Building Trust and Engaging People With Disability in Their Own Care

PERSON-CENTERED

RESPECT

PARTNERSHIP

RAPPORT

Partnering for Better Chronic Pain Management and Safer Opioid Use: A Knowledge Hub for People With Disability and Their Providers

Introduction | These resources offer information on applying person-centered communication techniques to engage people with disability and chronic pain in their own care. Research shows that person-centered communication that includes shared decision making can improve a person's satisfaction with care,[1] understanding, recall, and follow-through with the treatment plan and outcomes.[2,3]

In the *Knowledge Hub* resources, *disability* refers to when a person's chronic pain and health condition reaches a level that substantially limits one or more of their activities of daily living, such as eating, bathing, and dressing.

General Tips for Communicating With People About Their Chronic Pain

The following tips suggest approaches to building trustful and therapeutic relationships in which people feel engaged as partners in managing their chronic pain. The tips are based on qualitative research with people with chronic pain and communication practices that have proved over time to be effective. People with chronic pain and disability respond well when clinicians treat them as whole persons, taking an interest in their life situation and acknowledging their experience living with chronic pain as well as their disability.[4,5]

TIP 1 Explain the trial-and-error nature of chronic pain management.

Setting the Tone and Expectations

- **Speak directly to the person and acknowledge their experiences living with chronic pain and disability** to set a respectful tone and encourage information sharing.

- **If a family member or friend is present, acknowledge them and clarify their role as a support person.** A support partner may be a helpful source of additional information.[6] They can help remember and reinforce information you share.

- **Explain that a combination of biopsychosocial approaches is needed to manage pain.** Biopsychosocial approaches may include positive thought patterns, mindfulness, relaxation techniques, seeking out social support, self-pacing, low-impact physical activity, and strengthening and flexibility exercises. Some people may benefit from the help of an occupational therapist, physical therapist, counselor, and massage therapist to learn new behaviors and thought patterns for better managing pain. Finding the right combination of self-management and medical approaches to manage chronic pain requires trial and error. As circumstances change, the approaches may need to be adjusted. See the *Knowledge Hub* resources Methods for Managing Chronic Pain Other Than Medication and Developing a Plan for Self-Management of Pain for different approaches you can share with the person.

Discussing Treatment Options

- **Align treatment options with the person's values and goals**, considering what has and has not worked in the past. Share the *Knowledge Hub* resource Communicating With Your Provider to Manage Chronic Pain to help the person have this conversation with you.

- **Use plain language** to describe the potential for treatment efficacy for each approach and the risks and benefits most relevant to each person. Use the teach-back technique to make sure critical information is understood. In this approach, you ask the person to use their own words to explain back to you what you discussed.

- **Offer resources** to strengthen pain-coping and self-management skills, while considering factors that contribute to pain, such as deconditioning, stress, and lack of sleep. See these *Knowledge Hub* resources for tips on how people can manage chronic pain on their own:

  - Moving From a Cycle of Pain to a Cycle of Wellness

  - Developing a Plan for Self-Management of Pain

TIP 2

Engage the person as a partner in their treatment.

- **Empower** the person with information on their condition, treatment, and self-management options. Ask the person how much detail they would like to know about their options.

- **Elicit** the person's treatment goals, concerns, and the values that will guide their treatment preferences.

- **Set realistic expectations** about how much pain can be controlled.

- **Assure the person of your commitment** to continue working with them to achieve a tolerable pain level and reach their functional goals.

The research on patient–provider interactions shows that provider and patient treatment preferences may not align. Physicians placed greater focus on diagnosis and treatment, while people with chronic pain were more concerned with quality of life and having their pain concerns legitimized.

Source: Frantsve, L. M., & Kerns, R. D. (2007). Patient–provider interactions in the management of chronic pain: Current findings within the context of shared medical decision making. *Pain Medicine, 9*(1), 25–36.

TIP 3 — Approach the person with compassion, respect, and empathy.[7]

- **Listen and look for** a person's positive and negative emotional expressions. Clues to emotions may be subtle and can be detected by observing tone of voice, posture, eye contact, and other forms of nonverbal expression.

- **Acknowledge verbal and nonverbal communication** and ask probing questions to understand the meaning behind what is felt.

- **Ensure that the person feels heard and understood** before redirecting the discussion topic to diagnosis and problem solving. One way to do this is to summarize and validate what you heard from the person.

Addressing emotions will build rapport and understanding.

1. Look for and recognize emotional expression.
2. Acknowledge what is seen or heard ("You sound..." "You look...").
3. Explore the emotion with the person. ("Tell me more." "How are you feeling about this?")
4. Summarize and validate your understanding of their feelings, priorities, and concerns.

TIP 4 — Use person-first, destigmatizing language.

- Avoid language that refers to the person as a victim or a hero. Even though disability may affect the person's life and function, it does not define the person.

- Use person-first language, as shown below.

Avoid Saying

"Disabled person"

"Addict"

"Drug or drug abuser"

"Arthritis patient"

"Suffers from arthritis"

Instead Say

"Person with a disability"

"Person with opioid use disorder or someone experiencing a drug problem"

"Person with substance use disorder"

"Person with arthritis"

Resources on Disability Bias Assessment and Disability Etiquette

Harvard Implicit Association Test. The tests on this web page can be used to educate the public about hidden biases.

Disability Etiquette: Tips on Interacting With People With Disabilities (United Spinal Association). This 33-page booklet provides basic tips on how to interact with people with different types of disabilities.

For more information visit: Partnering for Better Chronic Pain Management and Safer Opioid Use: A Knowledge Hub for People With Disability and Their Providers | KnowledgeHub.air.org

Endnotes

1 Tallman, K. Janisse, T., Frankel, R. M., Hee Sung, S., Krupat E., & Hsu J. (2007). Communication practices of physicians with high patient satisfaction ratings. *The Permanente Journal, 11*(1), 19–29 Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3061374/

2 King, A., & Hoppe, R. B. (2013). "Best practice" for patient-centered communication: A narrative review. *Journal of Graduate Medical Education, 5*(3), 385–93. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3771166/

3 Howe, L. C., Leibowitz, K. A., & Crum, A. J. (2019). When your doctor "gets it" and "gets you": The critical role of competence and warmth in the patient–provider interaction. *Frontiers in Psychiatry, 10,* 475. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6619399/

4 We purposefully use the term *person* or *people.* The word *patient* is derived from the Latin word "patior," which means "I suffer or endure." People with disability want others to understand that disability is not an illness but, rather, a situational mismatch between the person and the environment. The word *patient,* a passive term, is incongruent with people taking an active role in their healthcare and taking responsibility for managing their pain.

5 Lavelle, M., Lucado, J., Lin, A., & Paez, K., (2019). *What I want my doctor to know about how arthritis and chronic pain affect my everyday life.* Issue Brief. Crystal City, VA: American Institutes for Research. Retrieved from https://www.air.org/sites/default/files/NIDILRR-Opioid-Issue-Brief-June-2019-508-rev.pdf

6 Omole, F. S., Sow, C. M., Fresh, E., Babalola, D., & Strothers, H. (2011). Interacting with patients' family members during the office visit. *American Family Physician, 84*(7), 780–784. Retrieved from https://www.aafp.org/afp/2011/1001/p780.html

7 Suchman, A. L., Markakis, K., Beckman, H. B., & Frankel, R. (1997). A model of empathetic communication in the medical interview. *JAMA, 277*(8), 678–82.

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