Dear Editor:

We have been challenged with how to best meet the needs of patients and families wishing to withdraw life sustaining treatment (e.g., ventilator, pressor support, or circulatory assistance) in the home with hospice care. We developed a guideline based on our experiences in our inpatient care center, homes and local hospitals.

Our major challenges have included clarifying the goals-of-care before the move home and the withdrawal occurs, assuring a smooth transition from a hospital setting to the home, and coordinating logistics for support personnel, equipment and medications in the home. In addition, it is important to ensure communication within our agency, with the referring facility, and with interested family/designated decision makers. Our interdisciplinary group (IDG) also focuses on addressing cultural and spiritual needs. The IDG has developed and refined competencies for assessing and determining goals of care in the field, but it is essential to have a physician trained in palliative medicine present during the life-support therapy withdrawal (LSTW). Our goal is to have a timely, well coordinated, but sensitive process that includes appropriate internal and external resources and ancillary support.

The guideline evolved through a rapid-cycle performance improvement process from a committed effort by nurses, social workers, spiritual counselors, physicians and managers from our departments handling admissions, triage, utilization review, crisis (continuous) care, and our rapid response home hospice team. Initial notification of all involved personnel occurs following a referral to our intake center or an admission nurse in the field. The main steps of the guideline are:

1. The **assessment, information sharing, and goal setting** process begins with the admission nurse and social worker collecting information on the decision-making capacity of the patient, advance directives and appointed healthcare surrogates, family dynamics, details of recent medical history including ventilator settings, intravenous access, and recent medication use. Then a family meeting is scheduled. At the family meeting, goals are determined, hospice services are explained, the timing and location of the withdrawal is ascertained, and support is offered about the emotional and ethical implications of the procedure. Education regarding logistics is provided to help manage the expectations of the patient and family. The desired level of sedation to balance comfort and alertness is explored. Plans are made in advance regarding the need for spiritual or religious rituals and emotional support for those who will be present at the time of the procedure.

2. The guideline organizes **care planning** with check lists to standardize our procedure. Consistent IDG members are maintained with each case to enhance continuity of care and ongoing communication. Consents for hospice admission are completed, and relevant medical records are transmitted to our agency. The admission nurse presents the case to the palliative medicine physician, who has been scheduled for the procedure. The nurse and physician then develop a list of the supplies, pharmaceuticals, medical equipment, and contracted services (e.g., ambulance and respiratory therapy) to be present in the home prior to the arrival of the patient. There is also consideration for withholding nutrition and hydration (prior to LSTW) to prevent excess secretions. The hospice managers maintain daily communication with the patient and family during the planning process and coordinate a final planning meeting with the IDG on the day before the planned procedure.

3. On the day of the procedure, the **care delivery** plan coordinates travel logistics, reconfirms the roles of staff, introduces the team to the family, and prepares for proper documentation of the process. The palliative medicine physician reconfirms the goals and plans as decided by the patient, family and proxy. At the time of the procedure, a limited time is provided for last goodbyes and any desired rituals before the LSTW is conducted.

4. **Follow-up** after withdrawal of life support ensures having a secondary team available for continuing care if the patient survives the removal of life support. A debrief for the IDG, including bereavement, has been found to be essential for process evaluation and emotional support for the team members.

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Included in our guideline are samples of documentation, language for communication, and supply checklists (which can be provided upon request from the authors).

The development of this guideline has greatly enhanced coordination and trust among our interdisciplinary personnel resulting in greater ease and efficiency of providing this needed service to our community. The family and staff satisfaction in providing this service has been high. We plan on reassessing the process in more detail in a year’s time.

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