Alzheimer’s risk and research

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Common Dementing Illnesses

- Alzheimer's Disease
- Lewy Body Dementia
- Vascular Dementia
- Parkinson's Dementia
- Frontotemporal Dementia
- Alcoholic Dementia
- Alzheimer's Disease
Risk Factors for Alzheimer’s

1. Aging!
2. Genes
3. Gender
4. Head injury
5. Vascular disease
6. Lifestyle

Mostly out of our control
Opportunity!
Auguste D. and Alois Alzheimer

- Admitted 1901, age 51
- Frankfurt am Main
- Memory loss
- Language deficits
- Persecutory delusions
- Progressive decline
- Died 1906, age 55
Dementia Symptoms

• Memory Loss
• Repetition of words, stories, phrases
• Loss of bowel and bladder function
• Inability to independently dress, groom, toilet, feed or manage finances or meals
• Gait instability- falls
• Personality Changes- belligerent, apathy
• Psychoses- paranoia
Dementia Behaviors

- Wandering
- Personality Changes - irritability
- Paranoia - fear, suspicion
- Hallucinations
- Unusual Spending/Buying
- Compulsive Behaviors
- Driving Difficulties - accidents, getting lost
How do you Address Behaviors?

See a Doctor!

- Persons with dementia cannot be reasoned with
- A careful medical evaluation is required to look for treatable causes
- Failure to address problems with a trained professional may create familial problems, health problems
- Research is NOT a substitute for medical evaluation
Questions to Ask

1. What is the main purpose of this study?
2. Does the study involve a placebo or a treatment that is already on the market?
3. How will the treatment be given to me?
4. How long is the study going to last and what will I be asked to do as a participant?
5. What has been learned about the study treatment and are any study results published?
6. Do I have to pay for any part of the study? Will my insurance cover these costs?
7. Is there any reimbursement for travel costs or childcare?
8. Will I be able to see my own doctor?
9. If the treatment works for me, can I keep using it after the study?
10. Can anyone find out whether I’m participating in the clinical trial?
11. Will I receive any follow-up care after the study has ended?
12. What will happen to my medical care if I stop participating in the study?
13. Does the physician/investigator have any financial or special interest in the clinical study?
Savvy Caregiver and Tele-Savvy: Psychoeducation for Caregivers

Ken Hepburn, PhD
Emory Roybal Center for Dementia Family Caregiving Mastery
Goizueta Alzheimer’s Disease Research Center
Nell Hodgson Woodruff School of Nursing
Emory University
Training for Caregiving

Relationship may provide a motive but not necessarily the capacity

Think about what family caregivers do

- Nursing
- Social work
- Occupational therapy
- Recreational therapy
- Legal and financial management
- Safety officer and infection control specialist

How many have the training for this role?
What Kind of Training is Needed

Knowledge: understand what you’re dealing with

• What Areas of Life are Affected by Dementing Illnesses?
  • Thinking/cognition
  • Behavior
  • Emotions
  • performance

• What kind of trajectory do these illnesses follow?
  In Short: All Areas
  Progressive and Irreversible
What Kind of Training is Needed

**Skills: Be Able to do the Work**

- Design of appropriate tasks and activities
- Effective communication
- Management of uncomfortable behaviors
- Management of family resources
- Self-care behaviors
- Navigate the health and social care system
What Kind of Training is Needed

Attitude/Outlook – Mastery

• Confidence in ability to manage the situation
  • DON’T JUST DO SOMETHING: STAND THERE

• Strategies for coping
  • In the moment
  • Prospectively

• Realistic goals and expectations
  • Days as safe, calm, and pleasant as possible
  • Not sainthood
Psychoeducation

• Demands active learning
• Willingness to try out newly acquired information and strategies

• Develop mastery through:
  • Own Successes
  • Observation of other’s successes
  • Instruction
Next Research Steps

• Savvy and Tele-Savvy both
  • Are held with groups of caregivers
  • Have regular group meetings
  • Have a trained leader

• All of these are positive, but have problems

• Can the program be offered entirely online
  • To individuals
  • On their own schedule
  • Without group meetings
  • And with just a moderator

????????
Mindfulness for Care Partners

Practical Steps for Care Partners to Cultivate Calm

Megan Nare
Yoga Instructor, E-RYT 500
Emory’s Cognitive Empowerment Program
Overview for Today

1. Find Gratitude in the Moment
2. Pause and Take a Deep Breath
3. Listen to Your Body For Answers
4. Accept What Is, As it Is
5. Give Yourself Permission for Self Care
1. What is Mindfulness?
Gratitude in the Moment

- What is happening now? Be Present.
- Not remembering the past.
- Not planning or predicting the future.
POP QUIZ:
What are you grateful for in this moment?

Type your answer into the chat.
2. Pause and Take a Deep Breath

Create a moment of hesitation and come back into the moment with one deep breath.
3. **Listen to Your Body for Answers**

- Stopping to check how you feel
- Listen for alarm bells
- Reflect on experiences and responses without judgement
- Allow yourself to feel your feelings
- What do I need now?
4. Accept What Is, As It Is.

For yourself, and others

- Finding Acceptance
- Without Judgement
- Without Changing Anything
- Letting go "should/would/could"
5. Give Yourself Permission for Self Care: Take Refuge in Rest

"Drink As You Pour"

The anecdote to stress is relaxation.

Self care is any action you purposefully take to improve your physical, emotional or spiritual well being. By making time for self care, you prepare yourself to be your best so you can share your gifts with the world.
Next Steps

IT'S JUST PRACTICE.

1. Get Rest When You Can
2. Making Sacred Space in the Home
3. Know What You Need and Ask for It

APPS THAT HELP:
Glo.com - Restorative and Yin Yoga
Headspace - Meditation 101

LIVE CEP YOGA:
 Begins Thursday, July 30th
  1:30 - 2:15
YOU’RE INVITED!

Zoom Gentle Chair Yoga & Mindfulness
With the Cognitive Empowerment Program

Begins Thursday, July 30th
1:30 - 2:15 pm
What is the Georgia Memory Net?

06.23.2020

Rebecca Dillard – GMN Project Director
STATE OF GEORGIA ROLE & PARTNERSHIP

Program Establishment:

$4.12M allocated in July, 2017 by Georgia Assembly

Continuing Budget in Georgia Department of Human Services

Oversight assigned to Division of Aging Services
Georgia Memory Net Primary Goals

State Contract with Emory Cognitive Neurology Program & Alzheimer’s Disease Research Center

- Increase awareness and MCI screening among Primary Care Providers
- Expand access to diagnostic services statewide
- Enhance connectivity for Georgians with Alzheimer’s and related dementias to community services and support
Establishing the Need:
Know the numbers.

It all adds up: The citizens and healthcare professionals of Georgia need the Georgia Memory Net.

People With Alzheimer's Growing:
- 140k [2018]
- 190k [2025]

1.4M People Over 65 Years Old

385k with self-reported cognitive impairment
- 80% have not yet been evaluated or treated

$2B in Preventable Admissions Expenses

6 Year Average Delay in Memory-Loss Diagnosis
Memory Assessment Clinic Partnerships

- Albany, GA
  Memory Assessment Clinic at Phoebe Primary Care at Northwes

- Atlanta, GA
  Memory Assessment Clinic at Grady’s Marcus Stroke and
  Neuroscience Outpatient Center

- Augusta, GA
  Memory Assessment Clinic at Augusta University

- Columbus, GA
  Memory Assessment Clinic at Piedmont Columbus
  Regional’s Midtown Family Medicine Center

- Macon, GA
  Memory Assessment Clinic at Navicent Health –
  Family Health Center
The Process:
An always integrated path.

Our system is designed for efficiency and convenience to all parties involved.

PATIENT VISITS PCP’S OFFICE
Primary Care Provider identifies Risk through AWV model. Refers patient to MAC*.

PATIENT VISITS A MAC
Patient visits MAC for accelerated diagnosis testing using latest tools.

PATIENT RETURNS TO MAC
Patient diagnosed with Alzheimer’s, and their PCP receives Care Plan.

CARE PLAN PUT INTO ACTION
AAA connects Patient and Care Partner to local support. PCP follows Care Plan for ongoing medical care.

PATIENT AND CARE PARTNER MEET WITH CSE
Patient and Care Partner receive Customized Care plan.
CSE/Community Engagement

Community Services Educator & Area Agency on Aging

- Individualized care plans co-developed with local AAA
- Connect patients with local services for continued care
- Ongoing follow-up from GMN central staff in partnership with AAAs for continued care coordination

our collaborators:
PCPs identify risk through cognitive screening, the Annual Wellness Visit, or other observations.

**Most Likely** to Benefit from GMN
- Patient with **memory loss** and an **unclear diagnosis**

**Less Likely** to Benefit from GMN
- Patient with existing **clear diagnosis** of Alzheimer's disease or another dementia
- Patient resides in a skilled nursing facility
- Patient with history of traumatic brain injury
- Patient age younger than 50
Community Partners – Available to All

The Area Agency on Aging (AAA)

• Offers and coordinates services to help older adults and adults with disabilities remain in their homes

• Offers a wide range of services that make independent living a viable option

• Can help individuals choose the services and living arrangements that best suit their situation and needs
The Alzheimer’s Association

- Working to eliminate Alzheimer's disease through research, provide and enhance care and support, and reduce the risk of dementia through brain health
- Works on both national and local levels to provide care and support for all those affected by Alzheimer's and other dementias
- Offer local educational groups, social groups, and other support
ADDITIONAL QUESTIONS?

GAmemorynet.org

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