

Caring *for the Ages*

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Just a Face in the Crowd: Who are the Unrepresented?

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Introduction



After having written journal articles on end-of-life decision-making for unrepresented nursing home (NH) residents without decisional capacity and having spoken to hundreds of such individuals over the past two decades as an ethics consultant, one might think that I could quickly rattle off their distinguishing features and mindsets. However, that is not the case. What I have learned over the

years is that few of us truly get to know these individuals well, as many keep their distance and never open up to us, while others simply are incapable of telling us much at all.

For those of us who work in post-acute and long-term care (PALTC) settings, the opportunity to truly get to know these individuals well is quite limited, as we generally first encounter them when they exhibit major cognitive impairment due to Alzheimer's disease and related dementias (ADRD), and thus, they are only able to tell us very sketchy details about their prior lives. However, the little they can tell us may be invaluable in painting a portrait of their values and beliefs. In some cases, however, their cognitive impairment may be so severe that they cannot tell us anything meaningful about their prior lives. In such cases, we must search elsewhere, seeking family, friends, or acquaintances who may be able to shed some light on their prior personhood.

Performing a Diligent Search

What I have discovered is that many of those believed to be socially isolated have had meaningful relationships with others who can provide details about their prior lives. My advice is to first seek information from the referral source, usually a short-term acute care hospital (STACH), and look over the social work notes that were contained in the admission packet. In most cases, if there were known next-of-kin, that information would be found there. It is certainly worth a try, as quite possibly in the STACH, the initial attempt to contact a family member could have failed for various reasons, such as the person's voicemail box was full, and a message could not be left.

In general, in a PALTC setting, time is usually on your side, as opposed to in a STACH, so that even if your initial contact attempt fails, you will have ample opportunity to reach out again until you are successful. Even if repeated attempts over several weeks fail, based on my experience, you should not give up, as there may be additional clues out there, and other ways to connect with someone who can help you.

As an example, an internet search that we conducted for an unrepresented NH resident found a missing person post by a family member of a person who bore a resemblance to this resident, and who shared the same uncommon first name but with a different surname. We then found a chart signed by this resident who used the same surname as the post, which led us to contact the person's family. As was the case here, often the family member that you succeed in contacting is knowledgeable about the person's prior wishes and is willing to assume the role of surrogate decision-maker, in accordance with the default surrogate statute in your state.

Continue to Search for Clues

A key lesson I have learned is that you must become a good detective, as many of these individuals leave clues to their former personhood, shedding light on their values and beliefs. Such clues are commonplace, and we all have encountered them. For instance, when frail, elderly NH residents with ADRD consistently refuse to allow blood work and other diagnostic studies, as well as attend outside clinic appointments, it should occur to you that perhaps these individuals are sending signals that they do not like to undergo testing and medical evaluations. Should you succeed in locating a family member or friend, you will likely learn that the person exhibited these character traits well before the onset of dementia and always avoided medical visits and tests.

Nevertheless, their core values, even if they conflict with those of the medical community, are important and require careful consideration during care team discussions. This is particularly true when it comes to end-of-life decision-making, as individuals who

consistently refuse blood work, medical visits, other diagnostic studies, and even medications might not willingly choose to receive aggressive medical treatments, such as intubation with mechanical ventilation and live out their final days in the highly restrictive confines of an intensive care unit. Yet, without advanced directives in place, based upon their prior wishes and preferences, which few of them ever complete when the opportunity exists, the default standard will be applied in emergency situations. Often, default standards entail aggressive medical treatments and preclude withholding such treatments.

Always be mindful that many of those deemed unrepresented actually have family from which they became estranged, most often due to their aberrant behavior. In addition, many have been living on the fringes of society for decades for various reasons, such as mental illness, and alcohol or other substance use disorders. When they are no longer capable of safely residing independently in the community, often due to cognitive decline, and are placed in an NH, they generally reveal little of their prior lives.

What I have also learned from my years of experience is that although there are often many clues out there, few members of the care team take the time and make the effort to search for these clues that could enable them to discern the values and beliefs of these unrepresented individuals, or even locate a potential surrogate, which could help the care team in formulating appropriate care plans. Even though you may not always succeed in your search for new clues, this should not dampen your enthusiasm, as making the effort, even if you fail in your goal, can help to relieve lingering doubts that perhaps something may have been missed. In one recent case, the former domestic partner of a long-term unrepresented NH resident described him as always being “like a closed book,” even with his adult children, who eventually stopped speaking to him due to his inability to reveal his feelings and to relate to them in a meaningful way. In essence, what she told us was important, as it confirmed what we already suspected about this person, whose behavior we were unable to change.

Just a Face in the Crowd

To better illustrate my point, I would like to test your skills at discerning clues, which are often key to unraveling the mystery surrounding an unrepresented individual. Please read the poem below, which I wrote about an unrepresented person, whose identity should be familiar to most. This poem was recited at PALTC23 at the close of my presentation about end-of-life decision-making for unrepresented nursing home residents.

For many who were present at the time, the ending came as a complete surprise, even though I presented several clues in my poem to the person’s identity that most somehow

overlooked. Please read this poem carefully and then see if, with these clues, among which are the person's initials, you can readily determine the person's name, as well as identify these clues offered in the poem. You may also consider trying this out on friends and colleagues.

Just a Face in the Crowd®

by Howard J. Finger

They say, she died in her seat, quietly, alas,
just as the preacher concluded his mass.
All the parishioners thought she was merely asleep
as they passed her by without uttering a peep.

None of them really knew her, not even her name,
though every Sunday like clockwork, to church, she came.
She was kindhearted, always eager to lend folks a hand.
Like a vagabond, she wore a face that she bought at a drug store stand.

She'd this look about her that just didn't seem real.
She'd always ask folks how do you feel.
We all sensed, something about her just didn't seem right.
They say, there are many others like her adrift in the night.

Like a creature of habit, she'd sit in the third seat in the second row.
She was constantly on guard, rarely let her emotions show.
Once in-a-while, when she thought, no one was looking, she'd frown.
She lived alone in a flat on the outskirts of town.

Unlike Maxwell Hammer, she'd no dark secrets to hide.
She was just some lost soul, along for the ride.
She was spy as a kitten, never carried a walking stick.
Not even the Reverend McKenzie knew what made her tick.

In many ways, he was a lot like her, good Lord.
His godawful sermons left most folks feeling bored.
Late in the night, he'd write them when not a soul was near.
At church, he'd read them softly, you had to strain to hear.

'Cept for the Reverend McKenzie, when they buried her, nobody came.
In the end, it won't matter, for no one will remember her name.
Ever so quietly, the unrepresented go about their way.

Just a face in the crowd, hardly noticed,
was E _ _ _ _ _ R _ _ _ _ (sadly to say).

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<https://paltmed.org/news-media/just-face-crowd-who-are-unrepresented>