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Alone in Illness, Seeking Steady Arm to Lean On

By **JANE GROSS**

Every time Grace McCabe is handed a form in a doctor's office asking for an emergency contact, the blank space makes her shiver.

It is such a simple question for anyone with a spouse, partner or children. But Ms. McCabe, 75, has always lived alone. Who would stand by her in a crisis? Who would be there for her in the worst of times?

These were once hypothetical questions. But now Ms. McCabe's slowly fading eyesight is almost gone. She has always had lots of friends but had never asked one to take responsibility for her, to answer the middle-of-the-night telephone call from the emergency room, say, or to pay her bills because she cannot write checks herself.

Of all her friends, she has fixed on one with a good heart, a steady hand under pressure and a talent for problem solving. So time and again, she writes "Charlotte Frank" in the blank space and lightens the moment by calling to say, "Charlotte, you're on another list."

When Ms. McCabe was knocked to the crosswalk by a reckless driver and suffered a concussion, Ms. Frank, 70 and herself single, stayed overnight on the living room couch. When Ms. McCabe could no longer see standard type, Ms. Frank got her a computer and set the font to its largest size so she could read the newspaper and order from catalogs.

"You find out there are good friends who become great friends," Ms. McCabe said. "Charlotte told me to 'grab on,' both literally and figuratively, and I did."

There is no way to calculate how many Americans of all ages living alone happen to be sick or disabled, but hospital discharge planners and home health care agencies say they are serving more single people without an obvious person to look after them.

The growing number of single-person households - including the never-married, divorced and widowed - is evident in census reports. In 2003, nearly 27 percent of American households consisted of one person living alone, up from 18 percent in 1970, putting a premium on friendship, a relationship without the legal status or social standing of kin. And demographers warn that the graying of the baby boom generation will swell the ranks of single-person households, with illness and disability an inevitable corollary of old age.

People living alone are among the most difficult cases, said James Bentley, a senior vice president at the American Hospital Association. Anyone who is sick or disabled, Mr. Bentley said, "needs someone to quarterback their care," both in the hospital and afterward, but people who live alone can end up being their own quarterbacks at a particularly vulnerable time.

"The patient can't be at both places at once mentally," he said, "but we don't yet have a good mechanism to address that."

Making the situation worse is the increase in short stays in hospitals, which sometimes send people home before they can manage alone. Mr. Bentley said that hospitals must develop new ways of preparing such patients for what lies ahead and that people who live alone must "think, before they are ill," what organized networks they have to call upon.

"If we wait until the baby boomers need this, there'll be so many of them it will be impossible to manage ad hoc," he said. "It's something we need to think about now, or it's going to be an absolute mess."

Some single people need help with a temporary medical crisis, like a knee replacement that makes it impossible to bathe without help or climb stairs. Or the problem can be permanent but not life-threatening, like Ms. McCabe's fading sight, a result of rod-cone dystrophy. Her peripheral vision is gone, and what she can see seems draped in muslin, so her friends accompany her on errands and help with paperwork.

Then there are the grave illnesses, like [cancer](#) or Parkinson's disease. When a patient has no family member in charge, who sits sleepless in the surgical waiting room? Who argues with the insurance company, knows the dosage of each medicine, or calls far-flung loved ones with good news or bad?

To be sure, a spouse or grown children are no insurance policy against suffering or mortality. But people who live alone without the obvious next-of-kin for those emergency contact forms must rely on patchwork support from professionals and friends. And accepting help, let alone asking for it, may not come naturally after years of self-sufficiency.

"Maybe they haven't asked for a lot of help until now," said Christine Nolin, a social worker at CancerCare, which provides an array of free services for cancer patients. "Good for them. But this is a different time in their life. It's our job to help people get comfortable with asking."

A large circle of friends, in and of itself, may not be an answer. Take Roberta Van Laven, 71, a widow of 15 years whose daughter lives in [Australia](#). Ms. Van Laven has friends from her former job as a technical writer for the City of New York, friends from her book group, friends who share her love of opera.

Now this proud woman has advanced ovarian cancer. Over the course of several years, recurrences and rounds of treatment, friends have offered to accompany her to chemotherapy, but she will not permit anyone to sit with her for six hours, though the distraction might be welcome. "I tell them I'm saving them for an emergency," she said. "But it's really that it's just so hard to accept help."

A New Kind of Need

The wish for unconditional care from a family member must surely be primal, so hard is it to give up.

Barbara R., a 68-year-old former college professor, would have loved to have her older sister by her side last winter when she was given a diagnosis of breast cancer, had a lumpectomy, waited for the pathology report and went through radiation treatment.

"There is a kind of unconditionality and consistency when a family member cares for you," Barbara said.

But she knew her sister already had her hands full, with an elderly partner who had serious emphysema. "He needed her more than I did," Barbara said, acknowledging the hard truth single people face when relatives and friends have other, more pressing, responsibilities. (Barbara asked not to be identified fully because some relatives and colleagues are unaware of her illness.)

Barbara knew she was entering the parallel universe of illness with many advantages. She had always been single, socialized regularly and belonged to an array of women's organizations. "Friendship has been the organizing principle of my life," she said.

But as she faced a new level of neediness that could overwhelm even the most loving friends, her goal was to make sure "that no one person had to shoulder too much." The best way to do that, she figured, was to match her friends to the tasks they would be best at and that would fit their individual schedules.

Barbara chose friends who had had cancer to join her at doctors' appointments when she was assessing treatment options. She chose those who shared her love of art and theater to keep her distracted with outings to see Christo's "Gates," the art installation in Central Park, or the play "Thom Pain (Based on Nothing)" while awaiting the pathology report. The many excellent cooks among her friends stocked the freezer with homemade soup or brought dinner to a houseful of visitors after her lumpectomy, turning a dreaded day into something almost festive.

One night when Barbara felt especially shaky, she called a neighbor cherished for her calm demeanor and invited herself to dinner. They pooled the contents of their refrigerators and shared a bottle of Hogue fumé blanc. The day of her operation, she chose a college classmate who entertained her beforehand with chatter about a recent trip to Tasmania and joined her in the recovery room afterward to hear the surgeon declare that her lymph nodes were fine.

Barbara's hardest choice was whom to ask to sleep over after the operation, which meant an uncomfortable night on her living room couch. One friend who offered had pulmonary problems and was exhausted from caring for a 97-year-old mother. Another, with a bad knee, had just returned from a sister's out-of-town cancer operation. This was not the time, Barbara knew, to be worrying about anyone else as she surely would if she chose one of those friends.

Instead she called an acquaintance, a retired physician, who is part of a neighborhood group Barbara recently joined. All its members are women. All live nearby. Their purpose is to be available to one another in times of need, like when someone requires a companion for the trip home after a colonoscopy.

Barbara sees such nascent groups, and her own web of relationships that she calls a "mandala of friendship," as models for the growing cohort of people facing illness and old age alone. "Our whole society is organized around nuclear family," she said. "Legally, culturally, friendship doesn't have much standing. How do we get beyond that? How do we create the kind of communities for ourselves that make caretaking easier?"

Help in a Crisis

Elvia Moran, 37, has been on her own since emigrating from [Ecuador](#) as a teenager. So she came to a premature health crisis with courage and good cheer that few others could muster.

Watch her shuffle on a walker from the living room to the bedroom of her Yonkers apartment and gaze into the mirror, as if she did not even notice her body wasting under the assault of amyotrophic lateral sclerosis, or Lou Gehrig's disease. Instead, her dimples flash as she admires her freshly washed hair, blown dry and styled by her best friend, Cristina Martinez.

The pair giggle and gossip in Spanish, like two young girls playing beauty parlor. Ms. Martinez says her friend needs a better styling brush to tame the frizzies. But Ms. Moran is more than satisfied.

"Oh, Cristina, I look beautiful!" she said. "Thank you! Thank you!"

Ms. Moran says she would be lost without Ms. Martinez, whom she met nearly 20 years ago when they both lived in the same building. On daily visits, Ms. Martinez prepares Ms. Moran's favorite chicken soup, spiced with onion, garlic and lime. She folds laundry and rearranges the furniture to clear a safe path. She lends Ms. Moran money until her disability payments begin.

It is money Ms. Martinez cannot spare since she stopped looking for work when Ms. Moran received her diagnosis last winter. And it is time away from her own family in Harlem, where her husband, a restaurant worker, is left to tend to their 3-year-old daughter.

But for these two women there are none of the boundaries that usually distinguish friends from kin. "She is for me like a sister," Ms. Moran said. "There is nobody else in the world with a heart like that."

Ms. Moran's dark prognosis came shortly after her triumphant graduation from Westchester Community College, which was to have been her ticket out of a job at a cosmetics factory. Within months she could not walk unassisted. Her hands were weak and her speech slurred. Doctors at NewYork-Presbyterian/Columbia hospital told her that before long she would need a respirator to breathe and a feeding tube for nourishment. She said she wanted neither and gave Ms. Martinez her health care proxy. Her friend cried as she signed the forms.

Ms. Moran is in the [United States](#) without relatives while her mother in Ecuador pleads for a visa to come help. Ms. Martinez tried to move her friend closer to her own apartment but was unable to find a place on the ground floor or with an elevator for less than \$800 a month.

"I don't want her to feel lonely and be depressed," Ms. Martinez said. "She should be with people she knows, all the time."

For a while Ms. Moran managed at home with weekly visits by a nurse, a social worker, a physical therapist and an occupational therapist. An aide came four hours a day, five days a week. When all the helpers were gone, things got scary and Ms. Martinez wished she could stay overnight, an impossibility with a toddler at home and a husband already irritated by her long absences.

Once, Ms. Moran scalded her wrist when a pot of boiling water slipped from her hand. She called nobody, instead lecturing herself aloud to "Be strong!" and applying toothpaste to the burn, as is customary in her native country. Another time her body convulsed and she was rushed to the hospital, alone. Ms. Martinez found her there the next day, in a soiled hospital gown, and marched to the nurses' station to demand attention. But bravery and devotion are no match for this relentless disease. As spring turned to summer, Ms. Moran had no choice but to move to a nursing home in Westchester County.

Ms. Martinez, unfamiliar with commuter rail lines and struggling with English, tried to get from Harlem to the nursing home in Valhalla. Once, on a mystifying series of buses, the trip took three hours. Another time, using a car service, she spent \$80. Her husband's annoyance turned to anger. But Ms. Martinez was undeterred.

"Elvia, she don't have anybody," Ms. Martinez said. "So whatever he says I keep running and running."

Even now, barely able to speak, and confined to a wheelchair, Ms. Moran returns her friend's kindness the only way she knows how. "Cristina doesn't like it when I cry," she said. "So I try for her always to smile."

Fear of Being a Burden

Frank Daykin spent 17 days in the intensive care unit at St. Vincent's Manhattan Hospital last October, on a ventilator after a life-threatening reaction to chemotherapy for a rare form of lymphoma. Had he been alone, Mr. Daykin wondered, what health care decisions would have been made on his behalf and who would have made them?

But his friend Carol Kaimowitz watched over him. She was the one, at the doctor's request, who called his father in [Nevada](#) to say the end was near. She was the one who gave the approval for mysterious medical procedures and then worried they might kill him. Later she would admit to Mr. Daykin that "it was the darkest, most frightening time."

Mr. Daykin, 47, and Ms. Kaimowitz, 59, met through their chamber music; he is a pianist and she a soprano. Both describe their collaboration as the most intimate relationship in their lives. But until Mr. Daykin's illness they spent little time together away from rehearsal or recital halls.

Then Mr. Daykin woke in the night in his Queens apartment to blinding stomach pain. Like many people who live alone, he convinced himself it was something minor, like food poisoning, that could wait until the next morning. Only then did he board the subway for the hospital.

There, without forethought or pause, he asked that Ms. Kaimowitz be called at her Midtown home. "I just thought of the most responsible person I could imagine," Mr. Daykin said, "and that was Carol."

A tumor had perforated Mr. Daykin's colon, the first indication of lymphoma. From Day 1, Ms. Kaimowitz stayed by his side, "a quiet, persistent, unconditionally supportive presence," Mr. Daykin said. She went along to all his doctors' appointments because Mr. Daykin said, "I didn't completely trust my own ability to hear what I was being told."

In the hospital, she played Scrabble or read him German poetry or music reviews. She assured him, more than once, that this was where she wanted to be. He needed that to be true and stopped asking why.

Through a year of emergency operations, aggressive treatment and frequent hospitalizations, Ms. Kaimowitz never flinched. "I don't know what thoughts were going through her head," Mr. Daykin said. "But to me she seemed unflappable."

That was her intention. "I sometimes felt helpless, overwhelmed, even useless," she said. "But I tried not to let him know. I just kept going, controlled my emotions when I was with him and then went home and cried."

Several other friends helped out. One kept an appointment with the superintendent when the bathroom ceiling caved in. Another took Mr. Daykin to treatments and helped with paperwork. A third, a nurse who visited after his own 12-hour shift at another hospital, spoke knowingly with the medical team. All of them lifted Ms. Kaimowitz's spirits when she found herself flagging.

Like many independent people, Mr. Daykin's greatest fear was "to become a burden to anyone; to incur obligation."

So at home, between hospitalizations, he insisted on enough privacy "to renourish myself, as it were, in the way I'm accustomed." Ms. Kaimowitz baked chocolate chip brownies to fatten him up. But she visited only weekly, as he wanted.

In the hospital, by contrast, Mr. Daykin bowed to dependence. He said he "understood in some deeper part of myself, that is wiser than the 'everyday' part of myself, that I was in big trouble. So I tried to accept whatever came my way with a measure of grace."

Mr. Daykin has resumed performing, his health is stable and he is hoping for the best. The two friends are planning a European vacation. Ms. Kaimowitz said they were closer than ever. "We talk easily and often about everything, she said. "We e-mail one another our bad dreams. I have other close friends. But there is no one in my life like Frank, who I could hope would care for me during a serious illness."

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