Dear Dr. Jeff,

Our state Medicaid program allows “respite” admissions to nursing homes for up to 2 weeks. With a declining census, our facility is considering a formal program to facilitate these admissions. Do you have any suggestions?

Dr. Jeff responds: It’s summer and thoughts naturally turn to rest and recreation. The term “respite” is mostly used by full-time caregivers of the frail elderly, visions of relief are a shimmering mirage.

The invaluable manual for caregivers of people with Alzheimer’s disease is appropriately titled “The 36 Hour Day,” by Nancy L. Mace and Peter V. Rabins, now in its 5th edition (New York: Grand Central Life & Style, 2012). Its title obviously reflects the life experience of dementia caregivers, but the caregivers to cognitively intact, medically frail, seniors are also under strain, data suggest.

Multiple studies over several decades have confirmed that family caregivers experience extraordinary amounts of both physical and emotional stress. Despite the acknowledged satisfaction associated with providing care to a loved one, anxiety and depression emerge, as well. It can come as no surprise that family caregivers experience back problems of the type commonly seen among staff at long-term care facilities. Moreover, due to their caregiving responsibilities, caregivers frequently neglect their own health.

Respite programs seem like an ideal solution here – a boon to both caregivers and host institutions – allowing family caregivers to address their own physical and emotional needs. These interludes may also allow caregivers to participate in significant life events with other family members: graduations, marriages, and other milestones. They permit the caregiver to address personal life goals, such as travel and education.

Several studies have demonstrated that respite programs prolong the periods when patients with advanced disease are maintained in the community, ultimately saving money for the health system. Clearly, the development and expansion of programs to assist overburdened caregivers is medically wise and greatly needed.

But, respite comes with a raft of its own problems.

Consider Compensation

The economics of maintaining physically and cognitively disabled seniors “in the community” is clear and compelling. Home-based care is generally much less expensive than institutional care, if only the costs to health insurers (including, of course, Medicare and Medicaid) are tallied. These calculations generally treat the billions of hours of nonreimbursed care provided by family caregivers as free.

If employed home health aids replace family caregivers, even at the scandalously low wages that most of these caregivers receive, these illusory savings in health care costs tend to disappear. If two 12-hour caregiver shifts are required to make up the work of a family member, care at home is usually more expensive than nursing home care. This cost differential is even larger when the patient's share of food and rent is included.

Institutional operations secure economies of scale unattainable to home-based services. Our food service and housekeeping staffs are more efficient than individual homemakers, and a single certified nurse assistant can provide overnight care for up to 20 mostly sleeping residents.

However, when family care is available without charge to government or private insurance plans, a small investment in respite services to encourage this care model fairly scrimmage financial wisdom. Respite programs exist in a variety of models. These may include adult day-health programs, overnight or longer stays in health facilities, in-home respite, and sleep-away camps. Their availability varies greatly as they are mostly provided through Medicaid waivers that differ widely from state to state.

The United States Administration on Aging (AoA) administers the National Family Caregiver Support Program, which provides grants to states to support respite and other family caregiver programs. Funding has remained relatively flat, with about $50 million going to respite programs annually. These funds cover not only respite for caregivers of frail seniors and Alzheimer’s patients, but also nonparent relatives caring for children and adults with disabilities.

In addition to Medicaid and AoA funding, several states provide their own funding for respite. In 2007, AARP estimated that total funding from all of these sources was $227 million, with two-thirds of that coming from Medicaid. Given estimates that there are about 40 million eligible caregivers, this represented an average of $5.43 per caregiver annually. Alaska was the most generous, at $43.02, and Massachusetts the least, at 48 cents.

One obvious conclusion from these financial data is that utilization of your program is likely to be quite low, certainly not sufficient to solve census issues or financial worries. In addition, there are many barriers to using inpatient beds for respite.

Other Obstacles

First, to schedule a stay in advance, your facility will need medical and financial information to ensure that the person’s time there will be safe, appropriate, and reimbursed. In fact, most reimbursed respite programs require prior authorization. This might be suitable for an extended vacation or a major family event for the caregiver, but, generally, all the prep work required makes a 1- or 2-day stay unfeasible. After all, from a regulatory viewpoint, you will still be expected to do all the assessments, charting, and care planning that you would do for any other admission.

Caregivers, many of whom have promised their loved ones, “We will never put you in a nursing home,” may see your service as a violation of that promise. Similarly, the care recipient, frightened to be left in unfamiliar surroundings under the care of strange individuals, may resist the plan. The barrage of television advertisements and roadside billboards from rapacious plaintiff attorneys has served to heighten these fears.

If your facility does not have private rooms available for respite admissions, there may also be understandable hesitation to share a room with a stranger, particularly one who is very ill or confused. We know that many of the day-to-day realities of nursing home life require some adjustment over time, just as any new living situation would. These can be highly problematic during a mere 1- or 2-week stay. These admissions may carry the same staff demands of a typical postacute stay by a patient soon to go home, without the enhanced reimbursement of the latter.

There is no practical mechanism for a family caregiver who suddenly experiences a medical problem or other emergency to simply drop his or her relative off at your nursing home, even if your state does not require prior authorization of such stays. When the otherwise healthy wife of a 90-year-old patient with advanced dementia fell and broke her hip, she refused transportation to the emergency department until an agency nurse could come to take over for her. No institutional respite stay could possibly be arranged for him. Likewise, only a small portion of the need for respite care out there could be met by your proposed program.

Many states require that significant assessment occur before a respite admission, including accumulation of relevant medical information and preparation of initial medical orders. Nursing home transfers from hospitals may be our typical challenge, but transitions from home have their own potential problems. These include getting detailed medical and nursing information, diets, food preferences, and recreational interests – all to be received before admission.

After all, the whole idea of the respite stay is that the family caregiver, who is thesource of this information during a typical nursing facility admission, will not be present or available. If the community physician agrees to be the attending physician during the stay, the advantage of a smoother transition is traded for the specter of inappropriate orders or simple ignorance of facility procedures.

Dementia patients represent special issues for a respite admission. Due to their issues in learning to manage new environments, problems such as dislocation delirium, new-onset incontinence, and falls represent real danger. Nursing home admission, even to the best facility, is frequently associated with functional declines. The caregiver who returns from a short vacation to a deteriorated relative will undoubtedly experience guilt and may not appreciate your best efforts. In-home respite alternatives in familiar surroundings, whenever available, are probably preferable to an institutional stay.

Despite all these issues, many patients who spend a week in your facility will do very well. Often, the homebound senior is delighted to have the opportunity to attend musical performances, to play bingo or do other activities, to meet new people and socialize, to have a comprehensive review of one’s medical needs, and to enjoy different foods.

Just as the respite stay may be time off for the caregiver, it may also be a vacation for your patient. Might we think of the nursing home as a summer camp?

Some respite guests ultimately become long-term residents. A well-executed respite program will not solve short-term census issues, but it could provide a valuable and needed resource, a minor financial benefit, and an excellent mechanism to break down negative stereotypes and enhance community relations.

By Jeffrey Nichols, MD

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