Should I put my relative with Alzheimer's disease in a nursing home?

**DECISION POINT**

**Introduction**

This information will help you understand your health care choices and what the results may be, whether you choose to share in the decision-making process or to rely on your doctor's recommendation.

**Key points in making your decision**

The decision to put a relative with Alzheimer's disease in a nursing home is often a difficult one. Caring for someone with Alzheimer's disease at home requires significant social, financial, and personal sacrifices. Every family has different needs, preferences, and constraints to think about.

Consider the following when making your decision:

- People with Alzheimer's disease need a safe, healthy, structured environment. Some families are able to provide this at home; in other cases, nursing home placement is a better choice.
- People with Alzheimer's disease usually need an increasing level of care and assistance as time goes by. Many of those cared for at home eventually have to be moved to a long-term care facility.
- Adult daycare programs and part-time help, whether hired or offered by other family members and friends, are options for some caregivers.
- Your physical and emotional health is as important as that of the person you're caring for.
- Deciding to put your relative in a nursing home is not a sign of failure in your role as caregiver.

**Medical Information**

**What happens as Alzheimer's disease progresses?**

The level of care and assistance a person with Alzheimer's requires increases as the disease progresses. Basic activities like eating, dressing, bathing, using the bathroom, and simply moving around become more difficult or impossible for the person to do alone. Disruptive, frustrating, and sometimes dangerous behaviour problems may develop. These behaviours often pose the biggest challenge for caregivers. Taking care of the person at home often becomes more difficult or even impossible, both physically and emotionally.
At the same time, your relative may become less aware of who you are and where he or she is. Some people feel that caring for their spouse or parent at home is important only so long as the person knows them and knows that he or she is at home.

**What kinds of long-term care facilities are available for people with Alzheimer's disease?**

"Nursing home" is commonly used when referring to any long-term care facility, but there are several kinds of long-term care facilities. Each provides different levels of medical care, personal assistance, and programs and support services. The quality and costs of care and services at long-term care facilities vary widely, and options vary from community to community.

- **Assisted-living facilities** usually provide private, apartment-style housing and offer a range of services. These services may include meals, cleaning and laundry services, and help with personal needs, such as bathing, grooming, and dressing. Assisted-living facilities do not provide medical care. An assisted-living facility may be appropriate for people with early mild Alzheimer's disease who cannot live alone but who can still function fairly well on their own.

- **Residential care facilities**, which include board-and-care homes, retirement homes, and foster care homes, typically provide a greater level of supervision than assisted-living facilities. They offer community-style housing, meals, laundry and cleaning services, and help with other personal needs. They do not provide daily medical care. A residential care facility may be appropriate for a person with mild to moderate Alzheimer's disease who needs daily assistance and supervision but does not require daily nursing care. Residential care facilities are less expensive than nursing homes.

- **Nursing homes** can provide skilled nursing care up to 24 hours a day. All aspects of care are provided, including medical attention, medication, housing, meals, laundry, help with personal needs (such as dressing, bathing, and using the toilet), and other support services. A nursing home is the most expensive type of long-term care facility, but it also may be the most appropriate choice for many people with advanced Alzheimer's disease.

- **Special care units (SCUs)** for people with Alzheimer's disease are a feature of some residential care facilities and nursing homes. These units are designed to meet the needs of people with this disease, and they include staffs experienced in dealing with people suffering from dementia. Studies of these special care units, however, have been unable to confirm that they offer any clear benefits over regular care facilities. Also, they often are more expensive than regular long-term care facilities.

- **Continuing-care communities** offer different levels of care, from assisted living to full nursing care, within the same facility. These facilities are an expensive but appealing option for caregivers looking at long-term care for a person with Alzheimer's disease because they are well equipped to meet the person's changing needs as the disease progresses.

**What are the options for part-time care?**

Some people find that part-time help allows them to keep their relative at home for a longer time. Part-time care may take place either at home or in an adult daycare facility. As in long-term care facilities, home care can provide different levels of assistance. A home health aide, for instance, can help with tasks like bathing, cleaning, and washing clothes and linens, while a nurse may provide medical care and help with behaviour issues. Adult daycare and respite services assume temporary responsibility for the person with Alzheimer's disease and allow the
regular caregiver to take a break. This may relieve some of the stress of caregiving and allow time for other responsibilities and activities.

Hiring health professionals or other caregivers to provide around-the-clock care in the home is another option. This option is very expensive (more so than a nursing home) and also requires time to hire, supervise, and coordinate the team of caregivers.

**Your Information**

Your choices are:

- Care for your relative at home. Some caregivers may also consider part-time care at home with a home health aide or nurse or in an adult daycare facility.
- Put your relative in a nursing home or other long-term care facility.

The decision about nursing home placement should take into account your personal feelings and the medical facts.

<table>
<thead>
<tr>
<th>Reasons to consider putting your relative in a nursing home</th>
<th>Reasons to consider keeping your relative at home</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Relative's behaviour has become dangerous or disruptive to you and your household</td>
<td>• Risk of rapid decline in nursing home</td>
</tr>
<tr>
<td>• Your own health is at risk.</td>
<td>• Less individual attention for your relative in nursing home</td>
</tr>
<tr>
<td>• Burden of caregiving is too great and you have no one to help you</td>
<td>• Risk that your relative may receive poor care in the nursing home</td>
</tr>
<tr>
<td>• Nursing home may offer a safer, more controlled situation for your relative</td>
<td>• You will feel too much guilt or anxiety about relative in nursing home.</td>
</tr>
<tr>
<td>• Relative has other medical problems that require skilled nursing care</td>
<td>• Nursing home costs much more than caring for your relative at home</td>
</tr>
</tbody>
</table>

List other reasons why you might consider nursing home placement.

List other reasons why you might consider caring for your relative at home.

These [personal stories](#) may be helpful in making your decision.

**Wise Health Decision**

Use this worksheet to help you make your decision. After completing it, you should have a better idea of how you feel about putting your relative in a nursing home. Discuss the worksheet with your doctor.

Circle the answer that best applies to you.
### Factors affecting decision that apply to me
*(Table modified for workshop by MJJ)*

<table>
<thead>
<tr>
<th>Statement</th>
<th>No</th>
<th>Unsure</th>
<th>Yes</th>
<th>Decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving is negatively affecting my health or well-being or that of my family.</td>
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<td></td>
<td>Placement</td>
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<tr>
<td>My relative has developed medical or behavioural problems that require more care than I can provide.</td>
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<td></td>
<td></td>
<td>Placement</td>
</tr>
<tr>
<td>My relative has become a danger to himself/herself, me, or my family.</td>
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<td></td>
<td></td>
<td>Placement</td>
</tr>
<tr>
<td>I am healthy enough and physically strong enough to take care of my relative.</td>
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<td></td>
<td></td>
<td>Home</td>
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<tr>
<td>I can afford to devote most of my time to caregiving.</td>
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<td></td>
<td></td>
<td>Home</td>
</tr>
<tr>
<td>I have other family members and friends who can help with caregiving.</td>
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<td></td>
<td></td>
<td>Home</td>
</tr>
<tr>
<td>I have medical problems that are making it difficult to take care of my relative.</td>
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<td>Placement</td>
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<tr>
<td>There is a long-term care facility in my community that I trust.</td>
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<td>Placement</td>
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<tr>
<td>The cost of nursing home care will be an unbearable hardship.</td>
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<td></td>
<td>Home</td>
</tr>
</tbody>
</table>

Use the following space to list any other important concerns you have about this decision.

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### What is your overall impression?

Your answers in the above worksheet are meant to give you a general idea of where you stand on this decision. However, you may have one overriding reason to put your relative in a nursing home or to keep him or her at home.

Check the box below that represents your overall impression about your decision.

- [ ] Leaning toward putting my relative in a nursing home
- [ ] Leaning toward keeping my relative at home