# Now and Then

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For many of us in the fellowship, our lives now, at least in terms of physical and mental well-being, are pretty good. Can we imagine a future in which that may no longer be the case? What will we do then? Join us as we consider the challenging (and often unacknowledged) possibilities that we may have to confront as we grow older, and help us name the good news in these possibilities.

The hospital room was tight, confined, overly full of stuff. Some of it belonged to the woman in the bed, who was dear to me and had been my ally and advocate since I was a child. But most of it was hospital stuff, and of course it gave the room a very unnatural and uninviting feel. The woman in the bed had been in and out of the hospital so many times by then that I suppose the way the room looked didn't matter to her. There were other things on her mind.

"Why can't I die?" she asked me, and as much as I did not want to admit it to her, that was a question I had asked myself more than once over the course of this most recent setback.

"I don't know," I answered, determined not to betray her trust by saying something falsely comforting. "Maybe because there's something about your presence that's supposed to teach somebody something, and they haven't learned it yet. Maybe because somebody needs you to be alive right now."

"Who?" she asked, and that was a good question. Her husband had died recently and suddenly, she had no children, and her siblings had other primary people in their lives. I had no idea who, and I told her so. I knew I wasn't the one who needed her to be alive right now, although I wouldn't tell her that. I had been praying for weeks that she might be blessed with what she needed, and it was my own determination that what she needed was release. I had no idea how she might experience release, other than through death.

"I don't know," I told her. "I don't know what's at work here. I guess it's just not your time to die." I imagined that the woman in the bed thought that was a pretty lame reply from somebody with a theological education, and I imagined that she expected better from me. But nothing teaches us why we can't die. What I really longed for, then and now, was some way to let the woman in the bed experience the end of life in such a way that she wouldn't feel the need to ask, "Why can't I die?"

One of my professors years ago talked about the fact that in the New Testament there are two different concepts associated with the idea of the future. There's the future at the end of time, which is an idea and an ideal, and which calls us to imagine hopeful possibilities and aspire to a better world. Then there's another future, which he called the future after lunch--that's the future we can do something about. The woman in the bed was longing for the future at the end of time, because the future after lunch looked so grim to her, and for good reason. I believe that the future after lunch could have looked a lot better, although at the time I didn't see how. This points, though, to questions that loom large for people who are close to the end of their lives and are wondering why they can't die:

On the one hand, why *can't* they die? How is it that we have medicalized the end of life, as Oliver Sacks says, keeping people alive just because we know how to do that now? Is being kept alive always in a person's best interest?

On the other hand, what can we do to make the lives of infirm people rich enough, even if they are diminished, so that they don't have to ask, "Why can't I die?" Can't life be good right up until the last day, or at least close to that point?

I started out thinking I could engage each of these "hands"—the one hand and the other hand--but I came to realize that we don't have enough time in one morning, or in many mornings, to do that. So I want to concentrate on just one hand for now: how can life be better right up until the end?

I found some very good news in the midst of some difficult truths in a book by Atul Gawande called *Being Mortal*; I urge you to read it if this is a subject that you want to think further about. Gawande is a physician concerned with end of life issues, and he talked to many people who spoke of their lives in assisted living and nursing homes with varying degrees of satisfaction and contentment. One observation he made, which was affirmed for him over and over again when he spoke with residents, was that these facilities have safety as their top priority—prevent falls, prevent bedsores, prevent poor nutrition, prevent wandering. All of these are valuable objectives, but it's pretty obvious that the safety of the residents isn't the only safety they're concerned with. The safety of the institution is a high priority as well. How many of us have visited these facilities and come away with the feeling that their mission statement could be "Don't Get Sued"? As one woman told Dr. Gawande, she was glad to be in a safe place when living on her own proved no longer workable, but safety isn't everything.

Most of us would agree, I expect, that safety does not give life meaning. Dr. Gawande tells the story of a young doctor named Bill Thomas who took a job as medical director of a nursing home when he was thirty-one years old. He didn't know what he was doing, which was, he says now, very much to his advantage. Also, by Thomas's own definition, he had the heart of a salesman—he didn't mind being pushy and he didn't mind being rejected. From the outset, he was discouraged by what he experienced as the absence of life in the nursing home. As he got to know the residents, he identified what he called the three plagues of nursing homes: boredom, loneliness, and helplessness. He decided that the way to combat those plagues was to bring in life…literal life.

The first step in his plan was to put potted plants in every room and create vegetable gardens outside, but plants were not enough. They needed animals as well. The staff balked, because of safety and health concerns and because of state regulations. The codes allowed nursing homes to have one dog or cat, though, so Thomas said let's get two dogs. No, not allowed, replied the staff, but Thomas the pushy salesman insisted, "Let's just write it down for discussion purposes—two dogs."

Next Thomas proposed that cat lovers might not want to interact with dogs, so they would need cats as well. “A cat?” the nursing director objected. “We’re already talking about two dogs.” Well, no, Thomas explained, there were two floors so they would need two cats on each floor, so four cats. Just for discussion purposes. Just write it down. After that Thomas spoke eloquently about the sounds in a nursing home—moaning, PA announcements, television—but no sounds of *life.* No bird songs, for example, which opened the way for him to propose that they should get a hundred birds.

It took many meetings and much rejection, resistance, and persuasion, but Thomas was finally able to convince all parties that what they had written down was at least worth a try to combat the three plagues of boredom, loneliness, and helplessness. The introduction of some actual life was worth a try. His story of the delivery of the birds was all he needed, in my thinking, to make his point (but I admit to being a lot easier to convince than the staff of the nursing home). Somehow the delivery of the birds and the delivery of the cages didn’t get coordinated, so the birds arrived first. Nobody had planned how they were going to take delivery of a hundred birds all at the same time, so the delivery guy released them into the beauty parlor and shut the door and left. The cages came later that day, but they weren’t assembled, so Thomas and the staff put them together as fast as they could, catching birds as they went, while the nursing home residents stood outside the beauty parlor watching through the windows, laughing and laughing.

It would be untrue to the story to suggest that this experiment made everybody happy and glad they had taken the risk. That’s not so—staff members struggled with the adjustment, sometimes resented the additional work load, and experienced difficulty accepting the new environment. On the other hand, everyone could see the difference in the residents. People who were more able wanted to have a turn walking the dogs. Others got very interested in taking care of their own birds. Some could help with the daily feeding rounds, and those with very limited physical or mental capability did what they could. Sometimes that might be watering their own plants, or just observing when the plants were watered or the animals fed. A staffer described taking a resident with

dementia around with her one morning when she fed the birds, and she noted the attention the woman paid to each bird and the comments she made about them. In that moment, the woman with dementia was engaged with what was going on around her, more so than she ever was when she was sitting outside the nurses' station, where someone could keep an eye on her, but where she had no purpose.

Purpose—purpose provides a powerful deterrent to the three plagues of boredom, loneliness, and helplessness, and purpose can be scaled down to accompany the scaling down of our physical and mental capabilities. Taking care of something other than oneself, whether it's a dog or a bird or a garden or a plant in a pot, can take us outside of ourselves and give us something gratifying and rewarding to focus on, and there is plenty of research to show the positive effect that caring for animals has on the well-being of elderly people. Another deterrent to the three plagues is autonomy. Although we often dread giving up our independence as we age, Dr. Gawande points out that nobody is ever completely independent. We rely on others all our lives, especially at the final stages of our lives, even if we do live alone. It's not independence that we crave so much as it is autonomy. To quote Ronald Dworkin, we want to be free to be the authors of our own lives. In the course of his research, Dr. Gawande found over and over again that what mattered to many elderly people was autonomy: they wanted to decide how much risk to take. They wanted to choose what foods to eat, not their doctors or their dieticians or their family members—and that includes the choice to eat the wrong foods or not to eat at all if they didn't feel like it. They wanted to choose how to spend their time and who to spend it with. One of the most important factors in determining a resident's satisfaction in a nursing home or assisted living facility was a private room with a door that locked.

There are, fortunately, assisted living facilities and nursing homes emerging in many parts of the country that take into account their residents' need for purpose and autonomy. Bill Thomas created a nursing home concept he called the Eden Alternative; his was the first, but other Eden Alternatives have followed his model. A friend recently described to me a place he visited with his parents outside Chicago, a model which Dr.

Gawande also described in his book. The residence was organized in pods of sixteen people; each one had a private room, and within the pod there were community rooms: living room, dining room, and kitchen. The caregiving staff stayed in the pods rather than in separate nursing stations, so they interacted with the residents all day. People could spend time with friends or enjoy their privacy, eat when and what they wanted, but they were always close to people who cared for them and could help them if they needed help.

> Atul Gawande writes:
> "Whenever serious sickness or injury strikes and your body or mind breaks down, the vital questions are the same: What is your understanding of the situation and its potential outcomes? What are your fears and what are your hopes? What are the trade-offs you are willing to make and not willing to make? And what is the course of action that best serves this understanding?" *Being Mortal*, p. 259

We don't have to wait until crisis strikes to think about these four questions and discuss them with those who are close to us. In fact, as many of us know from experience, it's far better to begin talking about them now, before we're in a position where we have to make vital decisions with little time for discussion. It's also important that we talk about these four questions now, because our responses are likely to change over time, and change further over the course of an illness. Being at home with these questions, inviting them to our table, so to speak, lets us live with them comfortably and think about them over time without fear or anxiety.

In the best of all possible worlds, UU Fellowship of the Rappahannock would open an Eden Alternative, full of dogs and cats and birds and plants, right here in the Middle Peninsula, and you'd keep a room reserved for me. In the world as it is today, we can be agents of change within our own spheres of influence, even if it's just on behalf of one family member or friend. We can advocate for change when we have the opportunity, and we can encourage conversation among ourselves about how we see

our own aging, potentially diminished lives as rich and purposeful, so that we will never feel the need to ask, “Why can’t I die?”

Atul Gawande says this:

> If to be human is to be limited, then the role of caring professionals and institutions—from surgeons to nursing homes—ought to be in aiding people in their struggle with those limits. Sometimes we can offer a cure, sometimes only a salve, sometimes not even that. But whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person’s life. When we forget that, the suffering we inflict can be barbaric. When we remember it, the good we do can be breathtaking.” *Being Mortal*, p. 260

And so may it be.