New to Caregiving: An Orientation

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First: This is a New Role

• Different from the relationship you have with the person
  • Person and relationship persist

• Something you do with and on behalf of the person

• That “Something” can be described

• The knowledge, skills, and perspective needed to carry the role out can be named
  • Training for this rather clinical undertaking is available
Recognize and Acknowledge the Situation

In what ways is your life no longer “ordinary”?

- Think about “ordinary” thought processes
- Think about “ordinary” communication processes

The day-to-day challenge:
On what can you rely?
What must you supply?
Think and Act Like a Clinician
Don’t Just Do Something: Stand There

• Step back, scope out the situation
• Use what you know about dementing illnesses to figure out what might be going on – On what can you rely here?
  • So: learn about the condition
• Create a plan – what do I need to supply here? And how?
  • Learn and develop strategies
• Try it and see what happens

• Learn and repeat
Take Care of the Instrument

Self-Care is Essential and not Selfish

• Decades of research find caregiving to be wearing on physical and psychological health

• For a variety of socially- and culturally-based reasons, caregivers don’t or won’t admit the challenges of the role

• Mindfully identifying – and then sticking to – self-care practices is critical to caregiver well-being – and therefore to the person’s well-being
Assertively Ask for Help

Scan Your Resource Network

• A Reliable, Knowledgeable Clinical Provider
• Family
• Friends
• Social Network
• Community and Faith Networks
• Social Service Agencies
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Cognitive Empowerment Program
• As we age, it’s normal to have a slight decline in cognitive function
  • (memory, language, executive function, attention etc.)
  • When that decline is slightly worse than expected, we use the term Mild Cognitive Impairment (MCI.)
• When the decline is significantly worse than usual, we use the term dementia.
  • There are several possible causes of cognitive decline, but the most common irreversible cause is Alzheimer’s disease.
In MCI, cognitive changes are noticeable and show up on tests, but aren’t severe enough to stop the person from completing day-to-day tasks and usual activities—however, the tasks may take more time or be more difficult.

*Often, the first signs are: short term memory loss (forgetting appointments, forgetting conversations, asking the same question more than once;) having trouble doing finances; getting turned around while driving in familiar places.

Approximately 15 percent to 20 percent of people age 65 or older have MCI (all causes)
Progression

Normal Aging → MCI → Dementia

If cognitive impairment does progress, it’s not always clear-cut which category the person falls into—there’s often a gray area in between.

But a person is considered to have dementia when cognitive decline is severe enough to interfere with daily life and independent function.
is it alzheimer’s or just signs of aging?
Warning signs you should know

If you or someone you care about is experiencing any of the 10 warning signs, please see a doctor to find the cause. Early diagnosis gives you a chance to seek treatment and plan for your future. The Alzheimer’s Association can help. Visit us at alz.org/10signs or call 800-272-3900.

The Alzheimer’s Association is the world’s leading voluntary health organization in Alzheimer’s care, support and research. Our mission is to eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer’s disease.

For information and support, contact the Alzheimer’s Association:
800.272.3900
alz.org

Your memory often changes as you grow older. But memory loss that disrupts daily life is not a typical part of aging. It may be a symptom of dementia. Dementia is a slow decline in memory, thinking and reasoning skills. The most common form of dementia is Alzheimer’s (AHLZ-high-
mer) disease, a fatal disorder that results in the loss of brain cells and function.

Because African-Americans are more likely to have vascular disease (problems with blood circulation), they may also be at greater risk for developing Alzheimer’s. Risk factors for vascular disease — like diabetes, high blood pressure and high cholesterol — may also be risk factors for Alzheimer’s and stroke-related dementia.
KNOW the 10 SIGNS
EARLY DETECTION MATTERS

It may be hard to know the difference between age-related changes and the first signs of Alzheimer’s disease. For example, if the person was never good at balancing a checkbook, struggling with this task is probably not a warning sign. But if their ability to balance a checkbook has recently changed, it is something to share with a doctor.

To help, the Alzheimer’s Association has created this list of warning signs for Alzheimer’s disease and related dementias. Individuals may experience one or more signs in different degrees. If you notice any of them, please see a doctor.

One
Memory loss that disrupts daily life. One of the most common signs of Alzheimer’s, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; relying on memory aids (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own.

What’s a typical age-related change? Sometimes forgetting names or appointments, but remembering them later.

Two
Challenges in planning or solving problems. Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.

What’s a typical age-related change? Making occasional errors when balancing a checkbook.

Three
Difficulty completing familiar tasks at home, at work or at leisure. People with Alzheimer’s often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game.

What’s a typical age-related change? Occasionally needing help to use the settings on a microwave or to record a television show.

Four
Confusion with time or place. People with Alzheimer’s can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.

What’s a typical age-related change? Getting confused about the day of the week but figuring it out later.

Five
Trouble understanding visual images and spatial relationships. For some people, having vision problems is a sign of Alzheimer’s. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not realize they are the person in the mirror.

What’s a typical age-related change? Making a bad decision once in a while.

Six
New problems with words in speaking or writing. People with Alzheimer’s may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary or have problems finding the right word or call things by the wrong name (e.g., calling a sock “a hand-sock”).

What’s a typical age-related change? Sometimes having trouble finding the right word.

Seven
Mispacing things and losing the ability to retrace steps. A person with Alzheimer’s disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accrete others of stealing. This may occur more frequently over time.

What’s a typical age-related change? Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

Eight
Decreased or poor judgment. People with Alzheimer’s may experience changes in judgment or decision making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.

What’s a typical age-related change? Making a bad decision once in a while.

Nine
Withdrawal from work or social activities. A person with Alzheimer’s may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced.

What’s a typical age-related change? Sometimes feeling weary of work, family and social obligations.

Ten
Changes in mood and personality. The mood and personality of people with Alzheimer’s can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone.

What’s a typical age-related change? Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

Note: Most changes with age may also be a sign of some other condition. Consult a doctor if you observe any changes.

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Georgia Tech
If you think you are experiencing a decline in cognitive function:

• Talk to your primary care physician first.
  • Medicare covers an annual wellness exam which includes a cognitive test.
  • Your PCP may refer you to a neurologist—preferably a cognitive neurologist like the ones at Emory’s Brain Health Center.

• There are benefits to early detection:
  • Identifies potentially reversible causes of cognitive decline
  • Medications are more effective when started early
  • Allows time for you and your family to adjust to the diagnosis and for you to actively engage in planning for the future
  • Offers opportunity for access to advice, support
  • Lifestyle changes can be adopted to help reduce the rate of further progression (physical exercise, cognitive training, healthy diet, socialization)
  • Allows for opportunity to be involved in research
Healthy Aging & Participating in Research
Research and your health

Discoveries from research led to the medicines and treatments we take for granted today:

- **Vaccines** to prevent infectious diseases such as tuberculosis
- **Antibiotics** to treat bacterial diseases such as pneumonia
- **Medications** to manage ongoing conditions such as high blood pressure and pain
Continuing to look for answers

• How can we prevent, or cure:
  – Heart disease and stroke?
  – Cancer?
  – Alzheimer’s disease and dementia?

• How can we improve care and quality of life?

To find answers, scientists conduct research studies
Example: Alzheimer’s Disease

- Brain disease that destroys memory and thinking
- Affects as many as 5 million Americans age 65+
- A leading cause of death
- Currently no cure or treatment

Major research underway to understand the disease and learn how to prevent, cure, and treat it
Benefits of volunteering for research

Help others, including future generations of your family who may be at risk

Learn more about your health conditions from experts

Get information about support groups and resources in your community

Receive regular monitoring by health professionals
Research Studies Need *Everyone* – Including YOU!

- Men and women
- Adults of all ages
- Of different racial and ethnic backgrounds
- Who are healthy or who have health problems
Join in to make a difference!

Many research studies are going on right now that urgently need a large number of volunteers.

Can you help?
One *easy* way to make a difference

Sign up with a research registry or matching service.

- You will be contacted when studies are looking for people like you.
- You can learn more about a study and decide if you would like to participate.
- It’s always your *choice* whether or not to take part in a study.
- Your information will remain confidential.
CONVERSATION IS GOOD FOR THE BRAIN

Are you 75 years or older? Do you need more opportunities to talk with others? Become a part of our study.

What is I-CONNECT?

Help us understand if conversation can improve memory and prevent dementia in seniors. It is very helpful and beneficial for people of color to participate in research studies. Our results can possibly help people of color in the future. Study participation includes:

- Interesting chats and/or calls for up to a year
- All supplies provided
- Memory and thinking evaluations
- Compensation up to $775

Call I-CONECT today

Crystal Davis, Study Coordinator
404-727-6696

Visit our website
www.I-CONECT.org

Learn more about this online study at
www.healthyaging.emory.edu

Follow us:
EmoryHealthyAgingStudy
EmoryStudy

If you could change the world for the better, would you?

Resources in our community
Join your family, neighbors and friends participating in research to make a difference for yourself and future generations!

Go to www.ResearchMatch.org/roar or for help registering online call 1-866-321-0259