

The New Old Age
Caring and Coping

When There's No Family

By Paula Span September 23, 2013 12:10 pm

I rarely write about advance directives and end-of-life discussions without a few readers asking, sometimes plaintively: What if you don't have a family?

"The presumption is that everyone has someone available, someone most likely younger or in better health, and better able to carry out one's wishes or make decisions with your guidance," Cheryl from Westchester commented the last time the subject arose.

But not everyone does. Ten years ago, the American Bar Association's Commission on Law and Aging looked into this problem and cited estimates that perhaps 4 percent of older adults are "the unbefriended elderly," a chilling phrase referring to those who can't make decisions for themselves, have no advance directive or surrogate decision maker, and have no family or friends able to assist.

Most of those aren't computer-literate Times subscribers trying to plan ahead, like Cheryl. They're primarily lifelong loners in hospitals and nursing homes, the report found.

But it's an important question: If you don't have relatives or close friends who can serve as your health care proxy or hold your power of attorney (which

in most states involve two separate documents) are you supposed to resign yourself to whatever the emergency room physician or intensive care staff member decides to do, or not do, when you can't direct your own care?

Even when you've written advance directives, someone has to bring those documents to the attention of medical personnel. That person may have to become a forceful advocate on an incapacitated patient's behalf. If not a sibling or nephew, a friend or neighbor, who can do it?

One solution I've discussed before is a care committee: A senior recruits a cadre of friends and professionals, makes her values and preferences clear, and authorizes the committee to handle a variety of eventual decisions.

Steven M. Cohen, an elder law lawyer in Boston, has organized about 20 of these. "I can't say the idea has taken off, but for the right person it can work really well," he said.

Though most of his clients haven't activated their committees yet — they're still functioning well on their own — one man with Parkinson's disease has experienced worsening symptoms. "As his illness has progressed and he's withdrawn, the committee is taking more on," Mr. Cohen said.

You can also turn to professionals.

You can appoint almost anyone your health care proxy; the exception is that 38 states plus the District of Columbia place some restrictions on treating health care providers or their employees. In some states, "your cardiologist can't be your health care proxy," said Charles Sabatino, who heads the American Bar Association Commission on Law and Aging. Neither can a nurse-practitioner who works in your cardiologist's practice, or a social worker employed by the nursing home where you live. In other states, all of the above could be.

But you can always ask an independent professional: a lawyer, especially

an elder lawyer, or a geriatric care manager (generally a social worker who specializes in helping seniors manage their care).

The problem may be finding someone willing to shoulder that task. “Professionals are hesitant to get involved in this,” Mr. Cohen said. “You can’t make a more intimate choice for someone. It’s hard enough for families.” He’ll serve as a client’s decision maker occasionally, if he knows the person well, but doesn’t welcome the role.

Many elder lawyers feel that way, said Craig Reaves, former president of the National Academy of Elder Law Attorneys. Being someone’s surrogate means being willing to drop everything when a crisis strikes, and to continue monitoring when a client is hospitalized or needs long-term care.

“This is not a job for which an attorney can ethically charge a fee that is anything near the attorney’s normal hourly rate, if any fees are charged at all,” he said in an e-mail. And, lawyers being lawyers, he worries about liability. Mr. Reaves has taken on the role at times, “but I do not seek this job out.”

Geriatric care managers seem a better fit; they’re comfortable in hospitals and nursing homes and charge lower hourly rates than lawyers. Karen Wasserman, director of Your Elder Experts, part of Jewish Family and Children’s Services in Boston, serves as surrogate for a 97-year-old Holocaust survivor with no family, and she’s starting to see healthy people in their 70s putting their paperwork together and asking her staff to take that role.

“I don’t see it as that big a leap,” Ms. Wasserman said. “Often, it’s continuing the work we do anyway, advocating for our clients,” whom the staff has often known for years. “It’s often an honor to be there for these people. It’s part of the deal.”

Yet three of the nine care managers on her staff are uneasy with the responsibility and decline to serve as health care surrogates. At LivHome, a geriatric care management chain with branches in seven states, company rules

won't permit the staff to be proxies. "Somehow, it just doesn't feel right to me," said Bunni Dybnis, director of professional services.

Of course, courts can appoint legal guardians or conservators for incapacitated seniors, and guardians — often attorneys or geriatric care managers — can then make decisions on their behalf. But most seniors don't want to relinquish their autonomy in that way.

If you're thinking this all becomes a bit of a muddle, I agree. It's another way in which our traditional cultural expectations for aging — the Waltons-like family nearby pitching in to provide care and guidance — clash with the reality that more than a million older people may lack available family or friends. Extended life spans mean that people may have outlived their relatives, and many of them will suffer dementia.

Given that this situation will likely worsen for the baby boomers — who had fewer children, more childless marriages and more divorces — we may see the rise of professionals serving as clients' late-life surrogates. How individuals will pay for that is another question.

Meanwhile, people trying to plan ahead for aging without family will need detailed advance directives and a P.O.L.S.T. form as they near the end of life to tell physicians what to do. Then they're also going to need luck in finding a committee or a trustworthy professional willing to take on this daunting responsibility.

"We're in this interim period," Mr. Cohen said. "And we don't have good answers for people."

Paula Span is the author of "When the Time Comes: Families With Aging Parents Share Their Struggles and Solutions."