



Alzheimer's Disease International

PREPARING FOR THE FUTURE DURING PROGRESSION OF ALZHEIMER'S DISEASE

Alzheimer's disease can be a challenging journey, not only for the person diagnosed, but also for family members and loved ones. While there is no cure for Alzheimer's disease, there are many benefits to obtaining an early and accurate diagnosis, which includes more time to plan for the future and create the option to participate in clinical trials.^{1,2} If you or your loved one has been diagnosed by a medical professional with Alzheimer's disease, take the first step in preparing for the future by reading through this guide, which includes key information on planning for the road ahead.

WORKING TOGETHER

It's important to work together with your doctor to develop a plan that works best for you or your loved one. Scheduling regular doctor appointments to evaluate symptoms and current treatment is essential and referral to a specialist may be needed. In addition, maintaining an ongoing open communication with friends and family members can also help make the situation much easier.

Identifying a support system is crucial – even for the caregiver. No one should have to go through this alone, especially when there are so many resources available to help. Here are some quick ideas to consider when developing an action plan:

- > **Contact the Alzheimer's disease organisation in your country:** It may offer a variety of services, including a helpline that you or your loved one can call with questions, an informative website and information materials. It may have a group in your area which organizes support groups and other opportunities to meet people who understand what you're both going through.
- > **Arrange an appointment with a counsellor or psychologist:** Talking with a mental health professional who is knowledgeable about issues older people face may offer guidance and a comfortable venue to talk about feelings and emotions that may be difficult to do with friends and family. Remember that it can take time to find someone that's the right fit. Be sure to focus on what you or your loved one wants to discuss during an appointment to make the most out of your session.
- > **Reach out to a religious or spiritual advisor:** Seeking spiritual guidance often provides a broader perspective, while religious communities often provide support, offer a sense of belonging, provide new ways to think about life choices and help improve well-being.

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GETTING PERSONAL AFFAIRS IN ORDER

Locating and organising personal documents is one of the most important components of planning for the future. Putting everything in one place, telling someone where it is, and giving them consent to access it can help ensure all of you or your loved one's affairs are efficiently and properly handled. These are all important things to do anyway as you get older, but even more so if you are beginning to have cognitive problems. Here are some examples of key documents and people to designate for different purposes within these documents:

- > **Financial:** Sources of income and assets including social security, health, disability and long term care insurance information with policy numbers and agents' names and phone numbers, names of banks and account numbers are all essential pieces to have accessible.
- > **Legal:** Determining how to give legal proxy to a friend or loved one for financial or medical decision-making (e.g., power of attorney) will ensure your wishes for the future are executed appropriately and ease the decision-making process. Estate planning may need to be initiated or adjusted while you have the capacity to do so thoughtfully.
- > **Medical:** Advance directives let you make arrangements for healthcare decisions in the event you are incapable of making them and can make it easier for caregivers to know your wishes when making tough decisions on your behalf in the future. A living will gives you a say in what kind of care you do and do not want if you are too sick to communicate your own wishes. A durable power of attorney for healthcare lets you name the person you want to make medical decisions for you if you can't make them yourself.

You or your loved one should talk to a financial advisor or lawyer as appropriate about making these arrangements and ensure you understand the purpose that each of these documents serve. Take your time when making these decisions, and always ask questions if you feel unsure or need clarification. Your decisions can have an important impact on your family members as well, who may have different opinions.

LIVING ARRANGEMENTS

When Alzheimer's disease has progressed to a later stage, care needs usually exceed what a caregiver alone can provide. Exploring care options is essential since individuals have different personal and financial preferences, so mapping out a plan early will allow the person with Alzheimer's disease to be as involved as possible in contributing to those decisions. Comprehensive research and in-person visits to facilities can make a future decision easier.

- > **At-home care:** Some people choose at-home care with a part-time or live-in nurse or caregiver, so they can remain in the comfort of their own home for as long as possible. Adaptations to the home such as installing railings, intercoms, door alert alarms, and preparing an extra bedroom for the caregiver can make this a more feasible and safe option.
- > **Respite (short-term) care:** Respite care is oriented to give breaks to the caregiver and can be provided in the home — by a friend, other family member, volunteer or paid service — or in a care setting, such as adult day care or residential facility. This is usually for brief periods of time from a few hours to days, which allows the caregiver time away from the responsibilities of caring for the patient. Some arrangements can be on a regular schedule while others might be in emergency situations. This can be important if the family caregiver still has a job or is not able to do the caregiving all the time.
- > **Assisted living facilities:** These facilities often contain various amenities such as group dining halls, courtyards to walk around in and spend time with visitors, special events for entertainment, physical therapy and rehabilitation rooms, as well as an on-site medical team. Sometimes they are located in the same retirement community that has several levels of care in different buildings.
- > **Nursing homes/long-term care facilities:** Nursing homes (skilled nursing facilities) provide round-the-clock care in an institutionalized setting and long-term medical treatment. Most nursing homes have services and staff to address issues such as nutrition, ambulation, hygiene, care planning, recreation, spiritual needs and medical

care. Some facilities include special Alzheimer's disease care units, which are designed and staffed to meet the specific needs of individuals with Alzheimer's disease and other dementias.

> **Hospice:** In the worst cases, hospice care offers doctors, nurses, social workers, counsellors, chaplains, trained aides and volunteers who work together to focus on patients' needs when their condition remains life-limiting. Hospice care aims to keep the patient as pain-free and symptom-free as possible while offering spiritual and supportive counselling.

Note, other and/or different options for long-term care may be available in your country of residence. Your local Alzheimer's disease organisation can provide information on benefits your country may offer.

It's important to understand what is covered by your insurance and what you may have to pay out-of-pocket to help you prepare for the future and make choices that are right for your needs.

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1. Alzheimer's Disease International. World Alzheimer Report 2011. <http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>. Published September 2011. Accessed August 28, 2013.
 2. Alzheimer's Association. Alzheimer's Association report: 2011 Alzheimer's disease facts and figures. *Alzheimers Dement.* 2011;7:208-244.