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ROLE IN

CRITICAL

DECISIONS

Why physicians should talk with patients about end-of-life care

Neuromuscular diseases, by nature, are long-term battles that don't always have what patients call a "cure." Because of that reality, Jeffrey Rosenfeld, MD, PhD, Professor of Neurology at Loma Linda University Health, says it's common for patients to stray from follow-up care because they feel discouraged or don't understand its purpose.

Dr. Mehta typically begins the discussion with a patient (and, ideally, their care partner) by asking about how the disease is affecting their quality of life, how they define a meaningful quality of life, their goals and values, and worries they have about the future.

As the discussion evolves, together they may explore ways the patient can retain control of the care they receive, especially if they are unable to speak for themselves. Dr. Mehta notes that a physician guiding the discussion can help the patient explore any personal fears, such as suffocation, and educate them about their treatment options in various situations.

Essential documents

Patients should document the decisions they make in these conversations in an advance healthcare directive, living will, and/or power of attorney for healthcare. While the forms can differ from state to state, these legal documents cover:

- How the patient wants to be treated (or not), including code status (cardiac and pulmonary resuscitation)
- Acceptable and unwanted treatment options in situations involving invasive treatments, such as tracheostomies or feeding tubes
- Who will serve as the patient's healthcare power of attorney (agent/proxy) if they cannot communicate their wishes
- Any religious/spiritual and after-death preferences, such as organ donation

Providers and patients can learn more about advance healthcare directives and other essential documents in the Quest article "[Make Your Wishes Known](#)."

Once the patient has signed their documents, they should keep them somewhere easily accessible and make sure their care team, healthcare agent, and family know where to find it. The document should be reviewed annually and whenever there is a significant change in the patient's health.

Designating a decisionmaker

Identifying a healthcare agent or proxy to make decisions on the patient's behalf is an important, and sometimes overlooked, part of the advance healthcare directive. Unforeseen events can result in situations that do not fall within the document's purview. Ideally, the healthcare agent has been present at end-of-life discussions between the patient and physician and is familiar with the responsibilities they may be asked to fulfill, as well as the patient's likely choices.

If a patient is reluctant to document their wishes, they should be informed of local laws determining who would make treatment and end-of-life decisions for them. It may not be the relative they would prefer.

If a personal relationship, difference in values, or other concern leads a physician to feel they are the wrong person to discuss end-of-life decisions with a particular patient, they should consult with the social worker on their Care Center team to determine the best professional to provide this service to the patient. Social workers also can help physicians find advance healthcare directives and end-of-life planning resources to share with patients.

Resources

Ask your institution if they have advance healthcare directives on file. Here are more resources to learn about these important documents and help patients with end-of-life planning.

[Advance Care Planning: Health Care Directives](#) is an informative website by the National Institutes of Health.

[Five Wishes](#) provides easy-to-understand materials to help people consider and communicate how they wish to be cared for at the end of their life. They have special booklets written to help children, adolescents, and their families document their wishes.

[National POLST](#) provides information about advance care planning and medical order forms in different states.