Discontinuing medically administered nutrition

Support patient's values, beliefs, and goals.

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Mr. Rodrigues, who is 70 years old, has a 9-month history of bilateral leg fatigue and muscle cramps, and he recently began dropping things. After a thorough history, physical examination, diagnostic laboratory tests, and differential diagnosis, his provider refers him to a neurology clinic where he's diagnosed with amyotrophic lateral sclerosis (ALS).*

Mr. Rodrigues develops dysphagia and eventually can't feed himself because of progressive arm weakness. A speech-language pathologist and a nutritionist recommend nutrition supplementation, food in liquid consistencies, and swallowing techniques, but he continues to lose weight.

A meeting with the neurologist, the advanced practice registered nurse (APRN), Mr. Rodrigues, his wife, and their two adult children focuses on ensuring the family understands the ALS diagnosis and subsequent anorexia and weight loss. The APRN asks Mr. Rodrigues about his values, preferences, and meaning of life. He discusses his love of the outdoors, work, and holding and playing with his grandchildren. He hopes for improved function and decreased hunger. He worries about dependency, being a burden, and death. The APRN identifies independence as central to Mr. Rodrigues' quality of life.

The family describes the conflict, including angry outbursts, associated with trying to encourage Mr. Rodrigues to eat. A picture emerges that food and nutrition are important symbols of love, health, and social connection within the family. The APRN acknowledges everyone's emotions and encourages Mr. Rodrigues and his family to consider one another's perspective. The healthcare team describes medically administered nutrition and hydration (MANH), including its benefits and burdens. Based on the patient's goal of improved function, the team recommends a 2-month MANH trial to decrease conflict over food. The APRN documents this plan for short-term, temporary use of non-oral nutrition in an advance directive and refers Mr. Rodrigues and his family to a social worker for additional emotional support.

Many people living with chronic illnesses (cancer, advanced heart disease, neurocognitive disorders, or neurologic disease) experience swallowing difficulties. This may lead to malnutrition and myriad subsequent symptoms, including fatigue, dehydration, xerostomia, headache, delirium, nausea, vomiting, abdominal cramps, hunger, thirst, and lack of

energy. To address this issue, providers may prescribe MANH via I.V. line, a nasogastric tube, gastrostomy tube (G-tube), or jejunostomy tube. MANH can extend a patient's life and improve its quality. However, in patients with advanced illness, MANH may simultaneously sustain life and negatively affect its quality. In those instances, discontinuation may align with a patient's care goals. The nurse's role includes respecting and advocating for the patient's choices. (See *Benefits and burdens*.)

Ethics of MANH

Patients, families, and healthcare teams may find initiating or discontinuing MANH ethically challenging. MANH should be based on patient autonomy, informed decision-making, the diagnosis, and plan of care. Other considerations include the patient's culture, ethnicity, religion, values, preferences, and beliefs. For example, some religious faiths may view discontinuing nutrition and hydration as hastening death.

According to the American Nurses Association *Code of Ethics for Nurses with Interpretive Statements*, nurses should advocate for the patient and their preferences using the nursing process—assessment, diagnosis, planning, implementation, and evaluation. Start by assessing the patient's understanding of MANH, then identify knowledge gaps and provide education. Next, ask the patient about their care preferences, including their values and beliefs. With this information, you can determine whether MANH aligns with the patient's care preferences rather than your own values and beliefs.

From a scientific, ethical, and legal perspective, no difference exists between foregoing and discontinuing MANH. Several sources (including Schwartz and colleagues, Coyle and colleagues, and Berlinger and colleagues) describe four ethical principles—autonomy, beneficence, nonmaleficence, and justice—that should be equally applied in either situation.

To support patient *autonomy*, respect the patient's right to initiate or refuse MANH according to their beliefs, values, and life plan. Promote *beneficence* using best practices for managing conditions and symptoms. Offering MANH is seen as best practice because it may decrease delirium, provide nutrition, and promote improved quality of life. Promoting care also means avoiding distressing symptoms, which includes discontinuing MANH if the burdens outweigh the benefits. If MANH is discontinued, support the patient with ongoing care (hand-feeding, oral care, and symptom management).

Demonstrate *nonmaleficence* by protecting the patient from harm and avoiding care that causes suffering. In other words, you're under no obligation to offer MANH. Advance *justice* by ensuring MANH is equitably withheld or discontinued for all patients, if they so desire, regardless of socioeconomic status, ethnicity, race, or culture.

Initiating and discontinuing MANH

Initially, Mr. Rodrigues' overall quality of life is fair and MANH manages his nutritional needs associated with ALS-related dysphagia. Despite

Benefits and burdens

Although little research related to medically administered nutrition and hydration (MANH) exists, potential benefits and burdens have been identified. Benefits include improved sensorium for individuals with altered electrolytes, increased energy, and improved mood. Burdens include continued aspiration for those with dysphagia, diarrhea associated with the nutritional formula, sepsis and bleeding from catheter or tube insertions, and edema from fluid overload. Several sources, including Druml and colleagues, Baumstarck and colleagues, and Cardenas, state that MANH isn't beneficial in some cancers and dementia. Depending on the individual situation, MANH may offer benefits or present burdens.

Potential benefits	Potential burdens
Basic human right that connotes care.	Common medical alternative to oral intake.
Essential in some cultures and religions.	Required within some cultures and religions.
Offers hope and expectation of healing.	Creates unrealistic expectations.
Increases survival with effects on quality of life.	Decreases quality of life with little effect on function.
Honors patient and family wishes.	Disregards patient and family wishes.
Increases social interaction at mealtimes.	Decreases social interaction at mealtimes.
Offers a bridge to reversible conditions (obstruction, malnutrition, HIV wasting syndromes).	Reduces quality of life for nonreversible conditions.
Increases energy and reduces fatigue.	Increases infection, diarrhea, and pressure injuries.
Promotes alternative to oral feedings.	Does not prevent or reduce aspiration.
Decreases hunger and thirst.	Increases thirst.
As a time-limited intervention, offers time for closure.	As a time-limited intervention, increases care needs and time in a healthcare setting.

Position statements and guidelines

Several organizations have issued statements related to foregoing or discontinuing medically administered nutrition and hydration.

- **Academy of Nutrition and Dietetics:** Ethical Decisions for Withholding/Withdrawing Medically Assisted Nutrition and Hydration. bit.ly/3vb6P6C
- **American Academy of Hospice and Palliative Medicine:** Statement on Artificial Nutrition and Hydration Near End of Life. bit.ly/3Jx64cX
- **American Academy of Pediatrics:** Guidance of Forgoing Life-Sustaining Medical Treatment. bit.ly/37Dnrvx
- **American Medical Association:** Withholding or Withdrawing Life-Sustaining Treatment. bit.ly/3rjj8g0
- **American Medical Association Code of Medical Ethics:** Opinions on Care at the End of Life. bit.ly/3JyyZgW
- **American Nurses Association:** Nutrition and Hydration at the End of Life. bit.ly/3veAP1g
- **American Society for Parenteral and Enteral Nutrition:** Ethical aspects of artificially administered nutrition and hydration: An ASPEN position paper. bit.ly/3xkIK0Q
- **European Society for Parenteral and Enteral Nutrition:** ESPEN guideline on ethical aspects of artificial nutrition and hydration. bit.ly/3uyFBrn
- **Hastings Center:** The Hastings Center guidelines for decisions on life-sustaining treatment and care near the end of life. bit.ly/3xCfFgD
- **Hospice & Palliative Nurses Association:** Position statement: Withholding and/or withdrawing life-sustaining therapies, 2016. bit.ly/3jvns7x
- **National Hospice and Palliative Care Organization:** Commentary and position statement on artificial nutrition and hydration. bit.ly/3LPg2rU

hunger, he has the energy to participate in activities he enjoys. Unfortunately, G-tube insertion-site infection and enteral formula-related diarrhea require that Mr. Rodrigues be hospitalized twice. He laments the time spent in the hospital and recognizes that the ALS weakness isn't reversed with MANH. Mr. Rodrigues decides to stop MANH, but his family disagrees. Everyone agrees to meet with a chaplain to explore the religious connotations of discontinuing MANH.

At a goals-of-care meeting, Mr. Rodrigues describes feeling like a burden despite his children's assurances otherwise. Citing his value of independence, Mr. Rodrigues decides to focus on comfort. He says, "This feeding tube is prolonging a quality of life I find intolerable." Mr. Rodrigues and his family are appropriately emotional and receive support from team members. The patient's wishes for comfort and no further medically administered nutrition is documented in the electronic health record and in a new order for life-sustaining treatment form. Mr. Rodrigues' provider refers him to home hospice.

Initiating and discontinuing MANH should be viewed through a patient- and family-centered lens that ensures informed decision-making and reflects cultural, religious, and ethnic considerations in the context of values, preferences, and beliefs. In some situations, the patient and healthcare team may initiate a time-limited MANH trial, with agreement about indicators to evaluate success. According to Schwartz and colleagues and the American Academy of Hospice and Palliative Medicine, positive indicators may include increased energy, decreased fatigue, decreased malaise, and increased function. Negative indicators include infection, diarrhea, increased time in clinical settings, and increased burden for caregivers. Russo and colleagues suggest asking these questions:

- How does the patient define quality of life and the role of MANH in that definition?
- What are the goals of care and what role does MANH play in those goals?
- What are the benefits and burdens of MANH?
- What are the outcomes of continued MANH?

Many professional organizations support foregoing or discontinuing MANH. The Academy of Nutrition and Dietetics maintains that individuals have the right to request or decline nutrition and hydration as medical treatment. They state that when nutrition and hydration are no longer beneficial or when the burdens outweigh the benefits, it's ethically appropriate to withhold or withdraw it. The American Society for Parenteral and Enteral Nutrition states that discontinuing MANH should align with ethical principles and legal requirements. (See *Position statements and guidelines*.)

The American Nurses Association recommends that nurses honor, support, and accept patients or their surrogate decision makers "in decision-making about accepting or refusing clinically appropriate nutrition and hydration at the end of life." Within the process, nurses provide "accurate, precise and understandable information about risks, benefits and alternatives." (See *MANH discontinuation process*.)

Collaborative compassion

Two days after being admitted to hospice, the

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MANH discontinuation process

Patients and families consider discontinuing medically administered nutrition and hydration (MANH) a significant decision. To honor and respect MANH as a life-sustaining therapy, consider taking the following approach.

Discontinuation education

- Explain to the patient and family what they can expect after MANH discontinuation, including prognosis. According to the literature, a person may continue to live without food or fluids for days or weeks. This process typically culminates in a comfortable death.
- Use the Palliative Prognostic Index to evaluate functional status, oral intake, cognition, and other symptoms and offer a prognosis.
- Review signs and symptoms of the dying process and interventions to treat discomfort.
- Provide psychosocial support in decision-making, explaining that no right or wrong answer exists. Instead, the best choice is the one that matches patient and family goals, preferences, and definitions of quality of life.

Discontinuation preparation

- Review the procedure with the patient and family.
- Encourage the family to be present at the discontinuation as appropriate to their culture, religion, ethnicity, and beliefs.
- Encourage any rituals that might be important, such as blessings from spiritual leaders, prayers, or music.

Discontinuation steps

- At an agreed upon time, in the selected setting, and with the chosen family and friends in attendance, prepare the patient for the process of MANH discontinuation. Some patients and families may view the process as seriously as removing a ventilator. Inform them that discontinuation won't be painful and that initially the patient is unlikely to feel any different than before discontinuation.
- Allow time for any rituals or prayers.
- Disconnect, cap, or remove the appropriate catheter and discontinue fluids.

Comfort measures

- Provide teaspoons of soft foods, fluids, or ice chips.
- Offer mouth sponges with favorite liquids (tea or coffee, fruit juice, carbonated drinks, alcohol, cooled clear soups, ice cream, yogurt).
- Offer patient favorites such as fruit-flavored ice cubes or frozen treats.

Oral care

- Regularly clean the patient's teeth and gums using soft toothbrushes, face cloth corners, or finger brushes.
- Provide lip balm and substitute saliva every 2 to 3 hours.
- Monitor for thrush and sores. Use viscous lidocaine for any mouth sores or discomfort.
- To decrease excess saliva production, consider hyoscine drops.
- Avoid suctioning because it may cause more secretions, is uncomfortable, and may add to distress.

Skin care

- Provide skin care to catheter sites.
  - Change protective dressings daily.
  - Cleanse the catheter site daily with mild soap and water.
  - Apply protective ointments.
  - Check for redness, swelling, pain, or discharge.

Psychosocial and spiritual support

- Continue to support the patient and family throughout discontinuation and provide comfort care.
  - Support care that aligns with the patient's culture, religion, values, preferences, and quality of life.
  - Provide evidence-based education and information to promote informed decision making.
  - Dispel disinformation that may impede informed decision making.
  - Validate decision making that aligns with goals and values.
  - Help the patient and family understand the benefits and burdens of MANH.
  - Refer the patient and family to chaplaincy or community spiritual leaders for further support.

Sources: American Nurses Association, Druml et al, Hospice and Palliative Nurses Association

hospice nurse meets with Mr. Rodrigues and his family to plan for discontinuing MANH. The nurse provides education about what to expect and how to manage hunger, thirst, and dry mouth. On day three, Mr. Rodrigues' priest arrives and offers the Sacrament of the Sick. With his family in attendance, the hospice nurse disconnects and caps his G-tube. Mr. Rodrigues' children then provide careful hand-feeding, fluids using a mouth sponge, and mouth care. Mr. Rodrigues expresses gratitude, shares his love for his family, and asks for forgiveness. The family spends meaningful time reminiscing and engaging in a life review. Over time, Mr. Rodrigues becomes more somnolent and eventually dies peacefully with his family at his side. Though sad, his children take comfort and pride in honoring their father's wishes.

Decisions about MANH should be guided by patient autonomy, treatment beneficence, nonmaleficence, and justice. You can help ensure that patients and surrogate decision-makers have accurate information to make informed choices consistent with their culture, ethnicity, religion, beliefs, and values. Your collaboration with the patient and family advances compassionate care that focuses on comfort and quality of life. AN

Access references at myamericannurse.com/?p=325552.

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