Communicating with a Person Living with Alzheimer’s or a Similar Illness

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Emory Roybal Center for Dementia Family Caregiving Mastery
Goizueta Alzheimer’s Disease Research Center
Nell Hodgson Woodruff School of Nursing

Emory University
What’s Involved in Communication?

Moving Information Effectively

• Clear message
• Proper mode of transmission

• Message received
• Message understood as intended
Easy. Right? What Could Go Wrong?

On the part of the communicator

• Misjudge capacity of the receiver
• Misread attention of the receiver
• Includes conflicting signals in message
• Uses difficult to understand words
• Fails to account for other signals (body language; tone)
• Fails to account for larger environmental confounders
• Baggage from the past

Some Examples: Labor-Management Negotiations; Congress; Diplomacy; Talking with Teenagers
Communicating with Your Person: On What Can you Rely? What must you Supply?

These illnesses put you in the communication driver’s seat

• Assess what capacities remain
• Design communication strategies with these in mind
• See what works
• Adjust accordingly
Communication in Dementia Care

What Dementing Illnesses Do to Receptive Capacity

• Ability to decode language diminished
  • Complex sentences
  • Sophisticated vocabulary
  • Pace of speech
  • Eventually, words themselves

• Capacity for receiving non-verbal and emotional cues enhanced

• Noise from the environment becomes louder

• No self-directed capacity to make compensations
Consider the Spectrum of Communication

Abstract  Concrete

Regular Speech
- Usual Sentences
- Shorter Sentences
- Words or Phrases

Visual Cueing
- Speaking and Pointing to objects
- Holding up objects

Tactile Messaging
- Touch to gain attention
- Placing object in hand
- Mimicking action
Relationship Between Disease Progression and Communication Strategies

Abstract

Concrete

Early Early-Middle Late-Middle Late
So, to Recap: It’s Always Experimental and You’re “It”

Assess what capacities remain

Design communication strategies with these in mind

See what works

Adjust accordingly
AD Research and Current medications
Monica W. Parker, MD
Director, Minority Engagement Cor
Goizueta Alzheimer’s Disease Research Center
The Revitalization Act of 1993 requires that women and minorities be included in all clinical research studies funded by NIH because:

- Disease prevalence varies by population
- Effective treatment for chronic diseases may differ for gender or ethnicity
The NINDS reports US volunteers for Neurocognitive Disorders (NCD) research studies are:

- 70% European American
- 12% African American
- 8% Asian American
- 10% Hispanic
- 53% Female 44% Male
Clinical Research Participation by Women and Minorities

Research is Essential

• For eliminating health disparities

• Maintaining the integrity of science and generalizability of medicine

• Upholding the principle of justice, a founding principle in the regulations surrounding human subjects research (Belmont Report)

Shavers, et al. (2002); Mouton et al (1997); Corbie-Smith et al. (1999); Wendler et al. (2006); Van Ryn et al. (2000)
Traditional Characteristics of Research Volunteers

- Male
- Caucasian
- Middle Class
- Highly educated
Clinical Research participant needs

- Ethnic/Racial groups
  - African American, Hispanic, Latino, American Indian, Asian
- Persons with Disabilities
- Women
- LGBT
- Low Income
- Low literacy
- Adolescents at Risk
- Mental Illness
Alzheimer’s Disease Management

• Cholinesterase inhibitors
  – Donepezil (Aricept)
  – Galantamine (Razadyne)
  – Rivastigmine (Exelon)
• Weak NMDA antagonist
  – Memantine (Namenda)
  – Moderate to severe AD
• Other medications
  – Antidepressants
  – Antipsychotics

• Non-pharmacological
• Caregiver support
  – Education and training
  – Planning, Respite care
  – Support groups
• Hope and encouragement
  – The promise of more effective treatments
  – Access to clinical trials
  – A better world for future generations
For more information!

www.alzheimers.emory.edu
Maintain Your Brain: The Importance of Keeping Cognitively Stimulated

Felicia C. Goldstein, Ph.D.
Department of Neurology
Neuropsychology Program
“Dose-Response Relationship”

- Greater engagement in activities associated with slower cognitive decline.
- This is true as well for older adults with mild cognitive impairment.
Neuroprotective Benefits of Keeping Your Mind Active

(“Cognitive Reserve”)
Cognitive Stimulation: Mentally engaging in activities that challenge a person’s ability to think

- Learn something new
- Take a cooking, art, or computer class
- Form or join a book club
- Learn (or relearn) how to play a musical instrument
- Learn a new language
Cognitively Stimulating Activities

Should be challenging and **fun**!
Additional Tips

• Engage your brain along with someone else
• Make it easy on yourself
• Choose activities involving both mental and physical engagement
• Find ways to re-engage in old activities that you once found to be cognitively stimulating which you may have given up.
• **Free Online Games - Internet Game Sites ... - AARP Connect**

• *https://games.aarp.org*

• Daily **games** and puzzles to sharpen your skills. **AARP** has new **free games** online such as Mahjongg, Sudoku, Crossword Puzzles, Solitaire, Word **games** and Backgammon! Register on **AARP.org** and compete against others to find out if you are a Top Gamer.
12:30-1:30PM
• T’ai Chi (Dance 101)

1:45-2:45PM
• An Adventure into Wine
• French for Fun, Part II
• Singalong
• Woody Allen: Themes, Reaction, & Discussion
• World War II: A Devastating Global Conflict
• Yoga for the Truly Inflexible (Dance 101)

3:00-4:00PM
• Estate Planning and Probate Issues
• Spanish I
• Writing for Health
Cognitive Training

Computerized programs that utilize structured practice on cognitively challenging tasks.

**Advantages:**

- Visually appealing
- Can adapt difficulty to individual performance levels
Cognitive Training
AKA: Interactive Video Games

• Place demands on attention (focused and divided), processing speed, visuospatial/visuomotor abilities, and executive functions
• Can enhance social stimulation if played in groups
• Can increase physical activity (exer-gaming)
1. Lumosity
   • http://www.lumosity.com

2. Posit Science
   • http://www.positscience.com
Computer based CT should be considered a possible helpful tool to be used *in combination* with other interventions and healthy lifestyle choices.
Be an informed consumer!

"Buyer Beware"
**SUMMARY**

- Incorporate enjoyable cognitively stimulating activities as part of a healthy lifestyle to help maintain your brain health.
- Seek out new activities that are challenging and will lead to the development of new skills and encourage social engagement.
- Choose activities involving both mental and physical engagement.

Engage Your Brain: Global Council on Brain Health
“Don’t let age limit the scope of your cognitively stimulating activities or intellectual life. Your attitude plays an important role and can shape outcomes even when there are physical limitations to overcome.”

COVID-19 Data and treatment
United States Laboratory Testing
Commercial and Reference, Public Health, and Hospital Laboratories

Preliminary data: Reported by U.S. Laboratories including Commercial and Reference, Public Health, and Hospital Laboratories. Totals may include antibody data from some states.

**USA**

**TESTS REPORTED**
23,467,981
CDC | Updated: Jun 13 2020 6:45PM

**USA**

**POSITIVE TESTS**
2,509,121
CDC | Updated: Jun 13 2020 6:45PM

**USA**

**OVERALL % POSITIVE**
11%
CDC | Updated: Jun 13 2020 6:45PM

[Map of United States showing COVID-19 testing data by state]

- **COVID-19 Tests Performed by State**
  - New York: 2,966,368, 11-20%
  - California: 2,183,608, 6-10%
  - Florida: 1,956,790, 6-10%
  - Massachusetts: 1,134,737, 11-20%
  - Texas: 1,195,931, 6-10%
  - New Jersey: 1,048,209, 11-20%
  - Illinois: 826,373, 11-20%
  - Tennessee: 759,709, 6-10%
  - Pennsylvania: 756,137, 11-20%
  - Michigan: 693,188, 11-20%
  - Georgia: 585,888, 6-10%
  - Indiana: 566,050, 11-20%
  - Maryland: 540,568, 11-20%
  - Ohio: 534,337, 6-10%
  - North Carolina: 494,894, 11-20%
  - Louisiana: 486,013, 11-20%
  - Virginia: 457,564, 11-20%
  - Washington: 430,950, 6-10%
  - Utah: 417,108, 0-5%
  - Wisconsin: 410,773, 6-10%
  - Arizona: 396,818, 6-10%

[Map of United States showing COVID-19 testing data by state]

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[Map of United States showing COVID-19 testing data by state]

Testing Data in the U.S.

- Viral tests tell you if you currently have an infection with SARS-CoV-2, the virus that causes COVID-19. A positive test result means you have an infection.

Updated June 15, 2020

<table>
<thead>
<tr>
<th>TOTAL TESTS REPORTED</th>
<th>POSITIVE TESTS REPORTED</th>
<th>% OF POSITIVE TESTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>23,467,981</td>
<td>2,509,121</td>
<td>11%</td>
</tr>
</tbody>
</table>

- These data are compiled from a number of sources. Not all tests are reported to CDC.
- The number of positive tests in a state is not equal to the number of cases, as one person may be tested more than once.
Take note:

It is important to note that **not everyone** that has been diagnosed with COVID has developed antibodies so it is important that even if you have had COVID previously to still adhere to the recommended prevention methods.

• If you have symptoms of COVID-19 and want to get tested, call your healthcare provider first.
• You can also visit your state or local health department’s website to look for the latest local information on testing.
• Although **supplies of tests are increasing**, it may still be difficult to find a place to get tested.
Patients with COVID-19

• There are no drugs or other therapeutics presently approved by the U.S. Food and Drug Administration (FDA) to prevent or treat COVID-19.

• Current clinical management includes infection prevention and control measures and supportive care, including supplemental oxygen and mechanical ventilatory support when indicated.

  ❑ The recommendations for using remdesivir, chloroquine, and hydroxychloroquine to treat COVID-19 have been revised based on data from recently published clinical trials and observational cohort studies.

For more information about treatment guidelines visit: https://www.covid19treatmentguidelines.nih.gov/whats-new/
Symptom checker:
This system is not intended for the diagnosis or treatment of disease or other conditions, including COVID-19 and is based on best clinical practices, CDC guidelines, illness severity and risk factors like age and pre-existing conditions.

https://c19check.com/start
# How to Get a Test

Find A Testing Location Near You

<table>
<thead>
<tr>
<th>Company</th>
<th>States with Testing Sites</th>
<th>Link</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Local Independent Pharmacies in partnership with Health Mart and eTrueNorth</strong></td>
<td>Alabama, Arkansas, Arizona, California, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Iowa, Illinois, Indiana, Kansas, Kentucky, Louisiana, Maryland, Massachusetts, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, Utah, Washington, West Virginia, and Wisconsin</td>
<td>Make an appointment for a COVID-19 Test</td>
</tr>
<tr>
<td><strong>Kroger in partnership with eTrueNorth</strong></td>
<td>Alaska, Indiana, Michigan, North Carolina, Ohio, South Carolina, Tennessee, Texas, Washington, and Wisconsin</td>
<td>Kroger Health’s Drive-Thru COVID-19 Testing</td>
</tr>
<tr>
<td><strong>Rite Aid</strong></td>
<td>Connecticut, Delaware, Idaho, Maryland, Massachusetts, Michigan, New Hampshire, New Jersey, New York, Ohio, Pennsylvania, and Virginia</td>
<td>COVID-19 Testing</td>
</tr>
<tr>
<td><strong>Walmart in partnership with eTrueNorth</strong></td>
<td>Arkansas, Florida, Georgia, Idaho, Illinois, Indiana, Kansas, Kentucky, Louisiana, Massachusetts, Missouri, North Carolina, Oklahoma, Texas, Virginia, and Wisconsin</td>
<td>Drive-Thru COVID-19 Testing</td>
</tr>
<tr>
<td><strong>Walmart in partnership with Quest Diagnostics</strong></td>
<td>Alabama, Arkansas, Florida, Louisiana, Michigan, Minnesota, Mississippi, Missouri, New Mexico, Nevada, New York, North Carolina, Ohio, South Carolina, Texas, Vermont, and Virginia</td>
<td>COVID-19 Drive-Up Testing</td>
</tr>
</tbody>
</table>
THE STATE OF MEN’S HEALTH:
Mental, Physical and Emotional Wellness and Self-Care

3 PART WEBINAR SERIES

Part 1 Matters of the Heart and Brain
Wednesday, June 17, 2020 at 2:00 pm

Presenters:
James Luh, MD, PhD — Brain Health
Aaron Anderson, MD — Heart Health
James Bennett, MD — Prostate Health
Derek M. Griffith, PhD — Psychological Health
Joe Nocera, PhD — Physical Health

Part 2 Matters of Racial Disparities
Wednesday, June 24 at 2:00 pm

Presenters:
Monica Parker, MD — Brain Health
Ihab Hajar, MD — Physiological and Psychological Stress on the Brain
Laurence Spelling, MD, FACC, FACP, FAHA, FASPC — Stroke and Cardiovascular Disease

Part 3 Men’s Health Matters Moving Forward
Wednesday, July 1, 2020 at 2:00 pm

The Path Forward: Improving disparities in healthcare access, policies and research for the health and well-being of diverse populations beyond COVID
Allan Levey, MD, PhD • Clinton Dye, PhD • David Satcher, MD PhD
Patrick Griffith, MD • Ambassador Andrew Young
Sheryl Heron, MD, MPH • Patrice Harris, MD

RSVP Required. We are using Zoom to host the webinars. When you register you can choose one or all three events to attend.

Please RSVP by visiting www.alzheimers.emory.edu or call Chelsea Walker at 404-712-4702 or chelsea.walker@emory.edu.

www.alzheimers.emory.edu | Cornelya Dorbin, MPA • Project Director • 404-712-1416