A parishioner with Alzheimer's speaks for herself

## She came to our events on dementia and faith. She believed we could do better.

by <u>Samuel Wells</u> in the <u>May 22, 2019</u> issue



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John the Baptist wasn't completely convinced about Jesus. "Are you the one who is to come, or are we to wait for another?" Jesus had a simple answer. "The blind receive their sight, the lame walk, the lepers are cleansed, the deaf hear, the dead are raised, the poor have good news brought to them."

At my church we're won by the rhetoric but a bit chary about the details. We're not sure about the blind receiving their sight; we focus on how people with visual impairment develop extraordinary depth of insight in other ways. Likewise with the deaf: we're keen to focus on a person's assets rather than define them by their deficits. We'd probably make an exception for raising the dead—where the pastoral needs justified it, of course. We're all for upholding the poor, but we'd be anxious to hear what the poor had to say for themselves before assuming the only good news in their lives was the news that came from us.

But in spite of our inhibitions, we still see miracles. We still see the Holy Spirit do unbelievable things.

Alzheimer's can be almost invisible. It hides itself away because people with the condition become less likely to enter public spaces. It can be hard to know how to think about Alzheimer's, what category to put it in—though you'd better decide, because Alzheimer's takes over quickly.

When I came to the church, one woman stood out. You couldn't miss her. She would shout out from the congregation at unexpected moments. If you quoted Ecclesiasticus and said "Let us now praise famous men," you wouldn't get as far as "and our fathers that begat us" without hearing her shout, "And what about the women?" It was like a tripwire. If on a given Sunday the roles of preacher and presider were both taken by men, you could be sure that as you greeted her at the door she would look at you with her withering gaze and say, "Have you forgotten about the women?"

It wasn't just one issue. She had the same seek-and-destroy, guided-missile approach when it came to vegetarianism. Rare was the clergy member who had not been cornered by her strong handshake, pleading escape from her vice-like grip as she "talked and explained the scriptures" and how they made the consumption of meat unconscionable. From everything I was told, dementia hadn't made her a fanatic: she'd always been like that. If anything, her faltering faculties slightly reduced her passionate advocacy and scaled the volume down just a little.

She came to the first two evenings we organized around dementia and faith. She listened as people spoke movingly about caring for a beloved husband or mother and absorbingly about how dementia works and how its varieties differ. But then she made it clear she believed we could do better. She buttonholed two friends and hatched a plan. Over two lunches together they spoke and the two friends wrote things down—about her, about her life, about her mother, about her condition. And so it was that we beheld her glory. On the third dementia-and-faith evening, she stood behind a lectern. In her hands were four pages of notes, typed out by her two friends from their conversations. Slowly, and with extraordinary dignity, she began to tell us her story—and what a story. "Mummy was Baroness von Hundelshausen. She spoke six languages. I was born in Mexico and brought to Britain as a baby." She went on to speak of the "battle": "Jesus made it very clear that women are equal and not to be pushed around by men. But women's role in life and society has always been undervalued and must be equalized."

She spoke of working for a newspaper and then taking it over a few years later. "It was really lovely because I could say anything I wanted to say." She talked of being elected as a councillor for Westminster and making sure that Buckingham Palace paid local taxes—which it had never done before. She talked of being radicalized by her mother's dementia and realizing that "the government didn't give a damn about old women."

And then, astonishingly, she spoke about her own experience of Alzheimer's. "Fear and anger can be very close together, especially when you have memory problems. And I was angry." She explained what we'd all experienced of being with her. "I hate people deciding for me or speaking for me. I want people to understand that I'm still me; I still have a sense of self and my own rights."

How awesome is the sight. Here was the one brought to Jesus through the roof by friends carrying a stretcher—through the roof of ignorance, prejudice, impatience, and hasty judgment. And in that moment I saw what prophetic ministry means. Not berating authorities or denouncing congregations but slowly, patiently, building sufficient trust with a person who is socially excluded. Not assuming that one has to speak on their behalf but taking time over a transformative meal to listen, take notes, and assemble thoughts, so that one day—with a fair wind and a sympathetic audience—that person could speak her own words, sing her true song, and let the whole room thud with the sound of jaws dropping.

They that wait upon the Lord shall mount up with wings like eagles. That night I saw a miracle. I saw what church can be.

A version of this article appears in the print edition under the title "Glory amid dementia."