



FINDING YOUR WAY

WEB SITES

**"Your Guide to Choosing a Nursing Home"** is a booklet available from the Health Care Financing Administration of the U.S. Department of Health and Human Services, 7500 Security Boulevard, Baltimore, Md. 21244. Write or call (800) 633-4227, or visit online at [www.medicare.gov/Publications/Pubs/pdf/nhgguide.pdf](http://www.medicare.gov/Publications/Pubs/pdf/nhgguide.pdf)

**American Association of Homes and Services for the Aging** offers information on how to connect with 6,000 nonprofit providers nationwide who offer various levels of care, including supportive senior housing, continuing care retirement communities, adult day care, assisted living and board and care homes, as well as nursing homes; [www.aahsa.org](http://www.aahsa.org).

**Medicare's** Web site offers the Nursing Home Compare database, with information on every Medicare/Medicaid-certified nursing home in the country, organized by state, county and city; [www.medicare.gov/Nursing/Overview.asp](http://www.medicare.gov/Nursing/Overview.asp)

**AARP** has four free booklets on nursing home care — "Choosing Good Care: A Family Guide to Finding a Nursing Home" (D17064); "Paying for Nursing Homes: Understanding Medicaid" (D17249); "Solving Nursing Home Problems: A Guide for Families" (D17065) and "Partners in Caring: A Family Guide to Working with Nursing Assistants for Better Nursing Home Care" (D17310). Send a postcard or letter to AARP Fulfillment, 601 E St. N.W., Washington, D.C. 20049, or by visiting [www.aarp.org](http://www.aarp.org).

BOOKS

**"Choosing Medical Care in Old Age: What Kind, How Much, When to Stop,"** by Muriel Gillick (Harvard University Press, 1994; \$19.95)

**"Changing Places: A Journey With My Parents Into Their Old Age,"** by Judy Kramer (Riverhead Books, 2000; \$24.95)

**Consumer Reports Complete Guide to Health Services for Seniors: What You and Your Family Need to Know About Finding and Financing, Medicare, Assisted Living, Nursing Homes, Home Care, Adult Day Care,** edited by Trudy Lieberman (Consumer Reports, 2000; \$18.95)

**"Choosing a Nursing Home: A Step-by-Step Guide,"** by Rick Wilfong (ZWI and Associates, 2000; \$19.95)

For more resources, go online to [www.findingourway.net](http://www.findingourway.net)

ABOUT THE AUTHORS



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# Changing places

## For many Americans, care facilities will be the last homes they know

BY MURIEL GILLICK AND LEN FISHMAN

Putting my mother in a nursing home was the hardest decision I ever made. Ever," said Cynthia Cooper, recalling the day just over three years ago when she knew her mother could never return home.

Her mother, Frances Zaft, had lived in her own apartment in Randolph, Mass., with minimal outside help until, at age 88, she underwent a hysterectomy. She sailed through the surgery, only to develop a major infection a few days later, leading to a prolonged hospital stay and transfer to a rehabilitation facility. Weak, debilitated and depressed, she needed help with dressing, going to the bathroom, even getting out of a chair.

"The only alternative to her going to a nursing home would have been moving in with me," said Cynthia. "That would have meant my husband moving out. She needed so much care."

For people like Frances, who require skilled nursing care as well as physical therapy, a nursing home is the only answer. Currently, 24 percent of Americans over the age of 85 live in a nursing home. According to projections by Peter Kemper and Christopher Murtaugh, published in the *New England Journal of Medicine* in 1991, 43 percent of Americans over the age of 65 will live in a nursing home for some period before they die.

They face a series of challenges: Choosing the right home, finding ways to make life meaningful in their new surroundings and, ultimately, making decisions about how they will die. As Cynthia found out, the process can be a complex one.

Because her mother was a patient in the New England Sinai Hospital, the social work department there matched her up with a home. "It was clean and the care was good," Cynthia recalled, "but my mother wouldn't eat the food there. There was no Jewish-style cooking, nothing she was used to. That's when I realized I had to arrange for her to be admitted to the Hebrew Rehabilitation Center for Aged in Boston."

Adjusting to nursing home life was not easy for mother or daughter. Frances lived in a double room and complained that her first roommate was downright nasty to her. Occasionally, a lost male resident wandered into her room to use her bathroom.

"My mother was miserable at first," Cynthia said. "But she had a wonderful nursing assistant. She literally brought my mother back to life. She made such a difference in her mental stability. And, frankly, in mine."

But that wasn't the end of the decisions Cynthia would make about her mother's care. When Frances arrived at Hebrew Rehab, the facility social worker asked her to choose a health-care proxy — the person doctors would turn to for help in making difficult medical decisions if Frances were unable to make her own. She readily selected her daughter.

Cynthia's decision-making abilities were put to the test early on in her mother's stay. The nursing home physician asked Cynthia whether cardiopulmonary resuscitation should be attempted if her mother's heart stopped and she was not breathing. "We had talked about what my mother would want in terms of medical care if she got sick again. Whenever a friend developed a problem and had an operation or a procedure, I would ask my mother, 'Would you want that if you were in her shoes?' Mom told me that she wouldn't want me to keep her alive with machines. So I knew what she wanted."

Many family members don't find this decision an easy one, even though, according to a 1989 study by Don Murphy and colleagues in the *Annals of Internal Medicine*, the odds of a nursing home patient surviving a cardiac arrest are less than 3 percent. And the rare elderly survivor, reports a 1996 article in the *Archives of Internal Medicine*, often can no longer dress or walk independently.

Back in 1998, Cynthia thought any medical intervention short of CPR would make sense for her mother. She hoped Frances ultimately would regain her strength



Cynthia Cooper struggled to find a nursing home for her mother, Frances Zaft, before deciding on the Hebrew Rehabilitation Center for Aged in Boston.

and emotional well-being. Her goals for her mother were simple: To keep her going and to help her remain as independent as possible.

Then Frances did what one of about every 300,000 people over the age of 65 do each year — she broke her hip.

She was rushed to the hospital for surgery. During her mother's brief hospital stay, Cynthia discovered even first-class hospitals often are not the best place for elderly nursing home patients.

"The hospital stay was horrible, really horrible," she recalled. "It was the weekend and the nursing staff was minimal. My mother was in pain. Everyone was in and out and no one seemed to care. No one knew her. Then she 'sundowned' — she became so confused every evening. She refused to eat. She was incontinent in the bed. I came and found her in soiled sheets and she looked at me and said, 'Where were you?' It broke my heart."

Cynthia decided then and there to avoid hospital care for her mother in the future if at all possible.

"I called the doctor and told him it was time to concentrate on comfort. He said he could write a 'do not hospitalize' order. Mom would still get medicines like antibiotics and fluid pills if she needed them. But if she got sick, she would be treated in the nursing home, in her own bed, with nurses who knew her."

Achieving comfort in the nursing home is not always easy. A 1997 report by the Institute of Medicine revealed between 40 percent and 80 percent of nursing home residents experience pain regularly, mostly because the staff may be reluctant to use narcotics to relieve suffering. Cynthia said she made sure to speak with the nursing home physician to get the message across that controlling her mother's symptoms — especially her pain — was her primary goal.

Nursing homes are not always good places to die, though 24 percent of Americans over the age of 65 do just that, according to a 2000 report from the Rand Center to Improve Care of the Dying. Not only is pain control often inadequate, but doctors generally don't get involved in care. Some families draw on support from a hospice program, which often will send a nurse to make recommendations about symptom management and provide a personal attendant for several hours a day as the end draws near. Hospices typically offer counseling to families as well as to patients.

For Cynthia, the center's chaplain has been invaluable.

"I sit with Cynthia and her mother whenever I have the chance," says Hali Diecidue, who, together with a full-time rabbi, offers religious services, pastoral counseling, study groups and sing-

## Making an informed decision

For most people, nursing homes are like black boxes. You can't tell what's inside, and they all seem alike. But there are important differences, and it's not that hard for a shopper to tease those out to make an informed and thoughtful choice. Here's how:

The first thing to do is talk to people you trust: friends, a doctor, a social worker — preferably people who have lots of contact with nursing homes. They are in the best position to make meaningful comparisons. Your state or county offices on aging are good places to find listings and maybe get opinions "off the record." Long-term care ombudsman programs are also good sources of information.

Consider whether it is important to you that a nursing home has a particular affiliation — religious, ethnic, fraternal or otherwise. About one-third of the nursing homes in the United States are nonprofit; most of these are religiously sponsored and offer some clerical and spiritual services. Many nursing homes will even try to arrange for access to these services.

Location, location, location. The axiom about real estate applies to nursing homes as well: You want to pick a nursing home where friends and relatives can visit as often as possible. Why? Because nothing matters more to a resident than those visits, and because even at good nursing homes, staff pay more attention to residents whose families are present. Those interactions help staff focus on "what's left rather than what's lost," as nursing home professionals put it. That is, the staff sees a fuller human being when a resident interacts with the people who love her. Family members and staff can really bond with each other, and everyone starts to feel that they're part of a team.

along to the residents. "We don't feel we have to talk to Frances all the time. Often it's enough just to be with her."

Smaller and non-denominational homes do not have their own chaplains, but most have relationships with clergy who visit regularly. For many family members of nursing home residents, their own minister, priest or rabbi provide support.

Despite the decision to avoid hospitals and limit diagnostic tests, Frances Zaft is very much alive. She sits in her wheelchair, her white hair neatly coiffed, her clothes clean



SEAN DOUGHERTY/KRT

Visit the homes you are considering. Talk with the nursing home staff, and, more important, with the residents and their family members. Ask to talk to members of the residents' council. They will be among the more lucid and verbal informants, with an insider's view broader than most. Here are two good questions to ask staff members:

"How are you going to accommodate what's unique about my Mom? If she wants to eat breakfast later than your regular serving time, or be wheeled outside at a certain time of day, how will you handle that?" Get a sense of whether she'll have to conform, or whether the nursing home will confirm to her, or at least meet her halfway.

"Is there an active volunteer program?" If there is, that's both a meaningful sign of community support as well as a significant source of stimulation for residents.

Contrary to what many Americans believe, Medicare coverage for nursing home care is extremely limited. Many of the nursing

home residents covered by the Medicaid program started by paying with private funds until "spending down" — using up their assets — and qualifying for Medicaid.

Ask to see the two most recent state and federal inspection reports. This is public information. If there are serious violations, you want to know.

Finally, don't beat yourself up. Remember that 80 percent of long-term care in the United States is provided by families in their own homes. When families make the choice to put a loved one in a nursing home, it's because they've honestly run out of alternatives. Console yourself with this truth: Almost no one puts a mother or father in a nursing home until it's absolutely necessary. You can figure out which facility will give your loved one the best quality of care and the best quality of life. And then remember that your own attentiveness to your loved one at the nursing home you choose can make a world of difference

— Len Fishman

For more resources and contacts on end-of-life issues, go to [www.findingourway.net](http://www.findingourway.net).