

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 ^[i]

- ▶ 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 ^[i, ii]

- ▶ 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 ^[iv,v]

Communicate Clearly ^[iv,v]



- ▶ Use verbal and nonverbal communication aligned with the patient profile and needs (eg, use gestures, writing, drawing and pictures ^[vi,vii,viii])
- ▶ 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 ^[ix,x]



- ▶ 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 ^[xi,xii]



- ▶ 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/
- v. **Communicate CARE**
Curriculum of Caring, McMaster University [video] 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
- 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.

References

- Bach M, Kerzner L. *A new paradigm for protecting autonomy and the right to legal capacity*. Commissioned paper. Ontario, Canada: Law Commission of Ontario; 2010.
- Boyd, K. *Communicate CARE when you interview*. In: *Curriculum of caring: A curriculum of caring for people with developmental disabilities* Hamilton, ON Canada: McMaster University. 2015.
- Burns M, Baylor C, Yorkston K. Words of preparation for patients. *The ASHA Leader*. 2016;21(3):52-6.
- Casson I, Broda T, Durbin J, Gonzales A, Green L, Grier E, et al. Health checks for adults with intellectual and developmental disabilities in a family practice. *Can Fam Physician*. 2018;64(Suppl 2):44-50.
- Griffiths C, Smith M. Attuning: A communication process between people with severe and profound intellectual disability and their interaction partners. *Journal of Applied Research in Intellectual Disabilities*. 2016;29(2):124-38.
- Kelly M. Communicating effectively with people with developmental disabilities. 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. 18-20.
- McNeil K, Gemmill M, Abells D, Sacks S, Broda T, Morris C, et al. Circles of care for people with intellectual and developmental disabilities: communication, collaboration, and coordination. *Can Fam Physician*. 2018;64(Suppl 2):51-6.
- Sullivan WF, Diepstra H, Heng J, Ally S, Bradley E, Casson I, et al. Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Can Fam Physician*. 2018;64(4):254-79.
- Sullivan B, Heng H. Supporting adults with intellectual and developmental disabilities to participate in health care decision making. *Can Fam Physician*. 2018;64(Suppl 2):32-6.
- Wullink M, Veldhuijzen W, Lantman-de Valk HM, Metsemakers JF, Dinant GJ. Doctor-patient communication with people with intellectual disability: a qualitative study. *BMC Fam Pract*. 2009;10:82.
- Yorkston K, Baylor C, Burns M. Simulating patient communication strategies. *The ASHA Leader*. 2016;21(3):46-51.

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 Program (DDPCP) of Surrey Place and *Canadian Family Physician*, volume 64(4): April 2018, p254-279. This document is an updated version of *Communicating Effectively with people with developmental disabilities*. 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. 18-20. This tool is adapted with permission from *Communicate CARE*. In: *Curriculum of caring: A curriculum of caring for people with developmental disabilities* Hamilton, ON Canada: McMaster University, 2015.

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.

Karen McNeil, MD CCFP FCFP, Department of Family Medicine, Dalhousie University and Dr. Kerry Boyd, MD FRCPC, Department of Psychiatry and Behavioural Neurosciences, McMaster University. The content development was subject to review by primary care providers and other relevant stakeholders.

All rights reserved. The content of this tool may not be reproduced or stored in a retrieval system in any form or by any means without the prior written permission of the copyright owner, Surrey Place. Permission to use, copy, and distribute the tool is granted with proper citation as outlined below. Contact ddpcp@surreyplace.ca for permission to adapt this tool to your local practice setting.

This tool is developed as a guide only. While great effort has been taken to assure the accuracy of the information provided, Surrey Place, the Developmental Disabilities Primary Care Program, the reviewers, printer and others contributing to the preparation of this document cannot accept liability for errors, omissions or any consequences arising from the use of the information. Primary care providers and other healthcare professionals are required to exercise their own clinical judgement in using this tool.

PLEASE USE THIS CITATION WHEN REFERENCING THIS TOOL: Communicate CARE: Guidance for person-centred care of adults with intellectual and developmental disabilities. McNeil, K., Bell, E., Boyd, K., Heng, J., Sullivan, W.F., Vogt, J., Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019. Care Program of Surrey Place, Toronto, 2019.