



“I didn’t know dementia was a fatal disease. Why didn’t anybody tell me before?”

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Case: Mrs. X was the 79 year old wife of a man with end-stage dementia. Mr. X was diagnosed five years earlier and lived with his wife. Regular medical follow up was provided by an internist, neurologist, cardiologist, and in the last year of his life, by home health nursing. Mr. X became dependent on his wife for all aspects of care and was admitted to the hospital for pneumonia and failure to thrive. He had not eaten for over a week and was minimally responsive. Mrs. X hoped her husband would return home with a feeding tube so she could continue to care for him with help from family; her daughter had made arrangements to take time off from work to help. The palliative care team was consulted by the admitting medical team five days after admission in order to talk to Mrs. X about “goals of care.”

Upon talking to Mrs. X, it quickly became apparent that, despite caring for her husband for five years and having multiple contacts with healthcare professionals, she did not realize that her husband was at the end of life. She often made the following types of comments:

- “How can he be dying? The doctors told me that his heart and lungs are fine.”
- “I don’t understand. Why didn’t anybody tell me this before?”
- “I never thought it would be so soon.”

Mr. X died two days later of respiratory failure. A member of the palliative care service had the opportunity to interview Mrs. X several months later. Ms. X made several comments referring to the fact that she was not fully prepared for her husband’s death. Not being prepared, in turn, was a source of great distress for her and the family as demonstrated by the following comments she made:

- “It still bothers me that I didn’t know he was going to die. I still wonder if I should have done things differently or if his death was my fault.”
- “Why didn’t anybody tell me that you could die from dementia? I thought you needed a heart attack, stroke, or cancer to die.”
- “The doctors and nurses were nice and everything but they just talked to me about the medical things. Why didn’t they tell me he could die?”

Discussion: Approximately 70% of the 2.4 million deaths a year in the United States result from chronic diseases. Because these disabling conditions often compromise the ability of individuals to function independently, deaths are typically preceded by a period of family caregiving.¹ The intensity and duration of care provided may make healthcare providers believe that family caregivers have ample opportunity to prepare for death. This is often not the case. Approximately 20-25% of surviving family caregivers say they were unprepared for the death and wish that healthcare providers would have done more to prepare them.^{2,3}

Preparing caregivers for the death of a loved one is very important. Caregivers who perceived themselves as unprepared have more depression, anxiety, and grief.⁴ Preparing for the death may have medical, psychosocial, practical, or existential/spiritual dimensions (Table). For example, caregivers have described preparedness as “knowing what symptoms to expect” (medical). Others believe that “resolving family issues” (psychosocial) or “praying to God for guidance” (existential/spiritual) are most important. Finally, for some “having finances in order” (practical) is a major component of preparing for the death of a loved one.

<p><u>Medical preparedness:</u></p> <ul style="list-style-type: none"> • Knowing what signs and symptoms to expect • Knowing the timing of the loved one’s death 	<p><u>Psychosocial preparedness:</u></p> <ul style="list-style-type: none"> • Maintaining relationships with friends and family • Discussing grief, emotions, or fears
<p><u>Practical preparedness:</u></p> <ul style="list-style-type: none"> • Ensuring that the patient has his/her financial affairs in order • Having funeral arrangement planned 	<p><u>Existential/spiritual preparedness:</u></p> <ul style="list-style-type: none"> • Talking about the meaning of the death • Being at peace with God

A major implication of these findings is that preparedness means different things to different caregivers. As such, all healthcare providers involved in end-of-life care—physicians, nurses, social workers, psychologists, clergy etc.—must communicate openly, honestly and with sensitivity with each other and with patients and families in order to allow caregivers to prepare for the death in the appropriate manner.

References:

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