States Leading the Way through Dementia Partnerships

2018 HCBS Conference
August 28, 2018
Today’s Session

• How can states and communities partner to effectively prepare for the increasing number of individuals living with dementia and their care partners?

• Learn about experiences and initiatives in: Alabama, Georgia and Florida
Speakers

- Victoria Helmly, Alzheimer's and Related Dementias State Plan Coordinator, Georgia Department of Human Services Division of Aging Services
- Rebecca Dillard, Project Director, Georgia Memory Net, Department of Neurology, Emory University School of Medicine
- Stephanie Holmes, Project Coordinator, Dementia Friendly Alabama Initiative, Central Alabama Aging Consortium
- Christine Didion, Program Manager, Dementia Care and Cure Initiative, Florida Department of Elder Affairs
- Meredith Hanley, Director, Community Capacity Building, National Association of Area Agencies on Aging
What Do People With Dementia Want

GLOBAL DEMENTIA CHARTER

‘I can live well with dementia’
Dementia Friendly America Initiative

Initiative Goal

– Foster dementia friendly communities across the US
– A dementia friendly community is informed, safe and respectful of individuals with the disease, their families and caregivers and provides supportive options that foster quality of life.

www.dfamerica.org
Responding to the Need: Dementia Friendly Communities
Dementia Friendly Communities Across U.S.
Dementia Friends USA

www.dementiafriendsusa.org
Dementia Friends USA

- Dementia Friends USA is part of a global social awareness movement.
- By helping everyone in a community understand what dementia is and how it affects people, each of us can make a difference for people touched by dementia.
Key Stats

• Less of half of people with Alzheimer’s receive diagnosis

• 70 percent of older adults with Alzheimer’s or another form of dementia live in the community.

• Of individuals with dementia:
  • 74 percent live with someone
  • 26 percent live alone

• Stigma and stereotypes are a barrier to seeking diagnosis and care and an obstacle to well-being and quality of life for those with dementia and their families. Access to community

• Family caregivers provide a majority of long-term services and supports but supply of caregivers is slowly compared to demand (AARP study)
For More Information
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Georgia Memory Net: A State & Healthcare Partnership

08.28.18
DISCLOSURES

• Georgia Memory Net is funded by the GA Department of Human Services, Division of Aging Services as part of the Georgia Alzheimer’s Project passed by GA Assembly FY18 (ongoing)

• No financial conflicts to disclose
LEARNING OBJECTIVES

– Identify key services and community partners within this Georgia-based collaborative for program implementation and sustainability

– Articulate Georgia Memory Net initiative and primary care and community services driven process

– Summarize workflows, processes, and linkages to community services offered via the regional Memory Assessment Centers
STATE OF GEORGIA ROLE & PARTNERSHIP

$4.12M allocated for Georgia Alzheimer’s Project in SFY18 Budget in Georgia Department of Human Services (continued line-item)

Contract with Emory University to carry out contract

Oversight assigned to Division of Aging Services:

Continued role of monitoring, oversight, and coordination of state agency and other partner collaboration

• Reporting and oversight
• Legal & Contracting
• General Assembly
• Area Agencies on Aging
• GA Department of Public Health
• Alzheimer’s/Dementia State Plan group
• Other agencies and partners
Georgia Alzheimer’s & Related Dementias (GARD) State Plan

• Signed in 2014
• Six work groups
  – Workforce Development
  – Service Delivery
  – Outreach & Partnerships
  – Public Safety
  – Healthcare, Research, & Data
  – Policy
• Georgia Memory Net goals align with State Plan goals
• Input and collaboration between Georgia Memory Net team and GARD work groups
Setting Our Goals: It's only a wish without a plan.

Our objective is to improve outcomes and quality of life for people dealing with memory loss, while streamlining services and offering more efficient care.

- Improve Assessment During Annual Wellness Visits
- Diagnose Accurately at Memory Assessment Clinics
- Improve Care with PCPs and Community Services
- Provide Oversight and Evaluation of Performance and Data Collection
Collaboration is Key: It takes more than one.

A partnership including academic institutions, community organizations, professional associations, and state networks.
Providing Accessibility: Launching statewide clinics.

Starting with five clinics in 2018, we hope to have a Memory Assessment Clinic convenient to every Georgian in the near future.

Memory Assessment Clinic Locations

ATLANTA
AUGUSTA
MACON
COLUMBUS
ALBANY
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.

Patient and Care Partner have a clear path for the best care possible.
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:

[List of logos and names]
THANK YOU!

Questions?

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State & Health Care Partnerships: GMN

Slide archive follows for additional information
Establishing the Need: Know the numbers.

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

- **1.4M** People Over 65 Years Old
- **385k** People 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
What to Expect: Key benefits.

Georgians who make appointments at a MAC, and the doctors who recommend them, benefit from a variety of integrated services.

- Trained Clinicians: Proactive planning & support services, Expert diagnoses, Increased caregiving competence & quality of care
- Comprehensive Diagnosis and Care of Planning: Comprehensive best-practice care plans, In-depth memory evaluations taken off time-crunched PCPs schedules, Care plans shared with PCPs, patients & community support
- Community Services Educator
- Education and Community Support
- PCP Receives and Manages Care Plan: Supported by National Institutes of Health, Connected to Georgia’s only Alzheimer’s Disease Research Center
GMN for PCPs: Supporting, not supplanting. In depth memory evaluations are taken off the schedules of time-crunched PCPs.

Training provided through GMN & Reporting to guide your ongoing care
Identifying & Referring:

If we can manage these three, outcomes could improve.

1. ENCOURAGE Annual Wellness Visits (AWV)
2. ADMINISTER the Mini-Cog™ assessment tool (embedded in the AWV)
3. REFER patient to a Memory Assessment Clinic if Mini-Cog™ indicates an impairment
FY19 Targets

1. Website Expansion
2. App Development
3. Data Repository Build
4. Expansion of MACs and Community Services driven by data
5. Solidified National Partners and Visibility
What Does It Mean To Be “Dementia Friendly?”
More than just being kind...

*Included
*Supported
*Engaged
*VULNERABLE!

Provide an environment where people with dementia can live and THRIVE!
= Dementia Friendly Communities
2016

ADSS awarded CAAC $45,000 Dementia Friendly Communities Grant

CAAC hired me P/T

I reached out to Dementia Friendly America...
...Foster a Dementia Friendly Community

STEP 1: Develop a Partner Panel of “Champions”

STEP 2: Convene Partner Panel

STEP 3: Decide “where to begin?”

STEP 4: Kick off your initiative
We Started in Schools

The students of today are the caregivers of tomorrow!

• 137 9th Graders-Alzheimer’s Disease Education:
  ➢ Partnered with Troy University
  ➢ Docu-Drama
  ➢ Sparks an interest
  ➢ Creates student involvement
  ➢ Encourages students to think outside their normal comfort zone
  ➢ FUMC RESPITE Ministry
“I am just a little pencil in the hand of a God who is writing a love letter to the world.”
“dementia” - 52M Results

“alzheimers” – 123M Results
• Dementia Resource Guide (Electronic & Paper)
• Care to Plan Developed
• Resource Directory
• Dementia Friendly Alabama Website
• Respite @ FUMC
• PLS / Gizmo Gadget
• Plan. Prepare. Share (McGriff developers)
• AFA Support Groups
Alzheimer’s Foundation of America

- Caregiver Support (866) 232-8484
- Young Onset Spousal Support TUE 2:30-3:30P (EST)
- Long Term Care Support – THU 4-5P (EST)
- Care Connection Webinar (1P EST)
  - Jul – When its Time to Move to a Care Community – And What To Do next
  - Aug – Guardianship
  - Sep – Drama Improv

✓ Dramatic improvisation can be used as a therapeutic tool for dealing with memory loss.
Training

• Started with Financial Sector (Banks)
  • Banks made perfect sense.
  • Tellers on the front line.
  • People want to handle their OWN banking.
    • VDT’s
    • Memory Screenings
    • Dementia Education

• AFA PIC Tour of Alabama Training
2017

• Awarded $100,000 DFC Grant
• We selected (5) cities to each receive a $10,000 Mini-Grant

  ❖ 1st Responder / Law Enforcement Training
  ❖ Brought renown theologian Dr. James Houston to Birmingham April 26, 2018
  ❖ Dementia Care Specialist Training (TTT) thru Crisis Prevention Institute
  ❖ Memory Cafes
  ❖ Church Sector

• 1st Annual Dementia Friendly AL Golf Classic
• Distributed 5,000 DRG’s
• Awarded 2\textsuperscript{nd} $100,000 DFC Grant
• Certified 136 care professionals thru AFA \textit{Partners In Care Training 4-Cities/4-Days}
• Selected (3) cities to receive a $10,000 Mini-Grant
• 2\textsuperscript{nd} Annual Dementia Friendly Alabama Golf Classic
• Distributed 8,000 DRG’s
• Fostered more than 100 partnerships.
• Held the 1\textsuperscript{st} of 7 Memory Cafés
• NEW Website
• Initiative even mentioned in a book “Blessed: Stories About Caregiving”
We’re part of something rare, something special and something utterly revolutionary.

But NONE of it would be possible without PARTNERSHIPS!
Do Your P.A.R.T
Help us fight for those who can’t remember!

(P)artnerships
(A)cademics
(R)esources
(T)raining
“I can do things you cannot, you can do things I cannot; together we can do great things!”
CONTACT INFO

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DementiFriendlyAlabama.org
Mission:
To engage communities across the state to be more dementia friendly, promote better care for Floridians affected by dementia, and support research efforts to find a cure.

Vision:
To see all Florida communities engaged in providing better care for those affected by dementia while we work towards a cure.

Goals:
• Increase awareness of dementia and of services and supports for those with dementia, their families, and caregivers.
• Provide assistance to dementia-caring communities.
• Continue advocacy for care and cure programs.
Why focus on dementia?

• Florida has the second highest incidence rate of Alzheimer’s Disease in the nation – only behind California.

• There are approximately 540,000 individuals currently living with Alzheimer’s Disease in Florida.

• By 2025, it is estimated 720,000 individuals will be living with Alzheimer’s disease in Florida.

• There are approximately 1,121,000 unpaid caregivers in Florida that care for loved ones with Alzheimer’s disease or a related dementia.

• Alzheimer’s disease is the 6th leading cause of death across all ages in the United States.

• 1 in 7 persons with Alzheimer’s disease lives alone.

Source: Alzheimer’s Association, 2018
Alzheimer’s disease Facts and Figures
Participating DCCI Communities

- Pensacola
- Tallahassee
- Jacksonville
- Gainesville
- Orlando
- Tampa
- Sarasota
- Ft. Myers
- Miami
MEMORY DISORDER CLINIC LOCATIONS

1. West Florida Hospital
   8383 N Davis Hwy, Pensacola, FL 32514
   (850) 494-6490

2. Tallahassee Memorial
   1401 Centerville Rd, Ste. 504
   Tallahassee, FL 32308
   (850) 431-5001

3. Mayo Clinic Jacksonville
   4500 San Pablo Rd.
   Jacksonville, FL 32224
   (904) 953-7103

4. University of Florida
   1149 Newell Dr.
   Gainesville, FL 32611
   (352) 273-5550

5. Orlando Health Center for Aging
   21 W Columbia St.
   Orlando, FL 32806
   (321) 841-9700

6. East Central Florida
   3661 S Babcock St.
   Melbourne, FL 32901
   (321) 434-7612

7. Morton Plant
   430 Morton Plant St., Ste. 402
   Clearwater, FL 33756
   (727) 461-8635

8. University of South Florida
   3515 E Fletcher Ave.
   Tampa, FL 33613
   Phone: (813) 974-3100

9. St. Mary’s Medical Center
   5305 Greenwood Ave., Ste. 102
   West Palm Beach, FL 33407
   (561) 882-6363

10. Florida Atlantic University
    777 Glades Rd., Bldg. AZ-79
    Boca Raton, FL 33431
    (561) 297-0502

11. Lee Memorial
    12600 Creekside Ln., Ste. 7
    Fort Myers, FL 33919
    (239) 343-9220

12. Broward Health North
    201 E Sample Rd.
    Deerfield Beach, FL 33064
    (954) 786-7392

13. Mt. Sinai Medical Center
    4300 Alton Rd.
    Miami Beach, FL 33140
    (305) 674-2543 ext. 54461

14. University of Miami
    1695 NW 9th Ave., Ste. 3202
    Miami, FL 33136
    (305) 355-9065
What is a Dementia-Caring Community in Florida?

- Education and awareness of what dementia is and on inclusive and respectful Dementia-Caring practices.
- Input from and advocacy roles for individuals living with dementia.
- Appropriate community engagement activities for those living with dementia and their caregivers.
- Examining current resources and advocating for their continued funding while spreading awareness of services to those in need.
- Explanation of and encouragement to participate in research.
Education Specifics

• Basic information about dementia
• Minimal pathophysiology review
• Embedded with scenarios specific to the audience
• Open discussions of experiences
• Strong emphasis on local resources
• Pre and post test for measuring acquired knowledge
• Face-to-face presentations or embedded on online training platforms

Example: You are a firefighter responding to a call where neighbors reported smelling smoke coming from a home. Upon arrival, you find an elderly, very confused female with smoke coming out of the oven.
DEMENTIA-CARING
SARASOTA COUNTY
ELDERAFFAIRS.ORG

DEMENTIA-CARE AND CURE INITIATIVE
FLORIDA DEPARTMENT OF ELDER AFFAIRS

MISSION
To engage, empower, and advocate for the needs of individuals with dementia and their families through education, resources, and support.

VISION
A community that recognizes and supports individuals and families affected by dementia, ensuring a quality of life for everyone.

Need help? Call the ELDER HELPLINE
1-800-96-ELDER
(1-800-963-5337)

Signs and Symptoms of Dementia
- Memory loss that disrupts daily life
- Changes in planning and problem solving
- Difficulty completing familiar tasks
- Confusion with time and place
- Withdrawal from work or social activities
- Easily losing track of thought

Tips for Communicating
- Ask simple questions
- Be patient when waiting for a response
- Make eye contact
- Give visual cues

Resources in Tallahassee/Leon County
Tallahassee Memorial HealthCare
Memory Disorder Clinic
1401 Center Pointe Drive, Suite 201
Tallahassee, FL 32308
(850) 434-6060

Area Agency on Aging for North Florida
2401 Mahans Drive
Tallahassee, FL 32312
(850) 488-0005 or 1-800-336-ELDER

ELDERAFFAIRS.ORG
LEE COUNTY

DEMENTIA CARE AND CURE INITIATIVE
AWARNESS • ASSISTANCE • ADVOCACY
Contact Information

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Panel Discussion