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Being mortal 5. "A better life"

In 1991, in the tiny town of New Berlin, in upstate New York, a young physician named Bill Thomas performed an experiment. He didn't really know what he was doing. He was thirty-one years old, less than two years out of family medicine residency, and he had just taken a new job as medical director of Chase Memorial Nursing Home, a facility with eighty severely disabled elderly residents. About half of them were physically disabled; four out of five had Alzheimer's disease or other forms of cognitive disability. Up until then Thomas had worked as an emergency physician at a nearby hospital, the near opposite of a nursing home. People arrived in the emergency room with discrete, reparable problems—a broken leg, say, or a cranberry up the nose. If a patient had larger, underlying issues—if, for instance, the broken leg had been caused by dementia—his job was to ignore the issues or send the person somewhere else to deal with them, such as a nursing home. He took this new medical director job as a chance to do something different.

The staff at Chase saw nothing especially problematic about the place, but Thomas with his newcomer's eyes saw despair in every room. The nursing home depressed him. He wanted to fix it. At first, he tried to fix it the way that, as a doctor, he knew best. Seeing the residents so devoid of spirit and energy, he suspected that some unrecognized condition or improper combination of medicines might be afflicting them. So he set about doing physical examinations of the residents and ordering scans and tests and changing their medications. But, after several weeks of investigations and alterations, he'd accomplished little except driving the medical bills up and making the nursing staff crazy. The nursing director talked to him and told him to back off.

"I was confusing care with treatment," he told me. He didn't give up, though. He came to think the missing ingredient in this nursing home was life itself, and he decided to try an experiment to inject some. The idea he came up with was as mad and naïve as it was brilliant. That he got the residents and nursing home staff to go along with it was a minor miracle. But to understand the idea—including how it came about and how he got it off the ground—you have to understand a few things about Bill Thomas. The first thing is that, as a child, Thomas won every sales contest his school had. They'd send the kids off to sell candles or magazines or chocolates door-to-door for the Boy Scouts or a sports team, and he'd invariably come home with the prize for most sales. He also won election as student body president in high school. He was chosen captain of the track team. When he wanted to, he could sell people on almost anything, including himself.

At the same time, he was a terrible student. He had miserable grades and repeated run-ins with his teachers over his failure to do the work they assigned. It wasn't that he couldn't do the work. He was a voracious reader and autodidact, the kind of a boy who would teach himself trigonometry so he could build a boat (which he did). He just didn't care about doing the work his teachers asked for, and he didn't hesitate to tell them so. Today, we'd diagnose him as having Oppositional Defiant Disorder. In the 1970s, they just thought he was trouble.

The two personas—the salesman and the defiant pain in the neck—seemed to come from the same place. I asked Thomas what his special technique for sales was as a kid. He said he didn't have any. It was simply that "I was willing to be rejected. That's what allows you to be a good salesperson. You have to be willing

to be rejected." It was a trait that let him persist until he got what he wanted and avoid whatever he didn't want.

For a long time, though, he didn't know what he wanted. He had grown up in the next county over from New Berlin, in a valley outside the town of Nichols. His father had been a factory worker, his mother a telephone operator. Neither had gone to college, and no one expected Bill Thomas to go either. As he came to the end of high school, he was on track to join a union training program. But a chance conversation with a friend's older brother who was visiting home from college and told him about the beer, the girls, and the good times made him rethink. He enrolled in a nearby state college, SUNY Cortland. There, something ignited him. Perhaps it was the high school teacher who predicted as he left that he'd be back in town pumping gas before Christmas. Whatever it was, he succeeded far beyond anyone's expectation, chewing through the curriculum, holding on to a 4.0 grade point average, and becoming student body president again.

He had gone in thinking he might become a gym teacher, but in biology class he began thinking that maybe medicine was for him. He ended up becoming Cortland's first student to get into Harvard Medical School. He loved Harvard. He could have gone there with a chip on his shoulder—the working-class kid out to prove he was nothing like those snobs, with their Ivy League educations and trust fund accounts. But he didn't. He found the place to be a revelation.

He loved being with people who were so driven and passionate about science, medicine, everything. "One of my favorite parts of medical school was that a group of us had dinner at the Beth Israel Hospital cafeteria every night," he told me. "And it would be two and a half hours of arguing cases—intense and really great." He also loved being in a place where people believed he was capable of momentous things. Nobel Prize winners came to teach classes, even on Saturday mornings,

because they expected him and the others to aspire to greatness. He never felt the need to win anyone's approval, however. Faculty tried to recruit him to their specialized training programs at big-name hospitals or to their research laboratories. Instead, he chose family medicine residency in Rochester, New York. It wasn't exactly Harvard's idea of aspiring to greatness. Returning home to upstate New York had been his goal all along. "I'm a local guy," he told me. In fact, his four years at Harvard were the only time he ever lived outside upstate New York.

During vacations, he used to bicycle from Boston to Nichols and back—a 330mile ride in each direction. He liked the self-sufficiency—pitching his tent in random orchards and fields along the road and finding food wherever he could. Family medicine was attractive in the same way. He could be independent, go it alone. Partway through residency, when he'd saved up some money, he bought some farmland near New Berlin that he'd often passed on his bike rides and imagined owning some day. By the time he finished his training, working the land had become his real love. He entered local practice but soon focused on emergency medicine because it offered predictable hours, on a shift, letting him devote the rest of his time to his farm. He was committed to the idea of homesteading—being totally self-reliant. He built his home by hand with friends. He grew most of his own food. He used wind and solar power to generate electricity. He was completely off the grid. He lived by the weather and the seasons.

Eventually, he and Jude, a nurse who became his wife, expanded the farm to more than four hundred acres. They had cattle, draft horses, chickens, a root cellar, a sawmill, and a sugarhouse, not to mention five children. "I really felt that the life I was living was the most authentically true life I could live," Thomas explained. He was at that point more farmer than doctor. He had a Paul Bunyan beard and was more apt to wear overalls beneath his white coat than a tie. But the emergency room hours were draining.

"Basically, I got sick of working all those nights," he said. So he took the job in the nursing home. It was a day job. The hours were predictable. How hard could it be? FROM THE FIRST day on the job, he felt the stark contrast between the giddy, thriving abundance of life that he experienced on his farm and the confined, institutionalized absence of life that he encountered every time he went to work. What he saw gnawed at him. The nurses said he would get used to it, but he couldn't, and he didn't want to go along with what he saw. Some years would pass before he could fully articulate why, but in his bones he recognized that the conditions at Chase Memorial Nursing Home fundamentally contradicted his ideal of self-sufficiency. Thomas believed that a good life was one of maximum independence. But that was precisely what the people in the home were denied. He got to know the nursing home residents. They had been teachers, shopkeepers, housewives, and factory workers, just like people he'd known growing up. He was sure something better must be possible for them. So, acting on little more than instinct, he decided to try to put some life into the nursing home the way that he had done in his own home—by literally putting life into it. If he could introduce plants, animals, and children into the lives of the residents-fill the nursing home with them—what would happen?

He went to Chase's management. He proposed that they could fund his idea by applying for a small New York State grant that was available for innovations. Roger Halbert, the administrator who'd hired Thomas, liked the idea in principle. He was happy to try something new. During twenty years at Chase, he had ensured that the facility had an excellent reputation, and it had steadily expanded the range of activities available to the residents. Thomas's new idea seemed in line with past

improvements. So the leadership team sat down together to write the application for the innovation funding. Thomas, however, seemed to have something in mind that was more extensive than Halbert had quite fathomed. Thomas laid out the thinking behind his proposal. The aim, he said, was to attack what he termed the Three Plagues of nursing home existence: boredom, loneliness, and helplessness.

To attack the Three Plagues they needed to bring in some life. They'd put green plants in every room. They'd tear up the lawn and create a vegetable and flower garden. And they'd bring in animals. So far this sounded okay. An animal could sometimes be tricky because of health and safety issues. But nursing home regulations in New York permitted one dog or one cat. Halbert told Thomas that they'd tried a dog two or three times in the past without success. The animals had the wrong personality, and there were difficulties arranging for proper care. But he was willing to try again.

So Thomas said, "Let's try two dogs."

Halbert said, "The code doesn't allow that."

Thomas said, "Let's just put it down on paper."

There was silence for a moment. Even this small step pushed up against the values at the heart not just of nursing home regulations but also of what nursing homes believed they principally exist for—the health and safety of elders. Halbert had a hard time wrapping his mind around the idea. When I spoke to him not long ago, he still recalled the scene vividly.

The director of nursing, Lois Greising, was sitting in the room, the activities leader, and the social worker.... And I can see the three of them sitting there, looking at each other, rolling their eyes, saying, "This is going to be interesting."

I said, "All right, I'll put it down." I was beginning to think, "I'm not really into this as much as you are, but I'll put two dogs down."

He said, "Now, what about cats?"

I said, "What about cats?" I said, "We've got two dogs down on the paper."

He said, "Some people aren't dog lovers. They like cats."

I said, "You want dogs AND cats?"

He said, "Let's put it down for discussion purposes."

I said, "Okay. I'll put a cat down."

"No, no, no. We're two floors. How about two cats on both floors?"

I said, "We want to propose to the health department two dogs and four cats?"

He said, "Yes, just put it down."

I said, "All right, I'll put it down. I think we're getting off base here. This is not going to fly with them."

He said, "One more thing. What about birds?"

I said that the code says clearly, "No birds allowed in nursing homes."

He said, "But what about birds?"

I said, "What about birds?"

He said, "Just picture—look out your window right here. Picture that we're in January or February. We have three feet of snow outside. What sounds do you hear in the nursing home?"

I said, "Well, you hear some residents moaning. You possibly hear some laughter. You hear televisions on in different areas, maybe a little more than we'd like them to be." I said, "You'll hear an announcement over the PA system."

"What other sounds are you hearing?"

I said, "Well, you're hearing staff interacting with each other and with residents."

He said, "Yeah, but what are those sounds that are sounds of life—of positive life?"

"You're talking birdsong."

"Yes!"

I said, "How many birds are you talking to create this birdsong?"

He said, "Let's put one hundred."

"ONE HUNDRED BIRDS? IN THIS PLACE?" I said, "You've got to be out of your mind! Have you ever lived in a house that has two dogs and four cats and one hundred birds?"

And he said, "No, but wouldn't it be worth trying?"

Now that's the crux of the difference between Dr. Thomas and me. The other three that were sitting in the room, their eyes were bugging out of their heads now, and they were saying, "Oh my God. Do we want to do this?"

I said, "Dr. Thomas, I'm into this. I want to think outside the box. But I don't know that I want to look like a zoo, or smell like a zoo." I said, "I can't picture doing this." He said, "Would you just hang with me?"

I said, "You've got to prove to me that this is something that has merit."

That was just the opening Thomas needed. Halbert hadn't said no. Over a few subsequent meetings, Thomas wore him and the rest of the team down. He reminded them of the Three Plagues, of the fact that people in nursing homes are dying of boredom, loneliness, and helplessness and that they wanted to find the cure for these afflictions. Wasn't anything worth trying for that?

They put the application in. It wouldn't stand a chance, Halbert figured. But Thomas took a team up to the state capital to lobby the officials in person. And they won the grant and all the regulatory waivers needed to follow through on it.

"When we got the word," Halbert recalled, "I said 'Oh my God. We're going to have to do this."

The job of making it work fell to Lois Greising, the director of nursing. She was in her sixties and had been working in nursing homes for years. The chance to try a new way of improving the lives of the elderly was deeply appealing to her. She told me that it felt like "this great experiment," and she decided that her task was to navigate between Thomas's sometimes oblivious optimism and the fears and inertia of the staff members.

This task was not small. Every place has a deep-seated culture as to how things are done.

"Culture is the sum total of shared habits and expectations," Thomas told me. As he saw it, habits and expectations had made institutional routines and safety greater priorities than living a good life and had prevented the nursing home from successfully bringing in even one dog to live with the residents. He wanted to bring in enough animals, plants, and children to make them a regular part of every nursing home resident's life. Inevitably the settled routines of the staff would be disrupted, but then wasn't that part of the aim?

"Culture has tremendous inertia," he said. "That's why it's culture. It works because it lasts. Culture strangles innovation in the crib." To combat the inertia, he decided they should go up against the resistance directly—"hit it hard," Thomas said.

He called it the Big Bang. They wouldn't bring a dog or a cat or a bird and wait to see how everyone responded. They'd bring all the animals in more or less at once. That fall, they moved in a greyhound named Target, a lapdog named Ginger, the four cats, and the birds. They threw out all their artificial plants and put live plants in every room. Staff members brought their kids to hang out after school; friends and family put in a garden at the back of the home and a playground for the kids. It was shock therapy.

An example of the scale: they ordered the hundred parakeets for delivery all on the same day. Had they figured out how to bring a hundred parakeets into a nursing home? No, they had not.

When the delivery truck arrived, the birdcages hadn't. The driver therefore released them into the beauty salon on the ground floor, shut the door, and left. The cages arrived later that day, but in flat boxes, unassembled.

It was "total pandemonium," Thomas said. The memory of it still puts a grin on his face. He's that sort of person.

He, his wife, Jude, the nursing director, Greising, and a handful of others spent hours assembling the cages, chasing the parakeets through a cloud of feathers around the salon and delivering birds to every resident's room. The elders gathered outside the salon windows to watch.

"They laughed their butts off," Thomas said. He marvels now at the team's incompetence. "We didn't know what the heck we were doing. Did, Not, Know what we were doing." Which was the beauty of it.

They were so patently incompetent that most everyone dropped their guard and simply pitched in—the residents included. Whoever could do it helped line the cages with newspaper, got the dogs and the cats settled, got the kids to help out. It was a kind of glorious chaos—or, in the diplomatic words of Greising, "a heightened environment."

They had to solve numerous problems on the fly—how to feed the animals, for instance. They decided to establish daily "feeding rounds." Jude obtained an old medication cart from a decommissioned psychiatric hospital and turned it into what they called the bird-mobile. The bird-mobile was loaded up with birdseed, dog treats, and cat food, and a staff member would push it around to each room to change the newspaper liners and feed the animals.

There was something beautifully subversive, Thomas said, about using a medication cart that had once dispensed metric tons of Thorazine to hand out Milk-Bones. All sorts of crises occurred, any one of which could have ended the

experiment. One night at 3:00 a.m., Thomas got a phone call from a nurse. This was not unusual. He was the medical director. But the nurse didn't want to talk to him. She wanted to talk to Jude. He put her on.

"The dog pooped on the floor," the nurse said to Jude. "Are you coming to clean it up?" As far as the nurse was concerned, this task was far below her station. She didn't go to nursing school to clean up dog crap. Jude refused.

"Complications ensued," Thomas said. The next morning, when he arrived, he found that the nurse had placed a chair over the poop, so no one would step in it, and left.

Some of the staff felt that professional animal wranglers should be hired; managing the animals wasn't a job for nursing staff and no one was paying them extra for it. In fact, they'd hardly had a raise in two or three years because of state budget cuts in nursing home reimbursements. Yet the same state government spent money on a bunch of plants and animals? Others believed that, just as in anyone's home, the animals were a responsibility that everyone should share. When you have animals, things happen, and whoever is there takes care of what needs to be done, whether it's the nursing home director or a nurse's aide. It was a battle over fundamentally different worldviews: Were they running an institution or providing a home?

Greising worked to encourage the latter view. She helped the staff balance responsibilities. Gradually people started to accept that filling Chase with life was everyone's task. And they did so not because of any rational set of arguments or compromises but because the effect on residents soon became impossible to ignore: the residents began to wake up and come to life. "People who we had believed weren't able to speak started speaking," Thomas said. "People who had

been completely withdrawn and nonambulatory started coming to the nurses' station and saying, 'I'll take the dog for a walk.'"

All the parakeets were adopted and named by the residents. The lights turned back on in people's eyes. In a book he wrote about the experience, Thomas quoted from journals that the staff kept, and they described how irreplaceable the animals had become in the daily lives of residents, even ones with advanced dementia:

Gus really enjoys his birds. He listens to their singing and asks if they can have some of his coffee. The residents are really making my job easier; many of them give me a daily report on their birds (e.g., "sings all day," "doesn't eat," "seems perkier").

M.C. went on bird rounds with me today.

Usually she sits by the storage room door, watching me come and go, so this morning I asked her if she wanted to go with me. She very enthusiastically agreed, so away we went.

As I was feeding and watering, M.C. held the food container for me. I explained each step to her, and when I misted the birds she laughed and laughed.

The inhabitants of Chase Memorial Nursing Home now included one hundred parakeets, four dogs, two cats, plus a colony of rabbits and a flock of laying hens. There were also hundreds of indoor plants and a thriving vegetable and flower garden. The home had on-site child care for the staff and a new afterschool program.

Researchers studied the effects of this program over two years, comparing a variety of measures for Chase's residents with those of residents at another nursing home nearby. Their study found that the number of prescriptions required per resident fell to half that of the control nursing home. Psychotropic drugs for agitation, like Haldol, decreased in particular. The total drug costs fell to just 38 percent of the comparison facility. Deaths fell 15 percent.

The study couldn't say why. But Thomas thought he could. "I believe that the difference in death rates can be traced to the fundamental human need for a reason to live." And other research was consistent with this conclusion. In the early 1970s, the psychologists Judith Rodin and Ellen Langer performed an experiment in which they got a Connecticut nursing home to give each of its residents a plant. Half of them were assigned the job of watering their plant and attended a lecture on the benefits of taking on responsibilities in their lives. The other half had their plant watered for them and attended a lecture on how the staff was responsible for their well-being.

After a year and a half, the group encouraged to take more responsibility even for such a small thing as a plant—proved more active and alert and appeared to live longer. In his book, Thomas recounted the story of a man he called Mr. L. Three months before he was admitted to the nursing home, his wife of more than sixty years died. He lost interest in eating, and his children had to help him with his daily needs more and more. Then he crashed his car into a ditch, and the police raised the possibility of its having been a suicide attempt.

After Mr. L.'s discharge from the hospital, the family placed him at Chase. Thomas recalled meeting him. "I wondered how this man had survived at all. Events of the past three months had shattered his world. He had lost his wife, his home, his freedom, and perhaps worst of all, his sense that his continued existence meant something. The joy of life was gone for him." At the nursing home, despite antidepressant medications and efforts to encourage him, he spiraled downward. He gave up walking. He confined himself to bed. He refused to eat. Around this time, however, the new program started, and he was offered a pair of parakeets. "He agreed, with the indifference of a person who knows he will soon be gone," Thomas said. But he began to change. "The changes were subtle at first.

Mr. L. would position himself in bed so that he could watch the activities of his new charges." He began to advise the staff who came to care for his birds about what they liked and how they were doing. The birds were drawing him out. For Thomas, it was the perfect demonstration of his theory about what living things provide. In place of boredom, they offer spontaneity. In place of loneliness, they offer companionship. In place of helplessness, they offer a chance to take care of another being. "[Mr. L.] began eating again, dressing himself, and getting out of his room," Thomas reported. "The dogs needed a walk every afternoon, and he let us know he was the man for the job." Three months later, he moved out and back into his home. Thomas is convinced the program saved his life.

Whether it did or didn't may be beside the point. The most important finding of Thomas's experiment wasn't that having a reason to live could reduce death rates for the disabled elderly. The most important finding was that it is possible to provide them with reasons to live, period. Even residents with dementia so severe that they had lost the ability to grasp much of what was going on could experience a life with greater meaning and pleasure and satisfaction. It is much harder to measure how much more worth people find in being alive than how many fewer drugs they depend on or how much longer they can live. But could anything matter more?

IN 1908, A Harvard philosopher named Josiah Royce wrote a book with the title The Philosophy of Loyalty. Royce was not concerned with the trials of aging. But he was concerned with a puzzle that is fundamental to anyone contemplating his or her mortality. Royce wanted to understand why simply existing—why being

merely housed and fed and safe and alive—seems empty and meaningless to us. What more is it that we need in order to feel that life is worthwhile?

The answer, he believed, is that we all seek a cause beyond ourselves. This was, to him, an intrinsic human need. The cause could be large (family, country, principle) or small (a building project, the care of a pet). The important thing was that, in ascribing value to the cause and seeing it as worth making sacrifices for, we give our lives meaning.

Royce called this dedication to a cause beyond oneself loyalty. He regarded it as the opposite of individualism. The individualist puts self-interest first, seeing his own pain, pleasure, and existence as his greatest concern. For an individualist, loyalty to causes that have nothing to do with self-interest is strange. When such loyalty encourages self-sacrifice, it can even be alarming—a mistaken and irrational tendency that leaves people open to the exploitation of tyrants. Nothing could matter more than self-interest, and because when you die you are gone, selfsacrifice makes no sense. Royce had no sympathy for the individualist view. "The selfish we had always with us," he wrote. "But the divine right to be selfish was never more ingeniously defended." In fact, he argued, human beings need loyalty. It does not necessarily produce happiness, and can even be painful, but we all require devotion to something more than ourselves for our lives to be endurable. Without it, we have only our desires to guide us, and they are fleeting, capricious, and insatiable. They provide, ultimately, only torment. "By nature, I am a sort of meeting place of countless streams of ancestral tendency. From moment to moment... I am a collection of impulses," Royce observed. "We cannot see the inner light. Let us try the outer one."

And we do. Consider the fact that we care deeply about what happens to the world after we die. If self-interest were the primary source of meaning in life, then

it wouldn't matter to people if an hour after their death everyone they know were to be wiped from the face of the earth. Yet it matters greatly to most people. We feel that such an occurrence would make our lives meaningless.

The only way death is not meaningless is to see yourself as part of something greater: a family, a community, a society. If you don't, mortality is only a horror. But if you do, it is not. Loyalty, said Royce, "solves the paradox of our ordinary existence by showing us outside of ourselves the cause which is to be served, and inside of ourselves the will which delights to do this service, and which is not thwarted but enriched and expressed in such service." In more recent times, psychologists have used the term "transcendence" for a version of this idea. Above the level of self-actualization in Maslow's hierarchy of needs, they suggest the existence in people of a transcendent desire to see and help other beings achieve their potential.

As our time winds down, we all seek comfort in simple pleasures companionship, everyday routines, the taste of good food, the warmth of sunlight on our faces. We become less interested in the rewards of achieving and accumulating, and more interested in the rewards of simply being. Yet while we may feel less ambitious, we also become concerned for our legacy. And we have a deep need to identify purposes outside ourselves that make living feel meaningful and worthwhile.

With the animals and children and plants Bill Thomas helped usher into Chase Memorial Nursing Home, a program he called the Eden Alternative, he provided a small opening for residents to express loyalty—a limited but real opportunity for them to grab on to something beyond mere existence. And they took it hungrily.

"If you're a young doc, and you bring all these animals and children and plants into a sterile institutional nursing home circa 1992, you basically see magic happen in front of your eyes," Thomas told me. "You see people come alive. You see them begin to interact with the world, you see them begin to love and to care and to laugh. It blows your mind."

The problem with medicine and the institutions it has spawned for the care of the sick and the old is not that they have had an incorrect view of what makes life significant. The problem is that they have had almost no view at all. Medicine's focus is narrow. Medical professionals concentrate on repair of health, not sustenance of the soul.

Yet—and this is the painful paradox—we have decided that they should be the ones who largely define how we live in our waning days. For more than half a century now, we have treated the trials of sickness, aging, and mortality as medical concerns. It's been an experiment in social engineering, putting our fates in the hands of people valued more for their technical prowess than for their understanding of human needs. That experiment has failed. If safety and protection were all we sought in life, perhaps we could conclude differently. But because we seek a life of worth and purpose, and yet are routinely denied the conditions that might make it possible, there is no other way to see what modern society has done.