Within the aging population, people are living longer with chronic and severe illnesses. As times over the course of disease progression, patients with severe illnesses may lose decision-making capacity. In those situations, the decision-making process may become more challenging if the health care proxy (HCP) also lacks the capacity to make decisions.

**Case Description**

Mr. X was a 75-year-old with severe amyotrophic lateral sclerosis (ALS) causing severe dysphagia, aspiration, aphasia, inability to follow any commands, and neurogenic bowel and bladder. In addition, his ALS had also caused restrictive lung disease, leading to chronic hypoxia requiring 40% oxygen via tracheostomy. Mr. X had a feeding tube for nutrition, tracheostomy with 40% oxygen, and a Foley catheter. He was bed-bound and required a mechanical lift for transfer. Mr. X was totally dependent for all his activities of daily living and was unable to make his needs known. He experienced frequent hospitalizations due to aspiration pneumonia, so a focus of care discussion was initiated.

Mr. X lacked the capacity to make any health care and safety decisions, including decisions regarding his treatment preferences and living arrangements. He lived at home with his wife and had four children who were supportive of their parents and involved with the care of Mr. X. His wife was his duly appointed HCP, and a daughter was his duly appointed alternate HCP.

During a focus of care discussion, Mrs. X agreed with the recommendations of the treatment team to forgo life-prolonging and life-sustaining treatments and to let nature take its course. However, in those discussions it became apparent that Mrs. X was emotionally overwhelmed, and her own mental health was affecting her decision-making. She demonstrated a lack of understanding of her husband’s serious condition as well as its impact on his life expectancy with and without life-sustaining measures. In short, Mrs. X also lacked decision-making capacity to make decisions on behalf of her husband.

Mrs. X’s lack of decision-making capacity was discussed with her children, who agreed that this was the case. Their daughter (the alternate HCP) was willing to make decisions on behalf of her father and consented to hospice care. However, the children requested that their mother not be told that she could not make decisions for her husband because it would upset her and likely lead to further mental health decompensation.

**How to Approach This Case**

Autonomy is a well-established ethical principle. Health care providers are obligated to follow a patient’s decisions as long as he or she has the capacity to make these decisions. However, if patients lack decision-making capacity, then their autonomy is still honored via their surrogate decision-maker. In this case, a challenge arose when Mr. X’s appropriate surrogate decision-maker also lacked decision-making capacity. When a HCP also lacks decision-making capacity, health care providers proceed to the next person in the hierarchy of surrogate decision-makers. In this case, the alternate HCP, his daughter, became the decision-maker. This aspect of the case demonstrates that health care providers should not assume that a person has decision-making capacity just because she or he agrees with the recommendations of treatment team.

Mr. X’s daughter asked us not to tell her mother that she would make decisions for her father. However, ethical principles also require health care providers to tell the truth and not to compromise the ethical principle of nonmaleficence (do no harm). Beneficence and nonmaleficence principles are mostly used in reference to patients; however, there is also a moral obligation to do no harm toward the general population, including the family members of a patient.

Even if the care team withheld information from Mrs. X about the change, she would likely come to know of it when the hospice election form required her signature. In this case, the children believed that telling Mrs. X of this change in HCP would decompensate her mental health as it was apparent that her mental health was already very frail. The health care providers needed to develop a way to address the need to uphold the ethical principles of care while also addressing the needs of the family.

**Outcome of Case**

A family meeting was held which was attended by Mrs. X, all the children, and the health care team (including the palliative care attending physician, palliative care coordinator, and primary team social worker). Mr. X’s condition was reviewed as well as prior discussions to address the need to uphold the ethical principles of care while also addressing the needs of the family. The health care team encouraged the family to consider enrollment in hospice.

**Conclusion**

This case illustrates a feasible approach that may be used when a patient and his or her primary HCP both lack decision-making capacity. With this approach, the health care team was able to gain consent from the previous HCP without further decompensation in her mental health. The team was also able to honor the autonomy of Mr. X (via a surrogate decision-maker) while also practicing beneficence to him and nonmaleficence to his wife.