

New Name  
&  
New Look!

# THE HALO VOICE

A Voice for The Medically Vulnerable

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## HALO IN ACTION - A CALL TO THE HELPLINE

By Anne O'Meara

*The following is a recap of a recent, heart-wrenching Helpline call from a patient's daughter who is fighting to keep her mom alive. Names have been changed for privacy.*



*"I heard a sermon this morning that, if God has called you to do something, He will provide the way."*

*Quote from Ellen, Susan's daughter*

The call came in on a Saturday afternoon from Ellen in Pennsylvania. Ellen was calling about her 81-year-old mother, Susan, who had been hospitalized with pneumonia. A few days before Ellen called HALO, Susan had asphyxiated and was placed on a ventilator. Ellen called because doctors had just informed Susan's husband (Jim) and her two adult children (Ellen and Elliot) that Susan had suffered brain damage, would have

a low quality of life, and should be removed from the ventilator. Jim (Ellen and Elliot's stepfather) agreed with the doctors that the ventilator should be removed on Monday, which was less than two days away. Susan's two adult children both argued that their mom should stay on the ventilator, so her body might have a chance to heal.

Ellen told the Helpline patient advocate that several months ago, her mom had stated in front of Jim that she wanted Ellen to be her medical decision maker (health care agent). Unfortunately, Susan never put this desire in writing by filling out and signing a Health Care Power of Attorney (HCPA). When doctors asked the family who Susan's health care agent was, the stepfather

**"There are many more Ellen's out there and families like hers that are in need of help to protect their loved one's from the medical death culture. As a donor it helped me to understand even better how my donations are are put to work."**

**- Donor from FL -**

responded that he was. Although he didn't have any paperwork, the hospital and the family assumed that, as the spouse, he was automatically the default agent. Thus, Jim had authorized the removal of the ventilator.

Ellen questioned the doctors and her stepfather. "What is the urgency? Why does the ventilator need to be removed so soon? Why not leave Mom on the ventilator and see if she will start improving?" She received vague responses like "This is better for your mother" and "This is what your mother would want," but she never received satisfactory answers.

Ellen also mentioned to the patient advocate that she observed her mom making movements. When Ellen turned on the TV, Susan would look over at it. Also, even though her mother slept a lot, she was opening her eyes, looking around the room, and moving her hands and arms.

When Ellen reported this to the doctors and nurses, they said they hadn't noticed anything and attributed everything Ellen was seeing to reflexes. When Susan's son, Elliot, made short visits, he did not observe

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GRANDMA WON'T DIE FROM  
ALZHEIMER'S...UNLESS WE KILL HER

By Rick Becker

***“A man must be certain of his morality for the simple reason that he has to suffer for it.”***

***G.K. Chesterton***

Several months ago, I heard an ad that got me muttering. It was for a non-profit Alzheimer's research fund. “The first person to survive Alzheimer's disease is out there,” said the lady in the voiceover. “Wait – what?” I asked out loud. “Everybody survives Alzheimer's!”

It's true. Alzheimer's itself is a devastating disease but it does not directly attack vital bodily functions. Instead, its progressive and inexorable assault on nerve connections in the brain leads to cognitive deterioration, which makes it progressively difficult for those suffering from Alzheimer's to care for themselves or safely perform what healthcare workers call “activities of daily living.” Folks with advancing Alzheimer's are more prone to falls and other injuries and, when they become less mobile, they'll be more susceptible to skin

***“Death by dehydration is a horrendous, agonizing process, no matter how much we gussie it up in medical lingo and references to compassion.”***

breakdown and lung infections. They're especially at risk for swallowing problems – which can lead to a deadly aspiration pneumonia when food or fluids go down the wrong pipe and into the lungs.

So, there's no question that Alzheimer's, the most common form of chronic dementia, truly has a terminal trajectory. In fact, Alzheimer's is considered the sixth leading cause of death for adults in the USA – and some researchers suggest that more accurate data would put it in third place. Yet, no matter the disease's official mortality rank, the fact remains that Alzheimer's is in the running only as an “underlying cause of death” – something the World Health Organization (along with the Center for Disease Control) defines as “the disease or injury which initiated the train of events leading directly to death.”

In other words, despite the radio ad's rhetoric, everyone survives Alzheimer's itself – unless we kill them on account of it before they die of something else.

Does that sound harsh? Maybe, but what is really harsh is the silent killing that has become pretty routine in dementia care. It rarely makes the news because it is perfectly legal and, frankly, most don't even think of it as killing. I'm talking about the intentional removal of nutrients and fluids from those who can no longer feed themselves safely or the discontinuation of feedings administered through a tube. Although there are situations in which such deferrals of food and fluids may be morally acceptable (e.g., when certain gastrointestinal diseases make it impossible for a person's body to digest nutrients), most such deferrals hasten the dying process with no legitimate ethical justification.

The rationalization of this common practice takes a variety of forms – such as assertions that an individual should not be allowed to eat or drink because of aspiration risks and that the autonomy of the person suffering dementia should be respected when he refuses meals and water – but they all lead to the same result: death by dehydration within a matter of days. Those who defend this practice even argue that it's a comfortable way to go, and so it's actually compassionate to remove food and fluids when Alzheimer's advances.

Wrong. Death by dehydration is a horrendous, agonizing process, no matter how much we gussie it up in medical lingo and references to compassion. Besides, when anything is done with knowledge that it will hasten death, it is killing, pure and simple.

The bottom line is that we should be making the necessary sacrifices to genuinely care for those who suffer from Alzheimer's, especially when the disease takes away memory and cognitive abilities. We should keep them clean and warm; help them move about to avoid skin problems; monitor them for infections and give them antibiotics when they get sick; and, yes, feed them safely – and gladly, especially when we consider the admonition of the Lord in Matthew 25: “When you did it to one of the least of these, you did it to me.”

*Rick Becker is a husband, father of seven, nursing instructor, and religious educator. Rick has studied theology at Evangelical institutions as well as Franciscan University of Steubenville. He currently serves on the nursing faculty at Bethel University, Mishawaka, Indiana. You can find more of Rick's writing at God-Haunted Lunatic (<https://godhauntedlunatic.wordpress.com/>).*

# Thank you!

## Important Update

Like other nonprofit organizations, HALO has been feeling the impact of the Covid-19 pandemic. As a result, we recently laid off one of our employees, Chris Rogers, a talented graphic designer. Please join us in thanking Chris for all his hard work for HALO. We wish him the best!

## UPDATED ORGAN DONATION FACT SHEET!

HALO extends a huge thank you to three renowned “brain death” experts -- Dr. Doyen Nguyen, Dr. Joseph Eble, and Dr. Alan Shewmon -- who graciously worked with our Board President, Julie Grimstad, to update and ensure the accuracy of HALO’s fact sheet “Are Organ Donors Truly Dead Before Their Organs Are Taken?” This fact sheet dispels the myth that “brain death” is a scientific fact and presents compelling evidence that people, even if they believe brain death is truly death, should not have confidence in the reliability of brain death determinations.

**HALO’s website is currently under construction. If you would like to request a copy or copies of this updated fact sheet, please email your request to [feedback@halovoice.org](mailto:feedback@halovoice.org) or call 1-888-221-4256.**



## 3 TIPS FOR SAFEGUARDING YOUR LOVED ONE IN A NURSING HOME

By Nancy Valko, RN, ALNC

Reprinted from [www.nancyvalko.com](http://www.nancyvalko.com)

I have had many relatives and friends who lived in nursing homes and, especially as a nurse, I am always saddened by how few of the other residents had any visitors, even family members. I have even heard relatives say they would just prefer to remember their relative “the way they were”.

This is not only tragic for the family member’s or friend’s psychological well-being but also potentially for their safety. Nursing home residents without visitors are at greater risk of neglect or even abuse. With sometimes inadequate staffing and/or high nurse and aide turnover, it is important that people in a nursing home have someone who knows them to look out for them.

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### Here are 3 tips that can help safeguard a friend or relative:

1. Get to know the staff and tell them about your friend or relative, especially likes or dislikes. Visit at different times or days in order to know the staff and when it is most convenient to talk with them.
2. Notice “red flags” like poor personal hygiene, unexplained injuries, weight loss, emotional changes, environmental hazards, etc. and know who to contact if you see a problem.
3. Especially if you are have health care power of attorney for your relative or friend, ask about care conferences so that you can attend them. Such conferences usually cover how the resident is doing in terms of activity, possible pain, eating, mobility, etc. It is also crucial to know what medications have been ordered and given, especially the PRN (as needed) ones. For example, you may notice a change such as sleepiness or fatigue that can be helped with a medication change.

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By 2020, it is projected that the global population of human beings who are 65 and older will surpass those under 5 for the first time in human history. At the same time, families have fewer children, older adults are more likely to have never married or to be divorced and adult children often live far from their parents. This makes it harder for many older people who prefer to live independently in their own homes indefinitely without help.

According to the CDC, 1.4 million people are nursing home residents in the US, those residents really benefit from visitors as do all of us who volunteer to help the elderly!

Susan's story continued.

these movements, so he questioned his sister, "Why would the hospital lie about this?" He thought Ellen was seeing movements because she so desperately wanted to believe that.

According to Ellen, her stepfather had spoken to two neurologists who both said basically the same thing: "Susan is gone. The ventilator is keeping her alive artificially. You need to remove her from the ventilator." Jim did not want to use "extraordinary care, like a ventilator;" to keep his wife alive. Realizing the gravity of the situation, HALO took some critical steps to give Susan a "fighting chance."

## SEVEN CRITICAL WAYS HALO MADE A DIFFERENCE

### 1. HALO's patient advocate informed Ellen that ventilators are not generally "extraordinary" care.

Ventilators can be used on a short-term basis to give the body a chance to heal. Ventilators move air into the lungs, but do not cause respiration—the exchange of oxygen and carbon dioxide that occurs in lungs and body tissues. While a ventilator supplies oxygen, it cannot provide the hemoglobin that carries oxygen in the blood, nor can it circulate the blood; these bodily processes must continue on their own for the ventilator to work. The patient advocate shared an analogy she had heard from a HALO friend, a physician, that, if you use a ventilator to supply oxygen to a cadaver, the dead body is not going to start breathing on its own as other bodily processes would still need to happen. The patient advocate also addressed another misconception. "Many people assume, if you are on a ventilator, you will live the rest of your life in a care facility. While this is true for some people, many patients go home on a ventilator and others are healed and removed from a ventilator."

### 2. HALO researched Health Care Power of Attorney rules in PA and informed family that the stepfather was not the sole medical decision maker (agent) under PA law.

PA law prioritizes the "classes" of people who will make medical decisions for the person. The first "class" is "Spouse and adult children not of your spouse." This meant that the authority to make medical decisions for Susan was to be shared, with Jim, Ellen, and Elliot each having an equal vote!

### 3. We consulted a physician, an expert regarding

ventilators, who educated family members on ventilator use and answered questions.

### 4. We located a neurologist in the patient's healthcare system who reviewed the patient's test results and spoke with the patient's family.

When the neurologist looked at the tests, he was shocked. In his opinion the doctors had not done much testing at all. He advised the family to push for an MRI immediately.

### 5. We recommended that the Helpline caller tape her mom's movements and show videos to her brother which cemented his decision to leave his mom on the ventilator.

After viewing the videos, Elliot was angry because "the hospital lied to us." He wondered, "If they lied about this, what else were they lying about?"

### 6. HALO's prayer warriors prayed for the patient and her family!

### 7. HALO stopped a potentially lethal dose of Fentanyl that had been prescribed to her mom.

We provided the daughter with a written warning published by Janssen Pharmaceuticals which essentially states that individuals who are brain-damaged, unconscious, or comatose should not be given this powerful drug. The difference between a therapeutic and a deadly dose is small. We also checked with the physician we had contacted regarding the ventilator. He responded, "Fentanyl will not solve anything and has the potential to kill this person. It must be stopped." With this information, the daughter notified the hospital that she wanted her mom taken off Fentanyl.

HALO is pleased we could assist Ellen and her family in this difficult situation. As Ellen heard the day she called us, "If God has called you to do something, He will provide the way." HALO proved to be the "way." While Susan is not yet out of the woods, we are hopeful. She remains on a ventilator and we are assisting the family to find another hospital so that Susan can be moved to a facility that will provide her with the life-sustaining treatment her children want her to receive.

HALO is committed to making a difference for patients like Susan. We will continue to fight for life-affirming outcomes! Please join HALO's prayer warriors in storming heaven with prayers for Susan and her entire family.