

# Navigating Long-Term Care

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## Abstract

Americans over age 65 constitute a larger percentage of the population each year: from 14% in 2010 (40 million elderly) to possibly 20% in 2030 (70 million elderly). In 2015, an estimated 66 million people provided care to the ill, disabled, and elderly in the United States. In 2000, according to the Centers for Disease Control and Prevention (CDC), 15 million Americans used some form of long-term care: adult day care, home health, nursing home, or hospice. In all, 13% of people over 85 years old, compared with 1% of those ages 65 to 74, live in nursing homes in the United States. Transitions of care, among these various levels of care, are common: Nursing home to hospital transfer, one of the best-studied transitions, occurs in more than 25% of nursing home residents per year. This article follows one patient through several levels of care.

## Keywords

Alzheimer's/dementia, assisted-living, long-term care, hospice

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## Case: AB

Mrs. AB is an 84-year-old Caucasian female with a history of hypertension, osteoporosis, type 2 diabetes, dyslipidemia, osteoarthritis, and persistent depression who presents to the office as a new patient with worsening ambulation: “I’m just not getting around well.”

The patient lives in a small house above the family farm, on the side of a mountain. She describes her difficulty as an unsteadiness, and stiffness, in her knees and hips. She has moderate pain in her right hip and in her left knee, especially late in the day. On clinical examination, AB has reduced internal and external rotation of the hips, right side more affected than the left, with some pain to the maneuvers, and widened knees with some tenderness. A Mini-Mental Status Exam (MMSE) is consistent with mild cognitive impairment, with a score of 24. (Generally, scores of 27-30 are normal, 24-26 suggest mild cognitive impairment, 19-23 mild dementia, 10-18 moderate dementia, and <10 severe dementia.) She is taking 17 different medications, listed in the box below.

AB has a son, Fred, who lives in the main farmhouse below her house, but AB does not get along with him well: He has a diagnosis of bipolar, and they argue frequently. Her other son, Rod, lives in Texas, and has recently been diagnosed with leukemia. Rod helps her with medical decisions—For example, he helped her pick her current Medicare part D plan. AB also has one surviving brother, 89 years old, but he is rather debilitated. He lives close by her house, but is unable to assist her; in fact, she assists him—she buys groceries for him every 2 weeks.

Based on the evaluation so far, AB is at risk of requiring institutionalization from both her worsening

ambulation and her mild cognitive impairment. Physical therapy may benefit her ambulation. Both the mental status and the mobility are likely to be adversely effected by her polypharmacy. Taking multiple medications—some research suggests four or more, some seven or more—increases the risk of falls and other adverse effects, as well as significant drug–drug interactions (Hajjar, Cafiero, & Hanlon, 2007). AB’s list of 17 drugs suggests multiple significant drug–drug interactions.

AB’s 17 medications are listed in the adjacent box.

Medications: D = Stop; C = Continue

• Diltiazem XR 300 daily	C
• Simvastatin 40 daily	D
• Amitriptyline 75 at bedtime	D
• Paroxetine 40 daily	C
• St. John’s Wort 300 3 times per day	D
• Celecoxib 200 twice daily	D
• Metformin 850 3 times per day	C
• Alendronate 10 daily	C
• Glyburide XR 10 daily	D
• Pioglitazone 450 daily	D
• Hydroxyzine Palmoate 50 at bedtime	D
• Chromium	D
• Cinnamon	D

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Medications: D = Stop; C = Continue

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• Ginkgo	C
• Glucosamine	D
• Niacin	D
• Vitamin C	D

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Looking over her medication list, there are serious potential interactions between diltiazem XR and simvastatin, and between amitriptyline and paroxetine (and potentially St. John's wort). There is no benefit from celecoxib for her (celecoxib does not reduce GI bleeding, if co-administered with aspirin), or from metformin greater than 2000 mg per day, or from daily alendronate versus the weekly form. Furthermore, she has been on alendronate for 14 years, with stable Dual Xray Absorption (DXA) results. Given her age and debility, amitriptyline, glyburide XR, pioglitazone, and hydroxyzine palmoate are probably ill-advised. It is unclear if chromium, cinnamon, glucosamine, niacin, hydroxyzine palmoate, or vitamin C offer any real benefit for her. (Ginkgo may have a small prevention effect against Alzheimer's.) The box also lists some of the medication recommendations made at that first visit; amitriptyline and St. John's wort were both weaned off over 3 months, alendronate 70 weekly was used, and metformin was changed to 1,000 mg twice daily with meals. Medications replaced included atorvastatin 20 for simvastatin, naproxen 250 twice daily with food for celecoxib, and glimepiride 4 for glyburide. Medications can contribute to cognitive impairment, and stopping medications may help improve cognitive impairment (Ancelin et al., 2006). Accordingly, medication review is a reasonable first step to keeping patients at home.

In addition to the medication changes, the physician recommends home health to assist with her home medications, to monitor glucose levels and blood pressures, and to provide physical therapy. AB, like many elderly patients, is resistant to changing medications, but may be most open to making multiple changes at the first visit to a geriatric medicine expert.

At the follow-up visit one month later, AB reports, "My legs hurt a little more, but I feel better!" She is able to ambulate more effectively, even in her steep driveway. Although she does not report any mental status change, her MMSE result has improved to 29—perhaps due to the medication changes.

### Care Level Summary: Independent Living

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To succeed in independent living, a patient must be

- Nearly functionally intact, with preserved instrumental activities of daily living (IADLs); or
  - Capable of arranging for others to help with grocery shopping, paying bills, arranging transport, cooking, and cleaning; and
  - Able to tap into family support, or agency assistance, to delay placement to a facility.
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AB next presents 2 years later. She is brought by her son Rod; he reports that she's having more memory lapses, and more difficulty getting around. Rod also has had deterioration of his medical status: His acute myelogenous leukemia has relapsed, and he is moving back with AB while he gets chemotherapy. AB states, "I feel fine!"

Rod describes a pattern of short-term memory loss, difficulty naming common objects, and uncertainty with long-established skills such as knitting. She is also having trouble managing her medications and her medical appointments. Repeat MMSE score is 22. These results are interpreted as suggesting early stage Alzheimer's disease. Ron notes that between his retirement and AB's annuity, AB can afford assisted-living (AL). As he is unable to care for AB during his chemotherapy, he persuades his mother to "try" a local AL facility. She reluctantly agrees to "try" AL.

### Care Level Summary: Assisted-Living (<https://www.caring.com/articles/assisted-living-versus-skilled-nursing-care>; Doyle, 2015)

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Activities are almost always provided, but are not required.

Because medical insurance, other than some long-term care insurance policies, usually does not pay for assisted-living (AL), AL facilities compete for paying customers. Accordingly, activities are usually offered, and usually reflect the higher functional level of AL residents. Most AL residents continue to see their community-based physicians. The typical cost of an apartment in an AL facility is US\$3,400 to US\$5,000 per month, i.e. about half the cost of a skilled care nursing home bed. There are no federal regulations on AL facilities, only state.

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Requirements for AL residents (may vary by state):

- Must be able to ambulate in and out of the facility without help (assistive devices permitted);
  - Must not require skilled nursing care;
  - Regular meals are provided by the facility, but the resident may fix his or her own meals;
  - Assistance with medications is provided, but the facility need not have a nurse;
  - Maintenance and cleaning of the apartment is provided.
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AB sees her doctor 2 months after her move to AL. Her son Rod accompanies her. Rod is doing poorly, and is considering hospice care. AB really likes not having to cook, but she complains that the meals are "too predictable." Rod is worried that he may die soon; he strongly encourages AB to stay in the AL facility. She agrees: "I will stay there for the time being."

Six months later, Rod dies. The AL facility is in contact with AB's physician, reporting that she is very distraught. AB agrees to see her physician. At the visit, AB seems to be grieving appropriately, and is comforted by all her new friends at the AL facility. She and her doctor agree that she will try to manage her grief without additional medications, and she will participate in some

social activities at the assisted living facility each week. (AB's AL facility does offer frequent activities.) On the physical exam, AB has a somewhat worsened memory—MMSE score is 19—but she remains functional. AB is still driving, and because she now has definite dementia, she agrees to be retested by the state highway department. Her ambulation is slowed from her baseline, and she has more tenderness in her knees and hips, consistent with worsening osteoarthritis. Her physician does not change any of her medications and agrees to see her as often as needed.

AB does well at the assisted living facility for another year. By that time, her dementia is moderate—Not only has she improved from her grief, but usually she no longer remembers that Rod has died: “When is Rod coming to see me?” She stops driving, after her repeat testing suggested slowed reaction time. She agrees to take the assisted living facility's van to appointments and shopping.

After that year, however, AB is noticeably worse: She has trouble recognizing her other son Fred, and her two granddaughters, who now share power of attorney authority. Although she remains continent of feces, she is often incontinent of urine. She has begun to wander in the AL facility, and has walked off the grounds, toward a major street, once in the past week. The AL administration asks about a transfer to their locked Alzheimer's Unit.

*Care Level Summary: Locked Dementia Unit in AL (<http://www.aplaceformom.com/blog/2013-3-4-assisted-living-vs-memory-care/>)*

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Locked dementia units are still considered Assisted-Living (AL) level of care, with standard AL requirements: Ability to enter and leave the facility, and no need for skilled nursing on a regular basis. Locked units typically offer more help with self-care: assisting with toileting (including changing diapers), bathing, feeding, and dressing. The AL facility must regularly obtain a signed physician's statement that the AL locked unit remains an appropriate level of care for the patient. The typical cost of a bed in a semi-private locked unit is US\$400 to US\$800 more per month than an AL apartment.

Locked units are still subject to the requirement that patients be able to ambulate on their own, but there is an exception: If life expectancy is less than 6 months, a resident can be enrolled in hospice, and stay among staff who are familiar to the resident.

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AB knows many of the staff in the locked unit, as they also work on the AL side; she does not become agitated after her move. She continues to wander. Urinary incontinence is less of an issue now, as the staff is assisting her with diaper changes. After about a year in the locked unit, the nurses note poorer ambulation. Her doctor plans to evaluate her at his next visit, but AB needs a visit to the ER first: She chokes on her dinner, and

subsequently develops fever, cough, and shortness of breath: “I can't breathe!”

The chest X-ray shows a right lower lobe infiltrate. AB is hospitalized for IV antibiotics. Speech therapy (ST) is consulted, as aspiration is likely. The speech therapist orders a modified barium swallow, which confirms mild aspiration of thin liquids, then recommends a mechanical soft diet with honey-thick liquids.

The pneumonia responds to antibiotics, but AB is not able to return to her AL locked Alzheimer's unit: She needs more intensive physical therapy and ST than she could obtain via home health at the AL facility. Instead, she is transferred to the rehabilitation unit at a local nursing home.

*Care Level Summary: Rehabilitation at a Nursing Home (Resnick, 2004)*

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Medicare pays for three levels of rehabilitation: Acute, subacute, or outpatient.

- Acute rehab occurs in a rehabilitative inpatient facility (a rehab “hospital”), and must average at least 3 hr of rehab therapy per day.
  - Subacute rehab occurs in skilled nursing facilities (SNF—pronounced “sniff”), which can be free-standing centers or hospital-affiliated units; most are in nursing homes (NHs). Subacute rehab centers must average 2 hr of rehab therapy per day, commonly PT (physical therapy), OT (occupational therapy), and ST (speech therapy).
  - Outpatient rehab occurs in one of two ways: Home health with PT, OT, and ST; or outpatient visits to a rehab facility, such as a therapy office.
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Medicare pays much more generously for subacute rehab than Medicaid pays for intermediate care (ICF) stays; nursing homes (NHs) compete for rehab patients. The NH Utilization Review Committee must meet monthly to confirm that rehab patients continue to meet criteria for skilled nursing facilities (SNF). Medicare pays for 100% of the cost of the first 20 days in rehab, and 80% of the cost of the subsequent 80 days. Depending on the patient's finances, many will leave after the 20-day period of full coverage. Once used, the Medicare rehab days are restored steadily over a 2-year period. Medicare pays approximately 10% of all NH charges.

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AB's dementia is now moderately severe. She has some difficulty cooperating with PT and ST at the NH, but overall makes slow progress. She reaches her endpoint—the point of “maximal medical improvement” (MMI)—after 4 weeks, at which time her swallowing and ambulatory capacity are no longer improving. Once MMI is reached, AB no longer qualifies for SNF, and her family must decide on disposition. Her granddaughters, familiar with the locked dementia unit at the AL, decide to transfer her back.

However, upon her return to the locked dementia unit, after a month away, AB no longer recognizes the staff. She is less cooperative with staff's attempt to change her

diapers, bathe her, and to assist her with feeding and walking. She is agitated much more often. Despite walking better after rehab than she had before her pneumonia admission, her refusal to walk with staff and reluctance to walk on her own causes her to quickly lose strength: She cannot walk on her own within 2 months. The AL administration notifies her niece that AB no longer meets criteria for the locked unit. AB is not yet felt to be an appropriate hospice candidate, so her granddaughters arrange for her admission to a nearby nursing home.

**Care Level Summary: Nursing Home Intermediate Care (ICF)** (<https://www.caring.com/articles/assisted-living-versus-skilled-nursing-care>; Doyle, 2015)

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About two of every three nursing home (NH) patients in the United States are in ICF beds. Intermediate care (ICF) requires intermittent skilled nursing needs, which fall short of the requirements for skilled nursing facilities (SNF) beds. In contrast to SNF, ICF patients tend to stay in the NH for long periods of time. Most ICF patients have Medicaid; Medicaid pays approximately 50% of all NH charges. Federal law requires that a patient “spend down” all financial assets, until less than US\$2,000 remains, before qualifying for Medicaid. Once impoverished, Medicaid will continue indefinitely. Most ICF patients remain in the NH until death.

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For long-term placement at the NH, AB must “spend down.” Her granddaughters cash in her annuity for US\$50,000, and sign over AB’s Social Security payments to the NH. Because the family farm has been in her son’s name since her husband’s death 12 years ago, the farm is not considered one of AB’s assets—but if she had co-owned the farm less than 5 years before, it would also have to be sold in the “spend down” process. The annuity and Social Security payments will cover more than 8 months in the NH.

Even though AB returns to the NH in which she had had rehab, she does not remember anyone there. She is often agitated, mostly at night. Even though the nurses put a mattress on the floor next to AB’s bed, she gets up at night and falls frequently. One week after NH admission, she is found on the floor near the bathroom, apparently in great pain. Her right leg is shorter than her left, and is externally rotated at the hip. The physician is called, and authorizes transfer to the ER. In the ER, a right intertrochanteric hip fracture is confirmed; AB is hospitalized (Pearson & Coburn, 2013). The surgical repair goes smoothly the next morning, but AB is extremely agitated in the evening. The physician sees her, and diagnoses delirium. Risk factors for delirium include hospital admission, recent surgery, opioids, and the Foley catheter. There is no apparent bleeding, AB is not impacted, and there are no unnecessary meds. A 2-mg haloperidol IM is given for the agitation, with a

repeat dose ordered as needed every 4 hr, and the opioids are changed to a PCA pump with a low basal rate. AB improves somewhat, but is intermittently more confused and agitated than her baseline. After 3 days, she returns to her NH on SNF, for rehab.

Of note, a meta-analysis published in 2016 concluded that antipsychotics, the standard treatment for delirium with agitation, are ineffective in preventing or treating delirium in hospitalized patients (Neufeld, Yue, Robinson, Inouye, & Needham, 2016). Similar to agitation due to dementia, use of antipsychotics must now be limited to an emergent need for sedation, when the subsequent harms are considered less severe than the benefit from the sedation.

When AB was in rehab 2 months earlier, she used 30 of her 100 Medicare rehab days, including all 20 of the days covered 100%. These days are restored over a 2-year period; after 2 months, she has 1 day covered at 100%, and 71 days at 80% payment. As AB is currently paying for her NH stay on “spend down,” 20% of her SNF bed is US\$120 per day. Her rehab stay prolongs her “spend down.”

Once again, AB is somewhat cooperative with rehab staff, but given her hip fracture and poor baseline ambulation, recovery of meaningful ambulation is not felt to be feasible. Physical therapy instead works to improve her ability to assist with transfer between bed and wheelchair. After 3 weeks, she is no longer progressing in rehab, so she is transferred back to her ICF bed. This time, her agitation has improved a little bit; she seems more comfortable with the NH staff.

After rehab, AB helps with transfer significantly, but requires feeding assistance and a pureed diet. She completes her “spend down” after 9 months, and obtains Medicaid. She experiences slow incremental decline over 2 years, until she requires “total care” (maximum assistance with all activities of daily living). She no longer speaks. Hospice is consulted.

**Care Level Summary: Hospice** ([http://hospiceactionnetwork.org/linked\\_documents/get\\_informed/issues/nursing\\_home/HAN\\_NH\\_QA](http://hospiceactionnetwork.org/linked_documents/get_informed/issues/nursing_home/HAN_NH_QA))

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Hospice cares for a dying patient. Whether the patient is at home, in Assisted-Living (AL), or in a nursing home (NH), hospice assumes control of the patient’s Medicare budget, to care for her last days. Hospice pays for physician visits and medical tests. Hospice patients pay an annual deductible, a monthly premium, and 20% of all Medicare-approved charges, which are deducted from the Social Security check. Hospice can continue to care for a dying patient who lives beyond 6 months, but must “dis-enroll” someone who appears to stabilize medically. Subsequently, after further decline, such a patient can be readmitted to hospice.

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As AB has declined, but has shown less agitation, her son and granddaughters resume their occasional visits. After enrollment in hospice, they come more regularly,

with occasional appointments with the hospice chaplain. Four months after starting hospice, AB dies, with apparent good control of pain and other symptoms. The counseling continues for the family after AB's death, for several months (up to 1 year is covered).

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As patients physically and cognitively deteriorate with age, they may progress through several care transitions (Centers for Disease Control and Prevention, 2014). This article has highlighted common care transitions, with some pertinent points about each. Although few people will progress through the many transitions AB did, all members of the health care team should become familiar with them, to better care for elderly patients.

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