

# **Communicating with your Support Team and Planning for the Future**

# How to Express Yourself Effectively

We all have different ways of getting our points across to the people we are communicating with. Speaking up for one's needs, or being assertive, can be very difficult when people are experiencing stress. In addition, sometimes when we are stressed we may not have the energy to talk to others about our needs, or we may not believe that we are worth getting what we want. Being assertive requires some straightforward skills that not all people know about.

There are three styles of communication that exist on a continuum:

**Passive**

**Assertive**

**Aggressive**



Each of these styles demonstrates different levels of respect for the **boundaries**, or rights, of individuals who are talking to one another. Now we'll explore these styles a bit more.

## **Passive communication**

- Involves failing to express our feelings honestly. Instead, thoughts and feelings are expressed indirectly and apologetically, leading others to easily disregard them.
- Lets others violate our rights and shows a lack of respect for our own needs
- Seeks to please others and to avoid conflict at any cost
- Sends the following message: “I don’t count. You can take advantage of me. My feelings don’t matter; only yours.”

### **An example:**

Sylvia takes care of her husband, who has memory problems. Sylvia has arranged for her brother, Daniel, to stay with her husband while she attends a weekly one-hour exercise class. An hour before she’s scheduled to attend her class, Daniel calls to say he has changed his mind and he won’t be coming after all. Sylvia responds by saying, “that’s ok, I didn’t really need to go after all, I guess.” She begins to think that perhaps she is being selfish for asking to take some time away from the house at all. After all, she’s sure Daniel has his own problems.

## Aggressive Communication:

- Involves standing up for your personal rights and expressing your thoughts in an inappropriate way (ie: attacking, yelling)
- Violates the boundaries of the other person
- Seeks to force the other person to lose
- Sends the following message: “this is what I think, and you’re stupid for disagreeing. Your feelings and wants don’t count.”

### Back to our example:

Sylvia responds to Daniel’s decision not to come by saying, “I’m sick and tired of you always giving me a hard time. You’re so unreliable. You’ve always been this way! How could you be so thoughtless? Don’t bother to come for Thanksgiving.”



# Assertive Communication

- Involves standing up for your own personal rights without violating another person's rights
- Involves expressing your thoughts directly and honestly
- Involves two types of respect: that for your own needs and feelings, and that of the other person's needs and feelings
- Increases the chance your requests are heard correctly, which will lead to a better result
- Engages you in a process of problem solving and negotiation

## **Example:**

Sylvia takes a second to take a deep breath and says, "it's very important to my health that I get a break from caregiving. I'd like to talk to you about this and try to work something out."

What do you think *your* communication style is?

# Tips for Assertive Communication and Getting the Help You Need

- Make a specific ask (ie: “Could you please call your brother on Mondays from 12-1?”)
- Explain specifically why this would be helpful to you and your loved one. Take opportunities to provide education, which builds empathy.
- Avoid thinking of requests as ‘either/or.’ Stay open to negotiation and compromise.
- Stick to the present issue. Do not raise issues from the past (ie: “you NEVER show up for me.”)
- Prepare them for what they may encounter in terms of language, behaviors, etc. and tell them how you handle these situations
- Explain how you’d like for them to bow out if they need to (ie: “I understand that this may become unmanageable – if you’re not able to come, please try to let me know a few days in advance so I can arrange for an alternate)
- If you are still learning to ask for help verbally, consider using a tool like Plenty of Helping Hands, or Caring Bridge
- Express gratitude often

## **Another example:**

Sam says, “I don’t understand why my daughter won’t come around more than once a month or so. I mean, she lives in the same neighborhood as us – how hard could it be to stop by and see her mother? These are the last years of her life. Doesn’t she want to spend time with her? I know she’s busy with work, but this is only an hour out of her day. The other day she texted me, “let me know if you need anything. I can swing by the grocery store and pick up some food for you.” But that’s not the kind of help I need – my wife loves to go to the grocery store as an outing. Then I saw on Facebook that she had posted how hard it is to watch her mom decline. Hard for her??? She never sees her! I’m the one that lives here!”

**What would you suggest to Sam to help him communicate more effectively with his daughter?**

# Tips to Help you Communicate with Your Doctor:

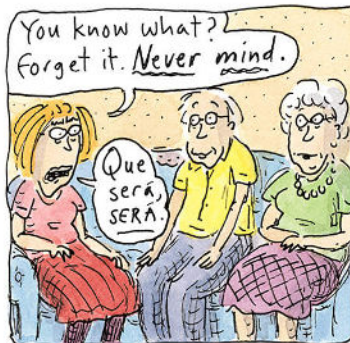
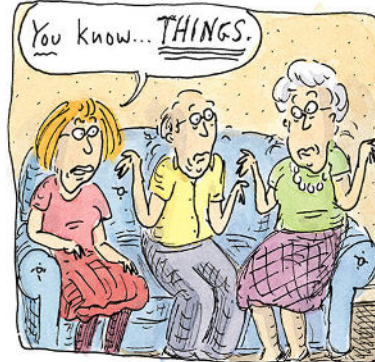
1. Make a list of questions and bring it with you to the appointment.  
Order the list from most to least important in case you aren't able to address everything.
2. Be clear and concise when you speak to the doctor. If you want to discuss a change in your relative's status, have a specific example in mind to illustrate it. If you can't describe something verbally, consider taking a video on your phone.
3. Ask your doctor how they prefer to communicate in-between appointments
4. Sign up for your health system's electronic portal, if they have one
5. Get to know the support staff at your doctor's office (ie: nursing, social work, scheduling, etc.)
6. Recognize that not all questions have answers, and not all problems have solutions.
7. Educate yourself about your relative's disease
8. Be realistic. If you feel you need extra attention, consider hiring a case manager or working with a concierge doctor.



# Care planning

CAN'T WE TALK ABOUT SOMETHING MORE PLEASANT?

My parents and I never discussed **DEATH...**



Alzheimer's Disease and related dementias are unpredictable in nature, and progression looks different for each individual. However, the more planning you can do in advance, the less you will have to do in times of even greater stress as your loved one's disease progresses. An ideal care plan should have multiple options. For example:

**Plan A:** Keep my loved one at home with me for the duration of their life

**Plan B:** Keep my loved one at home with me for the duration of their life, and bring in informal and/or professional help

**Plan C:** Move my loved one to an assisted living or memory care facility, or skilled nursing facility

**Remember:** Just like there's no "one size fits all" approach to other lifestyle decisions, there's not one right way to care plan. Whether you choose to care for someone in their own home or place them in a facility has no bearing on whether you're a 'good' caregiver. Individuals with dementia can do well in *both* settings given the proper supports.

## General Tips for Creating a Care Plan:

- **Who will be involved?** Are there individuals who should be instrumental in helping you plan? Are there individuals who will need to know about the plan once complete but won't be involved in creating it?
- **Focus on goals.** Think about what your ultimate goal is for your loved one's care, and what their goal is for their life moving forward, and return to this often.
- **Acknowledge reality.** All of us have different strengths and limitations on our time, energy and finances. These things will not disappear in the context of your loved one's disease.
- **Have a family meeting.** If there are more than two people involved in care planning, schedule a series of in-person or virtual meetings to make sure everyone is on the same page. Consider using a mediator or facilitator if you're concerned there may be conflict you're unprepared to handle alone.
- **Write it down.** Keep your plan in a place that's easily accessible and distribute it to any family members or professionals involved in your loved one's care.

# **If You Can Only Do One Thing, Create a Power of Attorney.**

As the person you are caring for progresses through the stages of dementia, they will become less able to make or communicate their decisions. It is important to have a POA in place before your loved one becomes “incapacitated” (a legal term which refers to the point where they can no longer manage their own affairs). There are many types of POA, but the most commonly used amongst caregivers is the Durable Power of Attorney (DPOA), which allows a designated agent to act on behalf of an individual only once they can no longer act themselves (as designated by at least one doctor). You will need a lawyer to prepare this. Some things you may need a POA to access if your loved one is unable to manage his/herself:

- Banking
- Social Security or other retirement benefits
- Medicare
- Online patient portal/medical records

You may also consider working with your loved one to create a **living will**, or a document that states their medical wishes if/when they are no longer able to communicate them. Decisions that may be discussed in a living will include:

- Use of artificial nutrition
- Ventilator use
- CPR
- Pain management methods

Anyone can create a living will – it does not have to be prepared by an attorney. There are many tools to walk you through the process. For example, Penn's My Care Wishes (<https://www.ourcarewishes.org/>) walks you through decisions about medical treatment, quality of life, and funeral arrangements.



# Now What?

## Next Steps After an Alzheimer's Diagnosis

A diagnosis of Alzheimer's disease can be difficult, but getting accurate information and support can help you know what to expect and what to do next. Use this checklist to help you get started.



### Learn about Alzheimer's disease

Being informed will help you know what to expect as the disease progresses. Here are some resources:

- ✓ Alzheimer's and related Dementias Education and Referral (ADEAR) Center  
[www.alzheimers.gov](http://www.alzheimers.gov) | 800-438-4380
- ✓ Alzheimer's Association  
[www.alz.org](http://www.alz.org) | 800-272-3900
- ✓ Alzheimer's Foundation of America  
<https://alzfdn.org> | 866-232-8484
- ✓ Local hospitals and community centers may have educational programs about Alzheimer's disease and related dementias.

### Get regular medical care

- ✓ Make regular appointments with your primary care doctor or specialist (neurologist, neuropsychiatrist, geriatric psychiatrist).  
[www.nia.nih.gov/health/doctor-patient-communication/talking-with-your-doctor](http://www.nia.nih.gov/health/doctor-patient-communication/talking-with-your-doctor)
- ✓ Consider going to a memory disorders clinic. Ask your doctor for a referral if desired.

### Find local services and support

- ✓ Find local services by contacting Eldercare Locator  
<https://eldercare.acl.gov> | 800-677-1116
- ✓ Contact your local Alzheimer's Disease Research Center  
[www.nia.nih.gov/health/alzheimers-disease-research-centers](http://www.nia.nih.gov/health/alzheimers-disease-research-centers)
- ✓ Find local chapters, organizations, and support groups:
  - Alzheimer's Association  
[www.alz.org](http://www.alz.org) | 800-272-3900
  - Alzheimer's Foundation of America  
<https://alzfdn.org> | 866-232-8484

### Do some legal, financial, and long-term care planning

- ✓ Get information to help you plan.  
[www.nia.nih.gov/health/legal-and-financial-planning-people-alzheimers](http://www.nia.nih.gov/health/legal-and-financial-planning-people-alzheimers)
- ✓ Prepare or update your will, living will, health care power of attorney, and financial power of attorney. To find a lawyer, contact your local bar association or the National Academy of Elder Law Attorneys.  
[www.naela.org](http://www.naela.org)
- ✓ Learn about care you may need in the future and how to pay for it.  
<https://longtermcare.acl.gov>
- ✓ Explore getting help to pay for medicines, housing, transportation, and more.  
[www.benefitscheckup.org](http://www.benefitscheckup.org)

### Get help as needed with day-to-day tasks

- ✓ Use simple memory aids like a notepad or sticky notes to jot down reminders, a pillbox to keep medications organized, and a calendar to record appointments.
- ✓ Ask family members or friends or find local services to help with routine tasks, such as cooking, paying bills, transportation, or shopping.
- ✓ Consider using technology solutions for medication management, safety (e.g., emergency response, door alarms), and other care.
- ✓ See tips about coping daily, changes in relationships, and more.  
[www.nia.nih.gov/health/alzheimers/caregiving](http://www.nia.nih.gov/health/alzheimers/caregiving)

## Be safe at home

- ✓ Get home-safety tips.  
[www.nia.nih.gov/health/home-safety-checklist-alzheimers-disease](http://www.nia.nih.gov/health/home-safety-checklist-alzheimers-disease)
- ✓ Ask your doctor to order a home-safety evaluation and recommend a home health care agency to conduct it. Medicare may cover the cost.
- ✓ Consider wearing a medical ID bracelet or necklace in case you get lost or need help, or joining the MedicAlert and Alzheimer's Association's Wandering Support program.  
[www.medicalert.org/alz](http://www.medicalert.org/alz)

## Stay safe on the road

- ✓ Talk with your doctor if you become confused, get lost, or need lots of help with directions, or if others worry about your driving.
- ✓ Get a driving evaluation. Ask your doctor for names of driving evaluators, or visit the American Occupational Therapy Association.  
[https://myaota.aota.org/driver\\_search](https://myaota.aota.org/driver_search)
- ✓ Learn about driving safety.  
[www.nia.nih.gov/health/driving-safety-and-alzheimers-disease](http://www.nia.nih.gov/health/driving-safety-and-alzheimers-disease)

## Consider participating in a clinical trial

- ✓ Ask your doctor about trials or studies.
- ✓ Contact an Alzheimer's Disease Research Center for assessment and potential research opportunities.
- ✓ Search for a clinical trial or study near you or that you could participate in remotely:
  - NIA Clinical Trials Finder  
[www.nia.nih.gov/alzheimers/clinical-trials](http://www.nia.nih.gov/alzheimers/clinical-trials)
- ✓ Learn more about clinical trials:
  - NIA Clinical Trials Information  
[www.nia.nih.gov/health/clinical-trials](http://www.nia.nih.gov/health/clinical-trials)
  - National Institutes of Health  
[www.nih.gov/health-information/nih-clinical-research-trials-you](http://www.nih.gov/health-information/nih-clinical-research-trials-you)

## Stay healthy

- ✓ Be active! Getting exercise helps people with Alzheimer's feel better and helps keep their muscles, joints, and heart in good shape.  
[www.nia.nih.gov/health/exercise-physical-activity](http://www.nia.nih.gov/health/exercise-physical-activity)
- ✓ Eat a well-balanced diet that includes fruits, vegetables, and whole grains.  
[www.nia.nih.gov/health/healthy-eating](http://www.nia.nih.gov/health/healthy-eating)
- ✓ Continue to enjoy visits with family and friends, hobbies, and outings.

## If you live alone

- ✓ Identify someone who can visit you regularly and be an emergency contact.
- ✓ If you are at risk of falling, order an emergency response system. A special pendant or bracelet lets you summon help if you fall and can't reach the phone.
- ✓ Consider working with an occupational therapist. This person can teach you ways to stay independent. Ask your doctor for more information.
- ✓ Stick with familiar places, people, and routines. Simplify your life.
- ✓ Get tips about self-care, safety, staying connected, and more.  
[www.nia.nih.gov/health/tips-living-alone-early-stage-dementia](http://www.nia.nih.gov/health/tips-living-alone-early-stage-dementia)

## If you are working

- ✓ If you have problems performing your job, consider reducing your hours or switching to a less demanding position.
- ✓ Consider consulting your employer's HR department or employee assistance program about family leave, disability benefits, and other employee benefits.
- ✓ Find out if you qualify for Social Security disability benefits through "compassionate allowances."  
[www.ssa.gov/compassionateallowances](http://www.ssa.gov/compassionateallowances)  
800-722-1213