

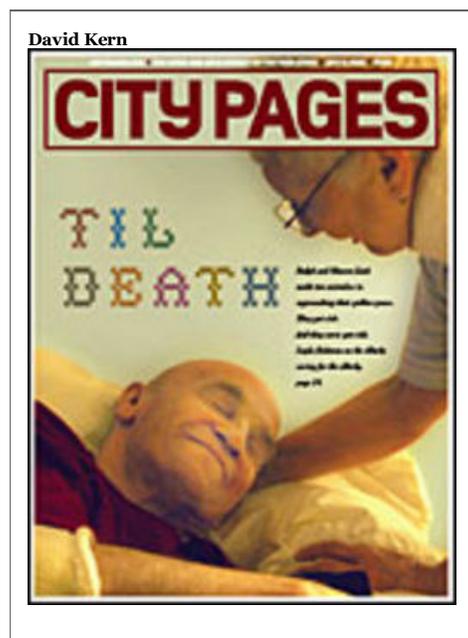
Til Death

After 52 years of marriage, Ralph and Sharon Link still have each other. Yet despite a life played by the rules that's about the only thing that turned out the way they planned it.

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Ralph Link first saw Sharon O'Brien at a party at the university in 1949. She was wearing a pink angora sweater that night, and he decided on the spot that he would marry her. Sharon, she took more convincing. First a double date to a Hepburn-Tracy movie, then a Count Basie concert, then a Lakers game. She'd just about decided she wasn't interested when he said something to her in the crowd, as they were going down the stairs. In the 53 intervening years, she has forgotten exactly what it was he said. "It was the humor," she remembers. "A Ralphism. We connected." Two months later he proposed. They married in 1951, had three kids, endured all the requisite ups and downs.



Their life wasn't grand, but it was so good. They raised the kids and managed to save some money. Eight years ago they sold their southwest Minneapolis house and bought a condo in an Uptown senior complex. There they planned to live out their days indulging in mundane pleasures: sunset walks around the lake, movie matinees at the Uptown, holidays with their kids and grandkids.

As dreams go, theirs were nothing extraordinary. They only seem that way now.

Once Sharon asked Ralph how he had managed to survive that first months-long bout in the hospital in 1996. "He said he didn't want to leave me," she recalls. "If it was his time, he put up a good fight."

The good fight didn't end there. Those seven years have stretched into one long, difficult day.

"Every day is painful for him, looking at me," she says. "I don't want him to be in pain. If I could get through every day and not show any pain and make him think everything's fine, I'd be happy about it. He's in pain every day and he never deserved it.

"I don't dare ask him now if he wishes he hadn't lived through it," she whispers. "I wonder what his answer would be. I wish he hadn't fought as hard as he did. I guess I'm sure his answer would be he wished he hadn't, too."

Ralph Link sits quietly in his wheelchair, which is neatly tucked under the table in the living room/dining room. His 78-year-old head, bald on top, bobs above the newspaper as he surveys the contents through thick bifocals. His angular face and slight underbite point into a gentle smile.

Sharon scurries around the apartment. Her petite frame, 5-foot-2 at most, gives her a delicate appearance, but her stride is determined. This is a woman with things to do. She pops into the foyer gathering laundry, then goes back to the kitchen to get a move on lunch. At 73 she has a no-nonsense air. Her white hair is cropped close and her face is filled with lines. Her sandpapery voice ticks off the things she needs to remember.

She needs to manage all the details--when is the nurse coming? when is the dermatologist appointment? when does the air purifier filter need changing?--because if she doesn't, no one will. Many people have been designated to help them over the years: a battalion of doctors who have treated Ralph; county caseworkers, home health aides, and nurses who were supposed to visit; even sons and brothers and sisters who live in the area. Yet despite them all, Sharon and Ralph routinely are left to their own devices to make it through each day.

The Links aren't the kind of people you'd expect to find falling through the safety net. They're well educated, solidly

middle-class folk. They saved, they planned, they bought insurance. They did everything the way they were supposed to.

And here they are, more or less alone.

Years ago the elderly were routinely trucked off to nursing homes. Today the idea, ostensibly, is to help them stay in their homes, and independent, for as long as possible. The problem is, the services aimed at facilitating that autonomy are increasingly difficult to get, due to program cuts and staffing shortages. Families are more scattered across the country than ever, too.

Sharon Link pours some bottled water ("No tap water for Ralph," she chides) and places a bowl on the table in front of him. It's kind of a khaki-colored pudding: a recipe invented and perfected, Sharon explains, over many months. The present version includes bananas, soy protein powder, egg white powder, and organic apple juice. It's the only way they've found to get Ralph the nutrients he needs in a form he can digest.

"Don't want to spill," he says, as he takes a bite of what they've come to call his "slush."

"I wish we could call it another term," says Ralph, as Sharon leans over his shoulder and puts some drops of medicine and ground-up pills in the bowl. "It looks terrible, but it tastes okay."

It's about 2:00 p.m., time for the afternoon nap. Ralph brushes his teeth as Sharon clears away the lunch dishes. Then she joins him in the bathroom and empties the bags that collect his stool and urine. She wheels him into the bedroom and pulls the chair up against the bed, then grabs a white plastic board that helps him traverse the three feet from his wheelchair to the mattress. He slips on gardening gloves. "They help me grip better," he explains.

What follows is a strenuous session of hard, heavy lifting that no 73-year-old should be expected to perform. Ralph's main job is to pull and steady himself; it's Sharon who does most of the huffing and puffing that goes along with moving him.

"It's like having a baby," Sharon says afterward. "But when you have a child, you go through all the stages. First you can get rid of the bottle, then you get rid of the diapers. Now, none of these stages come.

"I'm concerned about the day that I can't do it. The fact that this body has held up for two years--every day it's amazing I can do it. One day I won't be able to."

It was Sharon who suffered with physical ailments first. In 1983 she contracted Lyme disease, and the result was joint and back pain that made it hard for her to extend her neck up or down. For the most part she was fine, but heavy lifting and turning her head were impossible. Now she wears a neck brace for extra support.

Ralph, on the other hand, had always been healthy--didn't smoke, ate right, exercised. Then, in October 1996, he had a stomach pain while driving to work one day. (Even after retiring, he worked part-time as an insurance inspector.) He drove himself to Fairview Southdale, where Sharon worked as a health unit coordinator. It turned out he had an impacted bowel.

Doctors planned to operate the next day, but in the meantime his kidneys failed. He went into shock and nearly died. For months he was in and out of the hospital, with feeding tube problems, dehydration, and sepsis. By February, doctors had cut out most of his bowel and performed a colostomy to evacuate his stool. His weight had fallen from 170 to 118 pounds. It took two years to recuperate and to master a new set of nutritional habits.

"I didn't think he'd make it back from the colon surgeries," says son Brien Link. "It's incredible that he was even able to come back from that. It testifies to his overall constitution."

Then, two and a half years ago, Ralph slipped on some wet leaves and broke his hip. An ambulance took him, again, to Fairview Southdale. Again there were complications in his surgery, this time due to a problem with anesthesia. First there was the excruciating pain. Then the nurses tried to get him out of bed, and he couldn't stand. A blood clot had formed along his spine, and the doctors operated to relieve the pressure. He was sent to a nursing home for rehab, but it was too late. He was effectively paralyzed from the waist down. (The family has since filed a lawsuit against Fairview Health Services.)

After only a brief stint in rehab, Ralph was sent home, with only Sharon to look after him. They began to realize that the safety net wasn't going to catch them.

Ralph's condition had already been difficult, but now it was even more complicated. He still had the short bowel, the difficult nutrition, the toilet needs--but now, owing to his paralysis, he could no longer take care of himself at all. He needed help to move from his bed to his wheelchair and back. He needed help to bathe. He needed help to empty his ostomy bag, as well as a new leg bag that collected his urine--and to clean up the inevitable spills.

Step by step, the Links discovered that all the support systems they had assumed they could count on were unreliable. Ralph's constant needs precluded the possibility of a move to an assisted living facility; he had to have round-the-clock care and supervision. His very specific dietary needs, on top of his paralysis, would have confounded a lot of nursing homes. And besides, nursing homes are notorious incubators for infections, and even an innocuous one could turn into a mortal crisis for Ralph.

Faced with the truth that there were no good options for Ralph, they came home and made do with their apartment. There's a hospital bed in the den. The cabinets are filled with supplies such as latex gloves and gauze pads. The table is piled with insurance papers and pill bottles. The carpet had to go to make way for linoleum--easier to navigate in a wheelchair and easier to clean. The bathroom door was taken off its hinges to make a little more room for the wheelchair.

But rearranging the apartment was child's play compared to finding the human help they needed. Many of the Links' friends have died or moved away. Her sister in Brainerd can't drive, his brother in Lake City has a hard time dealing with the sickness. Their daughter lives in California. Their sons have helped out when they could, lifting Ralph and running errands. But they can't be there every day. And "they don't do the bags," Sharon notes, sardonically.

In time, the Links figured out how to maneuver through the social service network, eventually qualifying to have a home health care aide come for visits. But the agencies were often short-staffed, unable to send aides when the Links most needed them. Often it became a question of adapting the Links' schedule to accommodate the care workers' needs. And the complexity of Ralph's care only intensified the problem. One aide dropped Ralph in the shower, pulling out his catheter. Another, whom they had grown to trust, left the agency the couple contracted with.

Frustrated, Sharon turned to their church for help. It was such a big congregation; she figured someone would know where she could turn.

"I couldn't believe it," she murmurs. "The two places I trusted most, the hospital I worked for and my church, they both broke my heart. I asked for help and they chose not to help or to listen or to care.

"We're invisible. We're not very pushy people. We're easy to let slide. We don't make a lot of noise," Sharon concedes. "They just passed on it. They dropped the ball. I needed somebody to fight for us."

But no one did.

Some of their problems could be solved with money. If they had the funds, they could buy more health care support. They could modify the apartment, making it easier for Ralph to get into the kitchen or the shower. But even after all those years of saving, they've already run down most of their retirement funds. They've spent Sharon's pension and 401K just to survive this long. The only thing that keeps them out of debt is Social Security and Ralph's monthly pension.

And if he dies, that pension dies, too. Concerns about their financial future terrify the two of them.

"What keeps my mom going is that she's doing it for my dad. That's the love of her life," says their son, Brien Link. "The only thing that keeps Dad going is he's so worried she's not going to be taken care of if he dies. Because when he dies, his pension ends. So he's going to hang on a little longer, hoping there's a settlement from Fairview or litigation. Maybe there's more there if he's alive. He really wants to hang on until they've won that and he's ensured that she's not going to be destitute.

"From Dad's perspective, if he felt like he could die in peace, knowing that Mom isn't going to just have Social Security," Brien Link continues, "he would feel a lot better about letting what has to happen happen.

"Anyone who knows them just sees right away how much they care for each other. She doesn't want Dad to know how hard it's been on her because that'll make it harder for him," he adds. "It's like the Gift of the Magi. They're always thinking about the other person. It's like an endless loop of who's caring about the other more."

One of the consequences of a longer life expectancy is that more people are living with complicated medical

conditions, whether chronic diseases or sudden health-altering events. According to a report by the Minnesota Department of Health's Aging Initiative, in 2000 there were 594,000 Minnesotans over the age of 65. That number is expected to rise to 674,000 by 2010. There's also considerable growth among the above-85 population. The same report shows 85,000 Minnesotans in that group in 2000, with an anticipated 121,000 in 2010.

And that's to say nothing of the coming explosive growth of the elderly as the baby boomers age. How and where to take care of this population is a looming question, especially since more and more people want to stay at home for as long as possible.

"This is a gigantic experiment," says Steven Miles, a professor of medicine and geriatrics with the University of Minnesota's Center for Bioethics. "We have never before in human history ever faced this kind of demographic transition of having 20 percent of the population in a category called elderly. It just hasn't happened."

But even as the need is poised to skyrocket, our social service systems are woefully ill-equipped to deal with it.

"We have not matched the commitment to keeping people out of nursing homes with the commitment to create sustainable systems to keep them in the community," says Miles. "It's fair to say that we have a crisis of caregiving that has become extraordinarily severe."

Part of the problem is the U.S. health care system and medical training programs. While there are more than 160,000 medical students and residents in the United States, Miles notes that only 120 doctors graduate with a specialty in geriatrics. "Which is just crazy," he says.

Beyond that, our health care system is designed to deal with acute problems, he adds, rather than the chronic problems and disabilities that invariably arrive with old age--and, over time, cost more.

"Health care has to be universally available, and designed to work as well in the clinic as in the hospital, and incorporate home health care needs," he stresses. "We need to move to the idea that disability is a normal part of the life cycle, particularly toward the end."

That, in part, means changing the way we view, and compensate, jobs like home health care aides, who, according to Miles, may make as little as \$6 an hour.

"The payment rate for home health care aides is so incredibly low," agrees Anita Raymond, a social worker with the nonprofit social service agency Volunteers of America Minnesota. "People leave home health care jobs to work in a fast food restaurant, because the pay is about the same and it's less stressful. As a society we value independence, we value the concept of helping older adults stay home. But the basic work--the people who deal with the bodies and the bodily fluids--somehow as a society we aren't valuing that work enough to pay."

"We have to invest in getting more people into this work," says Kathleen Kelso, executive director of the nonprofit Advocacy Center for Long-Term Care. "We have to have an investment in long-term support. We have to have an investment in training. We have to understand the care of the aged. We have to care for people differently as we age, and none of that is being covered. That should become a fundamental part of health care today--not just an add-on."

And in the interim, the burden of caring for the old and frail falls on families, most often on the women--the wives and the daughters.

It was a winter afternoon like all the rest: a gray sky outside, Ralph napping on his hospital bed, Sharon rushing around the apartment doing chores. The washer and dryer in the apartment weren't working, so Sharon left the door ajar and went down the hall to throw in a load. On her way back she stopped to chat with a neighbor.

And then she heard the screaming.

Through the cries of pain she heard Ralph's voice, so rarely raised during their five decades together: "I hate the fact that I'm paralyzed." He was still shouting as she sprinted down the hall, into the apartment.

In his sleep, somehow, he had rolled into an uncomfortable position, but the trapeze hanging above the bed wasn't down for him to grab on to, and he didn't have enough arm strength to shift his body.

Sharon helped him roll over, then lay down next to him. "If you dwell on the anger, you're going to get depressed," she told him. "If you get depressed, you're not going anywhere but down. Let's hold each other and then move on."

A week later, Ralph thinks about the incident, a little embarrassed at his loss of control. "I just was mad, I guess at the whole world," he says. "I just let it out for a few minutes."

Growing old is freighted with psychological potholes. Growing old with a chronic condition, or taking care of someone with a chronic condition, is even more demanding. "There is a high incidence of depression, a high incidence of being run down in dealing with the system all the time," says the U of M's Miles. Beyond that, family caregivers often have a higher mortality level, due to the stress, the depression, and their own neglected medical issues. And the suicide rate of older people--especially older men--is much higher than that of young people.

The pressure a chronic illness places on individuals, and relationships, can be extreme, notes Ken Hepburn, a professor and associate dean for research at the University of Minnesota's School of Nursing. "There's what's happening to the person, all the extra work I have to do as a result, and what's happening to us," he says. "When a chronic disease enters the picture, the scene is changed in a temporal fashion. It'll never go away. Hopes and dreams get altered, and there's a disappointment factor."

Isolation is an added burden, he says, whether you're used to spending time with lots of friends, or just a few, or simply enjoy going to movies and people-watching. "We live in a social world," Hepburn says. "Chronic disease prevents you from living in that world. It's a very substantial loss."

The stress can lead to increased agitation and snapping at one another--even the preternaturally steady Sharon Link admits she's raised her voice at Ralph on occasion ("I have to try not to do that," she laments. "He just retreats.") Under extreme circumstances, the pressure boils over into neglect or abuse. But that, Miles says, is more the exception than the rule.

"It's not so common," he says. "Generally these people really love each other."

That love, like the Links' love, helps explain why so many elderly and sick people are taken care of by their families.

"The phenomenon is not rare," Miles explains, then spins off a dazzling array of statistics to bolster his point.

"There are 26 million [informal] caregivers in the United States," he says. "Half give less than eight hours, the other half more than eight hours. A third give between 21 and 40 or more hours each week." The unpaid work of these family caregivers, he adds, is valued at \$200 billion to \$250 billion each year.

Beyond that, he notes, one-third of families assume the major caregiver role for a sick person and have a specific person as the set caregiver. Of those, one-third lose all or most of their life savings, and one-third lose their major income source.

At the same time, the changing nature of families in the United States makes it even tougher for them to manage the burden. Families are more decentralized than ever, with kids often moving hundreds, if not thousands, of miles away from their parents. While this is especially significant in rural areas, "it happens pretty much all over," Miles says. "You wind up with families trying to make do, working long distance with social service agencies.

"If family is not available for an older person in the area," he adds, "there's an increased chance that the older person will be neglected or exploited by various folks."

Even when the family is local, Hepburn adds, the health care system isn't really set up to help those families cope.

"Families are what keep people at home, but they don't have the training to do it," he says. Nor is there communication in place between hospitals, nursing homes, home health care aides, and families to help the old and sick stay independent. "Hospitals are not responsible for my independence. They are responsible to their own bottom line and to getting me out of the hospital safely."

Today, he says, there are no bridges among our health care organizations. Those must be built, and then extended to reach the families.

Until then, seniors like the Links are likely to be in a position to fend for themselves. Kathleen Kelso notes that the system only caters to those who know how to manipulate it. That means, in short, that on top of dealing with the daily stresses of survival, folks in need must also make enough noise to demand support.

"People don't plan for this. It's not in our human nature," she admits. "You have to learn to cope, and at the most vulnerable point in your life."

Ralph is once again sitting at the dining room table, a bowl of slush in front of him. It's a few minutes before 9:00 a.m. and the home health care aide is getting ready to leave.

She tells him it was nice to meet him, shakes his hand, and takes off.

Ralph has been home for several days now, after weeks in the hospital and a nursing home for rehab. The doctors are still trying to kill off a bacterial infection they think is hiding behind his heart, so he takes two kinds of antibiotics--one delivered in a constant drip, the other a shot administered once daily. Sharon has to give Ralph the shot. Squeamish, she didn't think she'd be able to do it. But now it's become just another of those things she does out of necessity.

The home health care aide situation is still complicated. When Ralph was first discharged from the hospital, Sharon worried they wouldn't have any help at home. Then they hoped they'd be able to get services from an agency where one of their previous aides now works. (He just adores Ralph, Sharon says. He still stops by a couple of times a week, on his own. Sharon can't pay him, but she offers him gas money.)

But now they've learned that the agency doesn't have enough staff to pick them up as clients. So, for the foreseeable future, they're likely to get someone new every day.

"You train these people and then they never come again," Sharon complains. "You need consistency. Someone who can tell, is this wound getting better, or worse?"

So again, they're at the mercy of an overburdened system. "You get a change in schedule for an aide, and you've got to adapt your schedule to theirs rather than the other way around," Ralph says.

But despite the difficulties, they're just relieved to have Ralph at home again. Memorial Day marked their 52nd wedding anniversary. It was a lovely day, sunny and mild. That evening they went down to the garden outside their building, where there's a new glider on the patio.

"I sat in the glider, and he pulled up next to me," Sharon says, a lilt of happiness for once caressing her voice. "We looked at the gardens and the sky."

Those simple moments are so sporadic now. Yet when they come, there's still hope. And that, for now, is enough to carry them through. "I told him," she continues, thinking back to that anniversary evening, "that I've got a good feeling."