

My Sister's Last Pleasure

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My sister, who was born with Down syndrome, has end-stage dementia with advanced Parkinson's disease. She can no longer recognize anyone, and her quality of life is limited to eating and sleeping. Now her doctors are asking me to let them insert a feeding tube, which would keep her from choking but prevent her from ever actually eating again. I love her. How can I remove one of her last pleasures? Should I make the decision for her that I would want for myself in similar circumstances?

Not so long ago, people with Down syndrome died too young to encounter geriatric diseases like dementia. Now more and more of them are living long and happy lives. And at the end of those long lives, more and more families are faced with wrenching decisions like yours.

Complicating everything, these intimate family decisions are inseparable from broad public issues over which you have no control — things like what treatments insurance companies cover, how overextended a facility's nurses are, what the law considers an appropriate standard of care. Those complications are part of why debates about health care get so hot so fast.

Here's one way to simplify matters: Take the Down syndrome out of the equation. With it or without it, your sister has end-stage dementia, which affects her cognitive functioning, and advanced Parkinson's, which affects her ability to swallow, and like many others suffering from those diseases, she did not or could not set forth her medical preferences.

Eva Feder Kittay, co-editor of the volume "Cognitive Disability and Its Challenge to Moral Philosophy," is an expert in ethical issues like the one you face. She is also the mother of a severely disabled 42-year-old woman, and as such she has had to wrestle with some similar issues herself. Kittay says your first consideration should be how well you know your sister and her pleasures — how much you sense eating means to her. You could also ask her doctors how great the risk of choking is, and how much a feeding tube might prolong her life.

Kittay's other main consideration may be the most important of all: don't ask yourself what you would want if you were in your sister's circumstances; ask yourself what your sister — with the capacities and joys that are available to her now — would want. "That's the imaginative leap

that you have to make,” she says. “To just imagine yourself is to erase that other person and what she’s experiencing.” In some ways the idea is obvious, but it’s terribly easy to forget.

Knowing how much her daughter loves to eat, Kittay says: “If the pleasure of food were the only pleasure left for her, I do not think I would want to put in a feeding tube. I would just want people to be very careful in how they fed her.” But that, again, is a judgment specific to her daughter. Your knowledge of your sister and her condition may lead you to a different conclusion. Whatever guidance a scholar of ethics might offer, it’s you — and your sister — who must live with your decision.