/uploads/2019/02/New-Epilepsy-Classification.pdf>
6. Edmonton Epilepsy Association. Seizures and First Aid. Retrieved June 10 2019 from: <http://www.edmontonepilepsy.org/documents/Epilepsy%20-%20Seizures%20&%20First%20Aid.pdf>

CHECK

how to respond when a seizure happens. If you are living with or caring for someone with a seizure disorder, ask their doctor if:

- ▶ he/she wants to be notified every time the individual has a seizure, or just in certain specific situations.
- ▶ there are any special warning signals that you should look for.
- ▶ whether or when you should call an ambulance.
- ▶ health care provider can help you complete a Seizure Action Plan for the person you're caring for.

KNOW

- ▶ what the **triggers** are for the person's seizures; help the person avoid these.
- ▶ the usual or possible **signs and symptoms** of the person's seizures.
- ▶ **if and when** to provide seizure **medication**. PRN medication prescribed by a medical doctor should be given as directed or ordered by the doctor.
- ▶ seizure medication side effects which can include:
 - » short-term memory loss
 - » fatigue or drowsiness
 - » changes in hand coordination, balance, speech coordination
 - » hyperactivity
 - » dizziness
 - » vomiting
 - » mood changes

FOLLOW

- ▶ the **First Aid protocol** when the person has a seizure: gently roll the person onto their side and put something soft under their head to protect from injury. In fact:
 - » *A person cannot swallow her/his tongue during a seizure.* This is physically impossible.
 - » *Do not force something into the mouth of someone having a seizure.* That may cause more injury, eg, chip teeth, puncture gums, or even break someone's jaw.
 - » *Do not restrain someone who is having a seizure.*

DOCUMENT

- ▶ the **seizure incident** (eg, through the Seizure Baseline Chart, if new or unstable seizure, or the Seizure Monitoring Chart, if regular, short seizure) as soon as possible once the client is safe, describing what happened before, during and after the seizure. Be sure to put the length of time and any observations about how the seizure looked.
- ▶ **videotape the seizure**, if possible. The doctor and/or the person's health care provider will be able to actually see what their patient is doing during a seizure. This will help in diagnosis, management, and treatment plans for the patient.
- ▶ **inform the appropriate people** when the individual has had a seizure (eg, the person's family physician or neurologist's office, the person's emergency contacts or the substitute decision-maker).

ENSURE

- ▶ the individual has a **medical alert device** (eg, MedicAlert bracelet or ID).
- ▶ a **copy of the Seizure Management Plan** is with the person on any outings or trips, along with phone numbers of the substitute decision-maker(s), group home manager, and/or primary caregivers' information.

PRACTICE

- ▶ an **Emergency Drill** yearly and when orienting new caregivers. Re-create a pretend seizure disorder emergency (as a fire emergency is re-created for a fire drill):
 - » ensure all elements of the emergency treatment plan are in place.
 - » ensure everyone knows their role and what to do

REFERENCES

1. Epilepsy Ontario. First Aid for Seizures. Ontario: Epilepsy Ontario. Retrieved June 10, 2019, from www.epilepsyontario.org

2. Schachter S.C., Shafer P.O. Warning Signs of Seizures. United States: epilepsy.com. Retrieved June 10, 2019 from www.epilepsy.com/epilepsy/warning_signs

Seizure Action Plan

This person is being treated for a seizure disorder. The information below should assist you if this person has a seizure.

Name		Date of Birth
First	Last	

Parent/Substitute Decision Maker (SDM)	Phone	Cell
First Last		

Other Emergency Contact	Phone	Cell
First Last		

Treating Physician	Phone	Fax
First Last		

Significant Medical History

Seizure Information

Seizure Type	Length	Frequency	Description/What Happens

Seizure triggers or warning signs:

Response after a seizure:

Daily Medications to Prevent Seizures

Medication	Dosage and Time of Day Given	Comments

Basic First Aid: Care and Comfort

Basic first aid procedures adapted for this person

Does the person need time to recover after a seizure? No Yes

If YES, describe process for recovery and return to activity or program

Emergency Response

A "seizure emergency" for this person is defined as

Seizure Emergency Protocol (Check all that apply and clarify below)

- Call 9-1-1 for transport to hospital
- Notify parent or emergency contact/SDM
- Administer emergency medications as indicated below
- Notify doctor
- Other

Emergency Medications

Medication	Dosage and Special Instructions	Expected Outcomes/Side Effects

Special Considerations and Precautions (regarding activities, sports, outings, etc.)

Describe any special considerations or precautions:

Physician Signature

Date

Patient/Parent/Guardian/SDM Signature

Date

BASIC SEIZURE FIRST AID

- ▶ Stay calm and track time
- ▶ Keep them safe
- ▶ Do not restrain
- ▶ Do not put anything in mouth
- ▶ Stay with them until fully conscious
- ▶ Record seizure in log

FOR TONIC-CLONIC SEIZURE

- ▶ Protect head
- ▶ Loosen tight clothing around neck
- ▶ Keep airway open/watch breathing
- ▶ Turn them on their side once he/she relaxed

WHEN IS A SEIZURE AN EMERGENCY?

- ▶ Convulsion lasts longer than 5 minutes
- ▶ Repeated seizures without regaining consciousness, or second seizure within a few minutes
- ▶ Co-morbid diabetes
- ▶ First-time seizure
- ▶ Breathing difficulties
- ▶ Resultant injury, or seizure in water
- ▶ Persistent confusion or unconsciousness
- ▶ Significant change in seizure pattern

A Seizure Is Considered An Emergency When:

- ▶ It lasts longer than 5 minutes.
- ▶ The individual has repeated seizures without regaining consciousness, or has a second seizure within a few minutes.
- ▶ There is co-morbid diabetes.
- ▶ It is a first-time seizure.
- ▶ Breathing difficulties are present.
- ▶ It results in an injury or occurs in water.
- ▶ There is persistent confusion or unconsciousness.
- ▶ There is a significant change in that person's seizure pattern (type, length, associated symptoms).

In a seizure emergency, CALL 9-1-1 – Seek Medical Help Immediately!

During the Seizure

- ▶ **Non-convulsive seizure** (e.g., absence, simple partial or complex partial)
 - » Reassure the person.
 - » Protect the person from injury.
 - » Guide and support the person as needed.
- ▶ **Convulsive (tonic-clonic) seizure** (aka Grand Mal)
 - » Do **not** hold the person down.
 - » Do **not** put anything between their teeth.
 - » If the person starts to bleed from the mouth, do not panic. He or she may have bitten their tongue.
 - » Observe what happens so that you may tell the doctor about what you see, or record this information afterwards (length of seizure, types of movements, to which side the head and/or eyes turned, how long before returning to full consciousness).

After the Seizure

- ▶ Once the person has relaxed, turn them on their side to make sure there's an open airway and to prevent them from choking on anything.
- ▶ If he/she is in a wheelchair, set the wheelchair to a "partial recline" position (not "full recline") and gently turn the person's head to the side to let the saliva flow out of the mouth.
- ▶ Be reassuring, comforting and calm as awareness returns. After the seizure, let the person sleep if, needed.

As soon as possible, fill out the seizure monitoring chart (baseline) as accurately as you can.

REFERENCES

Epilepsy Ontario. *First Aid for Seizures*. Ontario: Epilepsy Ontario. Retrieved June 1, 2019 from www.epilepsyontario.org.

Pain Assessment

“...An anti-psychotic medication is not going to help an upset stomach.” - Emergency Room Doctor

Pain is a subjective experience—a warning sign to the body of danger. For people with intellectual and developmental disabilities (IDD), there may be challenges to communicating pain, or to identifying the location and intensity of pain. As a caregiver, your ability to help identify and communicate pain is crucial. When pain is unmanaged, it’s likely to manifest in behaviours. If we try to manage behaviour without addressing the root cause (pain!), we are doing a big disservice to people with IDD, by prolonging their suffering and invalidating their experiences.

There are many conditions that cause pain and warrant treatment. These include (but are not limited to):

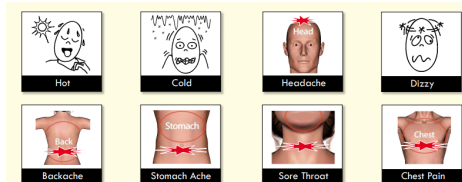
- Degenerative joint disease, arthritis and chronic immobility
- Migraine headaches, sinus headaches/pressure and other chronic headaches
- Gastroesophageal Reflux Disease (GERD)
- Constipation/diarrhea
- Premenstrual syndrome (PMS)
- Cancer
- Anxiety
- Depression
- Abuse and traumatic experiences

Some words associated with pain are: acute (short term), chronic (long term), sharp, full, boring, aching, burning, constant, intermittent, referred (pain in one part of the body but felt in another), ischemic (pain from lack of blood and nutrients to a body part), and phantom (very real pain triggered by a powerful memory often in an amputated body part).

Pain is often missed. This can occur even if we ask about pain—often because people with IDD may be conditioned to be agreeable, or because there are communication challenges. For this reason, it is helpful to ask about pain in a way that the individual understands. This may mean using visual aids to help.



The Wong-Baker Faces Scale. Ask the person to tell you how much it hurts. (Generally, avoid asking an abstract question, “How is your pain?” Be concrete and specific. Combine with an observational pain scale.)”



The Hospital Communication Book contains many examples of visual aids.

Observational pain scales are necessary:

Even if you’ve asked where it hurts, and how much it hurts, always include observations into your assessment. There are many tools that provide examples of outward signs suggestive of pain. The **Chronic Pain Scale for Non-verbal Adults with IDD** and the **Dis-Dat** are examples of observational tools. They ask you to look for signs suggestive of pain, like grimacing, crying, avoiding, etc.

Unfortunately, similar changes in behaviour in a person with IDD are often misidentified as psychotic symptoms. This leads to the increased use of inappropriate medication to control behaviour. When someone is in pain, help to obtain treatment for the underlying cause. Share your observations and ideas.

- **Chronic Pain Scale for Non-Verbal Adults with IDD:** <http://pediatric-pain.ca/wp-content/uploads/2013/04/CPSNAID.pdf>
- **Dis-Dat:** <https://www.wihb.scot.nhs.uk/LD/toolkit/disdat%20Assess%20tool%2009.pdf>

Aging

People with IDD are living longer than ever before. This is wonderful news!

But, for many people, living longer comes with some unique challenges.

For people with intellectual and developmental disabilities (IDD), aging is likely to begin at a younger age. This means that a person with IDD who is in their 50s may present with some similarities in their mind and body to a person without IDD who is in their 80s. As we age, every organ system changes. This is normal. The difference between healthy aging and *disease* associated with aging can be challenging to distinguish.

Let's go over some of the common diseases associated with aging, and then review how you can support your family member.



Brain health

- **Dementia:** Aging is associated with an increased risk of dementia. The most common cause of dementia is Alzheimer's disease. Symptoms of dementia include short term memory loss (forgetfulness) and having difficulty organizing one's daily routine (executive dysfunction). Over time, people with dementia lose their language, and their ability to function independently, so help will be needed to eat, get washed and dressed, and to walk around safely. This is a key difference from normal brain changes that come with aging, which may include forgetfulness but won't have the same impact on function.

In IDD:

In people with Down syndrome, the risk of dementia is generally increased and presents earlier in age. The decline, though still gradual, may occur more quickly. When people with IDD develop dementia, they will have a noticeable decline in skills, and changes in brain function (behaviour, language, organization, navigating spaces, memory etc.). Because the level of ability before dementia may have included a level of help, the key is to **look for and monitor any changes**. For more on dementia and IDD, please see the dementia section of this toolkit.

- **Depression:** Older adults are also at increased risk of depression. Signs of depression include things like a low mood (sadness), along with changes in sleep, having a hard time concentrating, poor appetite, and feelings of guilt. A person may also become more irritable or easily bothered. Movements may be slower, and you might see that it is harder for a person to be motivated to do things they used to enjoy. The risk for suicide is higher in older adults. Depression can be very treatable, so a doctor should be informed if you suspect that your family member has depression
- **Delirium:** While dementia is associated with a long term, gradual decrease in memory, delirium happens suddenly. Delirium is an **acute state of confusion**, and it can be a medical emergency. Unfortunately, delirium can often be missed. Older people, especially those with dementia or other brain diseases have a higher risk of developing delirium when there are any changes to their overall health. Even something minor like a medication change or poorly treated pain can lead to delirium. A physical examination and blood work is usually needed to assess for the underlying cause of delirium. A nurse or doctor should always be informed if you think your family member has delirium. **Signs to look for:**
 - ☑ sudden change;
 - ☑ fluctuating level of alertness;
 - ☑ unable to focus and maintain attention;
 - ☑ person is disorganized and not making sense, or they are very sleepy and hard to wake up—which is a change from their usual behaviour.

Muscles and bone health

- **Falls:** Older adults have a higher risk of falling. Since people with IDD are already at a higher risk of falling, as they grow older, they are even more vulnerable. Falls may seem minor in younger people, but older adults may suffer serious injury to the skin, muscle or even break bones because of a fall. Risk factors include taking too many medications (especially drugs that make them drowsy), joint problems (arthritis), weakness of muscles (from stroke or deconditioning), poor balance (from stroke or nerve damage), poor vision (cataracts or macular degeneration), and dementia. When an older person has repeat falls, a thorough assessment is needed to prevent the risk of future falls.



What are some ways you can keep your family member safe from falls?

- An Occupational Therapy (OT) home safety assessment is a good place to start. Contact your local Home Care Coordinator (in Ontario, this is through the Local Health Integration Network). An OT may be able to come to the home and make suggestions about ways to make the home safer, or recommend equipment like a walker or wheelchair.
 - Look around the home, and see if there are any changes you can make. Remove or secure things a person may trip over – like cords and clutter, mats and rugs.
 - Make sure floors are dry. Keep close supervision in the bathroom. There are also things that can go into the bathroom to make it safer like bars to hold on to, a stool to sit on in the shower or bath, and a raised toilet seat.
 - If there are stairs or steps, help to make sure all steps are clearly visible (adding reflective treads).
 - Have handrails on both sides of the stairs, if possible.
 - Make sure spaces are bright and well lit. Use night-lights or motion sensor lights for the bedroom and hallways.
 - Look at a person's shoes – do they look to loose or floppy? Or, are they too tight and uncomfortable? Do the treads on the bottom still work?
 - Stay home in icy weather.
 - Ensure walkways and driveways are cleared of snow in a timely manner.
 - Check a person's feet. If there are long toenails, sores or blisters etc., this is likely to cause a person to walk differently, which could throw off their balance. Be extra vigilant if someone has diabetes, since they are at an increased risk of foot ulcers. For more information, visit www.findingbalanceontario.ca.
- **Osteoporosis and fracture:** Related to falls is osteoporosis, which is a disease of bone loss. Both older men and women are at risk of osteoporosis, but postmenopausal women are at a higher risk because of the loss of estrogen, which protects bones. Older individuals with little exercise, living an indoor sedentary lifestyle are also at higher risk of osteoporosis. People who take certain medications like anticonvulsants (medications for seizures) are at greater risk. Bone loss leads to fractures, which can severely impact a person's independence. We know that people with IDD have higher rates of fractures when young, so as they age, the risk increases even more. Vitamin D is a useful supplement. There are medications to prevent bone loss and fractures.
 - **Frailty:** This is a term that describes a state of vulnerability, where the body is less able to handle an environmental or physical stressor. Aging is associated with increasing frailty, but not all older people become frail. Adults who exercise frequently and function like a younger person are robust - the opposite of frail. When an older person develops multiple illnesses leading to loss of independence, they are frail. Unfortunately, many people with IDD become frail the older they get. H-CARDD research suggests that adults with IDD are likely to be frail as young as 50 whereas adults without IDD show signs of frailty around age 80.

Sensory changes

- **Eyes:** Aging is associated with development of cataracts and other eye diseases. Other common changes are decreased peripheral vision, reduced nighttime vision, dry eyes, and challenges distinguishing shades of colours. Regular eye examinations are needed. If prescription glasses are available, they should be worn during the day. And don't forget to ensure glasses are clean and free of smudges.
- **Hearing:** Hearing loss is common with aging. Use of appropriate hearing aids (always check the battery) or a pocket amplifier (like a Pocket Talker) can help promote respectful communication with older adults. If a change seems sudden, ask to have their ears checked—wax can build up more quickly as people age.
- **Skin:** Older adults can get dry skin (xerosis). Regular moisturizers should be used to protect the skin. If an older adult is less mobile, pressure ulcers can develop. Proactive positioning and skin protection can help prevent ulcers. If a person is spending a lot of time in bed, or in a chair, it is a good idea to involve a nurse or occupational therapist for an assessment to see how to minimize pressure sores.



- **Pain:** Pain can often be missed. An essential part of care is to figure out if someone is in pain, and if so, where they have pain so that appropriate treatment can be started. Consider asking people about pain, in a way the person will understand (“Where does it hurt?” “Any ouches?”), while also using visual aids to help as needed. Also include observational pain assessment tools, in the event a person’s language abilities limit their abilities to reliably tell you if they are in pain. We should never assume that someone with IDD can’t feel pain. When looking for signs of pain, it’s important to contrast with their usual presentation.
- See the Non-Verbal Pain Scale for Intellectual Disabilities (link can be found in the Pain Assessment tool in this toolkit).
- Regular exercise, walking or range of motion activities can help prevent joint pain. If there’s low mood, treatment of depression (e.g. with therapy and/or medications) can help reduce pain as well.

As a person ages, their abilities may change. It is crucial that efforts are made to find a person’s strengths and abilities, so that their quality of life is as best as it can be.

Impacts of Aging on People with IDD

Vision

- Glaucoma = cloudy looking eyes
- Macular Degeneration = blotchy circles in the middle of eye; these can cause headaches, pain and nausea—look for signs.
- Decreased peripheral vision
- Decreased night time vision
- Eyes can become more dry and itchy.

Lungs

- Swallowing difficulties lead to high rates of aspiration (when food/saliva/vomit gets caught in the lungs).
- Diseases in the lungs are a common cause of death.
- Lung capacity and function decreases, making it harder to do activities.
- More rest may be needed.

Bones & Joints

- Bones become more brittle, increasing the risk of fracture.
- If people have previous fractures, they may have pain.
- Arthritis is common as joints lose lubrication.
- Balance troubles are common.

Brain Changes

- Dementia: gradual personality changes, forgetfulness, mixing up people, losing abilities, language loss.
- Delirium: sudden change; risks are higher.
- Depression: rates are higher.



Hearing

- Wax build up is more common.
- May have harder time locating noises.









Bowels & Bladder

- Harder to hold urine for longer periods of time.
- As metabolism slows, constipation increases.
- May lose control of bladder and bowels more easily.

Feet

- It can be harder to clean and care for feet. Skin can also become more dry.
- Aside from being painful, any blisters, sharp toe nails, or wounds to the feet can cause a person to walk off balance. This increases the risk for a fall.

Aging: Changes and Interventions

Aging change:	How you can help:
 <p>Brain Changes</p>	<ul style="list-style-type: none"> Track the person's baseline cognitive and functional abilities using a tool specific to IDD, i.e. National Task Group Early Detection Screen for Dementia (NTG-EDSD). If something changes suddenly, it could be delirium. Notify medical personnel. Be on the lookout for depression. It could be a recent life event (losing a friend, family member or staff), or something in the past that was triggered, or stays with that person.
 <p>Vision</p>	<ul style="list-style-type: none"> Encourage regular eye exams (generally covered by ODSP every two years). Make sure a person's glasses are on, and clean. If they have vision deficits, approach them in a way so they can see you. If there are depth issues, tape down contrasting coloured tape to help mark stairs/ surfaces. Make sure spaces are bright and well lit. Close blinds in the evening to reduce shadows. This is especially helpful for people with dementia who experience sundowning (i.e. increased confusion as the evening sets in).
 <p>Bones & Joints</p>	<ul style="list-style-type: none"> Review fall prevention strategies. www.findingbalanceontario.ca is a good resource. Ask the doctor if there are supplements or vitamins to keep bones strong. Monitor pain: look for wincing, grimaces, moaning. Share your impressions with a health care provider. Using an observational pain scale can help structure your findings. If there have been repeated falls, ask a health care provider if a comprehensive geriatric assessment would help.
 <p>Medication</p>	<ul style="list-style-type: none"> If an individual takes more than four medications, this increases their risk of falls, confusion, side effects and interactions. Flag this to the doctor or pharmacist. If there is a sudden change, it could be because of their medications. Request a medication review once a year.
 <p>Hearing</p>	<ul style="list-style-type: none"> Annual hearing assessment is recommended. Ask doctor to check ears for wax build up. Use hearing aids (and check the battery regularly). If hearing aids are too hard, try a Pocket Talker. Otherwise, speak simply, clearly and slowly and reduce environmental noise (TV, radio off). Write things down if a person is reading. Speak on their better side, if they have one.
 <p>Feet</p>	<ul style="list-style-type: none"> Seek out regular foot care (from chiropodist, foot care nurse). Monitor feet for any blisters, or long toe nails. Ensure shoes are form-fitting and treads intact. If someone has diabetes, be sure to check their feet more regularly.
 <p>Sleep</p>	<ul style="list-style-type: none"> Sleep disturbances and changes are common. People may need less sleep than before. Minimize caffeine after lunch. Discourage napping during the day. Use the toilet before bed, but keep hallways well lit in event of getting up at night. Rates of sleep apnea are high. If sleep troubles persist, speak with a health care provider.
 <p>Bowels & Bladder</p>	<ul style="list-style-type: none"> People may require more support to maintain bowel and bladder control. Support the person to use the bathroom before and after meals, and before bed. Keep track of bowel movements. Speak with the doctor or pharmacist about a bowel routine if constipation is an issue.

Aging: Syndrome-Specific Information

Every person will age in a unique way. For people with specific genetic conditions or syndromes, the following are things to be mindful of, as they may occur with greater frequency.



Down Syndrome

- Higher prevalence of Alzheimer’s disease.
- Higher prevalence of late-onset seizure disorders.
- May develop eye disorders earlier than the general population (cataracts, keratoconus).
- Rates of osteoporosis increase risk of fractures, falls, dental problems, pains.
- Rates of sleep apnea increase with age (can lead to poor sleep, behaviour changes, impacts on heart function).
- Thyroid dysfunction—can cause cognitive changes (but this is treatable!).

Fragile-X

- Associated tremor ataxia syndrome (FXTAS) is a rare neurodegenerative disorder that can affect a small number of people with Fragile-X. It can cause changes in cognition (memory loss, planning difficulties) and movement (tremors, balance and coordination problems).

Cerebral Palsy

- Chronic immobility results in increased musculoskeletal problems: decreased bone health, increased fracture rate, increased incidence of arthritis, contractures (tightened muscles or joints), spasticity (ongoing muscle tightening, resulting in altered movements).
- Already impaired muscle function may deteriorate further due to aging process.
- Risks of swallowing difficulty (aspiration pneumonia) increases.

Autism Spectrum Disorder

- Lifespan outcomes with autism may be unpredictable: some improve, some stay the same, some lose skills.
- There is an increased risk of seizures, accidental deaths (drowning, suffocation), earlier death from heart disease, aspiration pneumonia.
- Ritualistic, compulsive or self-injurious behaviours tend to lessen with age.

Seizures

- Some people experience cognitive decline and brain aging because of their seizures.
- Anti-epileptic medication may cause side effects that increase with age.
- If seizures limited a person’s activity while younger, this creates heart health risks as they age.
- Frequent falls during seizures may cause fractures that seriously impact a person’s mobility as he/she ages.

Prader-Willi

- Biggest factor: morbid obesity (if weight is uncontrolled) can lead to type 2 diabetes, hypertension, joint and lung problems.
- Premature aging with age related physical morbidity and functional decline.
- Increased cardiovascular disease – frequently right sided heart failure.
- Increased incidence of knee and hip problems (often require joint replacements).
- Increased incidence of dermatological problems.

For more information, check out the: Aging and Intellectual Disability pages of the United States’ Resources for Integrated Care, www.resourcesforintegratedcare.com/webinar/series/individuals-with-idd. The above information is from the specific talk, *Growing Older*, by L. Anderson and J. Dorsi (2014).

Dementia

With the rise in life expectancy for people with intellectual and developmental disabilities (IDD), the risk of developing age-related conditions also increases. One such condition is dementia. The rates of dementia among people with IDD are higher than in the general population, particularly among individuals with Down syndrome.

What is dementia?

Dementia is a general term for a decline in mental ability that is severe enough to interfere with daily life. Dementia is not a specific disease. It is a term that describes symptoms that are caused by diseases. There are many causes of dementia, but here are the most common:

Alzheimer's

This is the most common cause for dementia. It is caused by plaques and tangles that form in the brain. It causes memory loss, language loss, and eventually affects all abilities. There is a fairly predictable pattern of decline.

Vascular dementia

This is the second most common cause of dementia. It is caused by blood loss to the brain (from strokes, brain bleeds). Symptoms will vary depending on the area of the brain affected.

Frontal temporal

Named for the areas of the brain most affected (the frontal lobe). This controls judgment, mood, level of self-control, and behaviour (among other things). Initial signs will be personality and behaviour changes, then skill or memory loss.

Lewy body dementia

Caused by tiny deposits in the brain (Lewy bodies). Main symptoms are changing mental abilities, visual hallucinations, and spontaneous features of Parkinsonism (tremors, walking and balance changes, rigid muscles, lack of facial expression).

Some people will have more than one cause of dementia (such as Alzheimer's disease + vascular dementia). This is called "mixed dementia". Regardless of the cause of dementia, memory loss will eventually become apparent. Often, people will forget things that occurred most recently (what they ate for breakfast, the name of a new staff member), but over time, longer term memories of information, and how to do familiar tasks will be forgotten too.

Screening tools for dementia in IDD

The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) was formed (in America) to develop guidelines around screening, treatment and practices for people with IDD and signs of dementia. This is because there is no accepted 'gold standard' quick cognitive screening tool for dementia in IDD. The scores for tools that exist for the general population (like the MoCA, and the Mini-Mental) are not valid for people with IDD, so should not be used. For individuals with IDD, **the first signs of dementia are often behavioural**, and may include:

- losing interest in hobbies/activities (apathy);
- losing ability in skills they previously had;
- changes in speech (trouble finding words, repeating words, speaking softly);
- becoming disoriented/lost, and confused.

Memory loss may not be obvious at first – this likely occurs later.

The NTG-EDSD (National Task Group Early Detection Screen for Dementia) is freely available at www.aadmd.org/ntg/screening. Caregivers have unique knowledge and information about their family member that helps establish a baseline for measuring change. The NTG-EDSD is a tool that will help you identify changes that can be reviewed with the health care provider.

The NTG-EDSD form includes a disclaimer stating it is for use with individuals with intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. It also contains fields for:

- Name of person (First, Last)
- Date of birth, Age
- Sex (Female, Male)
- Best description of level of intellectual disability
- Current living arrangement (e.g., Lives alone, Lives with spouse or friend, etc.)

The NTG-EDSD, a baseline measure. Consider doing annually for people over 40 to capture baseline—and any change.

What to do if you suspect someone might have dementia?

- 1) Complete the NTG-EDSD tool with others who know your family member well. (It is helpful if you have a previous one to compare with).
- 2) Accompany your family member to a doctor's appointment. Be prepared to offer your impressions about any changes that have been noticed. Share the findings of the NTG-EDSD.
- 3) Share as much information as you can about their health and social history.
- 4) Support your family member through any investigations that the doctor orders. This might include blood work, urine testing, and perhaps imaging of their brain. This will help figure out if there are reversible medical issues that could be causing the changes and can be treated. See below for examples.
- 5) Specialist involvement may also be sought out—from a neurologist, a psychiatrist, geriatrician or a psychologist. Accompany your family member to these appointments as your knowledge of your loved one's health and social history may be helpful.
- 6) Continue to offer reassurance and support. Help your loved one to feel important and useful, and connected to things that they enjoy. Remember, having dementia does not change who they are—it is just one aspect.



...Could it be something else?

Because dementia is a progressive condition and there is no cure, it is important to know if the change you are seeing is actually dementia—and not something that can be treated and reversed. The following are common causes for memory/behaviour change that should be addressed before jumping to a diagnosis of dementia.

Sensory changes	Vision or hearing loss. Depth perception challenges.
Metabolic disturbances	Electrolyte abnormalities; hypo/hyperglycemia; B12 or folate deficiencies; thyroid dysfunction; anemia; toxicity from medications.
Mood changes	Depressed/low mood.
Medications	Drug interactions or side effects.
Sleep problems	Sleep apnea or undetected sleep disorders.
Seizures	Undetected or worsening seizures.
Pain	Undiagnosed or worsening pain.
Mobility problems	Mobility disorders causing decreased movement or function, limiting activity.
Psychosocial/environmental	Changes to routines, death or impairment of family member or friends, new routine at home/work.

Down Syndrome & Alzheimer's Disease

Over half of adults with Down syndrome older than 50 years of age will have symptoms of dementia - things like personality changes, memory loss, and skill loss. This is thought to happen because the extra chromosome characteristic of Down syndrome produces an additional protein—the same protein in the brain that is believed to cause the plaques and tangles of Alzheimer's disease.

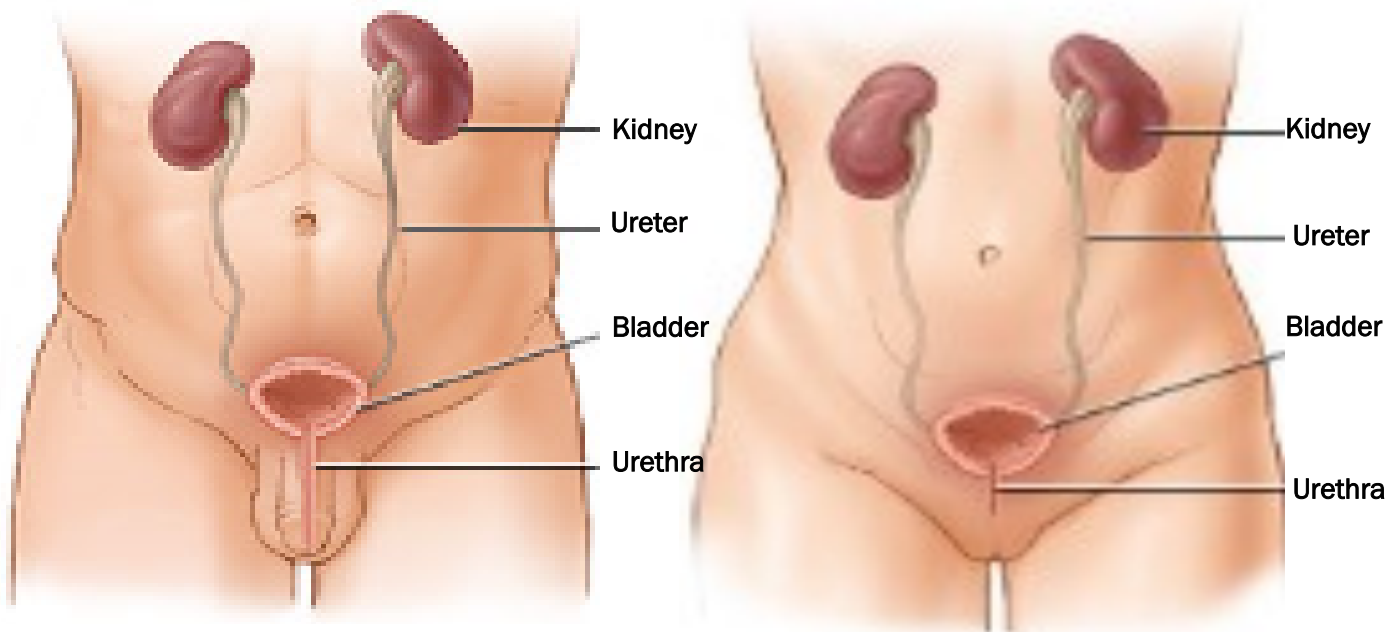
On average, people with Down syndrome who develop dementia tend to do so at a younger age than the general population, and the disease will progress more quickly.

Urinary Tract Infections

What is a urinary tract infection?

Urinary tract infections (commonly referred to as “UTIs”) are infections of the urinary system—meaning the urethra (the small tube that carries urine from the bladder to the outside of the body), the bladder, the ureters (the ducts that carry urine from the kidneys to the bladder), and the kidneys.

UTIs are common, and often happen in the lower urinary tract (the urethra and bladder). *Cystitis* is an infection of the bladder, and *urethritis* is an infection of the urethra. If a UTI spreads upwards to the ureters or kidney, this can be very serious. UTIs are treated with antibiotics.



<https://myhealth.alberta.ca/Health/aftercareinformation/pages/conditions.aspx?hwid=uh5234>

UTIs can affect both men and women, though they tend to be more common in women because of a woman’s body structure. Women have a shorter urethra—meaning that the distance bacteria needs to travel from the outside of the body to the bladder is shorter—and because their urethra is closer to the anus, it is easier for bacteria to enter the urethra, after wiping from a bowel movement, or from sexual activity. Also, as women age and enter menopause, they can become more prone to UTIs, as their body produces less estrogen and the lining of their urinary tract changes.

What are the signs of a UTI?

- More frequent trips to the bathroom; new accidents
- Pain when peeing (listen for noises, look for grimaces)
- Pee that smells bad
- Pee that looks darker or cloudy; stains on underwear
- Abdominal pain (holding/favoring abdomen)
- **BEHAVIOUR CHANGE**
- Pain in the back and side (“flank pain”)

If a UTI has spread up into the kidneys, there will also be other key signs:

- High fever, chills, nausea/vomiting
- Increased confusion, or behaviour change.



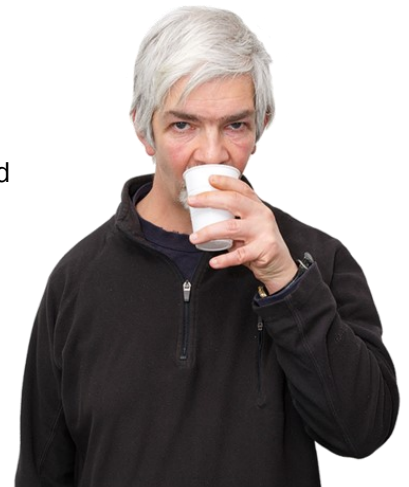
**Time for
the doctor!**

If you notice any of these symptoms, it is wise to inform the doctor as soon as possible. A UTI can cause much discomfort.

While waiting, encourage your family member to drink lots of water (as safely indicated) and offer pain relief and comfort measures (like a heating pad).

What are some things that make UTIs more likely to develop?

- Female anatomy.
- Poor personal hygiene/wiping techniques (mistakenly wiping from back to front, pulling bacteria into the urethra).
- Sexual intercourse (especially when it is coupled with poor personal hygiene).
- Catheter use.
- Incontinence and/or sitting in soiled underpants/briefs.
- Dehydration from not drinking enough fluids.
- Compromised immune system (which makes it harder to fight infections).
- Having a blockage anywhere in the urinary tract (e.g. a kidney stone, enlarged prostate in men).

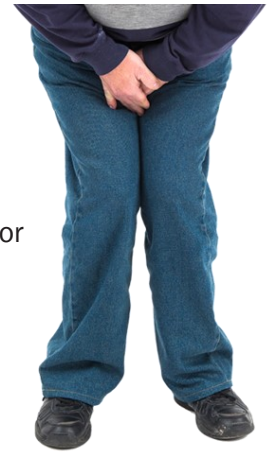


How you can help with a suspected UTI?

#1) Assist with a urine collection:

Ideally, a urine sample is “mid-stream”, or a “clean catch”, which means that a person pees for a bit first (to flush out any outlying bacteria), then a sample is taken. The sample must be caught in a sterilized container (the doctor’s office can provide this). This reduces the chance for a contaminated sample (and increases the chance of an effective treatment).

- **Explain and teach** why this is important. **Ask** your family member if you can help.
- **Practice first.** This may take a few attempts. Try to teach your family member by practicing at the tap (turning the water on, letting it run for 1-2-3, then sliding the container in, then pulling it away). Once this step is learned, move to the toilet and practice sliding the container in between the legs a few times, before trying to pee in it. Wearing gloves may be helpful if the person will be upset if pee gets on their hands—encourage them to get familiar with gloves too.
- **Be prepared.** Ensure the person’s genital area is wiped as clean as possible before peeing.
- **Break the task down.** Cue your family member while they are on the toilet, by explaining each step as they go. Based on the person’s preferences, you may want to write this out, step by step (with or without pictures), or, you could be in the bathroom alongside them, providing single step verbal instructions and gestures.
- **Try a device.** See if the local medical supply store (or online) sells devices that can assist with collecting the sample. The *Peezy Midstream* is an example of a device that may help.
- **Get extra help.** If someone wears briefs, or does not use a toilet, a sample may need to be extracted from the incontinence brief. Speak to the doctor/nurse about strategies for this.
 - If further assistance is still needed, it may be worth trying to advocate with the doctor and home care coordinator, to request a home visit from a nurse. In some situations, the person may need to be catheterized in order to get a sample.



#2) Focus on prevention:

- Drink water!
- Review wiping techniques—front to back.
- If a person is sexually active, encourage them to pee as soon as possible after having sex.
- Review the signs of a UTI, and encourage your family member to share these with you if they ever notice them.



For more information: *Trouble with your Waterworks*, 2006 (Paynor and Naish)
Available at: [http://easyhealth.org.uk/listing/bowel-and-bladder-\(leaflets\)](http://easyhealth.org.uk/listing/bowel-and-bladder-(leaflets))

Medications

Many people with intellectual and developmental disabilities (IDD) are prescribed medication to help treat the higher rates of mental or physical health concerns. As more medications are prescribed, the risk of side effects or interactions also increases. To treat these effects, new medications may be further prescribed (sometimes this is referred to as the 'prescribing cascade').

As a caregiver, you may be very familiar with supporting your family member to take their medication, as prescribed. One thing that can be hard is to help the person monitor side effects and to determine if a medication is having the intended effect, as they may have difficulty reflecting on, or reporting this.

In this tool, we will review some statistics around medication use, some information on commonly prescribed medications and their side effects. We encourage you to always speak with a doctor, nurse or pharmacist about any questions you may have.



Research from H-CARDD has looked at medication use among people with IDD in Ontario. They found:

- Nearly **one in two** adults with IDD take **two** or more medications.
- **One in five** receive **five** or more medications at the same time.
- **Antipsychotics** were the **most commonly** dispensed class of medications.
- More than **half** of the most commonly prescribed medications were **medications for psychiatric concerns** (i.e., psychotropics). This includes antipsychotics, anxiolytics, antidepressants, anticonvulsants, and mood stabilizers.
- The remaining five most commonly dispensed medication classes are indicated for the treatment of **gastric acid reflux, high cholesterol, hypothyroidism, high blood pressure and constipation.**



Does this list resemble what your family member has been prescribed?

Terminology

Abbreviations and acronyms can often be helpful, but when it comes to medications, it's best to be specific and ensure instructions are written out completely to avoid confusion and error, as this can have serious implications. Medication errors can have serious consequences when communication is poor or unclear.

The following are some acronyms you may come across. Again, it is always helpful to write things out specifically and avoid these abbreviations!

What you might see // What it means:

- **AM** = morning
- **BID** = twice a day
- **ER or XR** = extended release
- **EC** = enteric-coated
- **HS** = bedtime
- **IM** = intramuscular
- **IU** = international unit
- **IV** = intravenous
- **NSAID** = nonsteroidal anti-inflammatory drug
- **PM** = evening
- **PO** = by mouth
- **PRN** = as needed
- **Q** = every
- **QID** = four times a day
- **SC** = subcutaneous
- **TID** = three times a day

When giving someone their medication, there are a number of things to make sure you get right. Here are the six Rights of Medication Administration:

1 Right person. **3** Right dose. **5** Right time.

2 Right drug. **4** Right route.
(pill, under the tongue etc.) **6** Right response.
(looking to see—did this help? Or has it caused side effects?)



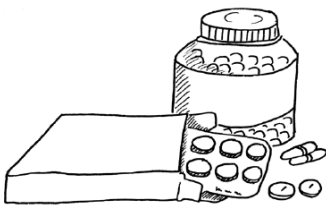
Improving medication success

- Consider the use of dosettes or blister packs, to help keep medicines organized.
- Request a yearly medication review/reconciliation with a pharmacist. This is a chance to review all of the medicines a person takes—prescribed, over-the counter, vitamins, supplements, etc. This can help you to look at any interactions between medicines, discuss side effects, and review back with the doctor if there are any suggestions on adding, changing or reducing medications. This is an especially good idea if your family member has multiple doctors who prescribe medications.
- Use the tools for health care visits (*About My Health* and *My Healthcare Visit*) to review medication side effects to bring forward **to** the doctor, and to also record any advice **from** the doctor about monitoring for side effects.
- Help your family member to learn about their medications, and the common side effects. [Easyhealth.org.uk](http://easyhealth.org.uk) includes examples of visual aids of commonly reported side effects. To locate these go to the Health Leaflets page, then Medications. You will see handouts of numerous specific medications. [http://easyhealth.org.uk/listing/side-effects-\(leaflets\)](http://easyhealth.org.uk/listing/side-effects-(leaflets))

Examples of clear language handouts about medication side effects from www.easyhealth.org.uk:

Northamptonshire Healthcare NHS Trust

What I should do if my medication makes me feel ill



I am taking Atypical Antipsychotics

The doctor wants you to take these tablets because you have mental illness.

You may feel funny when you take your tablets. Tell your family, your carer or your doctor if you feel like this.



• you wet the bed



• you can't do a poo



• you feel bunged up inside



• you feel sleepy

• you dribble



• you feel ill

• you have a sore throat



• your body feels hot

Use of antipsychotics

Also known as neuroleptics, antipsychotics are prescribed to help manage psychosis, which include symptoms like hallucinations, delusions and paranoia. Psychosis is commonly described as a break from reality, and is a common feature of schizophrenia, and bipolar disorder.

As we have seen, the rates of antipsychotic use are high among people with IDD. For some people, this is necessary – they may have a psychiatric disorder and this helps to decrease upsetting symptoms and keep them safe. Other times though, it seems as though antipsychotics are used to manage behavioural issues—sometimes in the absence of any psychiatric disorder, and people can keep taking them longer than is needed. This is an area of growing concern. In fact, the most recent version of the Canadian consensus guidelines, [Primary care of adults with intellectual and developmental disabilities](#) (Sullivan, et al., 2018) flags this issue, and suggests that people who are prescribed antipsychotics should review their medications with their doctor regularly (e.g. every three months), particularly when the medication is being prescribed in the absence of a psychiatric disorder.

In England, the health care system has produced guidelines called STOMP—Stopping Over Medication of People with Disabilities, recognizing the extent of the issue. See: <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/> for more information. As you know well, behaviour concerns are a form of communication. If a person has been sedated or medicated with an antipsychotic, their symptoms may be masked and we may not know why they were acting this way. This may result in needless suffering.

Medication Pathway, a resource by the UK’s Challenging Behaviour Foundation, is designed for family members of someone with IDD looking for information about psychotropic medication. The pathway focuses on how to make sure that your loved one is taking medication safely and only takes medication that they need. There is also a specific primary care guideline reminding us that antipsychotics are a last resort for behaviours that challenge.

Side effects

There are many side effects to antipsychotic medications. Typically, these depend on 1) the type of medication, which is frequently broken down into older medications (“typical antipsychotics”) and newer medications (“atypical antipsychotics”), 2) the person’s health status, and 3) the other medicines they take. Both the older and newer drugs can cause a cluster of side effects, though in general, the **older medications have more MOVEMENT side effects**, and the **newer medications have more METABOLIC concerns**, leading to higher rates of diabetes, weight gain, and for some people, cardiac consequences or even stroke and death. For this reason, a doctor might suggest monitoring metabolic symptoms when someone is prescribed antipsychotics.

Older (movement problems)	Newer (metabolic problems)
<ul style="list-style-type: none">• Haldol• Loxapine• Fluphenazine• Chlorpromazine	<ul style="list-style-type: none">• Abilify (aripiprazole)• Clozapine• Risperidone• Seroquel (quetiapine)• Zyprexa (olanzapine)



Side effect severity for people with IDD: When thinking about side effects, try to keep in mind how your family member may already have higher health vulnerabilities. If they have decreased muscle tone or poor balance, a motor side effect is likely to be even more serious. Similarly, if they are already at a high risk for obesity, taking a medication that increases that risk is even more concerning.

Mental Health and IDD

We know that the chance of having a mental health problem when you have an intellectual or developmental disability (IDD) is higher than it is for other people. Caregivers play a very important role in identifying mental health problems as they emerge and in helping to do something about it.

It can be hard for people with IDD to talk about what is going on in their thoughts or even to express their feelings. Sometimes all we see from the outside is behaviour. Some people call this problem behaviour, aggression or challenging behaviour. Those words describe what we see, but not what is behind what we see. Also, these sorts of words suggest that the person has a problem, like there is something wrong with them that needs to be fixed. Another way we could describe these behaviours is by calling them “behaviours that challenge.” When we say “behaviours that challenge”, what we are really saying is that person is telling us that there is something not right for them THROUGH their behaviours. And these behaviours, whatever they are, are challenging for us to handle. Talking about it this way reminds us that the behaviours themselves may not be the problem. It is just as much about the environment, the situation, and our own expectations.

What can you do to HELP?

There are four main things that can be helpful to know more about when we are trying to understand and promote the mental health of our family member: H-E-L-P (health, environment, lived experiences, and psychiatric disorders or concerns).



Health – Believe it or not, many of the problems we think are either behaviour problems or mental health issues are related to health issues that are not being picked up, even with regular doctor visits.

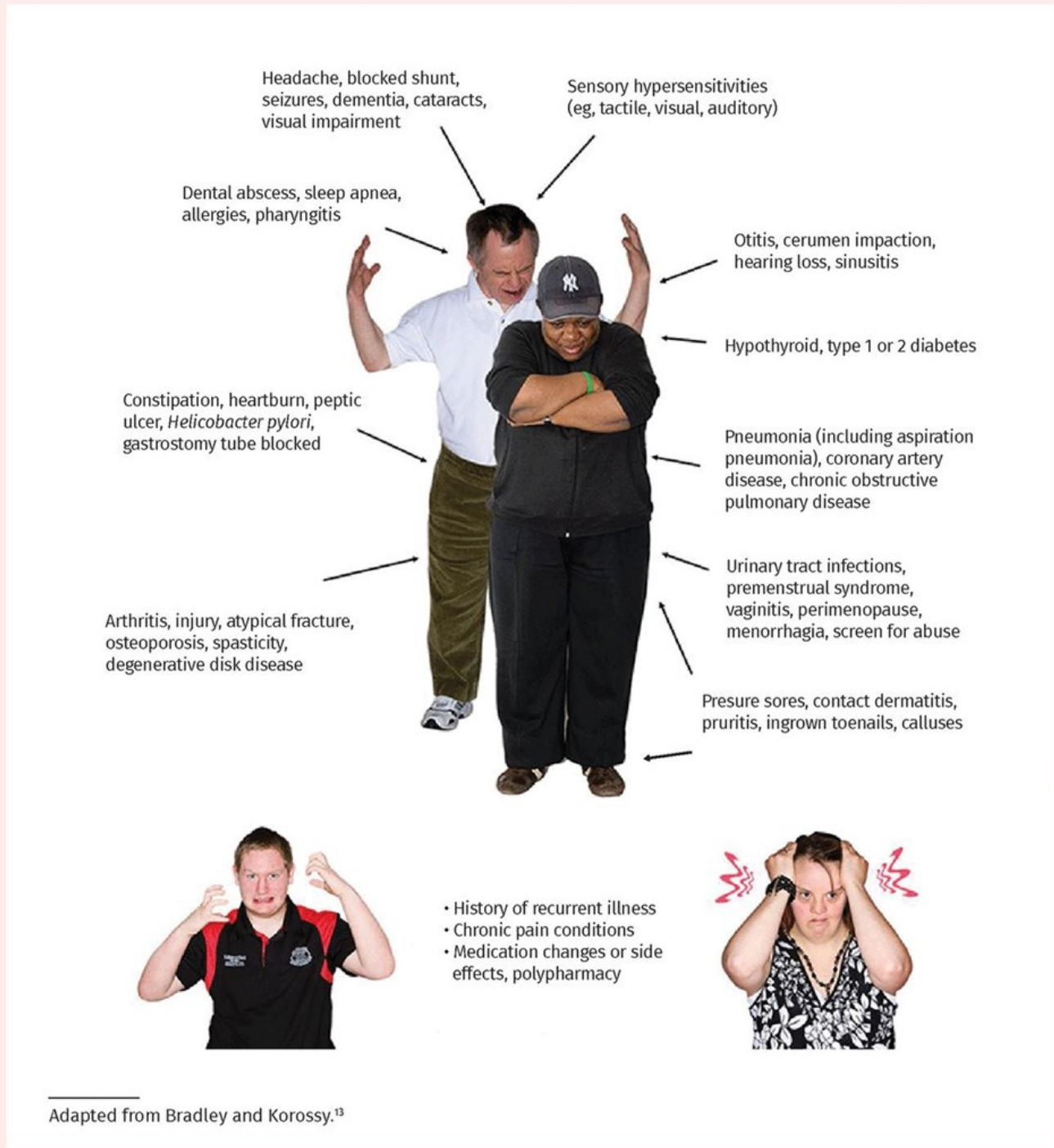
Imagine being in pain and nobody knows how much it hurts. What would you do to get the help you needed?

The diagram on the next page reminds us of many parts of the body where there could be pain or a health issue that might be missed. Before professionals start diagnosing or treating “behaviours” as though they are a mental health problem, we need to step back and think about a person’s health.

Start at the head, think about hearing, vision, and teeth, then work your way down the body all the way to the skin on someone’s feet, or ingrown toenails.



Figure 2. Health conditions causing behaviours that challenge



Green, L et al., (2018). HELP for behaviours that challenge in adults with intellectual and developmental disabilities. *Canadian Family Physician*, 64 (Suppl 2) S23-S31.

If your family member was in pain right now, how would others know? What are they usually like when there is a fever, or after hurting or cutting themselves? Could there be any side effects of medications that might be making things more difficult for the person? This could include dizziness, sleepiness, a fast heartbeat, dry mouth, stomach upset or nausea, constipation, or the need to move around a lot (akathisia). Knowing what these health issues are and doing something about them is always the first step.



Environment – Behaviour always happens somewhere, so we have to look as closely at what is going on around the person.

Sometimes an environment can feel stressful. There may not be enough support to help a person do what they need to do and that can be frustrating. An environment might become boring or dull because of lower expectations of what they can do. We may find that we do things for our loved one leading to a reduction in independence and potential increased feelings of incompetence. An environment might be disruptive, noisy, or unpredictable. Some people are able to manage well in this sort of situation, while others are not. So the next step is looking closely at the physical space the person is in and the emotional space. How can we make it more supportive, to match their needs?



Lived experiences – We know that many stressful and sometimes very traumatic things happen to people with IDD. What looks to us like a behaviour that challenges might be a response to a very difficult event that a person continues to struggle with.

Common life events that can lead to a lot of stress include the death or illness of a loved one, being bullied or teased or abused by someone, changes in staff where the individual may work or live, and changes in a favourite routine or activity. For people who can't understand why something bad has happened, it can be especially hard. It can also be hard when someone does not have a good sense of time. Something that happened a long time ago may still be very upsetting, like it happened yesterday. We might think it is better to pretend upsetting things didn't happen but that doesn't make the feelings go away.



Psychiatric disorder or concern – Just like people who don't have an IDD, those who do can also have psychiatric problems like depression or serious anxiety. Those sorts of things can be diagnosed and treated by a mental health professional after we have thought through H, E, and L.

There is important work for caregivers to do to support the individual prior to a problem becoming serious. Regular health check-ups, management of pain, and ensuring that eyes, ears and bodies are working well are all important. When something upsetting happens, caregivers can be there to provide support. Even when things seem okay, they can encourage healthy relationships, and make sure there are interesting activities happening that are not too stressful. Caregivers can't stop stress altogether, so it is important your loved one learns how to cope and manage stress in their lives. This includes helping them to find a way to communicate their needs and showing them that we are listening.

Other resources:

- Free MindEd Online Course on Supporting Adults with Developmental Disabilities with Mental Health Concerns or Behaviours that Challenge: https://www.minded.org.uk/Catalogue/Index?HierarchyId=0_41284&programmeld=41284
- “Let’s Talk about Mental Health and Developmental Disabilities” edition of The Direct Support Workers Newsletter: http://www.vitacsls.org/UserFiles/uploads/files/Vita_Newsletter%20V5_2_Links_FINAL.pdf

Section 4 :

Monitoring Charts



- **Direct Observation System**
- **Bowel Movement**
- **Menstrual Cycle**
- **Food Diary (Daily)**
- **Food Diary (Weekly)**
- **Seizures Yearly**
- **Seizure Record**
- **Sleep (24-hour sleep record)**
- **Weight (Adults)**
- **Diabetes Blood Sugar Diary**
- **Pain Assessment**



Direct Observation System (DOS)

The Direct Observation System (DOS) tool is used to monitor multiple behaviours and activities throughout a day for all days in a week. It allows you to assess possible relations between various behaviours.

When to use this chart:

- ▶ To track various behaviours or activities on one page.
- ▶ To assess if there are any behaviour patterns.
- ▶ To track frequency of behaviours that challenge.
- ▶ To track the impact of a medication.

Instructions:

- ▶ Add the person's name and dates to the chart.
- ▶ See the legend in the top left corner. Add in the behaviours or activities you want to track (no more than 8). Include positive or calm behaviour as well.
- ▶ You may also want to colour-code the behaviours to help see the patterns (for example, calm behaviours = green; neutral behaviours = yellow; high risk behaviours = red).
- ▶ For each 30-minute interval, record the number that best captures the behaviour.
- ▶ Review this chart as a team and share with health care provider, behaviour therapist, etc.

This tool does not go in any depth on one area, so you may want to use this to gather general data, then use a more specific chart (see other monitoring charts) for further detail.

Use the corresponding numbers to record the behaviour in 1/2 hour intervals.

1. Sleeping in bed

2. Sleeping in Chair

3. Awake/Calm

4. Calling Out

5. Verbal Aggression

6. Physical Aggression

7. Bowel Movement

DATE	<i>April 1</i>	<i>April 2</i>	<i>April 3</i>	<i>April 4</i>	<i>April 5</i>	
AM	12:00	1	1	1	3	5
	12:30	1	3	2	5	3
	1:00	3	4	6	3	1

To learn more, a helpful slideshow is available. The Direct Observation System (DOS) [Slideshow]; Logan, T., P.I.E.C.E.S. Manager Geriatric Services Resource Team, 2006. Available at: <https://slideplayer.com/slide/12391624/>

Adapted from The Dementia Observational System: A Useful Tool for Discovering the Person Behind the Illness. Schindel Martin, L..

Direct Observation System (DOS)

Use the corresponding numbers to record the behaviour in 1/2 hour intervals.

DATE					
AM	12:00				
	12:30				
	1:00				
	1:30				
	2:00				
	2:30				
	3:00				
	3:30				
	4:00				
	4:30				
	5:00				
	5:30				
	6:00				
	6:30				
7:00					
7:30					
8:00					
8:30					
9:00					
9:30					
10:00					
10:30					
11:00					
11:30					
PM	12:00				
	12:30				
	1:00				
	1:30				
	2:00				
	2:30				
	3:00				
	3:30				
	4:00				
	4:30				
	5:00				
	6:00				
	6:30				
	7:00				
7:30					
8:00					
8:30					
9:00					
9:30					
10:00					
10:30					
11:00					
11:30					

Monitoring Chart: Bowel Movement (BM)

Patient Name		Date of Birth
First	Last	

WHEN TO USE THIS CHART:

Constipation is a common issue that can cause pain and distress, and be a root cause for behaviour changes. It is important to track bowel movements (BM), and to review this information with the health care provider.

EXAMPLE:

1	BM	1	2	3	4
Size	S				
Type	7				
Medication*					

Type 1



Separate hard lumps, like nuts (hard to pass)

Type 2



Sausage-shaped but lumpy

Type 3



Like a sausage but with cracks on the surface

Type 4



Like a sausage or snake, smooth and soft

Type 5



Soft blobs with clear-cut edges

Type 6



Fluffy pieces with ragged edges, a mushy stool

Type 7



Watery, no solid pieces. Entirely liquid

*Source: Lewis SJ, Heaton KW. Stool form scale as a useful guide to intestinal transit time. Scandinavian Journal of Gastroenterology 1997; 32(9): 920-4.

INSTRUCTIONS:

- Record the BM size (L = Large; M = Medium; S = Small).
- Record BM type (1 to 7 of the Bristol BM Chart).
- Record (☑) if any medications were given for bowels.*

Month: _____

Year: _____

1	2	3	4	5	6	7																																																																																																																																												
<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*				
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
8	9	10	11	12	13	14																																																																																																																																												
<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*				
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
15	16	17	18	19	20	21																																																																																																																																												
<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*				
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
22	23	24	25	26	27	28																																																																																																																																												
<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*				
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
29	30	31																																																																																																																																																
<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Medication*</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	BM	1	2	3	4	Size					Type					Medication*					<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">BM</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">1</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">2</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">3</td> <td style="background-color: #2980b9; color: white; text-align: center; font-weight: bold;">4</td> </tr> <tr> <td>Size</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Type</td> <td></td> <td></</td></tr></table>	BM	1	2	3	4	Size					Type		</																																																																																																																
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type																																																																																																																																																		
Medication*																																																																																																																																																		
BM	1	2	3	4																																																																																																																																														
Size																																																																																																																																																		
Type		</																																																																																																																																																

Monitoring Chart: Menstrual Cycle

Patient Name	
First	Last

Date of Birth

WHEN TO USE THIS CHART:

To track a woman's period (menstrual cycle) if:

- 1) she is exhibiting behaviours that challenge, and you wonder if it is related to her period.
- 2) her period is causing difficulty for her or her caregivers (eg, it is unpredictable and hard to plan for, very heavy flow, painful, etc.)

WHAT SHOULD YOU DO WITH INFORMATION IN THIS CHART?

Bring it to the family physician for review.

Example	1	2	3	4	5	6	7	8	9
<i>April</i>	<i>XL</i>	<i>XL</i>	<i>XL</i>	<i>XL</i>	<i>XL</i>				
<i>2019</i>	<i>BP</i>	<i>BP</i>	<i>BP</i>	<i>BP</i>	<i>BP</i>				

INSTRUCTIONS:

Place an **X** on days of menstruation/vaginal bleeding (include 'spotting' in between period)

- 1) Record flow.
- 2) Record (**B**) if behaviour.
- 3) Record (**P**) if pain observed or expressed.
- 4) Record (*****) if medications given for pain or discomfort.

Record flow:

- L** = Light flow;
- N** = Normal flow;
- H** = Heavy flow

Record behaviour:

- B** = Behaviours noted
- P** = Pain observed or expressed;
- *** = Medication given for pain or discomfort

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Year																																
Month																																

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Year																																
Month																																

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Year																																
Month																																

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Year																																
Month																																

To capture in-depth information about the behaviour, consider using an ABC (antecedent-behaviour-consequence) chart. This can also be shown to the family physician or reviewed with a Behaviour Therapist.

Monitoring Chart: Menstrual Cycle

HOW DO WE KNOW ABOUT FLOW LEVELS?

The following is a visual guide of what might be visible on a brief or pad, or in a tampon to help give an idea.

L = Light Flow



N = Normal Flow



H = Heavy Flow



Adapted from: *Period Blood Loss Chart* by Cole, H. at [patient.info](https://patient.info/news-and-features/period-blood-loss-chart).
Available at: <https://patient.info/news-and-features/period-blood-loss-chart>

WHAT INFORMATION SHOULD BE TRACKED FOR BEHAVIOURS (B)?

- Mark a **B** on days when you've observed behaviours that challenge or target behaviours you are monitoring.

ASSESSING MENSTRUAL PAIN:

Ask about pain, but also look for signs that the person is in pain (**P**) or discomfort.

- See the Pain tool page on the Surrey Place Developmental Disabilities Primary Care Program website for more information. Suggested pain tools are:
 - Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID), available from the Centre for Pediatric Pain Research, Dalhousie University, Nova Scotia, Canada
 - Disability Distress Assessment Tool (DisDAT), by Northumberland Tyne & Wear NHS Trust and St. Oswald's Hospice, United Kingdom
- If you think a woman is experiencing pain, mark a **P** on the chart.

WHAT INFORMATION SHOULD BE TRACKED FOR MEDICATION?

- You may already record medication on a MAR (Medication Administration Record). If that is the case, bring the MAR sheet to any doctor's appointments, so it can be compared with this monitoring chart.
- If you don't use a MAR to track when medication is given for pain or discomfort, or you would like to track here, mark with a ***** when medication is given 'as needed' or "PRN" for menstrual pain.
- You can give more details in the notes section. For example, if medication seemed helpful or not.

Monitoring Chart: Food Diary (Daily)

Patient Name

First

Last

Date of Birth

WHEN TO USE THIS CHART: When you have concerns about a person's appetite (too much, too little), weight changes, or you want to closely record a person's diet.

INSTRUCTIONS: Record what is offered for every meal. Indicate how much of meal was eaten (for example, ✕ = not touched; 1/2 = half of serving eaten; ✓ = majority eaten). Remember to include snacks. Review this chart with a health care provider as needed.

BREAKFAST	Food Offered	Eaten
	Yogurt 350ml	✕
Banana	1/2 ✓	

Date of recording (dd/mm/yy):

BREAKFAST

Food Offered

Eaten

-
-
-
-
-
-
-

Snack

LUNCH

Food Offered

Eaten

-
-
-
-
-
-
-

Snack

DINNER

Food Offered

Eaten

-
-
-
-
-
-
-

Snack

Extra drinks:

Notes:

Monitoring Chart: Food Diary (Weekly)

Patient Name	
First	Last

Date of Birth

WHEN TO USE THIS CHART: When you have concerns about a person's appetite (too much, too little), weight changes, or want to closely record a person's diet.

INSTRUCTIONS: Record what is offered for every meal. Indicate how much of meal was eaten (for example, ✕ = not touched; 1/2 = half of serving eaten; ✓ = majority eaten). Remember to include snacks. Review this chart with a health care provider as needed.

<i>Monday</i>							
BREAKFAST	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 70%; border-bottom: 1px dotted black;">Food Offered</td> <td style="width: 30%; border-bottom: 1px dotted black;">Eaten</td> </tr> <tr> <td style="border-bottom: 1px dotted black;"><i>Yogurt</i></td> <td style="border-bottom: 1px dotted black; text-align: center;"><i>✕</i></td> </tr> <tr> <td style="border-bottom: 1px dotted black;"><i>Banana</i></td> <td style="border-bottom: 1px dotted black; text-align: center;"><i>✓</i></td> </tr> </table>	Food Offered	Eaten	<i>Yogurt</i>	<i>✕</i>	<i>Banana</i>	<i>✓</i>
Food Offered	Eaten						
<i>Yogurt</i>	<i>✕</i>						
<i>Banana</i>	<i>✓</i>						

Week of

BREAKFAST	Food Offered	Eaten	Food Offered	Eaten	Food Offered	Eaten	Food Offered	Eaten	Food Offered	Eaten	Food Offered	Eaten
	Snack		Snack		Snack		Snack		Snack		Snack	
LUNCH	Food Offered	Eaten	Food Offered	Eaten	Food Offered	Eaten	Food Offered	Eaten	Food Offered	Eaten	Food Offered	Eaten
	Snack		Snack		Snack		Snack		Snack		Snack	
DINNER	Food Offered	Eaten	Food Offered	Eaten	Food Offered	Eaten	Food Offered	Eaten	Food Offered	Eaten	Food Offered	Eaten
	Snack		Snack		Snack		Snack		Snack		Snack	
Extra drinks:												
Notes:												

Seizure Record To Establish Baseline – New Or Unstable Seizures

Name		Date of Birth
First	Last	

CALL 911: if seizure lasts more than 5minutes, if there is a impairment of breathing, or if patient continues to go in and out of seizures.

NOTIFY PHYSICIAN: if there is a change in the duration, frequency, or pattern of the seizures.

	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)
WHEN	Time of day					
	Duration (use watch; minutes/seconds):					
BEFORE SEIZURE	Possible triggers					
	Warning or aura					
WHAT HAPPENED DURING SEIZURE	<input type="checkbox"/> Conscious					
	<input type="checkbox"/> Unconscious not responding to name or pain					
	<input type="checkbox"/> Fell during seizure					
	<input type="checkbox"/> Confused					
	<input type="checkbox"/> Skin colour change (e.g., blue, grey, pale, red)					
	<input type="checkbox"/> Muscles stiffen Which side/ which muscles?					
	<input type="checkbox"/> Muscles jerk Which side/ which muscles?					
	<input type="checkbox"/> Became limp					
	<input type="checkbox"/> Bit tongue					
	<input type="checkbox"/> Eyes rolled back					
	<input type="checkbox"/> Eyes stared					
	<input type="checkbox"/> Cried out					
	<input type="checkbox"/> Incontinent (Urine or BM)					
<input type="checkbox"/> Breathing (fast rate, noisy, heavy, stopped)						
AFTER SEIZURE	<input type="checkbox"/> Sleeping/tired - how long?					
	<input type="checkbox"/> Confused					
	<input type="checkbox"/> Headache					
	<input type="checkbox"/> Speech slurred					
	<input type="checkbox"/> Increased activity					
COMMENTS						

***Possible triggers** – fatigue, exercise, hypoglycemia (low blood sugar), emotional stress, infection, alcohol, abnormal breathing menses, being startled, flashing lights, temperature changes, missed seizure medications, recent prescription change.

Provide the following information at a doctor’s visit:

- Any seizures since last visit? If yes: how many and detailed description. Any injury from seizure? Any medication used to stop the seizure?
- Has there been any change in the patient’s behavior/health from his/her baseline? Check as it applies.

<input type="checkbox"/> dizziness	<input type="checkbox"/> changes in way patient walks (gait)	<input type="checkbox"/> fainting spell	<input type="checkbox"/> sleep disturbance
<input type="checkbox"/> self-injury	<input type="checkbox"/> agitation without valid reason	<input type="checkbox"/> drowsiness	<input type="checkbox"/> other symptoms
- Up-to-date list of all medications patient is currently taking and whether there were recent changes, or missed medications.

Adapted from Community Living Toronto, Rehabilitative Resources, Inc, Sturbridge MA, and Westchester Institute for Human Development

Monitoring Chart: Sleep (24-hour sleep record)

Patient Name

First Last

Date of Birth

When to use this chart:

- ▶ If someone is having difficulty with sleep (see common reasons on bottom of page).
- ▶ If you want to know how well a sleep medication is working.

What should you do with information in this chart?

- ▶ Bring this chart with you to the family doctor.
- ▶ Please also bring information on medications (especially PRN, or 'as needed' medication) with dates and times for when the medication was administered (if it is recorded somewhere else).

Example:

	1	
AM	Midnight	X
	1am	X
	2am	X
	3am	X

Instructions:

- 1) Mark an **X** when person is sleeping, day or night.
- 2) Add an asterisk (*) when sleep medication is given.
- 3) Add details about the sleep issue on page 2.

Month:

Year:

	1	2	3	4	5	6	7	8	9	10	11	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
AM	Midnight																																
	1am																																
	2am																																
	3am																																
	4am																																
	5am																																
	6am																																
	7am																																
	8am																																
	9am																																
	10am																																
11am																																	
PM	12pm																																
	1pm																																
	2pm																																
	3pm																																
	4pm																																
	5pm																																
	6pm																																
	7pm																																
	8pm																																
	9pm																																
	10pm																																
11pm																																	

COMMON OR POSSIBLE SLEEP-RELATED PROBLEMS OF THIS PERSON:

- | | | |
|---|--|--|
| <input type="checkbox"/> Trouble falling asleep | <input type="checkbox"/> Falls asleep during the day | <input type="checkbox"/> Snores loudly |
| <input type="checkbox"/> Trouble waking up in the morning | <input type="checkbox"/> Trouble staying asleep | <input type="checkbox"/> Sweating a lot at night |
| | <input type="checkbox"/> Wakes up early | <input type="checkbox"/> Up frequently to bathroom |
| | <input type="checkbox"/> Up frequently during night | <input type="checkbox"/> Other: |
| | <input type="checkbox"/> Restless sleep | |

Monitoring Chart: Weight (Adults)

Patient Name

First Last

Date of Birth

When to use this chart:

Weight must be recorded every month in group homes and residential facilities. Monitor the person's weight more frequently if needed (eg, weekly).

Instructions:

Weigh a person using the same scale with shoes off. In the table below, record the person's weight in pounds (lb) or kilograms (kg) and include the date. Share with medical provider as needed

Example: Date 21
WEEK 1 Weight 195lb

Year:

Recent Weight:

Date of height:

	January	February	March	April	May	June	July	August	September	October	November	December
WEEK 1	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date
	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight
WEEK 2	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date
	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight
WEEK 3	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date
	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight
WEEK 4	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date
	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight	Weight

EXAMPLES: of images to use during discussion of blood sugar level symptoms with the person with IDD. To help explain diabetes to the people you support, see this resource from the UK: What to do when you have Type 2 diabetes: An easy read guide; Diabetes UK, London, UK, 2014. Available at: <https://www.diabetes.org.uk/professionals/resources/shared-practice/for-people-with-learning-disability>

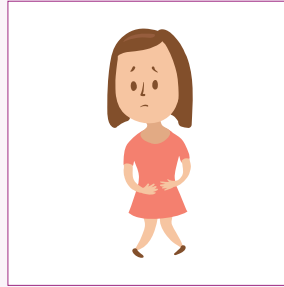
Some symptoms of HIGH blood sugar:



Feeling thirsty



Going to the toilet a lot



Stomach ache or nausea or 'fruity' smell on breath

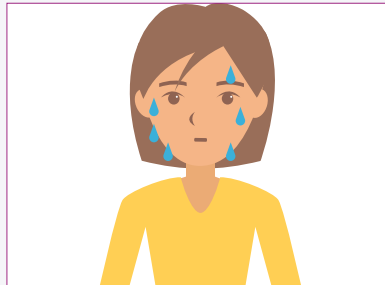


Feeling tired

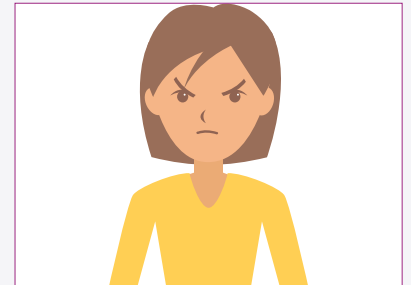
Some symptoms of LOW blood sugar:



Feeling shaky or dizzy



Feeling sweaty



Feeling very tired or grumpy

Pain Assessment of Adults With Intellectual and Developmental Disabilities

ABOUT PAIN ASSESSMENT AND IDD: Pain is often missed in people with Intellectual and Developmental Disabilities. Although self-report is often a recommended approach for assessing pain (eg, asking someone if they are in pain), it relies on expressive communication abilities and cognitive skills to understand and self-reflect – abilities that may be limited in a person with IDD.

It is important to also use observation tools developed for assessing pain in adults with IDD. These tools are designed to pay close attention to physiological indicators of potential pain (changes in breathing, skin colour, perspiration, tears), and behavioural changes that may indicate pain (facial grimacing, aggression, avoidance, posturing, verbal utterances).

When to use a pain assessment tool?

1. **WHEN YOU THINK A PERSON MAY BE IN PAIN** (eg, sustained an injury, if bowel movements are irregular, appetite seems less, sudden behavioural change, etc.).
2. **TO CAPTURE A BASELINE WHEN THE PERSON IS DOING WELL.** Because every person is unique, it is helpful to have a baseline on record, which you can then compare in the future to help assess for changes which may indicate a person is in pain. It is best for caregivers to proactively look for signs of pain, rather than waiting for a person to come and tell you they are in pain.

Recommended tools:

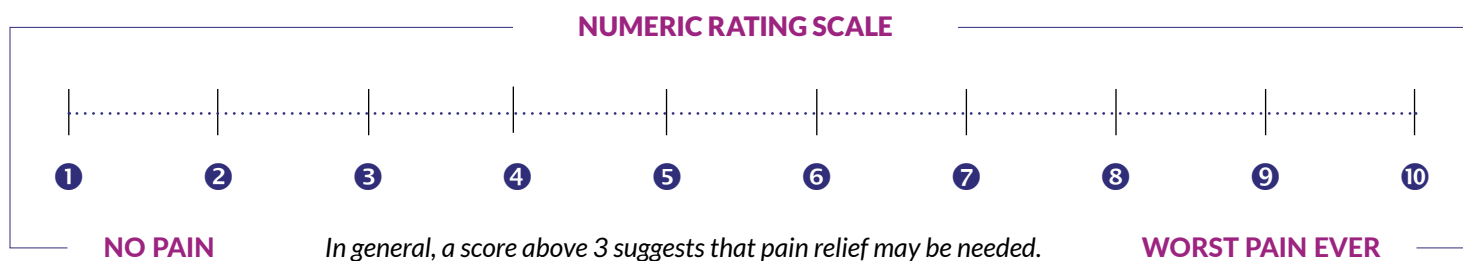
(Click on the underlined text below to access tools)

- ▶ [Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities \(CPS-NAID\)](#), available from the Centre for Pediatric Pain Research, Dalhousie University, Nova Scotia, Canada
- ▶ [Non-Communicating Children's Pain Checklist-Revised \(NCCPC-R\)](#), available from Centre for Pediatric Pain Research, Halifax, Canada
- ▶ [Disability Distress Assessment Tool \(DisDAT\)](#), by Northumberland Tyne & Wear NHS Trust and St. Oswald's Hospice, United Kingdom

Common self-report measures

To add to your observational assessment, use the following tools to ask the person how they are feeling and to report their response.

- ▶ Access the Wong-Baker FACES Pain Rating Scale at: <http://wongbakerfaces.org/>
- ▶ See page 2 for the Numeric Rating Scale



More information on pain and IDD

How do you assess pain if the patient can't communicate verbally? Slideshow by Lynn. B., Departments of Nursing, Pediatrics & Psychology, Dalhousie University. Available at: <https://portal.sd47.bc.ca/public/3kj3ua7/Documents/BREAU-NonVerbalPatients.pdf>

NUMERIC RATING SCALE



NO PAIN

WORST PAIN EVER

Section 5 : Health Care Handouts and Other Resources



- **Fecal Occult Blood Test (FOBT)**
- **Pap Test & Exam**
- **Mammogram**
- **MRI Scan**
- **Other Resources**
- **Glossary of Terms**
- **IDD: Frequently Asked Questions**
- **Genetic and Neurodevelopmental Conditions Linked to IDD**



Colon Cancer Screening

An “FOBT” is a test that checks my poop, to make sure that inside parts of my belly – my colon, or bowel – is healthy. I will be given a “FOBT kit” to take home with me. I will use it to collect samples of my poop. It is important that I follow all the steps.



This is an FOBT kit.

I will probably need to collect 3 samples of my poop, on different days. Then, the samples will be sent to the laboratory and checked to see if they are healthy. Doing the FOBT might be a little hard, and a little messy. Some people need help to use the FOBT kit.

The person that I will ask for help is: _____.

Once I am all done my FOBT, I will celebrate a job well done! To celebrate, I am going to: _____.



Would I like to learn more about the FOBT?

Do I want to watch a video?



“Doing Your Test Kit at Home”: <http://www.easyhealth.org.uk/content/part-2-doing-your-test-kit-home>

Do I want to read a booklet or look at pictures?



Bowel Cancer and Bowel Screening. From NHS in England: <http://www.easyhealth.org.uk/sites/default/files/null/Bowel%20Cancer%20%26%20Bowel%20Screening.pdf>

Do I want to learn more about colon cancer screening in Ontario?



<https://www.ontario.ca/page/colorectal-cancer-screening-and-prevention>
“10 Tips”: <http://tbrhsc.net/10-tips-to-help-you-successfully-complete-your-fobt-kit/>

Cervical Cancer Screening

A pap test and pelvic exam is a way for the doctor to make sure that women are healthy. This is done when they check inside our vagina. Some people might get nervous or feel a bit uncomfortable. But, this is important to do for health— and it does not take long! The doctor will tell me how often I should have this done.



Would I like to learn more about a pap test and pelvic exam?



Do I want to watch a video?

<https://www.youtube.com/watch?v=s9ylkUuKcXQ>



Do I want to read a booklet or look at pictures? This is a booklet that can be printed out and I can read at home. It is from England so some of the words might be different from Canada, but it may still have information that is helpful. [http://www.easyhealth.org.uk/listing/cervical-screening-\(leaflets\)](http://www.easyhealth.org.uk/listing/cervical-screening-(leaflets))



Do I want to listen to someone speak? This has drawings and a voice that I can listen to. This is on the computer. https://www.surreyplace.ca/documents/Flash/Checking%20all%20of%20me_F/data/swf/engage_258/Checking%20all%20of%20me-Female.html

Adapted from Simpson, K. (2001). *Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations*



There are lots of things I can do to help make my pap test better. Here are some ideas for you too:

- ❑ Learn more about the exam before the visit.
- ❑ Visit the clinic: see the exam room, and meet the provider.

- ❑ Have help making the appointment for the exam.
- ❑ See a video about the exam.
- ❑ Have someone with me - a friend, partner, relative, etc.
- ❑ Watch someone I know have an exam (mother, sister, friend).
- ❑ Decide if I would like to see a male or female doctor.
- ❑ See a provider who speaks/understands my language.
- ❑ Have the exam on an adjustable "high/low" table designed for people with mobility problems.
- ❑ Talk with someone about my fears.
- ❑ Practice breathing relaxation techniques to help me calm down.
- ❑ Bring and listen to my favourite music.
- ❑ Have a mild medication to help calm me down.
- ❑ Do other things before the appointment to help me be prepared.
- ❑ Do other things at the time of the appointment to help me remain calm.
- ❑ Know that I took good care of myself by having the exam.
- ❑ Reward myself afterward with something special.

Adapted from Simpson, K. (2001). *Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations*



I successfully completed my pap test on: _____

I know I can do it again!

I will plan my next exam for: _____ (Year).



These things were helpful to me. I will do them again for my next pap test:

1.

2.

3.

I will do these things differently for my next exam:

1.

2.

3.

Adapted from Simpson, K. (2001). *Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations*

Breast Cancer Screening

A mammogram is a special x-ray that takes pictures of my breasts. This is a way for a doctor to find out if my breasts are healthy. I will go to a special clinic to have this test done – this might even be at a hospital. Having a mammogram does not mean that I am sick! This is something that most women are asked to do. At the mammogram, I will do these things:

1. Take off my top and my bra.
2. Then, my breasts will be placed on the x-ray machine.
3. I need to stay very still. It might feel a bit uncomfortable, but it should not hurt me.
4. The machine will squeeze my breasts and take the x-ray pictures.
5. I am all done!



Would I like to learn more about mammograms?



Do I want to watch a video?

https://www.youtube.com/watch?v=7OVR_KP1QoA



Do I want to read a booklet or look at pictures?

<http://www.mcdc.info/uploads/pdf/Taking-care-breasts-2010.pdf>



Do I want to listen to someone speak?

https://www.surreyplace.ca/documents/Flash/Examine%20yourself_breast%20health/data/swf/engage_256/Examine%20Yourself-Breast%20Health.html

Adapted from Simpson, K. (2001). *Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations*



“Hi, my name is Janelle. Here are some things that help when I get a mammogram. I hope they help you too!”

- Ask to have an appointment time that is best for *me*.
- Remember not to wear any deodorant that day.
- Bring a friend, family member or someone I trust to come with me.
- Let the mammogram centre know that I might be a little nervous.
- Ask if I can sit down—if it is hard for me to stand up.
- Do something nice for myself when I am done.
- If I have questions, I can call someone before my mammogram: _____.



Adapted from Simpson, K. (2001). *Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations*

Preparing for an MRI Scan

MRI stands for Magnetic Resonance Imaging. This is a test that uses a powerful magnet and radio waves to take pictures of the inside of my body. These pictures are then sent to a computer for doctors to look at. MRIs are safe and painless, though I may be nervous during the scan. The only thing I need to do is keep very still while the MRI machine takes pictures. I will go to a special clinic or hospital to do this test. Here are some things I can do to prepare for an MRI scan:

- Ask lots of questions and let my doctor know if I am afraid of tight or small spaces.
- During the MRI, I will be lying in tube-shaped machine. It may take up to an hour but sometimes more to complete the test.
- Because an MRI is a large magnet, I will be asked to remove any jewelry and other metal items before entering the MRI machine.
- On the day of my MRI, I should arrive at least half an hour before the test. Bring a book or something to occupy myself while I wait.
- Bring a friend, family member or someone I trust to come with me. Ask if it is possible to have them in the room with me during the scan.
- Expect a lot of noise. While I am in the MRI machine, I will hear loud thumping noises as the machine takes pictures. The technician can give me headphones or earplugs to help with the noise.
- In order to take good pictures, I will need to lie very still during the MRI. I will be able to hear and talk to the technician in the other room.
- Some people may need sedation for their MRI. The doctor may also need to use a contrast dye to better see some parts of the body. If so, the dye will be inserted into a vein using a small needle.
- Contrast dye is like a highlighter for the inside of my body. It won't hurt, but after a few seconds my body might feel cold and I might taste something weird in my mouth. I might also feel like I peed in my pants. But this is totally normal and the feeling will go away in less than a minute.

Would I like to learn more about MRIs?



Do I want to watch a video?

<https://www.youtube.com/watch?v=GCUGED8pmBE>



Do I want to read a booklet or look at pictures?

https://www.easyhealth.org.uk/wp-content/uploads/2020/03/having_an_mri_scan.pdf
or <https://www.easyhealth.org.uk/wp-content/uploads/2020/03/MRIscan.pdf>

Other Resources

Ontario-based Resources For People with Developmental Disabilities

- [COVID-19 Information and Resources](#) *H-CARDD, Centre for Addiction and Mental Health (CAMH)*
- [How to Find a Doctor](#), *Health Care Connect, Government of Ontario*
- [Health Promotion \(Prevention and Nutrition\)](#) *Special Olympics*
- [Action Guides](#) for people with a disability, *Partners for Planning*
- [Adult Developmental Services](#), *Developmental Services Ontario*
- [Programs and Services](#), *Autism Ontario*
- [For 18 years and older](#), *Autism Ontario*

Ontario-based Resources for Caregivers

- [Caregiver Resources](#), *H-CARDD, Centre for Addiction and Mental Health (CAMH)*
- [Family Education Video Series](#), *Azrieli Adult Neurodevelopmental Centre, CAMH*
- [Family Guide to Dual Diagnosis](#), *CAMH*
- [Primary Care Tools](#), *Developmental Disabilities Primary Care Program at Surrey Place (DDPCP)*
- [Capacity for Decision Making Guidelines](#), *DDPCP*
- [Communicate CARE: Guidance for person-centred care of adults with IDD](#), *DDPCP*
- [Decision Making in Health Care Tool](#), *DDPCP*
- [Resources](#), *Community Living Ontario*
- [Resources](#), *Ontario Caregiver Coalition*
- [Fall Prevention Information](#), *Finding Balance Ontario*
- [Family Support Groups](#), *ConnectABILITY*
- [Sibling Resources](#), *The Sibling Collaborative*
- [Finding and Using Individualized Funding](#), *IF Library*
- [International Journal for Direct Support Professionals](#), *Vita Community Living Services*

International/Other Resources

- [EasyHealth](#), *UK*
- [STOMP—Stopping Over Medication of People with Disabilities](#), *NHS, UK*
- [Psychotropic Medication Monitoring](#), *Challenging Behaviour Foundation, UK*
- [Healthy Mind Easy Read Tool](#), *Black Dog Institute, Australia*
- [Thinking in Pictures](#), *Books Beyond Words, UK*
- [What to Do When You Have Type 2 Diabetes](#), *Diabetes UK*
- [Looking After your Eyes](#), *SeeABILITY, UK*
- [Asthma Resources](#), *Asthma UK*
- [Breaking Bad News](#), *Kingston University, UK*
- [Palliative Care Information](#), *CareSearch, Australia*
- [Aging and IDD](#), *Resources for Integrated Care, US*
- [Alzheimer's Disease and Dementia](#), *National Task Group on Intellectual Disabilities & Dementia Practices, US*
- [MindEd Online Courses on Supporting Adults with IDD](#), *UK*

Glossary of Terms

Caregiver

A caregiver is someone who is actively engaged in providing care to another such as a chronically ill, disabled or aged family member or friend. Often a caregiver finds themselves in this role with a lack of training, support or compensation.

Direct Support Professional (DSP):

Direct support professionals (DSPs) are people who work directly with people with disabilities to help support them in activities of daily living. Staff in developmental sector agencies are typically called DSPs.

Dual Diagnosis:

The term dual diagnosis means that someone has both an intellectual and developmental disability (IDD) and a mental illness or an addiction.

H-CARDD:

H-CARDD stands for [Health Care Access Research and Developmental Disabilities](#). H-CARDD is a program with a team of researchers who study the health of adults with developmental disabilities. H-CARDD has developed the Family Matters Toolkit, and it has also developed other toolkits on health and developmental disabilities for DSPs, staff in emergency care departments and primary care settings.

Health Care Provider (HCP):

It is true that all of us can be involved in health care, but health care providers are professionals who work in health care and who provide health care. This includes doctors, but it can also include other parts of the team like a nurse, social worker, psychologist, or x-ray technician.

Intellectual and Developmental Disabilities (IDD):

Intellectual and developmental disabilities (IDDs) are conditions that are usually present at birth or at a young age and that affect the trajectory of the individual's physical, intellectual, and/or emotional development. Some people with IDD have genetic conditions such as Down syndrome, Prader-Willi syndrome, or Fragile X syndrome.

Legal Capacity/Capacity to Consent:

Legal capacity means having the ability to understand the information that is being presented (knowing the risks and benefits of a decision), and to appreciate how it relates to you (for example, being able to explain what happens if you agree to treatment, but also understand the consequences if you refuse it).

Mental Health:

Mental health refers to our emotional, psychological, and social well-being. Our mental health affects how we think, feel, and act. People with mental health disorders such as depression, anxiety, schizophrenia, bipolar disorder, obsessive-compulsive disorder (OCD), or post-traumatic stress disorder (PTSD) may have difficulties with their thinking, mood, and behaviour.

Substitute Decision Maker:

When doctors see patients, they need to determine whether the person is capable or incapable of making their own health care decisions. When a person is found to be incapable, a substitute decision maker makes the decision.

IDD: Frequently Asked Questions

Intellectual and developmental disabilities (IDD) begin in childhood and are lifelong disabilities that impact thinking and day-to-day activities. Here is some general information:

Is there a formal definition for IDD?

Although we encourage you to look into the various definitions for IDD, criteria generally include:

- Originated before the person reached 18 years of age;
- Are likely to be life-long in nature; and
- Affect areas of major life activity, such as; personal care, language skills, learning abilities, and the capacity to live independently as an adult.

How common is IDD?

- Between 1 and 3 out of 100 people have an intellectual or developmental disability.

What causes IDD? Are people always born with an IDD?

- For some people, IDD will be genetic, like Down syndrome.
- Other times, an IDD can occur due to damage to the brain caused during childbirth or when the person is quite young.
- And sometimes, the cause or “etiology” of the disability is not known.

Does IDD affect people in the same ways?

- No. Everyone will be impacted by their IDD in a unique way. Some people may need more support in certain areas of life than other people.
- There are some people for whom it was very clear from the time they were young children that they had an IDD, and for others it may not have been as obvious.

What about people with more severe levels of disability?

- They may require help in all aspects of their day-to-day life.
- They are likely to have medical issues related to their disability.
- Their ability to describe and report on their health may be particularly compromised, so having familiar people who know the person well is important.

What about people with more mild disabilities?

- It is not always clear if people with mild IDD meet the criteria as defined in legislation, or in medical diagnostic criteria.
- Even though the disabilities may be more subtle for this second group, we know that their lived experience can still be quite stressful for them and their families.
- Sometimes, having a more mild disability means additional challenges accessing services, which is stressful and can lead to poorer health outcomes.
- Having independence can also mean having less supervision and support, which can lead to making choices that can be harmful to one's health.
- Not understanding a disability can also lead to interpersonal tensions at home, at school, and at work, because expectations are not realistic, and supports are not in place.
- Individuals in this group can have a host of physical and mental health issues that develop over time. If health care providers don't recognize that there is a disability, they might only see the health issues and wonder why the person is having difficulties explaining what is wrong and following through with treatment.

Genetic and Neurodevelopmental Conditions Linked to IDD

Angelman Syndrome

Angelman syndrome is a genetic disorder that occurs because of a lack of expression of a gene on a maternally inherited chromosome. Angelman syndrome is associated with severe intellectual disability and characteristic facial features.

People with the condition typically have physical challenges, such as delayed motor milestones, movement or balance disorders, limited or no speech, seizures, and sleep disturbances. Common behavioural characteristics associated with the condition include apparent bouts of excessive, often inappropriate laughter, easily excitable, and repetitive or stereotyped behaviours (such as hand flapping and mouthing).

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a condition that typically appears early in childhood development. The term “spectrum” refers to the wide range of symptoms and severity including impairments in social interaction and communication, and restricted, repetitive behaviours or interests. People with ASD can have different levels of difficulties in these areas. These difficulties can interfere with their ability to function in social, academic, and employment settings.

People with ASD are also more likely to have psychiatric problems such as anxiety, depression, obsessive-compulsive disorder, and eating disorders. People with ASD can have difficulties in understanding and using non-verbal social cues such as eye contact, facial expressions, gestures, and body language.

Cerebral Palsy

Cerebral palsy is an umbrella term, which means it refers to a group of disorders and symptoms. While all the possible symptoms, disabilities, and complications are related, one person’s experience is often very different from another’s.

Cerebral palsy is the most common disability that impacts movement and motor skills. It is a neurological disorder that affects motor skills, movements, and muscle tone. Brain damage is the underlying cause. The damage may occur while the baby is still in utero, during labor and delivery, or shortly after birth.

Having cerebral palsy can lead to a number of other medical conditions, depending on the severity of the disorder, such as speech problems, learning disabilities, cognitive impairments, problems with hearing and vision, epilepsy, emotional and behavioural issues, spinal deformities, and joint problems.

Down Syndrome

Down syndrome (or Trisomy 21) is a genetic condition that is associated with intellectual disability. The condition is caused by being born with an extra part or full chromosome. People with Down syndrome have a characteristic facial appearance.

People with Down syndrome may have a variety of physical health issues. About half of all affected children are born with a heart defect. Digestive abnormalities, such as a blockage of the intestine, also occur sometimes, but these are not as frequent. Adults with Down syndrome can have thyroid problems, sleep apnea, and may also develop Alzheimer’s disease as they age.

Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe the range of effects that can occur in an individual whose mother consumed alcohol during pregnancy.

When a woman drinks alcohol while pregnant, her fetus is exposed directly to alcohol through her bloodstream. Alcohol can interfere with the growth and development of all fetal body systems. The developing central nervous system (the brain and spinal cord) is most vulnerable to the damaging effects of alcohol. These effects, which can vary from mild to severe, may include physical, mental, behavioural, and/or learning disabilities with possible lifelong implications.

Fragile X Syndrome

Fragile X syndrome occurs in individuals with a specific genetic mutation and is the most common type of hereditary intellectual disability. Typically, males with this condition have moderate intellectual disability and females with the condition tend to have mild intellectual disability. Some males with this condition will have a large head, long face, prominent forehead and chin, protruding ears, joint laxity, and large testes after puberty. Behavioural abnormalities, including autism spectrum disorder, are common in people with this condition as well.

Prader-Willi Syndrome

Prader-Willi syndrome is associated with weak muscle tone (hypotonia) and feeding difficulties in early infancy. After infancy, individuals develop excessive eating patterns and usually develop obesity, unless their eating is controlled by others. Short stature is common (if not treated with growth hormone); characteristic facial features, strabismus (a vision problem), and scoliosis are often present.

People with Prader-Willi syndrome typically have delays in their motor and language skills. Everyone with this condition experiences some degree of cognitive impairment. Behavioural problems such as temper tantrums, stubbornness, and obsessive-compulsive behaviour are often present as well. Hypogonadism (the diminished functioning of the testes or ovaries), is present in both males and females and manifests as genital hypoplasia (the underdevelopment or incomplete development of a tissue or organ), incomplete pubertal development, and infertility in most.



References:

- <https://www.ncbi.nlm.nih.gov/gtr/conditions/C1510586/>
- <https://ghr.nlm.nih.gov/condition/down-syndrome>
- <http://ddprimarycare.surreyplace.ca/tools-2/health-watch-tables/>
- <https://www.cerebralpalsyguidance.com/cerebral-palsy/>