

# Self-Advocacy Steps for People Living with Dementia

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## **What is self-advocacy?**

Self-advocacy is the action of representing yourself, your views, or your interests. Self-advocacy is an important skill to have. Self-advocacy can look like you communicating your needs and wants, and ensuring your rights are respected. Self-advocacy maintains your autonomy and quality of life through voicing what you need to family, friends, and those on your care team.

## **Tips for self-advocacy**

Self-advocating is not an easy task. It is difficult to navigate a life-changing diagnosis. The following tips and suggestions can sound simple, but in action, can be difficult emotionally, mentally, and socially.

The first tip is to gain information and education on your diagnosis. Being informed about your diagnosis and its progression can support early planning and help you anticipate and adapt to potential life changes. Having information about your diagnosis can make it easier to express and communicate what you are experiencing to medical professionals, friends, and family. It is difficult to share a diagnosis with friends and family. It is intimidating and scary, but informing those close to you is the best way to receive support and help. You do not have to go through this alone; support from loved ones can help you in self-advocacy and in navigating the emotional and physical impact a dementia diagnosis can induce.

The second tip for effective self-advocacy is to stay informed. Staying informed and being open to new information will keep you up to date on your rights, policy changes that could be of aid, insurance changes, research, and new strategies for better services and outcomes. Self-advocacy is not just checking items off a list. It is about being actively involved in your life and the decisions made. Staying informed and being open to new information and ideas helps you make the most informed and best decisions for yourself and your loved ones.

Being active is the third tip for self-advocacy. Being active is representing yourself and your needs to others. This can look like making different care-based decisions, like choosing your doctor, getting a second opinion, deciding what treatment or supports would help you now and planning ahead for future needs. Being active can also include asking questions and requesting detailed explanations and information from your care team (medical professionals, doctors, etc.), family members, and friends. Another tip for being active in your care and life is to bring a trusted individual with you to appointments to assist in asking questions, taking notes, and helping to vocalize your needs and wishes.

The last tip for self-advocacy is to be proactive in your wishes and desires. This can be done in a variety of ways. First, it is important to communicate your wishes to a trusted individual to ensure you receive support with future planning and that your preferences are honored if you are ever unable to communicate them yourself.

It is advised that all your current legal documents are up to date, including your living will. A living will can legally ensure that your wishes for treatment are upheld. It is also recommended to name a trusted individual as your power of attorney for medical and financial decisions. A living trust can be created as part of future financial planning to provide instructions for managing your property and assets if you become unable to make financial decisions independently. You can also appoint a trustee for this trust who can carry out those directions. Legal documents and power of attorney laws vary by state. Please reach out to a lawyer in your area for specific and clear legal advice. There are multiple ways to ensure your requests and desires are met through legal means. Here is a link that has more detailed information on how to plan for the future and what options are available.

<https://www.alz.org/help-support/i-have-alz/plan-for-your-future>

Self-advocacy is important for making your needs and wants known and heard by loved ones and your care team. Self-advocacy can bring a sense of agency and independence as well as dignity to your life. Below is a link to the Alzheimer's Association website advocacy page for information on getting involved in helping to advance local and federal policies and sharing your story.

***Memory Keepers is here to help! We can provide resources, answer questions, and offer other services. Contact us at [info@MemoryKeepers.org](mailto:info@MemoryKeepers.org)***

## Important legal definitions

- Power of Attorney(POA)
  - This is a legal document authorizing or giving permission to a trusted individual to make financial or medical decisions on your behalf.
    - A Medical POA would make medical decisions
    - A Financial POA would only make financial decisions
  - Durable POA: Is in effect before and when you are no longer able to make decisions for yourself.
  - Springing POA: It only takes effect once you are no longer able to make decisions for yourself or are incapacitated.
- Living Will:
  - Is a legal document that ensures that you will receive, or not receive, specific medical treatment or assistance when you are no longer able to make decisions for yourself or are unconscious.
- Living Trust
  - A legal document that holds ownership over your assets. This can be used to avoid probate and provide living instructions for when you are no longer able to make decisions on how to manage your assets.
- Trustee
  - A trustee is an appointed, trusted individual who can legally manage your trust and follow its instructions. Usually, the beneficiary of the trust will be the trustee, but you can appoint a lawyer or a different trusted individual to be a trustee as well.

## Resources to explore and assist in self-advocacy

- <https://www.alz.org/get-involved-now/advocate>
  - A link to the national Alzheimer's Association advocacy page. This page can guide you on how to take steps to advocate for yourself and your loved ones on a larger political scale
- [Alzheimer's Association resource and support page](#)
  - A link that provides resources and support on future planning and advocacy.