ENCOUNTERS

Storms before the calm

One evening about a year ago, a resident in the emergency department paged to say: "The family of 'Mr. Q' wants to know if you think he should be intubated." Mr. Q had gone to sea at the age of nine, to catch lobsters with his father. In later life he had been a woodsman and a meat cutter. His last 30 working years were spent in a Canadian naval magazine keeping weaponry in tip-top condition. During WWII, he had survived, against some odds, a tuberculous empyema which left him with a pleural space half full of calcium and a restrictive deficit on his pulmonary function tests. A long smoking history and features of moderate chronic obstructive pulmonary disease added to the medical challenge. Quite how much of the challenge didn't become obvious until well beyond my deceptively simple response to the resident that evening: "Why wouldn't we give him a chance," or words to that effect. After all, he had walked independently into clinic some weeks earlier and had never needed an emergency visit or an admission. Another challenge, also not obvious early on, was how to balance caring well for Mr. Q within constraints of responsible resource allocation. As often happens, no amount of policy or institutional planning or logical analysis, let alone traditional concepts of advance care planning, can determine what course individual care will take for the Mr. Qs we will meet from time to time.

It took weeks to liberate him from a mechanical ventilator. After removal of his tracheostomy, a newly developed difficulty with swallowing doomed him some days later to the first of several episodes of minor aspiration. "Minor" in all aspects save outcome — for him and for us. Well-intentioned, well-reasoned and well-documented goals of care plans on the medical floor, clearly indicating "no heroics," didn't fly when Mr. Q's competent response in a crisis was: "I don't want that stuff, but if it's a matter of life or death. …"

His was the choice to carry on or to give up the fight — and fight he did.

He survived that first and several subsequent crises and continued to firmly refuse any technically assisted feeding. His aim was to go home — and eat. He wasn't interested in half measures that bypassed his taste buds. That's how the first few months played out: the intensive care unit in a crisis followed by a return to the "step-down" unit. Round and round it went. He'd go a few days with the tracheostomy "corked" and then start to crash, sometimes slowly, sometimes a bit faster and for longer. Each time he would come through, get beyond some short-term delerium, and settle down again.

With a Passy-Muir valve he could talk, but he didn't like his nasogastric tube, taped to the end of his nose. Liquid feeds weren't "food." Nevertheless, he was on the right side of the grass as he preferred to be, not so much for himself, but because he had a strong belief that his family needed him. He cared for his family in his role as patriarch and in turn was loved and cared for by family members in their various roles. His devoted family made it very clear they would never make a decision for him if he proved unable. His was the choice to carry on or to give up the fight — and fight he did..

A year ago, I could not have foreseen that my deceptively straightforward answer to the intubation question would be the first step along this uncertain, obstacle-strewn path. Day-by-day, episode-by-episode, this path defined a

man's life, and his preferred approach to care, as we charted our way through new storms. We came through, on our part, despite occasional dissension and discomfort, even some guilt at times, forgetting perhaps that as survivors of previous life and death crises, the Mr. Qs of this world may see the only option as living to the very last breath, no matter how tortured that course appears to others.

After many repetitions of the cycle, both he and his family finally agreed to a percutaneous endoscopic gastrostomy. He started again down the long road toward his goal of independence. He would sit in his chair and use a stationary bicycle to maintain some strength in his legs. He'd cruise around the unit with a walker, oxygen tank and respiratory therapist in tow. He was able to come off the ventilator again, but just during the day. He "simply" needed a few hours of assisted ventilation at night to keep him on the straight and narrow.

Many weeks ago, he went home for the first in a series of short visits, undoubtedly chatting up a storm and delighting in reacquainting with his beloved cats. If he could physically walk down to his boat, he'd be out to sea in a minute. He is, in all ways, a survivor. The family photographs on his wall and a special blanket on his bed are outward reminders of home and the values that have kept him going. He maintains what independence he can, eschewing the "remote" and choosing instead to manage the TV controls with the packaging of a long surgical instrument. Life suffices and he is content.

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This is a true story. "Mr. Q" has given his written consent for this story to be told.

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