

[Can my loved one stay at home?](#)

Category : Long Term Care

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Considerations when making the choice for keeping a sick loved one at home or seeking placement in a long term care facility.

Among the most painful choices that we are called upon to make is the choice to either keep an aging and sickly loved one at home or to place him or her in a long term care setting.

This article seeks to provide some help in making that decision. First, let it be resolved in your mind that you will make a decision that is guided by as complete a body of facts as you are able to assemble. Second, resolve that you will let facts and facts alone drive your decision. Guilt is a fine alarm. It is a poor steering column. Third, resolve that you will not punish yourself for making the choice that you made, having taken these steps.

Now to the facts (or questions that you must answer).

Here are four basic kinds of questions that you must account for if you hope to have a successful experience in taking your loved one home (trust us on this, please ).

1) Who will be caring for the patient? Many of those who are considering placement in a long term care facility are elderly and infirm themselves. They have little ability to do the lifting, transfers, and support that are needed (These activities are called Activities Of Daily Living or ADLs). Further, aspects of the medical care itself will generally need daily, and maybe hourly, attention from the caregiver, regardless of whether or not a home health agency is involved. (To our knowledge, neither home health agencies nor hospice agencies routinely provide round-the-clock nursing unless the patient has some form of private pay, or meets very specialized government qualifications. Don't depend on these agencies for this kind of care unless you are paying privately.) This attention will sometimes include dressing changes, hygiene care, and giving medication. Often, families have a great deal of difficulty being compliant with the prescribed medications. The patient says, "I don't need any medicine right now. " The family doesn't want to contradict the patient, and three hours later a crisis (often a pain crisis) ensues. Additionally, as noted above, caregivers must be able to bear weight and assist with transfers. Otherwise, there may be two injured persons. Finally, a caregiver must be available in a timely manner, sometimes around the clock. Whoever takes care of the patient must be able to take care of himself/herself, PLUS address the needs of the patient. Most hospices and home health agencies have a sitter list available to assist you with finding help. Taking care of an infirm adult is NOT like taking care of a child: adults are bigger, they have had a long history of self-determination, and they are able to act out more aggressively with more potential for harm.

2) What are the needs of the patient? The needs we are speaking of are not just physical but cognitive, as well. The physical needs focus on four areas: Bed Mobility, Moving About, Eating and Toilet Use. Families should take into account how well the patient is able to get in/out of bed.

Remembering that they may be taking medications, will they be able to move about safely? Are they able to feed themselves, or do they require assistance? Are they able to do toileting and hygiene care on their own or do they require assistance? In order to assess how you will be able to care for a loved one, their need for support in accomplishing these tasks MUST be taken into account.

If the patient is limited in his/her ability to do these tasks, adequate provision must be made to assist them as they have need. Twice daily "check up" visits ARE NOT ADEQUATE NOR ETHICAL for a person who is incontinent, for instance. Realistically gauge what you are able to do. In our experiences, there have been many times when a family idealistically (and, we would add, admirably) attempted to keep the patient at home, thinking that the care would be adequate. One such patient that we know of ended up with urinary tract infections on a regular basis and had frequent seizures because the family had trouble managing the medications. The patient ended up being MUCH WORSE OFF than if he had stayed in a nursing home. The patient must be able to have their needs managed and managed on a timely basis.

Additionally, as mentioned above, cognitive issues must also be taken into account. Is the caregiver able to handle the agitation that sometimes attends Sundowners in Alzheimer's Disease? Many illnesses have emotional components that can be very stressful for caregivers.

3) What are the implications of the illness? One of the most difficult scenarios for families is that of the Alzheimer's patient. While the patient may be able to manage some of their ADLs (Activities of Daily Living), the disease itself leaves them occasionally unmanageable. Because of the wandering, occasional aggressiveness, and occasionally inappropriate behavior, it may be unsafe to keep them at home, especially if children are present. If you have ever been in a locked Alzheimer's unit you know exactly what I mean. The demands of providing a safe environment, watching the patient and taking care of regular chores seems almost more than one can do. This is not to say that there are not some situations where, as in our example, the Alzheimer's patient cannot stay at home, at least early on in the disease process. We are saying, however, that when a person becomes a danger to himself / herself / others, it is time for placement in a long term care facility.

Additionally, there may be other concerns over the implications of the illness. If the illness is communicable, for instance, it is important to weigh the possible effects of the illness on others in the home, who, as an example may have compromised immune systems or be very young or very old. This, too, should be taken into account.

4) Finally, what are the social implications of keeping a loved one at home? Why are you considering this option? Is the patient flexible enough to allow the caregiver "away time"? We have spoken frequently with wives whose husbands have browbeaten them into keeping them at home rather than putting them into a long term care facility. The wives have significantly endangered their own health in order to make this work. It seems they can never do enough for the patient. Sometimes they themselves end up hospitalized after a fall while they were trying to help the patient. It sometimes ends up being an emotionally brutalizing experience. Illness taps into the deepest parts of the soul, both for the caregiver and the patient. The patient feels helpless; the caregiver feels helpless. This level of helplessness engenders poor decision making driven by that helplessness and by guilt. In our experience, it is far better to make the best decision up front and let the patient adapt to it (normally taking in the range of three weeks to a couple of months). To endanger your health is to diminish your role as caregiver. You cannot be a caregiver if you have no care to give, no strength to give it.

We have said much here that may sound as though we recommend against keeping a patient at home. On the contrary, as long as the qualifications noted above are adequately dealt with, there is **no better way** to care for a loved one. The rewards are many: the patient is in a relatively familiar place with people he / she is generally comfortable with. The care is personable. The caregiver is able to DO more for the patient and is likewise in a place of greater control. Still, all this must be balanced out to figure out what is best for the patient.