

# A Caregiver's Guide to Dementia

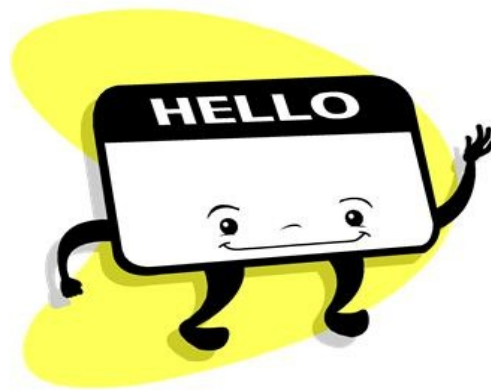
Tips and Strategies for a  
Positive Approach to Care



# Introduction

This guide is designed as a practical approach for caregivers to provide person-centered care to loved ones /care recipients with Alzheimer's disease and other forms of dementia. The guide examines some of the common issues caregivers may encounter and provides practical tips and solutions. As you get to know how the person you are caring for reacts, you will develop your own strategies and methods for coping, and determine things that most help your loved one. We welcome your feedback and discussion on our blog or Facebook community ([www.facebook.com/EasyLivingFL](http://www.facebook.com/EasyLivingFL)).

**About EasyLiving, Inc:** EasyLiving, Inc. is a fully licensed, private duty home healthcare company serving individuals and families in Pinellas and Pasco counties in Florida. We provide a range of care management and home care services, from short-term respite care or post-hospital support to long-term care and round-the-clock support. Our experienced management team has been advocating for seniors in Florida for many years and shares our expertise with family caregivers and professionals nationwide. **For more information, please visit [www.easylivingfl.com](http://www.easylivingfl.com) or contact our team at 727-447-5845.**



# Communication



- Communication abilities and needs will vary over the disease course. Difficulty finding the right word or misplacing one word for another are one common sign of dementia. It can be one of the greatest frustrations for the individual as well as their caregivers to struggle with communicating needs and feelings.
- Pay attention to what the person is trying to communicate (feeling, non-verbal clues, and signals even when words are confused). Focus and minimize outside distractions.
- Break your instructions or communications down in to steps.
- Use concise, simple (but not child-like or condescending) language.
- Be patient and calm. Your non-verbal clues and emotions can often be felt by the person and may be more powerful than your words.
- Do not argue with the person. Understand that what they are feeling or saying may be their reality.
- Use “yes, and...” statements. So, for example, if the person is concerned about “needing to go home”, say “Yes I understand you are worried about that and perhaps we can go over here and grab a drink and then talk more about it/find out what we can do...”.
- Be attentive-show interest and reinforcement even if you are having some trouble understanding. Laughter and kindness show through even when verbal communication is extremely limited.
- Use cues such as demonstrating or showing along with verbal instructions or information.

# Restlessness/Pacing

- Plan activities to keep busy. Find out what your loved one enjoys and what captures their attention.
- For pacing, walk with the person or provide a safe space to walk.
- Provide reassurance.
- Provide plenty of fluids and food to ensure adequate nutrition for someone who burns a lot of calories walking/being active.
- Learn routines: does the person get restless certain times of day or does something set off anxiety? Plan accordingly or try to minimize anxiety-producing stimuli.

**Sundowners Syndrome** (late afternoon/evening symptoms): Sundowning is a term used to describe a pattern of behaviors in the late afternoon and evening found in many dementia patients including increased anxiety, restlessness, and wandering.

- Anticipate timing and plan activities or additional help during this time. Do not plan outings or activities that will be difficult. Keep things routine.
- Find out if the person may be hungry or thirsty.
- Provide additional lighting.
- Ask for help with a task or provide a distracting activity (help sorting clothes, working on a simple project, etc.).
- Provide reassurance and empathy for their concerns/worries (there is often an underlying feeling of the need to do something, such as “go home” or waiting on someone).
- Take safety precautions for wandering.
- Play soothing music, watch a favorite TV show, provide the most calm environment possible.

# Refusing Care/Personal Care Issues

- Stick with a routine.
- Be prepared for the activity prior-have everything at hand.
- Explain what you will be doing in simple terms. Do not touch the person or begin activities without calmly explaining.
- Try to determine if fears or physical feelings are behind refusals (is the bath water cold? is the person afraid of slipping?) and make the situation as comfortable as possible.
- Simplify routines and “pick your battles”.
- Don’t act rushed. Use simple commands and allow more time than you think it will take so you are not both frustrated.
- Limit choices/simplify (for example, do not ask “Which shirt would you like to wear?” from a whole closet, instead ask “Would you like this blue shirt or this red shirt?”).
- Use easy-wear clothes (elastic waists, pullovers) and lay clothes out ahead of time when possible.
- Create a “bathroom schedule” in which you suggest/help the person to the bathroom every couple hours to help avoid accidents.



# Home Safety and Wandering

- Use a home safety checklist to do a review and remove obstacles/fall hazards. Download our [falls prevention checklist](#) You may also want to get a professional home safety assessment for suggestions and resource ideas.
- Watch for trouble areas such as curbs, stairs, pools. Consider blocking off trouble areas (gating stairs, locking doors, putting up a pool fence, etc.).
- Use locked areas for hazardous materials.
- Depending on the feasibility and level of concern, consider disabling the stove and removing other fire hazards.
- Sign the person up for the Alzheimer's Association's Safe Return® (an id bracelet with a special 800# to identify someone if they become lost).
- There are developing technologies using GPS to locate someone who is lost, which may be useful depending on the situation.
- Consider locking doors using keyed deadbolts and/or safety latches.
- Use visual distraction at doorways (a dark patch—painted floor, carpet—can stop a person with dementia from going forward as can doors painted to blend in with the wall or in ways that camouflage them).
- Provide activity/distraction especially during “high agitation” times and practice redirection.
- Anticipate wandering: not everyone with dementia wanders, but it is a common concern. Plan ahead and minimally enroll your loved one in the Safe Return program.

# Nutrition



- For individuals living on their own, consider providing meals through a meal delivery service, home caregiver to prepare meals or other options.
- If the person paces, talk to a physician or nutritionist about calorie and nutrition needs. Supplements may be needed (also true if the person sometimes refuses meals or has poor appetite).
- Provide a varied diet, with different textures and colors to appeal to the person.
- Make mealtimes a calm environment.
- Provide cues and assistance as needed. Demonstrate what to do if he/she seems confused.
- Allow as much independence as possible, but understand that processes become more difficult as the disease progresses and assistance may be needed. If your loved one refuses to eat, he may be unsure of what to do, feel overwhelmed with choices or be anxious.
- Find out about possible medication side effects related to eating, such as intestinal disturbances or reduced appetite.

# Tips for the Caregiver

- Get organized: gather your loved one's records-medical, legal, insurance, important papers. Consider setting up a "health notebook" or online health portal to track medical care, medications, etc.
- Gather family support. Consider a family conference after a diagnosis and perhaps at regular intervals. Discuss how different family members can help.
- Tell others how they can help you. People often want to help, but don't know what to do. Can a friend drive your Mom to an appointment, pick up groceries, cook meals? Do you need someone to do some research for you?
- Set aside time for at least one favorite activity.
- Try to get sufficient rest and eat well.
- Make backup plans. Who can step in to help if you cannot? How will care be handled?
- Share your feelings/concerns. A support group can be a great resource, or you can use online support/forums if you cannot attend a group in person.
- Research, and consider using, respite care. A home health agency like EasyLiving can offer professional caregivers right in the home environment to maintain routine and familiarity, allowing you to take short breaks. This also helps you and your loved one become comfortable with outside help to be better prepared for the future/prior to a crisis.
- For more tip sheets, links and educational information, check out EasyLiving's [blog](#).





# Resources

[www.easylivingfl.com](http://www.easylivingfl.com) –Home Health Care and Care Management in Pinellas and Pasco Counties in Florida, information about elder care and home health. Check out our blog for weekly hot news and tips or sign up for our monthly newsletter.

[www.agingwisely.com](http://www.agingwisely.com) –Our aging wisely care managers have created a huge catalog of resources for elders and caregivers.

[www.alz.org](http://www.alz.org) –The Alzheimer’s Association, offering resources for various topics and categories, message boards, information on current studies and more as well as connections with local chapters/local resources.

[www.eldercare.gov](http://www.eldercare.gov) –Eldercare Locator, a public services of the U.S. Administration on Aging. You can also find links to various other governmental services and resources.

<http://archrespice.org/> -ARCH National Respite Network

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