

Finding MS care away from home



Considering your needs, options and goals can help you outline your choices—and lessen your anxiety.

by Lori De Milto



Judy Youngclaus. Photo courtesy of Judy Youngclaus

Judy Youngclaus didn't want to leave her home. But when her multiple sclerosis got worse and she needed help with things like transferring from her wheelchair to the bed or toilet, Youngclaus knew it was time to think about moving to a nursing home. "I was no longer able

to do the things I used to do, and I needed a lot more help,” she says.

Youngclaus, who was diagnosed with MS in her 30s and is now 70, moved to the Boston Home, a National MS Society Center of Excellence in Long-term Care, in 2011. Now, Youngclaus participates in a writing group and a book club, plays cribbage and other games, and goes on trips to Red Sox games, plays and restaurants. “After a week or two, I thought that this was the best place I could ever be,” she says.

The Boston Home is one of a handful of nursing homes nationwide that specializes in caring for adults with MS. Most people with severe MS who need assistance with activities of daily living move to a regular nursing home, where they are younger and more active mentally than most residents. Staff members at many nursing homes don’t have experience providing the more specialized care that people living with MS need, but some are willing to learn.

Challenges of independent living

When MS progresses, family members can’t always provide the physical help needed for independent living at home. While assisted living is occasionally an option, some people need more help than assisted living provides, such as skilled nursing care.

Staff members in nursing homes have the training and experience to help people transfer safely from a wheelchair to the bed, toilet or shower, and help with activities like dressing and eating. Plus, they’re available 24/7. Nursing homes also offer a variety of rehabilitation and recreational therapies. Relief from isolation is another reason to make the move. “It can be very isolating at home if you can’t get out, and your spouse or caregiver is only there part time,” says Marva Serotkin, CEO of The Boston Home.

Progressed MS can cause swallowing problems, breathing problems, skin breakdown (including pressure sores caused by sitting or lying most of the day), urinary tract infections and other health problems that require professional care, which a nursing home can provide.

Linda Litton, 56, moved to Inglis House in Philadelphia in 2015 after repeated falls. “In the beginning, I could crawl to something, lean on it and get up. Over time, I would just lie on the ground and wait for my neighbor or my husband, and if they weren’t available, the fire department,” says Litton, who has been living with MS since she was 39. Inglis House is also one of the few nursing homes in the U.S. for people with MS and other disabilities, and another MS Society Center of Excellence in Long-term Care.

Checklist for MS care and activities at nursing homes

- Are there younger residents?
- Are there other people with MS?
- Do residents seem to be happy and well cared for?
- Do staff members seem to enjoy spending time with and caring for residents?

- Are staff members willing to learn more about caring for people with MS?
- What activities are available?
- Is transportation available to go into the community (e.g., for shopping and events)?
- What opportunities are available to stay engaged in the community?
- Is the physical facility clean, pleasant and accessible to power wheelchairs and other mobility equipment?

Thinking about moving to a nursing home can seem scary and stressful. But the time to do it is before you have to move. “Once you have a plan that gives you choices down the road, it’s a whole lot easier to function and cope,” says Gavin Kerr, president and CEO of Inglis.

Youngclaus first met with the staff from The Boston Home a few years before she moved there. At that time, she was using a walker and lived independently. When Youngclaus needed more help, she went to another nursing home for about seven months before a spot in the Boston Home opened up. That’s common, especially if you have Medicaid, as many people living with MS in nursing homes do. Some people have long-term care insurance.

While it’s never an easy decision, most people adjust to life in a nursing home, especially if the facility “pays attention to your unique needs and provides a socially rich environment,” says Debra Frankel, a National MS Society staff member who specializes in healthcare access initiatives. Frankel also notes that family relationships may improve when family members no longer are primary caregivers. Without the stress on the caregiver to be constantly available and do very physical work, and without the person with MS having to depend on the family member, they can go back to a more normal family relationship.

“My stay at Inglis House is fulfilling,” says Litton. “I like to be as independent as I can, but I can also get the extra help that I need.” If Litton drops or can’t reach something, for example, or she needs assistance setting up her computer or using the toilet, someone is available to help her, and she has access to nurses 24/7. She also likes being able to have physical therapy right at Inglis House. Litton has made many friends there and participates in activities like trivia, word games, a weaving class, and trips to stores and restaurants.

Age-appropriate care

Some 88 percent of nursing home residents are 65 or older, and 45 percent are 85 or older, according to the AARP Public Policy Institute. In contrast, the average age of residents is 54 at Inglis House and 57 at The Boston Home. People with MS who are living in nursing homes need interesting activities and access to transportation so they can get out into the community. But they also need more specialized clinical care, such as help managing spasticity and cognitive issues that are quite different from dementia, which staff members at many nursing homes don’t have experience providing. “Finding age-appropriate care and people who understand MS is a challenge,” says Frankel. “Visit several nursing homes, and ask a lot of questions.”

5 keys to independent living

1. Safe, affordable, accessible housing
2. Access to healthcare by professionals who understand the needs of people with MS
3. Support for daily living (from family and friends or paid caregivers)
4. Engagement in life
5. Access to transportation

While there are only a few nursing homes like The Boston Home and Inglis House nationwide, other nursing homes may have units or programs for younger adults with chronic conditions or disabilities. An MS Navigator—an information, referral and support service from the Society—can help you learn about options in your community.

“Have an open mind. If there is a nursing home administrator and nursing director who are open to learning more about how to take care of people with MS and helping you find age-appropriate activities, that nursing home may be an option. The National MS Society can provide training and materials for nursing home staff,” says Frankel.

Serotkin suggests talking to the director of nursing and notes that even at The Boston Home, staff members continue to learn a lot from residents about their needs. She also suggests chatting with other people living with MS about their experiences in nursing homes. “Find the best place where you’ll be able to have a satisfying life,” says Litton.

Lori De Milto is a Sicklerville, New Jersey-based freelance writer.

For advanced care information, visit [Advanced Care Needs](#) or connect with an [MS Navigator](#).

To find and compare nursing homes and get information about inspections, staff and quality measures, visit [Medicare](#).

[Your Guide to Choosing a Nursing Home or Other Long-Term Care](#), from the Centers for Medicare & Medicaid Services, includes a nursing home checklist on pages 26–32.