

# Family meetings

## *An essential component of comprehensive palliative care*

Ramona Joshi MD

*Mrs S. is an 83-year-old woman with advanced dementia who lives with her daughter. At baseline, Mrs S. is communicative but confused, requires assistance for her activities of daily living, and has little interest in food. Her daughter tries to feed her a puréed diet that she has been following since her discharge from hospital 3 months ago after aspiration pneumonia.*

*Over the past several weeks the daughter has noticed Mrs S. coughing after her meals. She has tried to keep her mother upright during meals and afterward, but the coughing persists and continues to worsen. Mrs S. has now developed a fever and increasing congestion, prompting her daughter to take her to the hospital.*

*Mrs S. is again admitted with a diagnosis of aspiration pneumonia. She is instructed to ingest nothing by mouth, given intravenous hydration, and started on dual antibiotic therapy. After several days her fever resolves but she remains congested. Although she is more alert, she is still drowsier than her usual state. Repeat assessments by the speech-language pathologist (SLP) deem her to be at high risk of recurrent aspiration pneumonia. Her daughter is concerned about Mrs S.'s lack of oral intake and is asking about feeding options.*

*Mrs S. is fairly new to your family practice. You first met her after her last admission 3 months ago for aspiration pneumonia. You recall the challenges you had in communicating with Mrs S.'s son and daughter during your first meeting when you attempted to discuss her advanced dementia and goals of care. You sensed that her children believed you were being overly pessimistic about the natural progression of her advanced dementia and that they were not ready to make any decisions about goals of care if their mother required readmission.*

Family meetings are an important part of a patient's care plan in hospital, but they often happen late in admission or at critical decision-making junctions. Clear, effective communication among patients, families, and health care teams enhances patient care and patient satisfaction, which correlate with physician competency in communication.<sup>1</sup> Family meetings are useful to discuss patient status and goals of care.<sup>2</sup> When held proactively, and when they include not only the medical facts, but also the patient's perspective on his or her illness and the development of a care plan, family meetings have been shown to reduce time in intensive care, allow

for earlier withdrawal of advanced supportive technology without increasing mortality rates, and allow for dying patients to access palliative care earlier.<sup>3</sup>

Delivering bad news or having family meetings that involve difficult decisions can be challenging for various reasons. With respect to physicians, some of the reasons identified include lack of training in communicating bad news, fear of uncertainty or lack of knowledge about further management options, fear of the emotional response they might receive, and discomfort expressing their own emotions with patients or families.<sup>4</sup> Medical trainees do not receive adequate training in discussing the transition from a curative philosophy of care to comfort-based end-of-life care with patients and families. Trainees are less likely to be directly observed and receive feedback on end-of-life discussions than they are on procedures and related skills.<sup>5</sup>

### SPIKES protocol

A number of protocols and guidelines exist for holding family meetings or breaking bad news. These guidelines share several common features such as arranging for a quiet space and dedicated uninterrupted time for discussion, eliciting from patients and families their understanding of the current situation and what additional information they want or need, providing information, recognizing the emotional effect on patients and families, and ensuring a follow-up plan.<sup>1,6,7</sup>

One protocol that can be used is the SPIKES protocol (**Figure 1**).<sup>8,9</sup> The SPIKES protocol is a 6-step guide that involves a preparation component, a communication stage, and a follow-up plan. This tool can be used as a framework for family meetings in which difficult decisions need to be made (eg, when discussing the transition from acute curative care to symptom-based palliative care). Getting to know the patient as an individual and understanding his or her expectations, hopes, and fears is vital. Anticipating any challenging or seemingly contradictory goals of care ahead of time will make communication on difficult topics easier by allowing you to relate the goals of care and management strategies directly to what the patient would want.<sup>1</sup>

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**Figure 1. The SPIKES protocol: A 6-step guide for holding family meetings in which difficult decisions need to be made.**

- S** *Setting* of the interview
- P** Assessment of the patient's or family's *perception* of the situation
- I** *Invitation* to share knowledge
- K** *Knowledge* (or information) sharing
- E** *Emotions* addressed with *empathy*
- S** *Summarize* or *strategize*

Adapted from Buckman.<sup>8</sup>

You follow the SPIKES protocol (Figure 1)<sup>8</sup> during the upcoming family meeting with Mrs S.'s daughter and son. You arrange to meet with them in a quiet room on the ward (setting). In addition to yourself, the SLP and social worker are present. After introductions are made, you take some time to allow the family members to tell you more about what Mrs S. was like when her health was better. You learn that she was an avid cook and that many fond family memories involve enjoying a meal around the kitchen table. Both of her children have become skilled cooks, and sharing food is akin to sharing love in their family. You indicate that you understand the centrality of food to them and how difficult it must be for them to see their mother not eating now.

You review with the family Mrs S.'s presentation to hospital, her diagnosis, and her current objective clinical status. You ask Mrs S.'s children what their understanding is of their mother's current status (perception). Her daughter sees Mrs S. as having improved but not being back to her baseline functioning. She is upset that her mother is not eating and is concerned that she cannot get stronger without food. She has noticed another patient on the ward with a feeding tube and requests one for her mother.


You offer to discuss feeding options (invitation), and ask the SLP to recount her assessments of Mrs S. The daughter is keen to hear what the SLP has to say. The SLP explains that with all attempts, Mrs S. opens her mouth to receive food, but she requires cuing to swallow and occasionally coughs after swallowing. You discuss the natural history of dementia, including the deterioration of swallowing function and reduction of oral intake as part of the disease process. You relate this to her last admission when her diet was changed owing

to early swallowing difficulties and the increased cough that her daughter noticed at home (knowledge).

Through discussion it becomes clear that Mrs S.'s daughter now better understands her mother's illness and its associated risks and complications compared with the first time you spoke months ago. However, she feels uncomfortable with the idea of her mother having nothing by mouth. You empathize with her, acknowledge that ingesting nothing by mouth seems inconsistent with her mother's love of food, and explore alternative options with her, including feeding, despite risk, versus insertion of a percutaneous endoscopic gastrostomy (PEG) tube (emotions, empathy). You explain that artificial feeding by a PEG tube has not been shown to lead to longer life and does not add to quality of life in patients with advanced dementia.<sup>10</sup> You suggest considering feeding orally despite risk, and explain this would entail offering small amounts of food of the safest possible texture only if Mrs S. were alert, upright, and accepting of the food offered to her (strategize). Mrs S.'s children agree to think about the options and update you with their decision.

### Resolution

Patients and families might feel pressured or intimidated by medical teams, especially when there are difficult decisions to be made. By giving them time and space to think, patients and families are more likely to make decisions that are in line with their goals of care and that are appropriate for their current situations.

Mrs S.'s daughter returns to update you on the family's decision regarding feeding. Given Mrs S.'s love of food, the family has decided to feed her orally for comfort. She and her brother believe their mother would have declined the more invasive PEG tube had she been able to make her own decision. Because Mrs S.'s care needs have increased, her daughter is no longer able to take her home. She has no food intake on many days, and only has 3 spoonfuls of pudding or ice cream on others. You are able to have Mrs S. transferred to the palliative care unit. She continues to deteriorate, and within a few days she has no intake at all. She dies peacefully several weeks later. 

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#### Competing interests

None declared

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• **BOTTOM LINE**

- Family meetings are an important component of a patient's care plan.
- Having a structured approach to guide meetings is useful, and the SPIKES protocol is one of many tools that can be helpful.
- The medical team and the patient, as well as the patient's family, should have the opportunity to share their perspectives.
- More than 1 meeting might be necessary to make decisions about important changes to a patient's care plan.

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