



**FACT SHEET 4**

**Commonly asked Questions by Family Member of an  
 Older Adult Diagnosed with Advanced Alzheimer’s Disease –AD**

*Patient Self-Management Resources*

QUESTION	ANSWER	AUTHORITATIVE PRINT & WEB RESOURCE CONTACT INFORMATION
<p>What can I expect as my family member with AD moves into the late stage of AD?</p>	<p>A person with advanced AD can live from months to years. As the AD gets worse, the person with AD will not know loved ones, will need help to dress, eat, and go to the bathroom, and will be less able to talk.</p>	
	<p>The Alzheimer’s Association has information about what to expect in the late stages of AD.</p>	<p>Google your local Alzheimer’s Association chapter or contact the national office &amp; 24 hour helpline: 800 272-3900; <a href="http://www.alz.org">www.alz.org</a></p>
	<p>The Alzheimer’s Association Pamphlet “Late stage dementia” can be helpful.</p>	<p><a href="http://www.alz.org/alzheimers_disease_publications.asp">http://www.alz.org/alzheimers_disease_publications.asp</a></p>
<p>Where can I find out about what Medicare, Medicaid, and other insurance pay for in advanced AD?</p>	<p>Medicare does not pay for long-term care for a person with advanced AD. (Medicare pays for office visits, hospital care, short term rehab, home care after a hospital stay, and hospice). Most “medigap” insurances do not pay for the long-term care of a person with advanced AD.</p>	
	<p>Medicaid, a state program, does pay for long-term care at home or in a nursing home for a person with advanced AD who meets the income limit. A social worker at a local hospital or the Alzheimer’s Association can give you information about Medicare and other insurance.</p>	<p>Google your local Alzheimer’s Association chapter or contact the national office and 24 hour helpline: 800 272-3900; <a href="http://www.alz.org">www.alz.org</a>  <a href="http://www.alz.org/alzheimers_disease_publications_financial_legal.asp">http://www.alz.org/alzheimers_disease_publications_financial_legal.asp</a></p>
	<p>The Alzheimer’s Association pamphlet “Money Matters” can be helpful. Your local Medicare office can be helpful.</p>	<p>Google your local Medicare office</p>
	<p>Elder lawyers are expert in financial planning and insurance.</p>	<p>National Academy of Elder Law Attorneys. <a href="http://www.naela.org">www.naela.org</a></p>

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<p>Where can I get help about difficult behaviors (e.g. hoarding, hitting, wandering) in my family member with advanced AD?</p>	<p>The Alzheimer’s Association Caregiver Center has information that helps family members manage difficult behaviors.</p> <p>Alzheimer’s support groups are a good place to get tips from other family members about how they manage difficult behaviors.</p>	<p><a href="http://www.alz.org/care/alzheimers-dementia-stages-behaviors.asp">www.alz.org/care/alzheimers-dementia-stages-behaviors.asp</a></p> <p>Google your local Alzheimer’s Association chapter or contact the national office and 24 hour helpline: 800 272-3900; <a href="http://www.alz.org">www.alz.org</a></p>
<p>How do chronic illnesses like heart disease affect my family member with advanced AD?</p>	<p>A person with advanced AD should have regular visits with a primary care doctor or nurse practitioner. Heart disease, diabetes, vision, hearing and dental problems can make the person with AD sicker.</p> <p>Alzheimer’s Association support groups are a good place to learn the names of doctors, dentists, eye doctors and others who give good care to people with advanced AD.</p>	<p>Google your local Alzheimer’s Association chapter or contact the national office and 24 hour helpline: 800 272-3900; <a href="http://www.alz.org">www.alz.org</a></p>

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<p>How will I know when and how to ask for home care services for my family member with advanced AD?</p>	<p>If your family member with advanced AD needs help a few hours a day with things like dressing and bathing, a certified home care agency can help.</p> <p>Certified home care agencies have nurses, home health aides, physical therapists, and social workers. They generally give care for a few hours a day a few days a week. Sometimes insurance pays for this home care.</p> <p>The Medicare web site has useful information on home health care agencies</p> <p>Medical Day Care programs and PACE programs can transport a person with advanced AD to a place that gives care and meals 3 to 5 days a week.</p> <p>Alzheimer’s Association support groups are a good place to learn the names of home care agencies that give good care to people with advanced AD.</p>	<p>Google a Visiting Nurse Service or Visiting Nurse Association in your area</p> <p>Google the home care department in your local hospital to get the names of good home care agencies</p> <p>Google Medicare Compare Home Care <a href="http://www.medicare.gov/HomeHealthCompare">www.medicare.gov/HomeHealthCompare</a></p> <p>Google Medical Day Care in your area Google Program for All Inclusive Care to the Elderly (PACE) program in your area</p> <p>Google your local Alzheimer’s Association chapter or contact the national office and 24 hour helpline: 800 272-3900; <a href="http://www.alz.org">www.alz.org</a></p>
<p>Who can help me decide when it is not safe for my family member with advanced AD to live at home?</p>	<p>Your doctor, nurse practitioner or a social worker can help you decide when a family member with advanced AD should no longer live at home.</p> <p>Alzheimer’s Association support groups are a good place to help you decide about keeping your family member at home.</p> <p>A person with advanced AD who might hurt themselves or others should not live alone at home.</p>	<p>Google your local Alzheimer’s Association chapter or contact the national office and 24 hour helpline: 800 272-3900; <a href="http://www.alz.org">www.alz.org</a></p>

QUESTION	ANSWER	AUTHORITATIVE PRINT & WEB RESOURCE CONTACT INFORMATION
	<p>An assisted living facility or nursing home may be the right place for a person with advanced AD who lives alone and needs more than 8 hours a day of care, or whose care is causing a family caregiver problems with their own health, mental health, or finances.</p>	
<p>How will I know if an assisted living facility (ALF) can give good care for my family member with advanced AD?</p>	<p>Each state decides the care and services an ALF must give to meet state standards. In some states, ALFs have dementia units.</p>	<p>Google assisted living facilities in your community                      Google Assisted Living Federation  <a href="http://www.alf.org">www.alf.org</a></p>
	<p>Insurance does not usually pay for dementia care in ALF. Some long-term care insurance pays for care in ALF. In some states, Medicaid pays for care in ALF.</p>	<p><a href="http://www.assistedlivinginfo.com/Dementia-Care">www.assistedlivinginfo.com/Dementia-Care</a></p>
	<p>It is important to visit an ALF to learn how they care for a person with advanced AD. The Alzheimer’s Association has useful questions you can ask during a visit to an ALF.</p>	<p><a href="http://www.alz.org/NY/in-my-community">www.alz.org/NY/in-my-community</a></p>
<p>How will I know if a nursing home can give good care for my family member with advanced AD?</p>	<p>Medicare and each state decide the care and services a nursing home must give to meet standards.</p>	<p>Google Medicare Compare  <a href="http://www.medicare.gov/NursingHomeCompare">www.medicare.gov/NursingHomeCompare</a></p>
	<p>The Alzheimer’s Association has a booklet “Carefinders Guide” and other good information on choosing a nursing home.</p>	<p><a href="http://www.alz.org/living_with_alzheimers_choosing_care_providers">www.alz.org/living_with_alzheimers_choosing_care_providers</a></p>
	<p>Leading Age represents nursing homes and has helpful information for family caregivers.</p>	<p><a href="http://www.Leadingage.org">www.Leadingage.org</a></p>
<p>Can my family member with advanced AD get Medicare</p>	<p>A person with advanced AD can get Medicare hospice care at home, in a nursing home, or in a hospice facility.</p>	<p>Google your local Alzheimer’s Association chapter or contact the national office and 24 hour helpline: 800 272-3900;  <a href="http://www.alz.org">www.alz.org</a></p>

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Hospice?	Ask your doctor or nurse practitioner about hospice for your family member with advanced AD.	<a href="http://www.alz.org/alzheimers_disease_publications_financial_legal.asp">http://www.alz.org/alzheimers_disease_publications_financial_legal.asp</a>
	The Alzheimer’s Association has helpful information about hospice care for people with dementia.	<a href="http://www.alz.org/care/alzheimers-dementia-hospice">www.alz.org/care/alzheimers-dementia-hospice</a>
	The National Hospice Foundation has information for caregivers about hospice.	<a href="http://www.nationalhospicefoundation.org">www.nationalhospicefoundation.org</a>
How will I know if my family member with advanced AD is at risk for elder abuse and neglect?	People with advanced AD are at risk for abuse and neglect by others and for self-neglect.	
	Choosing paid caregivers from agencies that are licensed and have a good reputation can help to prevent abuse.	
	The Alzheimer’s Association has helpful information about how to tell signs of physical, emotional and sexual abuse, neglect, confinement and financial abuse.	<a href="http://www.alz.org/care/alzheimers-dementia-elder-abuse.asp">www.alz.org/care/alzheimers-dementia-elder-abuse.asp</a>
	The Elder Justice Act has helpful resources about abuse.	Google elder justice or go to <a href="http://www.apa.org/about/gr/issues/aging/elder-justice.pdf">www.apa.org/about/gr/issues/aging/elder-justice.pdf</a>
Where can I get help about my own needs and feelings about advanced AD?	The Alzheimer’s Association has free support groups for family members and an on-line Alzheimer’s and Dementia Caregiver Center.	Google your local Alzheimer’s Association chapter or contact the national office, <a href="http://www.alz.org">www.alz.org</a>
	The Alzheimer’s Association pamphlets: “Caregiver Stress” & “Take Care of Yourself” can be helpful..	<a href="http://www.alz.org/care/overview.asp">http://www.alz.org/care/overview.asp</a> <a href="http://www.alz.org/alzheimersdisease_publications_care_topics.asp">http://www.alz.org/alzheimersdisease_publications_care_topics.asp</a>

[www.HartfordIGN.org](http://www.HartfordIGN.org)

[www.ConsultGerRN.org](http://www.ConsultGerRN.org)