

# Communicate CARE

## *Guidance for person-centred care of adults with intellectual and developmental disabilities*

### Introduction

This tip-sheet offers guidance to family physicians, nurses, allied health professionals for a person-centred health assessment of adults with intellectual and developmental disabilities. It provides information on best practices to prepare for appointments, communicate and plan interventions using a person-centred approach to shared decision making.

### Prepare to Communicate CARE

#### Know your patient <sup>[i]</sup>

- ▶ Review available patient information and plan to accommodate needs (eg, physical, cognitive, communication).
- ▶ Involve the patient as much as possible.

#### Create a safe and comfortable space <sup>[i, ii]</sup>

- ▶ Modify possible stressors that can make the patient feel uncomfortable or unsafe (eg, commotion, lights, smells).

#### Accommodate needs

- ▶ Book preferred appointment times.
- ▶ Plan for longer and several appointments.
- ▶ Determine and adapt to how the patient communicates (verbal, non-verbal, devices).

#### Establish rapport and set an agenda

- ▶ Welcome and introductions.
- ▶ Be present with a warm and positive regard.
- ▶ Explain that you will engage directly with the patient and will include caregivers for information or translation.
- ▶ Ask a few simple introductory questions; maybe attend to the patient's piece of clothing or what they brought with them.
- ▶ Ask whether the patient wants their caregiver to stay for all or part of the visit.
- ▶ Set an agenda for the visit.
- ▶ Consider rapport-building visits outside of problem-solving visits, for anxious patients.

## Communicate CARE: Clearly, Attentively, Responsively, Engaging with the patient and others as needed <sup>[iv,v]</sup>

### Communicate Clearly <sup>[iv,v]</sup>



- ▶ Use verbal and nonverbal communication aligned with the patient profile and needs (eg, use gestures, writing, drawing and pictures <sup>[vi,vii,viii]</sup>)
- ▶ Assume better receptive than expressive language ability, especially with severe or profound intellectual and developmental disability.
- ▶ Slow down, pause frequently and confirm understanding. Repeat and rephrase as needed.
- ▶ Use short, simple and plain language.
- ▶ Avoid abstract language, medical jargon and idioms (eg, “your throat is on fire”).
- ▶ Use clear sentences such as “Show me...”, “Tell me...”, “Do this...”.
- ▶ Avoid abstract concepts (eg, indicate time by referring to specific past or present events like breakfast, summer, holidays).

### Attentively listen and observe



- ▶ Assume a relaxed disposition (eg, breathe slowly), sit facing the patient, attentively listen, and observe body language.
- ▶ For patients with delayed processing, allow ample time to respond to questions (eg, 10 seconds or more).
- ▶ Be sensitive to cues, tones and silences (eg, if bored or restless consider transition to physical exam; if anxious, alleviate concerns; if silent, explore whether they are upset).
- ▶ Seek clarification when you do not understand the patient.
- ▶ For patients with atypical muscle tone or motor functioning, interpreting facial expressions or body language might be difficult.
- ▶ Engage caregivers to understand the patient’s experience.
- ▶ Allow the patient to confirm and supplement their information.

### Responsively address concerns during the healthcare visit <sup>[ix,x]</sup>



- ▶ Respond to verbal and nonverbal expressions of concern with empathy and adjust the approach as necessary.
- ▶ Be curious. The history and physical examination are useful to assess the patient’s mental processes and their physical or emotional discomfort.
- ▶ Enhance the enquiry and physical exam with words, actions, miming or audiovisual aids.
- ▶ A systems enquiry can target priority areas for a focused physical exam.
- ▶ Physical examinations can be difficult due to sensory, physical or trauma-related issues. Respond to concerns with explanation (verbal and nonverbal).
- ▶ Caregivers may be helpful to guide and facilitate your enquiry and actions.
- ▶ Collaborate with the patient: Ask permission and offer choices (eg, “Is it okay if we do your blood pressure now?”, “Should I listen first to your heart or look in your ears?”).
- ▶ Indicate what will happen next. Let the patient first handle and explore equipment before you use it.
- ▶ Go slow and check in often (eg, respond to changes in affect by asking, “Are you okay?”).
- ▶ Leave sensitive areas of the examination until the end (eg, ears).
- ▶ Prioritize or defer examination and investigations.

### Engaging the patient and others as needed <sup>[xi,xii]</sup>



- ▶ Engage the patient and others, as indicated throughout the healthcare visit (eg, interpret patient communications, goals and preferences).
- ▶ Use a decision-making tool to decide on the decision-making process.
- ▶ This process involves sharing information, explaining findings and discussing options with the patient always at the centre.
- ▶ Once the decision-making process is established, develop a care plan that includes the condition, action, who is responsible, and timeline.
- ▶ Provide a copy of the care plan to track management plan progress and follow-up.
- ▶ Engage the patient in planning the follow-up visit.

## Supporting materials

### Preparing to Communicate CARE

- i. **About My Health**  
Developmental Disabilities Primary Care Program of Surrey Place, Ontario.
- ii. **Treat me Well: Top ten reasonable adjustments**  
Mencap, UK <https://www.mencap.org.uk/sites/default/files/2018-06/Treat%20me%20well%20top%2010%20reasonable%20adjustments.pdf>
- iii. **Treat me Well: Giving your patients reasonable adjustments**  
Mencap, UK [video] <https://youtu.be/IdCDaovPVj0>

### Communicating clearly

- iv. **Curriculum of Caring**  
McMaster University, Ontario [https://machealth.ca/programs/curriculum\\_of\\_caring/](https://machealth.ca/programs/curriculum_of_caring/)
- v. **Communicate CARE**  
Curriculum of Caring, McMaster University [video] [https://machealth.ca/programs/curriculum\\_of\\_caring/m/mediagallery/2210](https://machealth.ca/programs/curriculum_of_caring/m/mediagallery/2210)
- vi. **Books Beyond Words**  
Beyond Words, UK [picture books] <https://booksbeyondwords.co.uk/>
- vii. **EasyHealth**  
Generate Opportunities, UK [videos and easy read leaflets] <http://www.easyhealth.org.uk/>

- viii. **The hospital communication book**  
Surrey Health, UK [includes picture repository] [http://www.surreyhealthaction.org/downloads/Hospital Communication Book - version 2 - web.pdf](http://www.surreyhealthaction.org/downloads/Hospital%20Communication%20Book%20-%20version%202%20-%20web.pdf)

### Responsively addressing concerns

- ix. **Keys to success when examining people with developmental disabilities, Curriculum of Caring**  
McMaster University [video] [https://machealth.ca/programs/curriculum\\_of\\_caring/m/mediagallery/2204](https://machealth.ca/programs/curriculum_of_caring/m/mediagallery/2204)
- x. **Best Practice Series**  
Health Care Access Research and Developmental Disabilities (H-CARDD) Centre for Addiction and Mental Health, Toronto [videos] <https://www.porticonetwork.ca/web/hcardd/resources/videos/healthcare-providers>

### Engaging patient and caregivers in the healthcare visit

- xi. **Decision Making of Adults with Intellectual and Developmental Disabilities, Developmental Disabilities Primary Care Program of Surrey Place, Ontario**  
Developmental Disabilities Primary Care Program of Surrey Place <http://ddprimarycare.surreyplace.ca/guidelines/general-health/capacity-for-decision-making/>
- xii. **My Health Care Visit**  
Developmental Disabilities Primary Care Program of Surrey Place, Ontario <http://ddprimarycare.surreyplace.ca/tools-2/general-health/todays-visit/>

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

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