



## Recommendations for Person-Centered Care of Patients with Intellectual or Developmental Disabilities (ID/D)

*Involve the patient as much as possible!*

|  | <b>Tips:</b>   | <b>Examples:</b>   |
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| <b>When First Meeting the Patient:</b>   | <p>Introduce yourself to the patient first.</p> <p>If a support person is present, ask the patient, “<i>Who is with you today?</i>”</p> <p>Ask the patient, “<i>Would you like (caregiver) to stay here with you during the visit?</i>”</p>  | <ul style="list-style-type: none"> <li>• Do not assume support person present is part of patients care team.</li> <li>• Clarify role of support person: caregiver, family member, guardian, staff from group home etc.</li> <li>• Oftentimes, the caregiver is a wonderful resource and <u>knows the patient better than anyone</u>. Caregivers can explain/provide collateral history, share information about pain level and history, routine at home, baseline behavior and note any changes. It is important to listen and act when a trusted caregiver is adamant or concerned about a change from baseline.</li> <li>• A support person may be present instead. This is a paid staff member who often does not know the patient well and is not helpful as a patient advocate.</li> </ul>  |
| <b>Use verbal and non-verbal communication strategies to meet the patients’ needs.</b> | <p>Slow down, allow time for processing (up to 10 seconds).</p> <p>Use short, simple, plain language.</p> <p>Repeat and rephrase as needed.</p> <p>Avoid abstract language or concepts (“Is your throat on fire?”).</p> <p>Use meaningful gestures.</p> <p>Assume better receptive than expressive language.</p> | <ul style="list-style-type: none"> <li>• Use phrases like “<i>Please show me....</i>” Or “<i>tell me...</i>”</li> <li>• In general, there is value in asking open ended questions, but in certain patients with communication disabilities, closed ended questions are preferred. <ul style="list-style-type: none"> <li>○ Better to ask <i>Yes/No questions or rate pain as a little or a lot</i>, than to ask patient to rate pain on a scale of 1 to 10.</li> <li>○ Ask specific questions (“<i>What did you eat for breakfast?</i>” Instead of asking “<i>What did you last eat?</i>”)</li> </ul> </li> <li>• When you ask patient if their stomach hurts, point to your stomach or their stomach.</li> <li>• Patients likely understand what you are saying but may have difficulty communicating their understanding with you.</li> <li>• Provide the patient with extra time to talk. Ask them if they have anything else to say. Do not interrupt, even if the patient is struggling to talk, give them time.</li> </ul> |



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|                             | <p>If they have a communication board or device with them, use this!</p>   |  |
| <p><b>Physical Exam</b></p> | <p>Explain using words, actions, or pictures what you are going to do before you do it.</p> <p>Let the patient hold/explore your equipment before you use it.</p> <p>Ask the patient, “Is it ok if I listen to your heart?”</p> <p>Go slow and check in during exam (“Are you okay?”)</p> <p>Pain assessment</p> <p>Leave sensitive areas of the examination until last (e.g. ears, GU region)</p> <p>Ideally, should complete a very thorough physical exam, especially if you are investigating to find a cause of pain/behavior change.</p> <p>It is ok to prioritize or defer examinations and investigations.</p> | <ul style="list-style-type: none"> <li>• If they say no, then NO means NO             <ul style="list-style-type: none"> <li>○ Oftentimes the patients’ wishes have been ignored in the health care setting (ex: blood draws or immunizations where they may have been forcibly held down). If you listen to their response of “no” and ask again later, they are often more agreeable.</li> </ul> </li> <br/> <li>• It may be helpful to touch the physical location when you are asking about the source of pain.             <ul style="list-style-type: none"> <li>○ Ex: “Does your knee hurt?” Can be accompanied by touching their knee.</li> </ul> </li> <li>• Observe facial expressions to gauge level of pain.             <ul style="list-style-type: none"> <li>○ Ex: Patient may not state they have belly pain, but you might notice wincing on abdominal exam.</li> </ul> </li> <li>• Sometimes interpreting facial expressions or body language might be difficult. In this case, engage caregivers to better understand patient experience.             <ul style="list-style-type: none"> <li>○ Ex: Patient with Down Syndrome who appeared comfortable to me, but mother noted that her toes were curled, which is a clear pain indicator for her.</li> </ul> </li> <li>• Examine feet with socks off. Condition of feet is an indicator of overall level of care.</li> <li>• Sometimes no physical exam can be done. Visit is for “rapport building.”</li> <li>• It is ok if vitals cannot be taken at the start of the visit, or at all. Re-assess throughout the visit.</li> </ul> |



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| <p><b>Assessment/Plan</b></p>      | <p>Engage the patient and others as indicated (caregiver) when discussing treatment options.</p> <p>Provide written after visit care instructions that are direct and simple.</p> <p>Dose medications as infrequently as possible (once per day is more manageable than three times per day).</p> <p>Summarize and check understanding.</p>   | <ul style="list-style-type: none"> <li>• Ex: Patient with Down Syndrome who had fungal infection of feet. Fungal infection occurred because when patient got out of the shower, he put his wet feet into socks, and directly into work boots. The ER and Dermatology both wrote in their Plan “Do not wear socks”. The patient has OCD, and wearing socks was not negotiable per both patient and caregiver.             <ul style="list-style-type: none"> <li>○ Plan: We made a compromise – dry feet well after shower with the help of caregiver, ok to continue wearing socks but do NOT wear work boots, wear clogs instead for better air flow.</li> </ul> </li> <li>• Dermatology also made the recommendation to soak feet in vinegar twice per day. Caregivers at group home were not following this recommendation. Learned that the barriers to implementation were 1) the instructions for mixing water and vinegar were confusing to the care team, and 2) the patient did not want to participate in soaks.             <ul style="list-style-type: none"> <li>○ Plan: Showed patient and caregiver in office how to mix water and vinegar. Patient then soaked feet in office and was happy to be sent home with a “gift” of basin that he could use to soak his feet in at home.</li> </ul> </li> </ul> |
| <p><b>Other considerations</b></p> | <p>If any concern for abuse during the visit, should screen for abuse with the patient alone.</p> <p>Modify possible stressors.</p> <p>Remember, it is ok if you make a mistake in your communication strategy. It is most important to recognize if you might have inadvertently hurt a patient/caregiver’s feelings, address the issue,</p> | <p>Screen by asking straightforward questions such as: “Are you afraid?”, “Has anyone hurt you?” “Is anyone mean to you?”, “Has anything terrible happened to you?”</p> <ul style="list-style-type: none"> <li>• Consider not wearing a white coat.</li> <li>• Can be helpful for those with sensory challenges if clinic can offer light covers, weighed blankets, noise-cancelling headphones, avoid crowded waiting room.</li> </ul>  |



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|  | apologize, and learn for next time 😊 |  |
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### Other Helpful Resources

**Describes CARE Communication Strategy:** <https://ddprimarycare.surreyplace.ca/tools-2/general-health/communicating-effectively/>

**Shares examples of different levels of IDD based on IQ scores, and offers suggested communication tips:**  
<https://ddprimarycare.surreyplace.ca/tools-2/general-health/adaptive-functioning/>

**Pictures with easy-to-understand explanations of common health conditions to share with patients with IDD** <https://www.easyhealth.org.uk/pages/common-health-conditions>

### **CARE TIPS FROM CAREGIVERS OF PATIENTS WITH IDD**

#### **DO:**

- Ask direct, simple questions (ex. Yes or No questions)
- Ask to rate pain as a “*little*” or “*a lot.*”
- Touch the location when are you asking the source of pain (ex. “*Does your knee hurt*” should be accompanied by touching their knee)
- Observe the patient’s facial expression to understand the level of pain in physical examinations.
- Ask specific questions (ex. Instead of “*what did you last eat?*” ask “*what did you eat for breakfast?*”)
- Complete a thorough physical examination regardless of caregiver information as patients may not always share all complaints with caregivers.
- Provide direct, simple instructions for medications.
- Reduce frequency of medication intake per day, if possible (ex. Once a day medication is more manageable than three times a day)
- Provide visual demonstrations of procedures beforehand if possible (ex. Demonstrate steps of bloodwork before taking blood) so the patient can understand what is happening.



- Use plain language to thoroughly describe steps of treatment during procedures and alert of anticipated pain (ex. Before a needle prick, let them know “*there will be a little pain, look away*”)
- Utilize images or icons to explain medical information.
- Have comic books or picture books of varying literary levels in the waiting room.
- Trust the caregiver as a resource to understanding patient concerns – they are most familiar with what happened and how the patient communicates.

**DON'T:**

- Ask to rate pain on a scale of 1 to 10 as numerical evaluation can be difficult for some patients.
- Ask patients to fill out forms without offering assistance, as some patients may not be able to answer questions on their own.
- Disseminate pamphlets or information with complex language.