



Office of Developmental Primary Care

Improving health outcomes for people with developmental disabilities

Communicating Positive Messages to People with Terminal Illness

Patients with communication and intellectual disabilities often have unique ways of understanding and communicating information, making medical decisions, and expressing specific wants and needs. Everybody communicates. Work with your patient and their supporters to identify the most effective communication methods. Some people have strong receptive language skills. They understand language in a preferred format, but have greater challenges with the expression of this language. It may be helpful to present information in a plain language format. Show pictures, offer written explanations, take patients to see equipment or demonstrate what will happen by modeling the steps of a procedure before it is done.

The words used by health care professionals have power. They have the potential to inform medical decisions and shape how people with disabilities perceive their lives and conditions.

Below are examples of messages people with disabilities may hear when physicians use certain words and phrases to describe their lives, mobility devices and medical equipment, or their current medical conditions. Each example is followed by a positive suggestion.

Burden - Significant disabilities will cause their friends and loved ones great physical and emotional stress. They will be a drain on their families and society. These thoughts lead to internalized guilt from external messages.

Instead: Help them to recognize their value and help caregivers find the support they need.

Bound/Confined/Dependent - Medical and mobility equipment will seriously lower or limit the quality of their life; they will be imprisoned by this equipment.

Instead: Assess the patient's need for new or additional services and supports, then make appropriate referrals. Nobody is bed or home bound if they have the right accommodations, funding, equipment, housing, transportation, and personal assistance in place. Tell patients how people can adapt to living well with this equipment. Offer role models, support groups, or information written by people who are living successfully.

Training wheels/Scooters/Other nicknames for pieces of medical and mobility equipment - These names, whether intentional or not, convey a lack of respect for the crucial role this equipment plays in patients' lives. People with disabilities have probably heard every joking reference from needing a license to getting a speeding ticket.

Instead: Use the proper names and terminology for this equipment. Ask for their input and include them in the process of selecting equipment and devices that will allow the patients to stay engaged with their corner of the world for as long as possible.

Severely disabled/High or low functioning/Complicated patient - Some people with disabilities think of these labels as value judgments about the quality of their lives.

Instead: Focus on our medical and support needs. Recognize strengths as well as challenges.

Spastic/Uncontrolled - Certain medical terms may have different connotations for some people in the disability community. They can be associated with negative judgments about how some bodies move or minds work. Some disabled people have heard these judgments throughout their lives. Clinicians may wish to discuss these different meanings with their patients.

Instead: Explain that you are using the medical definition of these terms.

At no time is the use of language more important than when someone is facing end of life care. This is a particularly meaningful and important time for most people. Even if they have lost function, people deserve high levels of acknowledgement, respect, and autonomy over their bodies. Consider the contrast of the words below:

Suffer/Hopeless/Tragic/ Robbing/Devastating/Horrible - These are scary, depressing words that no one should hear in reference to their life.

Instead: Focus on the things that will help a patient live a meaningful life right now. The end of life does not need to be framed as tragic. Sometimes, this period can represent a time of personal growth and discovery. Consider what the patient wants to accomplish in the time they have left. Do they have big or small personal goals, people and activities they love, or stories to pass onto their family and friends? How can the medical community best support these patients and their caregivers as they move through the final stages of life? Does the person have access to medication, technology, transportation, therapy, support at home, palliative medicine, social connections, emotional support, and quality hospice care?

In most cases, people with disabilities are competent to make most of their medical decisions with the right support. Everyone has the right to control what happens to their bodies to the greatest extent possible. When appropriate, patients should be encouraged to ask a trusted supporter (i.e. a caregiver, family member, spouse, aide, or friend) for help weighing their options. Whenever possible, follow and honor the decisions made by the person with the disability.

Remember to:

- Speak directly to patients.
- Include patients in care conversations.
- Listen to the perspective of the individual patient without judgment.
- Believe what patients say about their bodies.
- Avoid directing any health-related questions, prognoses, and treatment plans solely to caregivers.
- Ask for consent to speak with caregivers and/or other parties.
- Balance the input of caregivers with the input of the patient. Caregivers are active, front-line participants in the medical and everyday care of people with disabilities.
- Encourage the use of supported decision-making practices. Respect patients' decisions.