

# Communicate CARE

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

### Introduction

This tip sheet offers guidance to health care professionals for a person-centered 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-centered approach to shared decision making.

## Prepare to Communicate CARE—Be Clear, Attentive, Responsive, and Engaging with the patient and others as needed

### Know your patient

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

### Create a safe and comfortable space

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

### Accommodate needs

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

### Establish rapport and set an agenda

- ▶ Welcome and introductions.
- ▶ Be present with a warm and positive regard.
- ▶ Consider not wearing the white coat.
- ▶ Explain that you will engage directly with the patient and will include family member/support persons 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 family member/support person 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: Be Clear, Attentive, Responsive, and Engaging with the patient and others as needed

## Communicate Clearly

# C

- ▶ Use verbal and nonverbal communication aligned with the patient profile and needs (use gestures, writing, drawing and pictures).
- ▶ 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/concepts, medical jargon and idioms (indicate time by referring to specific past or present events like breakfast, summer, holidays).
- ▶ Use clear sentences such as “Show me...”, “Tell me...”, “Do this...”.
- ▶ If the patient uses a communication technique or device, involve a family member/support person who is familiar with it.

## Attentively listen and observe

# A

- ▶ Assume a relaxed disposition, (breathe slowly), sit facing the patient, attentively listen, and observe body language.
- ▶ Be sensitive to tone of voice.
- ▶ For patients with delayed processing, allow ample time to respond to questions (10 seconds or more).
- ▶ Be sensitive to cues, tones and silences (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. Let the patient know when you do and do not understand.
- ▶ For patients with atypical muscle tone or motor functioning, interpreting facial expressions or body language might be difficult.
- ▶ Engage family member/support person to understand the patient’s experience.
- ▶ Allow the patient to confirm and supplement their information.

## Responsively address concerns during the health care visit

# R

- ▶ 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 inquiry and physical exam with words, actions, miming or audiovisual aids.
- ▶ A systems inquiry 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).
- ▶ Family member/support persons may be helpful to guide and facilitate your inquiry and actions.
- ▶ Collaborate with the patient: Ask permission and offer choices ( “Is it OK 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 (respond to changes in affect by asking, “Are you OK?”).
- ▶ Leave sensitive areas of the examination until the end (ears, genitals).
- ▶ Prioritize or defer examination and investigations.

## Engaging the patient and others as needed

# E

- ▶ Engage the patient and others, as indicated throughout the health care visit (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 center of the discussion.
- ▶ 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 plan progress and follow-up.
- ▶ Engage the patient in planning the follow-up visit.

# Legal obligations to patients with disabilities

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 (Section 504) require doctors and other health care providers to ensure effective communication with patients with disabilities. This obligation includes providing auxiliary aids and services to assist with communication.

These federal laws require health care providers to provide and pay for auxiliary aids/services necessary for effective communication. These laws prohibit health care providers from passing costs of auxiliary aids/services to their patients.

Whether a patient needs an auxiliary aid/service and, if so, what aid/service will vary from individual to individual. Examples of auxiliary aids/services include but are not limited to the following:

- ▶ Sign language interpreters

- ▶ Braille materials
- ▶ Simplified language documents
- ▶ Computer Assisted Real Time text (CART)
- ▶ Large print documents

Keep in mind that if a patient with a disability is accompanied by a companion who has a disability that affects communication, the ADA and Section 504 require medical providers to ensure effective communication with that companion, if he or she is an individual who is involved in the patient's care.

Remember that these tips are general guidance and will need to be adapted depending on the abilities and needs of your individual patient. Your goal should be to treat people with disabilities just as you would other patients while respecting any disability-related needs those patients may have.

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## Supporting materials

### Preparing to Communicate CARE

- About My Health**  
Developmental Disabilities Primary Care Program of Surrey Place, Ontario. <https://ddprimarycare.surreyplace.ca/tools-2/general-health/about-my-health/>
- Treat me Well: Top ten reasonable adjustments**  
Mencap, UK [www.mencap.org.uk/sites/default/files/2018-06/Treat%20me%20well%20top%2010%20reasonable%20adjustments.pdf](http://www.mencap.org.uk/sites/default/files/2018-06/Treat%20me%20well%20top%2010%20reasonable%20adjustments.pdf)
- Treat me Well: Giving your patients reasonable adjustments**  
Mencap, UK [video] [www.mencap.org.uk/get-involved/campaign-mencap/treat-me-well/treat-me-well-campaign-resources](http://www.mencap.org.uk/get-involved/campaign-mencap/treat-me-well/treat-me-well-campaign-resources)

### Communicating clearly

- Curriculum of Caring**  
McMaster University, Ontario [machealth.ca/programs/curriculum\\_of\\_caring/](http://machealth.ca/programs/curriculum_of_caring/)
- Communicate CARE**  
Curriculum of Caring, McMaster University [video] [machealth.ca/programs/curriculum\\_of\\_caring/m/mediagallery/1864](http://machealth.ca/programs/curriculum_of_caring/m/mediagallery/1864)
- Books Beyond Words**  
Beyond Words, UK [picture books] [booksbeyondwords.co.uk/](http://booksbeyondwords.co.uk/)
- EasyHealth**  
Generate Opportunities, UK [videos and easy read leaflets] [www.easyhealth.org.uk](http://www.easyhealth.org.uk)

### Responsively addressing concerns

- Keys to success when examining people with developmental disabilities, Curriculum of Caring**  
McMaster University [video] [machealth.ca/programs/curriculum\\_of\\_caring/m/mediagallery/2204](http://machealth.ca/programs/curriculum_of_caring/m/mediagallery/2204)
- Best Practice Series**  
Health Care Access Research and Developmental Disabilities (H-CARDD) Centre for Addiction and Mental Health, Toronto [videos] [www.camh.ca/en/professionals/professionals--projects/hcardd/knowledge-exchange/videos/best-practices-series](http://www.camh.ca/en/professionals/professionals--projects/hcardd/knowledge-exchange/videos/best-practices-series)

### Engaging patient and family member/support person in the health care visit

- Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities**  
Health Care for Adults with Intellectual and Developmental Disabilities [iddtoolkit.vkcsites.org/decision-making/](http://iddtoolkit.vkcsites.org/decision-making/)
- My Health Care Visit: Understanding Today's Visit and Follow-up**  
Health Care for Adults with Intellectual and Developmental Disabilities [iddtoolkit.vkcsites.org/my-health-care-visit/](http://iddtoolkit.vkcsites.org/my-health-care-visit/)

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