PREFACE TO THIS GUIDE

The Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) provides care that supports Georgians with behavioral health challenges, and intellectual and developmental disabilities in a dynamic health care environment. Some of the individuals served may also suffer from related cognitive impairments, such as dementia.

This quick reference guide contains tips and techniques for caregivers of individuals with dementia and/or individuals with dementia and intellectual/developmental disabilities.

TOPICS INCLUDED

• Definitions
• Facts about Dementia
• Common Symptoms of Dementia
• Facts about Dementia and Intellectual/Developmental Disabilities
• Communication Strategies
• Ten Communication Absolutes
• Alzheimer’s Disease: A Caregiver’s List for Daily Care
• Symptoms of Caregiver Stress
• Management of Caregiver Stress Services for Caregivers
• Effective Treatment Environments for Dementia
• For Further Information

 selors and geriatricians http://dx.doi.org/10.1016/j.jalz.2013.05.992
 Mastery over dementia: An internet intervention for family caregivers of people with dementia http://dx.doi.org/10.1016/j.jalz.2010.05.276
 The relationship between coping strategies and caregiver burden in caregivers of people with Alzheimer’s dementia - http://dx.doi.org/10.1016/j.jalz.2013.05.988
 Communication trainings for caregivers of dementia patients: tandem project http://dx.doi.org/10.1016/j.jalz.2010.05.413
 Linking physicians, persons with dementia and family caregivers to improve dementia http://dx.doi.org/10.1016/j.jalz.2008.05.302

For Further Information
Definitions

Cognition - A combination of mental processes that includes the ability to learn new things, intuition, judgment, language, and remembering.
Cognitive Impairment - When cognition is impaired, a person has trouble with mental processes that begins to affect the things he or she can do in everyday life.

Dementia - The gradual deterioration of intellectual abilities and behavior that eventually interferes with daily living activities, such as keeping a job or driving a car.

Alzheimer’s disease - The most common form of dementia, accounting for 60 to 80 percent of dementia cases. It is a progressive disease, where dementia symptoms gradually worsen over a number of years.
Developmental Disability - A chronic condition that develops before a person reaches age 22 and limits his/her ability to function mentally and/or physically.

Intellectual Disability – A condition characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.

For Further Information...

A tremendous amount of information is available on dementia and caregiving. Some of these sources are listed below:

Resources on dementia for health care providers and caregivers
http://www.psychiatrictimes.com/articles/resources-dementia-health-care-providers-and-caregivers

Dementia and People with Intellectual Disabilities http://youtu.be/wrKLURsAy6Y
When People with Developmental Disabilities Age: Down Syndrome and Dementia http://youtu.be/MEtkmI2xE8th

Mental health symptoms in people with cognitive impairment and memory loss and their caregivers: Initial findings and implications for coun-

Cognition - A combination of mental processes that includes the ability to learn new things, intuition, judgment, language, and remembering.
Cognitive Impairment - When cognition is impaired, a person has trouble with mental processes that begins to affect the things he or she can do in everyday life.

Dementia - The gradual deterioration of intellectual abilities and behavior that eventually interferes with daily living activities, such as keeping a job or driving a car.

Alzheimer’s disease - The most common form of dementia, accounting for 60 to 80 percent of dementia cases. It is a progressive disease, where dementia symptoms gradually worsen over a number of years.
Developmental Disability - A chronic condition that develops before a person reaches age 22 and limits his/her ability to function mentally and/or physically.

Intellectual Disability – A condition characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.

For Further Information...

A tremendous amount of information is available on dementia and caregiving. Some of these sources are listed below:

Resources on dementia for health care providers and caregivers
http://www.psychiatrictimes.com/articles/resources-dementia-health-care-providers-and-caregivers

Dementia and People with Intellectual Disabilities http://youtu.be/wrKLURsAy6Y
When People with Developmental Disabilities Age: Down Syndrome and Dementia http://youtu.be/MEtkmI2xE8th

Mental health symptoms in people with cognitive impairment and memory loss and their caregivers: Initial findings and implications for coun-
Facts about Dementia

Dementia influences all aspects of the mind and behavior, including memory, judgment, language, concentration, personality, and social interactions.

- Dementia is not a normal outcome of aging.
- Dementia has affected 47.5 million people worldwide.
- A new case of dementia is diagnosed every 4 seconds.

Dementia treatment currently costs $604 billion per year

Dementia is not a single disease but a set of signs and symptoms related to multiple diseases

Source: https://www.openplacement.com/community/blog/dementia-facts-know/

Common Symptoms of Dementia

Dementia has both emotional and physical symptoms. Some of these symptoms include:

Emotional Imbalance
- Outbursts
- Withdrawal
- Dull Look
- No Emotions

Physical Indicators
- Dazed, confused appearance
- Glazed eyes
- Poor motor coordination
- Lack of balance and normal posture

Services for Caregivers

<table>
<thead>
<tr>
<th>Programs/Projects</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Association and National Down Syndrome Society</td>
<td>General information for caregivers</td>
</tr>
</tbody>
</table>
| Administration for Community’s National Family Caregiver Support Program (Title IIIE of the Older Americans Act) | Funding for community-based programs to support caregivers (age 18 and older):
- Counseling and training services (peer support groups and training to help better cope with caregiving stress)
- Respite services for temporary relief from caregiving responsibilities – at home or in an adult day care center (e.g., Lifespan Respite Care Programs) |
| Alzheimer’s Disease Initiative: Specialized Supportive Services (ADI-SSS) Project | Improvement of quality and effectiveness of programs and services dedicated to individuals with IDD and dementia:
- Training targeted to caregivers and providers of services to IDD and dementia individuals |
Management of Caregiver Stress

Caregivers should take advantage of ways to deal with the stress of their jobs, such as:

**Asking for help**
- Joining a support group (e.g., Alzheimer’s Caregiver Support)
- Maintaining social outlets—weekly visits with friends/relatives
- Using fatigue fighters—exercise, yoga, stretching
- Getting regular check-ups (including dental, vision and hearing)
- Sleeping at least 7-8 hours a night
- Eating nourishing foods
- Connecting with nature, pray/meditate

Symptoms of Caregiver Stress

Dementia can sometimes be overwhelming for caregivers. More than one-third of caregivers report symptoms of depression.

Common symptoms of caregiver stress include:
- Denial
- Isolation, loneliness
- Difficulty making decisions
- Easily irritated and frustrated
- Feeling overwhelmed and guilty
- Exhausted, tired most of the time
- Sad, cries easily, stops enjoying things
- Use of alcohol or

Facts about Dementia and Intellectual/Developmental Disabilities (IDD)

The loss of memory in dementia complicates treatment of other conditions, such as IDD.

Most adults with intellectual disabilities are generally affected by forms of dementia at the same rate as other adults (about 6% after the age of 60).

Adults with Down syndrome are particularly susceptible to dementia and may show early onset.

A large number of older-aged adults with intellectual disabilities live with their families. Dementia increases the challenges for these caregivers.

Early identification of symptoms of dementia is an important first step in managing the course of the disease and providing quality care.

Communication Strategies

- Make eye contact but do not stare
- Do not argue or scold
- Do not rush
- Eliminate noise and distraction while communicating
- Express affection—smile, hold hands, give a hug
- Move and speak slowly and calmly
- Provide one-to-two steps simple verbal instructions at a time
- Reassure individuals that they are doing a good job


Source: https://www.alz.org/care/dementia-communication-tips.asp

Dementia

Source: http://www.alz.org/care/dementia-communication-tips.asp
A major part of effective communication with dementia individuals is interacting in ways that are person centered. Know as much as possible about their needs, values, and goals. Use these “absolutes” in communicating with dementia individuals.

<table>
<thead>
<tr>
<th>Approach/Programs</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity engagement</td>
<td>Involvement of individuals in areas that are appropriate for their capabilities (e.g., events, crafts, and exercise).</td>
</tr>
<tr>
<td>Cognitive behavioral therapy to address anxiety (CBT-AD)</td>
<td>Integration of interventions for late-life anxiety with strategies that facilitate comprehension, encoding, and retrieval (e.g., memory cueing and spaced retrieval).</td>
</tr>
<tr>
<td>Cognitive rehabilitation</td>
<td>Treatment components include awareness training, breathing skills, coping self-statements, and sleep skills. Caregivers who spend at least 8 hours a week with the individual participate as “coaches” in assessment and treatment, and the intervention is conducted in the home.</td>
</tr>
<tr>
<td>Environmental redesign</td>
<td>Use of design principles to minimize the challenges surrounding individuals and enhance how they function within the environment. Simplification, color coding and placing objects in sight or out of sight are examples of environment redesign.</td>
</tr>
</tbody>
</table>

### Getting Dressed

- **Make it easy for him/her to dress on their own.** Lay out clothes in the order he/she puts them on or hand him one piece of clothing at a time.
- **If he/she wants to wear the same clothes every day, don’t fight it.** Buy 3 or 4 sets of them.
- **Make sure he/she has loose clothes that are easy to put on.** Shorts and pants with elastic waistbands and slip-on shoes are good. Skip shoesaces, buttons and buckles.

### Grooming

- **Show him/her how to brush his/her teeth** step by step, or brush yours at the same time.
- **Try an angled, long-handled, or electric toothbrush if you’re brushing for him/her.**
- **If a woman wants to wear makeup, encourage it. Help her with lipstick and powder, if she wants.**

### Bathing

- **Use a hand-held showerhead, rubber bath mat, grab bars, and a shower stool to prevent falls.**
- **To help relax him/her during bathing, play calming music and tell him/her what you are doing each step of the way.**
- **Give him/her as much privacy as you can.** Put a towel over his/her shoulders and lap. Clean under the towel with a washcloth or sponge.

### Eating

- **Helping with chores can boost self-esteem.** Ask him/her to dust, sweep, fix chores, sort socks, fold laundry, read a recipe for you, or measure when you cook.
- **Keep mealtime simple and calm.** Turn off the TV and radio. Move unneeded items off the table. If having many foods at once confuses him/her, serve one thing at a time.
- **Try an angled, long-handled, or electric toothbrush if you’re brushing for him/her.**

### Activities

- **Stay active.** Take a walk together every day to keep muscles strong, boost mood, and help with sleep. If he/she can’t get around well, he/she may be able to use a stationary bike or resistance bands.
- **If he/she tends to get anxious and hitting is a problem, give him/her a washcloth to hold.** He/she will be less likely to strike and may calm down.
- **If an activity isn’t working, give him/her a washcloth from his/her plate and his/her plate from the table.**

### Effective Treatment Environments for Dementia

Treatment programs for dementia care vary depending on the exact diagnosis. This table summarizes some of the treatment approaches that do not involve medicine.

---

*Source:* [webmd.com/healthy-aging/caregiver-14/alzheimers](http://www.webmd.com/healthy-aging/caregiver-14/alzheimers)

---

*Source:* caregivercards.biz/caregiver-blog/item/186-the-10-absolutes-of-caring-for-alzheimer-s-patients