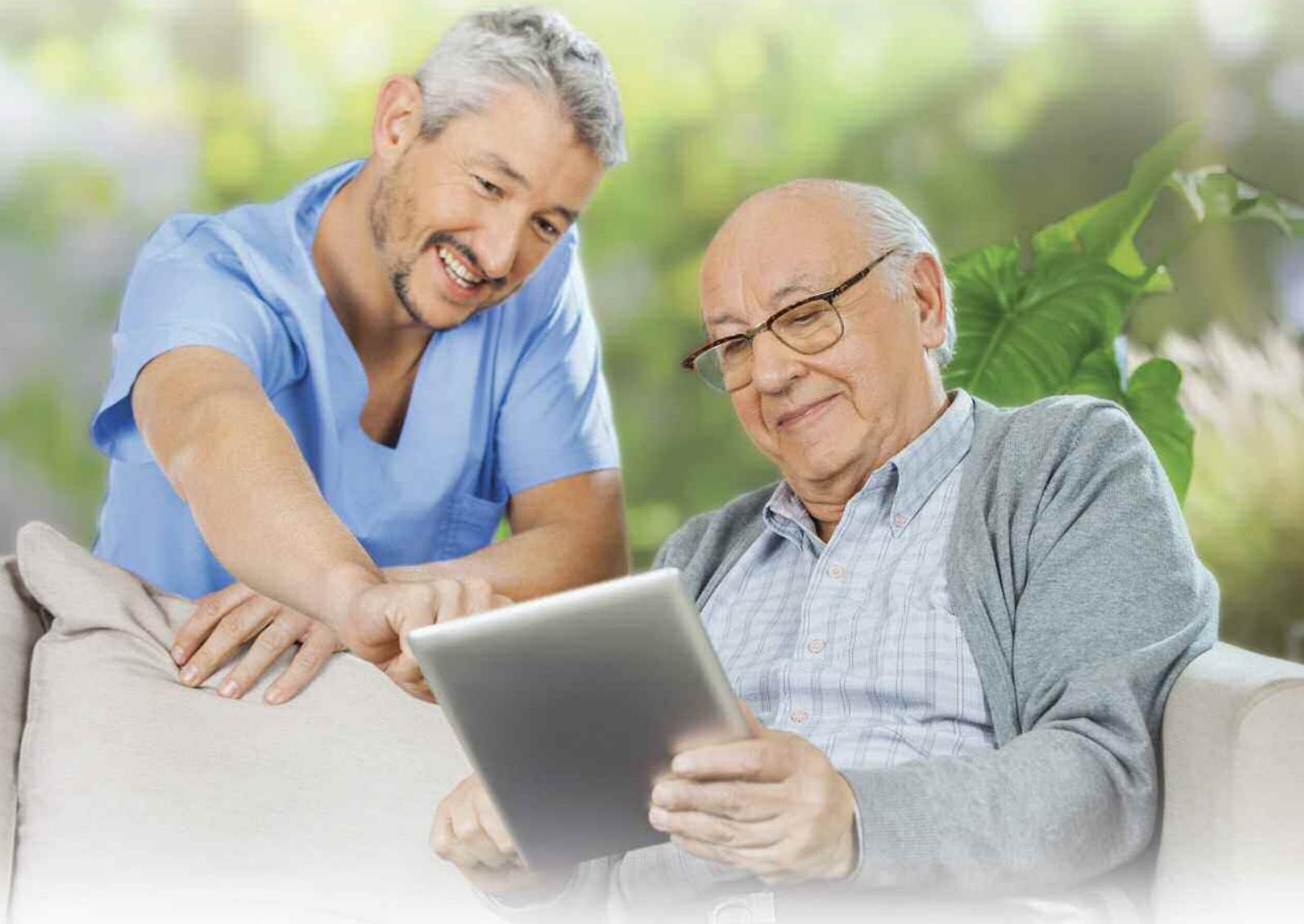


Moving Aging IG Patients into Nursing Homes



Many things need to be considered before choosing a nursing home, especially for PI patients who face considerably more challenges than the typical senior.

By Abbie Cornett and Roger H. Kobayashi, MD

UNTIL RECENT YEARS, individuals with a primary immune deficiency disease (PI) rarely survived to retirement age. Indeed, in the past, PI was thought to be a disease that occurred primarily in infants and young children, which led to many adults going undiagnosed and untreated. Today, however, because of advancements in early diagnosis, proper

treatment and continued monitoring, PI patients are living much longer. In recognition of this growing PI patient population, the Consortium of Independent Immunology Clinics surveyed three of its member clinics, and found surprising results: The three clinics had almost 300 PI patients over age 65!

Because so many PI patients are living longer, they are reaching the stage of life when residential nursing care may be necessary. And, this is where things start to get complicated. Regardless of whether a person has a chronic condition, the decision to enter a nursing home can be challenging and stressful for patients and their families. It is a decision that needs careful consideration to ensure patients are well cared for and have a good quality of life. And for PI patients, these concerns are magnified.

While change is scary at any age, it can be particularly stressful for older PI patients. One of the biggest concerns expressed by seniors is a loss of control over their lives. For PI patients, the transition to a nursing home adds another element of concern: It can affect where and how they receive their lifesaving medication. For the transition to be successful, patients should include their loved ones in the decision process. A good way to ease the stress of the transition is to start a conversation with family members well before the move is necessary. That way, the family can be included in decisions regarding their care.

Any decision that affects the care of patients should also involve their physician, the best resource in helping assess patient needs and how those needs may evolve over time. Fortunately, most patients have established relationships with their doctors and can ask for their input.

Are Nursing Homes Qualified to Care for PI Patients?

Nursing homes are equipped to deal with the common chronic conditions related to aging. In fact, 80 percent of adults age 65 and older have at least one chronic condition,¹ and many have more than one comorbidity. But, most older adults suffer from chronic conditions such as Alzheimer's, arthritis, hypertension, etc. So, while nursing homes are used to dealing with these typical illnesses, they may not be as prepared for senior PI patients who have more complex medical needs.

Before selecting a facility, patients must make sure it is certified. For a nursing home to meet certification standards, it must comply with more than 180 regulatory standards, including proper management of medications, measures to protect patients from physical and mental abuse, and safe food handling.² There are a couple of good options for checking facility ratings. The first is at Nursing Home Compare (www.medicare.gov/nursinghomecompare/search.html), which allows families to compare information on Medicaid- and Medicare-participating facilities. If a facility is not Medicare-certified, the second option is to go to the patient's state website to access ratings (www.medicare.gov/NursingHomeCompare/Resources/State-Websites.html).

Things to Consider When Visiting a Nursing Home

Before deciding on a nursing home, patients and their families should visit a candidate facility at least twice: one planned visit and one drop-in visit. Dropping in at an unusual time or on a weekend is a good way to detect any hidden problems such as poor staffing or uncleanliness.

Following are items PI patients and their families should specifically consider when choosing a facility:

- **Staff:** It's important for patients and their family members to have confidence in the staff's ability to meet the patient's needs. When visiting a facility, it's a good idea to talk to the staff and ask them how many hours per week they work on average. Many facilities require overtime and double shifts, and overworked staff can affect care.³

- **Cleanliness:** As people age, their immune systems diminish. This decrease in natural immunity is compounded in senior PI patients who are very susceptible to infections regardless of age. Further, what might be an uncomplicated infection for others can have a severe and potentially life-threatening effect on geriatric PI patients, making cleanliness of the facility even more important.

There should be a concerted effort on the part of nursing home staff to minimize the spread of infection through diligent hand-washing and avoidance of people with ongoing infections. Particular concern needs to be given to viral infections that can cause life-threatening illness in PI patients. Ask if there is a policy in place for the treating physician to be proactively contacted if patients are exposed to infection.

BEFORE SELECTING A FACILITY, PATIENTS MUST MAKE SURE IT IS CERTIFIED.

- **Dining facility:** When visiting the facility, plan on eating a meal there. Good food is an important quality-of-life issue, but it's also vital for proper nutrition. While healthy dietary habits are important for everyone, they are especially key for PI patients. A lack of adequate nutrition can lead to many illnesses, including infections for which PI patients are already at risk.⁴

Because all PI patients have been on antibiotics, which can affect their gastrointestinal tract, causing chronic diarrhea, bloating and malabsorption, they may have special nutritional needs. Therefore, patients should speak with the facility dietician to

make sure special dietary requirements can be accommodated. And, since each patient is different, coordination between the patient's doctors and the facility is necessary.

- **Transportation:** All nursing home patients need transportation, especially for doctor appointments. This is particularly true for PI patients who, because of their complex medical needs, may require more frequent doctor visits. Fortunately, most facilities are generally equipped to deal with transporting patients, but it's a good idea to verify that service is available.

- **Training:** Because PI patients can get very sick very quickly, staff at the facility must be trained to recognize when patients are ill. This is particularly important if patients have lost their ability to communicate.

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Treatment Location

Virtually all older PI patients require immune globulin (IG) infusions. Typically, these infusion services are not currently available in nursing homes. Therefore, proactive measures need to be taken to plan for how and where patients will receive treatment. Here are some items to consider:

- If treatment is administered intravenously (IV) at a doctor's office, infusion center or hospital, will the nursing home provide transportation to and from the site of care?

- If patients have been receiving IVIG at home, will the nursing home allow outside medical personnel into its facility to infuse patients? If it does not make these allowances, does it have staff properly trained to safely infuse patients?

- If patients have been receiving subcutaneous IG at home, will they be able to administer their own medication while at the facility? The Centers for Medicare and Medicaid Services

guidelines require the facility to have procedures for the control and safe storage of medications for residents who self-administer them. Further, residents may self-administer drugs if an interdisciplinary team has determined this practice is safe.⁵

Treatment Costs

Before transitioning into a nursing home, it is important to understand the costs. Nursing homes are expensive! The average daily charge for a shared room in 2016 was \$225.⁶ These costs, combined with the expensive treatment for PI, can be devastating. IG treatment itself can vary between \$40,000 and \$80,000 a year for the medication and supplies. If patients are hospitalized or suffer complications, those costs multiply quickly. Compounding this problem is how complicated reimbursement issues have become. Before making any decision, it is imperative patients and families understand insurance coverage to avoid substantial unexpected expenses.

An Ongoing Battle

The decision to transition to a nursing home and the selection of a facility is only the beginning of the battle. Even after the transition is complete, family follow-up should be part of the plan. Family members must remain vigilant to ensure their loved ones continue to receive appropriate care. Visiting as often as possible ensures their well-being is monitored. Some red flags that signal things are not going well are sudden weight loss, bedsores, unexplained injuries, confusion and sudden changes in behavior.

Senior PI patients have spent a lifetime advocating for their care, fighting with insurance companies and caring for themselves. Their family members need to be prepared to be advocates for aging loved ones who can no longer advocate for themselves. ■

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