Virginia's Care Coordination Program for Individuals with Dementia

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Disclaimer

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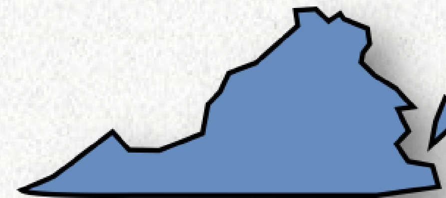
Dementia and Caregiving Snapshot

- Dementia:
  - 140,000 individuals aged 65 and older with Alzheimer's disease
  - ~92,106 FFS Medicare beneficiaries (9.2%) with Alzheimer's disease/dementia
  - ~6,427 Medicaid beneficiaries with cognitive impairment or dementia (conservative estimate)
  - 1 in 11 (8.9%) individuals aged 45 and older are experiencing memory loss/confusion
- Caregiving:
  - 458,000 Alzheimer's disease and dementia caregivers
  - 20.7% of Virginians providing care or assistance to a friend or family member with a health problem or disability
    - 7.5% selected dementia or other forms of cognitive impairment as the main health problem of the care recipient



Data Sources: Alzheimer's Association (2017), CMS (2015), BRFSS (2015), DMAS (2012)

The Alzheimer's Disease and Related Disorders (ADRD) Commission

Established in 1982 by the Virginia General Assembly

§ 51.5-154 of the Code of Virginia

15 Members;
Quarterly Meetings

Advises the Governor and General Assembly on policy, funding, regulatory and other issues related to dementia

ADRD Commission: Duties and Powers

1. Examine the needs and ways that state government can most effectively and efficiently assist in meeting those needs;
2. Develop and promote strategies to encourage brain health and reduce cognitive decline;
3. Advise the Governor and General Assembly;
4. Develop the Commonwealth's plan for meeting the needs;
5. Submit annual reports on activities to the Governor, General Assembly, and DARS; and
6. Establish priorities for programs among state agencies and criteria to evaluate these programs.

Timeline: Dementia State Plan

2009-2010

- Reviewed other state plans

2010-2011

- Drafted DSP
- Public listening sessions and comments received

December 2011

- Publication of the 2011-2015 DSP

2014-2015

- Drafted update to DSP
- Public listening sessions and comments received

October 2015

- Publication of 2015-2019 DSP

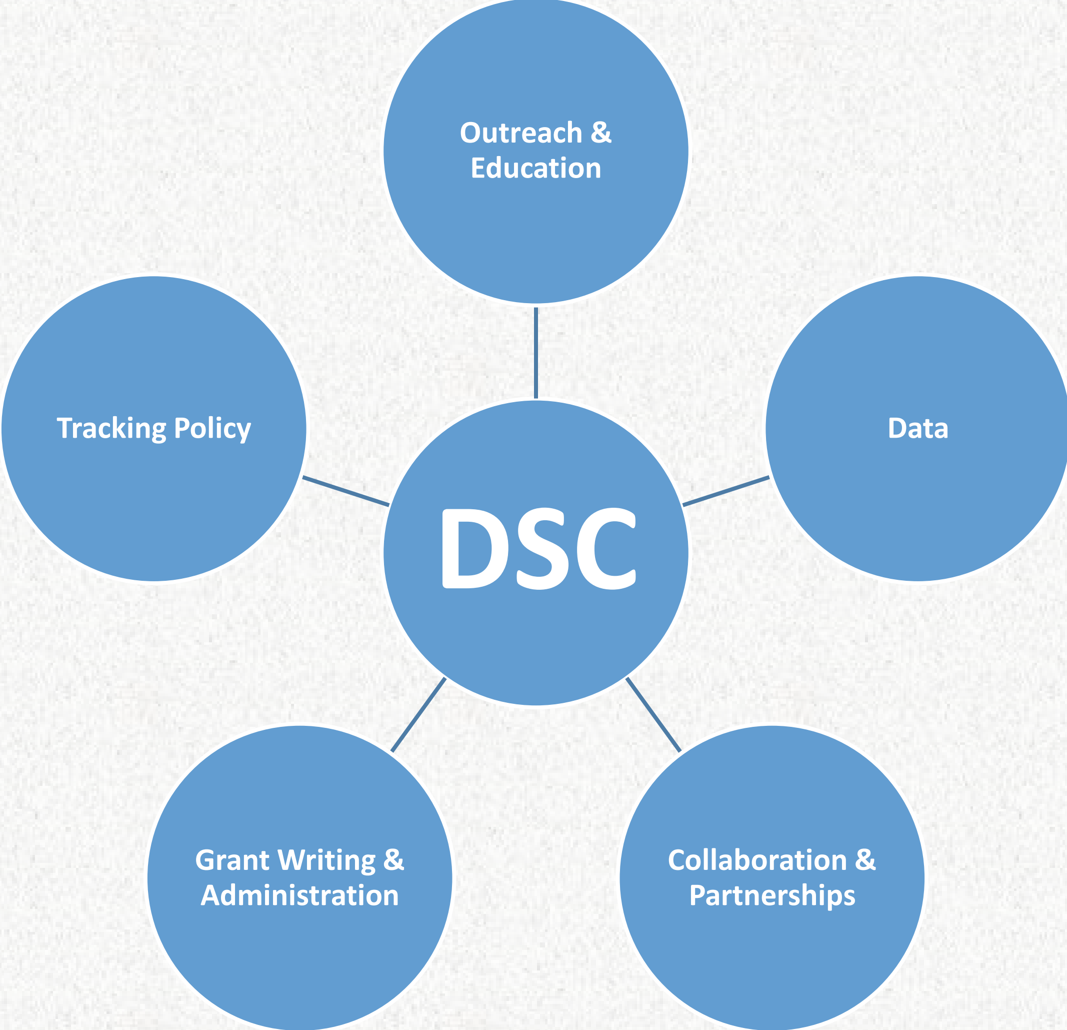
Goals of the Dementia State Plan

Goal	Description
Goal 1	• Coordinate Quality Dementia Services in the Commonwealth to Ensure Dementia Capability
Goal 2	• Use Dementia Related Data to Improve Public Health Outcomes
Goal 3	• Increase Awareness and Create Dementia-Specific Training
Goal 4	• Provide Access to Quality Coordinated Care for Individuals with Dementia in the Most Integrated Setting
Goal 5	• Expand Resources for Dementia-Specific Translational Research and Evidence-Based Practices

Work Groups

Training	Data & Research
Coordinated Care	Legislative

Dementia Services Coordinator



Virginia Alzheimer's Disease and Related Disorders Commission

DEMENTIA STATE PLAN

Virginia's Response to the Needs of Individuals with Dementia and their Caregivers

2015-2019

www.alzpossible.org

Overview of Goals

GOALS

Goal I: Coordinate Quality Dementia Services in the Commonwealth to Ensure Dementia-Capability.

A. Support and maintain a dementia services coordinator (DSC) who oversees Virginia's dementia-capability by recommending policy and coordinating statewide data collection, research and analysis, and training and awareness efforts in conjunction with the Commission.

B. Expand availability and access of dementia-capable Medicaid and other state-level administered services.

C. Review all state-funded services to ensure dementia-capable approaches and policies based on principles derived from the Person-Centered Care and Culture Change movements.

Goal II: Use Dementia Related Data to Improve Public Health.

A. Collect and monitor data related to dementia's impact on the people of the Commonwealth.

B. Collaborate with related public health efforts and encourage possible risk-reduction strategies.

Goal III: Increase Awareness and Create Dementia Specific Training.

A. Provide standardized dementia specific training to individuals in the medical, health- and social services-related fields and require demonstrated competency.

B. Provide dementia specific training to professional first responders (police, fire, EMS and search & rescue personnel), financial services personnel, and the legal profession.

C. Support caregivers, family members and people with dementia by providing educational information about dementia and available resources and services.

Goal IV: Provide Access to Quality Coordinated Care for Individuals with Dementia in the Most Integrated Setting.

A. Create a statewide network of interdisciplinary memory assessment centers with specialized, dementia-capable services for individuals with dementia and their caregivers from assessment and diagnosis through end-of-life.

B. Provide a system of services that are integrated, coordinated and diverse to meet the varied needs of individuals with dementia and caregivers during the disease trajectory.

C. Identify needed supports for informal and family caregivers and coordinate them to ensure positive caregiving experiences.

Goal V: Expand Resources for Dementia Specific Translational Research and Evidence-Based Practices.

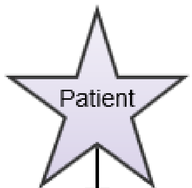
A. Support Alzheimer's and Related Diseases Research Award Fund (ARDRAF), especially projects that have a specific emphasis on "methods of treatment, ways that families can cope with the stresses of the disease, and the impact of the disease on the citizens of the Commonwealth" (§ 51.5-153).

B. Provide support to researchers and interested stakeholders across the Commonwealth through data sources and networking opportunities.

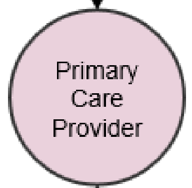
C. Promote the advancement of translational research, evidence-based practices and research participation in Virginia.

Dementia State Plan
GOAL 4A:

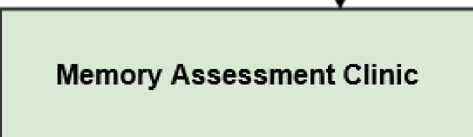
Create a statewide network of interdisciplinary memory assessment clinics with specialized, dementia-capable services for individuals with dementia and their caregivers from assessment and diagnosis through end-of-life



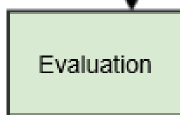
Patient or family have concerns about memory.



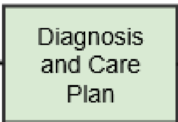
The patient's primary care provider (PCP) conducts a basic assessment. If needed, the PCP makes a referral for further evaluation.



Interdisciplinary Clinical Teams
Strategically located throughout the Commonwealth
Placed within health systems



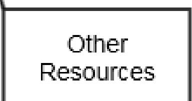
The MAC team provides a full evaluation that may include: a review of the PCP's records; clinical interviews with the patient, family and friends; neuropsychological and cognitive testing; blood and lab work-up; and neuroimaging.



Patient, family and PCP receive a clinical diagnosis and collaborate on a treatment plan.

The Dementia Care Manager (DCM) is located within the MAC.

The DCM supports the patient, family and PCP with in-person and telephone assistance and connects them with information, education and resources for an extended period.



OUTCOMES:

- Delayed Institutionalization
- Fewer Hospitalizations
- Caregiver Satisfaction
- Decreased Depression
- More Family Supports

Care Coordination Program
&
Effective Strategies Program

Care Coordination

United States Agency for Healthcare Research and Quality:

"…the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services.

Organizing care involves the marshaling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care."

Care Coordination

In Essence:

- Care coordination programs emphasize coordinated and comprehensive approaches to improving quality of care

Care Coordination

Most effective for diseases that are:

- High-volume and primarily managed in the outpatient setting
- Substantial variability in treatment
- Rely on coordination with community agencies/social services

Care Coordination: Positive Impacts

- Severity of patients' symptoms
- Patient's quality of life
- Social support
- Level of unmet caregiving needs
- Quality of caregiving
- Caregiver distress
- Adherence to published dementia care guidelines

Care Coordination: Positive Impacts

- Appropriate use of medications
- Use of community services
- Satisfaction with care and community service use
- Use of acute care services
- Institutionalization rates

Care Coordination: What Works?

Factors for success

- Expert knowledge of the care coordinators
- Investment in a strong provider network
- Coherent conditions for effective inter-organizational cooperation to deliver integrated care

Care Coordination: Costs

- Effects of interventions off-set start-up costs
    - Reductions in hospitalizations and other acute/unplanned health care

- Programs with substantial in-person contact that target moderate to severe patients can be ***cost-neutral*** and improve aspects of care

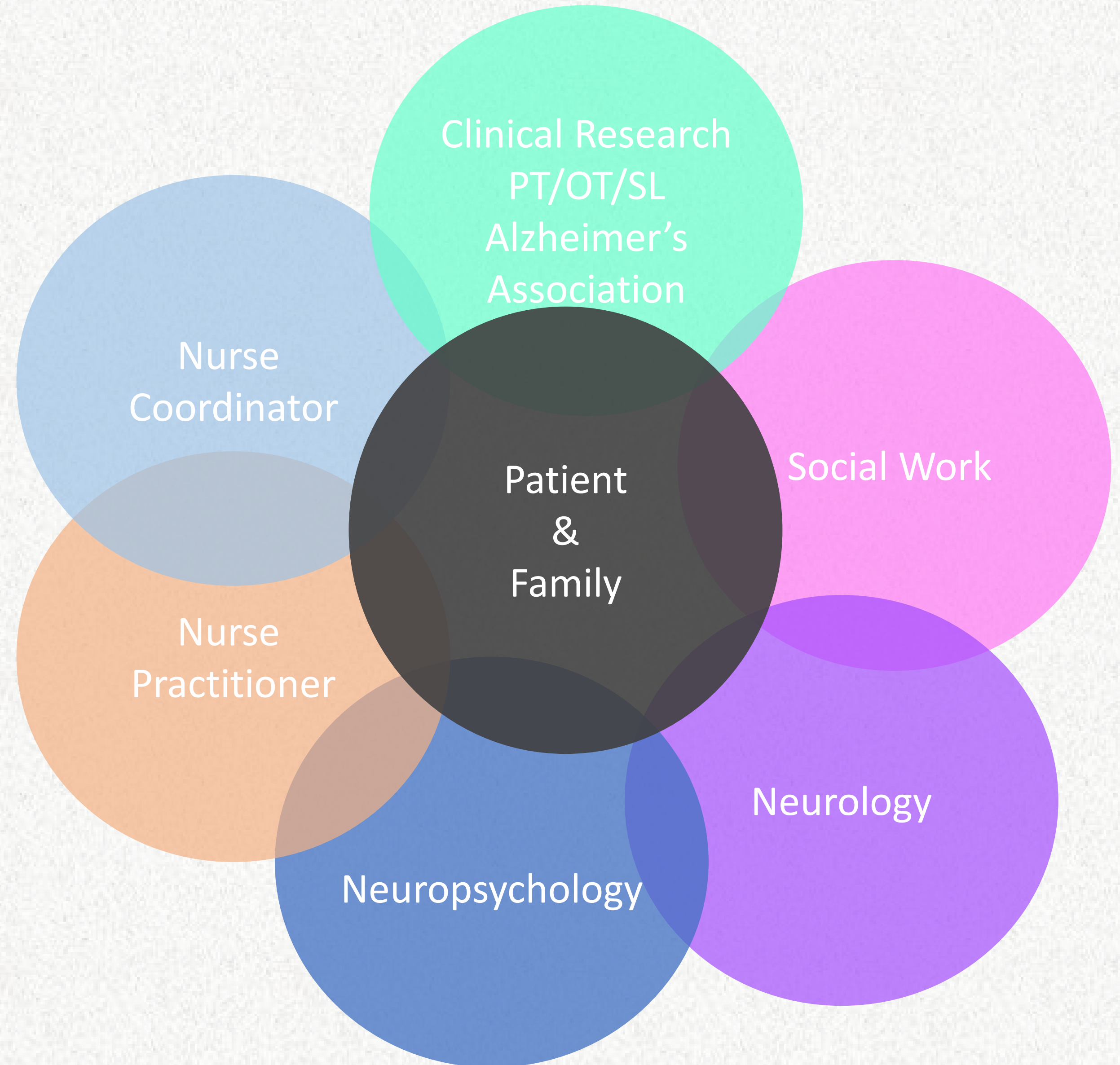
Care Coordination: Costs

- Payer Perspective: Mean monthly adjusted costs of healthcare and caregiving services during were **$219 less for those in CC**

Care Coordination at UVA

UVA Memory and Aging Care Clinic

- A multidisciplinary clinic providing patient/family centered care

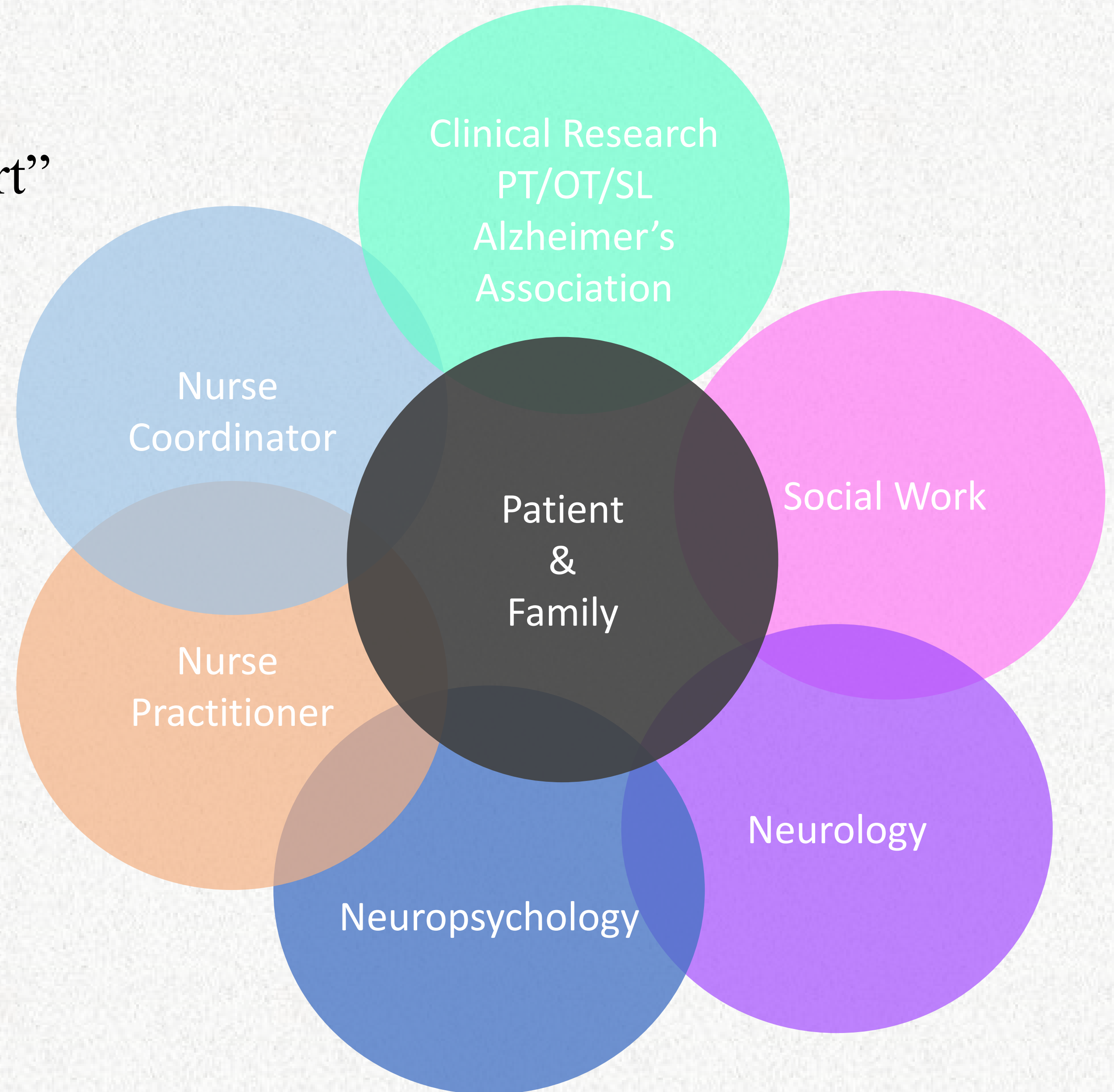


UVA MACC

Health care provision is better as a "team sport"

<u>Multi-Disciplinary Care</u>

- Improves patient outcomes
- Decreases hospitalizations
- Increases patient satisfaction



UVA's Memory and Aging Care Clinic

Initial Evaluation

- Neuropsychological testing
- Neurological evaluation
- Neuroimaging
- Advanced imaging/biomarker work-up

UVA's Memory and Aging Care Clinic

Subsequent Care

- Ongoing coordinated care
- Re-assessments of cognition, behavior, and functioning
- Non-pharmacological management of symptoms
- Speech evaluations and therapeutic strategies
- Social work services
- Medication management

Care Coordination UVA/JABA

- A model program of coordinated care for individuals and their primary care partners

- Open to all Virginians with a recent diagnosis of MCI or dementia

- Collaboration:
  - Virginia Department of Aging and Rehabilitative Services
  - UVA Health System
  - Jefferson Area Board for Aging (JABA)

JABA–Jefferson Area Board for Aging

- ACL Grant provided an opportunity to collaborate with Memory and Aging Care Clinic
  - Joint hiring and training of Care Coordinators (one employed by each organization)
  - Care Coordinators work with clinic staff and JABA's Options Counseling team
  - Able to access and refer to services provided by UVA hospital and JABA

- Dementia programs add to connections between JABA and largest area hospital

Care Transitions Program	Community outreach
Cross training	Research links

JABA–Jefferson Area Board for Aging

- Area Agency on Aging serving Charlottesville and five surrounding counties

- 42 years of providing services to older residents (60+)

- Programs defined by level of need:
  - Independent Seniors
  - Individuals needing Supports and Resources
  - Individuals needing 24-hour Assistance
  - Caregivers

JABA–Jefferson Area Board for Aging

- Wide range of services available at low or no cost

  - Information and Assistance
  - JABA Community Centers
  - Insurance Counseling (SHIP)
  - Volunteer Services
  - Affordable Senior Housing
  - Adult Care Centers
  - Options Counseling
  - Home Delivered Meals
  - Caregiver Support Groups
  - Chronic Disease Self Management Education
  - Ombudsman
  - PACE

Care Coordination Program

Goals

- Improve the quality of dementia care in Virginia
- Coordination of services
- Provide education about dementia
- Provide emotional support to patients and caregivers

Care Coordinators

Liz Boyd and Sam Fields

- Advanced degrees in fields related to area of work (psychology, social work)

- Knowledge of community services enhances cooperation and cross-referrals
    - (e.g., respite care available at JABA's Adult Day Centers)

- Seamless connection between multiple agencies

Care Coordinators

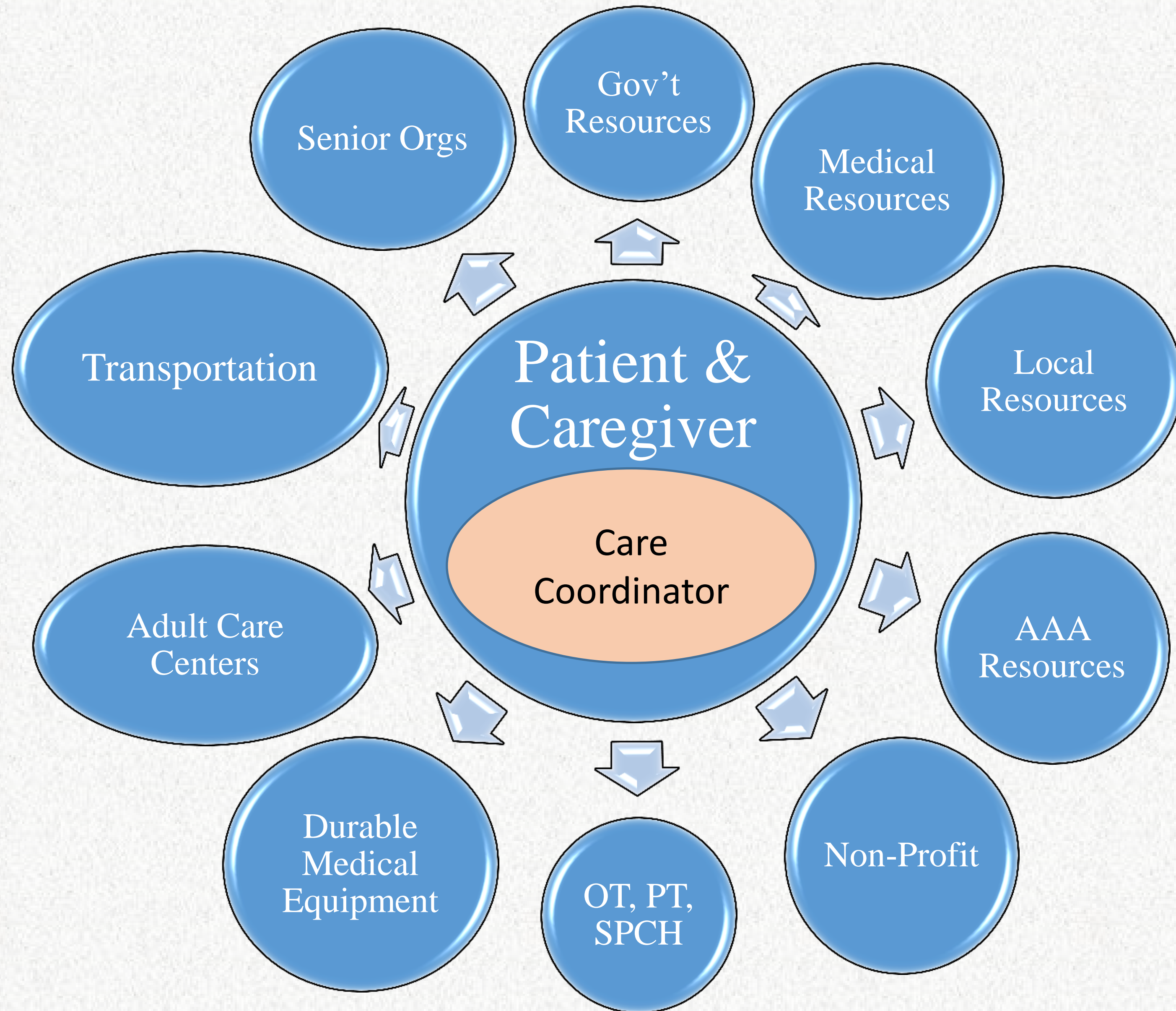
Extensive training in:

- Aging and dementia
- Dementia-capability
- Options Counseling
- Person-centered care
- Future planning needs (e.g. Advance Directives)

Care Coordinators

- Form proactive relationships with patient and family
- Conduct at least one home visit
- Central continuous point of contact
- Key advocates
- Share knowledge of the range of health and care services
- Assist in navigation of complex health care and social services
- Monitor and review care services

Care Coordination Program



Care Coordination: Outcome Measures

- Administer validated measures at the first visit and annually

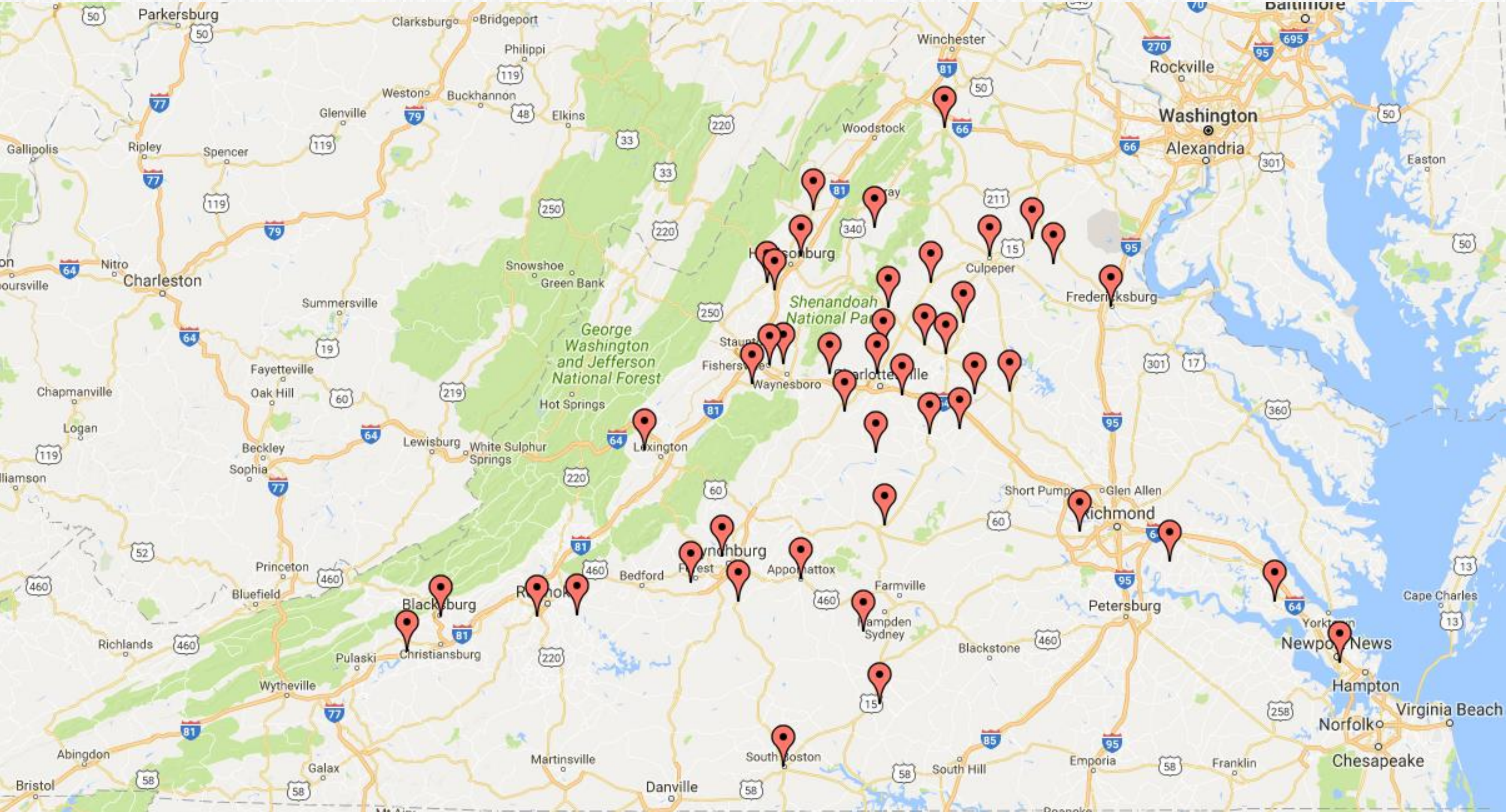
- Outcomes 1: (1) Decreased depression
(2) More steps to prepare for dementia
(3) Satisfaction with the Care Coordination program

- Outcome 2: (1) Decreased use of emergency or unplanned health care

Care Coordination Program: Patients

- 54% Female; 46% Male
- 86% White; 10% Black
- 27% Veterans
- 61% Rural; 39% Urban
- 85% Retired
- 71% Married
- 87% Medicare
- 4% Medicaid

Care Coordination



Basic ADLs

Patients: .28 (Range: 0-4)
Caregivers: .44 (Range: 0-6)

Dependency	Caregivers	Patients
Continence	17%	13%

Note: Caregivers = Caregiver report on patients

Instrumental ADLs

Patients: 5.56 (Range: 0-8)
Caregivers: 4.52 (Range: 0-8)

Dependency	Caregivers	Patients
Shopping	79%	52%
Food Preparation	71%	45%
Transportation	60%	56%
Medications	60%	40%
Finances	36%	21%

Note: Caregiver report on patient functioning

Neuropsychiatric Symptoms

<u>Total Number of Neuropsychiatric Symptoms</u>

- Caregivers: 4.0 (Range: 0-11)
- Patients: 1.9 (Range: 0-8)

Symptom	Caregivers	Patients
Delusions	18%	5%
Hallucinations	13%	5%
Agitation/Aggression	43%	15%
Depression	42%	32%
Anxiety	55%	33%
Apathy	46%	15%
Irritability/Lability	43%	32%

Note: Caregivers = Caregiver report on patients

Behavioral Symptoms & Reactions

Total Number of Behavioral Symptoms:

Patients: 4.98 (Range: 0-18)

Caregivers: 8.19 (Range: 0-17)

- Ratings: Not at all, A Little, Moderately, Very Much, Extremely

Symptom	Caregivers		Patients	
	Endorse	Bothers	Endorse	Bothers
Asking the same question	78%	63%	41%	11%
Forgetting significant past events	55%	36%	52%	13%
Starting, but not finishing, tasks	56%	45%	27%	39%

Bothers = moderately to extremely

Behavioral Symptoms & Reactions

- Ratings: Not at all, A Little, Moderately, Very Much, Extremely

Patients: Symptom	Endorse	Bothers
Feeling worthless or a burden	19%	32%

Caregivers: Symptom	Endorse	Bothers
Appearing anxious or worried	56%	57%
Appearing sad or depressed	57%	55%
Irritability	47%	47%

Bothers = moderately to extremely

Depressive Symptoms

Patients:	7.6	(Range: 0-42)
Caregivers:	7.33	(Range: 0-44)

Symptom	Caregivers	Patients
Could not shake off the blues	28%	23%
Felt depressed	40%	34%
Restless sleep	29%	29%

Note: Caregiver self-report

Depressive Symptoms

Patient Symptom	Frequency
Trouble keeping mind on task	43%

Caregiver Symptom	Frequency
Could not get going	29%
Wished I were dead	3%

Note: Caregiver self-report

Quality of Life

Patients: 40.51 (Range: 23-52)
Caregivers: 40.5 (Range: 23-52)

- Ratings: Poor, Fair, Good, Excellent

Symptom	Caregivers	Patients
Ability to do things for fun	22%	22%

Note: Endorsing ‘poor’ or ‘fair’

Caregiver Wellbeing

Total Score: 66.4 (Range: 43-80)

- Ratings: Rarely/Occasionally/Sometimes/Frequently/Usually

Rarely to Sometimes	Caregivers
Expressing anger	64%
Rewarding myself	57%
Having time to have fun with friends/family	45%
Participating in community events	45%
Making financial plans for the future	32%
Maintaining the home	24%
Attending to my own medical needs	13%

Care Coordination: Feedback

“I know I’m not alone.”

“I know if push comes to shove, I can call.”

“It’s been helpful to have somebody on your side to help expedite caregiver and future planning support.”

“How wonderful you have been to us.”

“I am so thankful you are involved.”

“I love having a personal advocate during this difficult time.”

Effective Strategies Program

Fondation hospitalière Sainte-Marie

Mission: To increase and preserve autonomy to patients with neurological illness

- Inpatient and outpatient facilities
- 3000 patients annually
- Serves majority of the left bank

French MCI- Dementia Program Overview

<u>Topics covered</u>

- Memory
- Language
- Planning and organization
- Emotions
- Health and safety
- Social services
- Real world engagement – “field trips”

- Pre- and post- assessments

Effective Strategies Program

- Modeled after FSM in Paris
- Group education program for individuals with MCI or early dementia
- Programs are held in the community
  - Independently living facilities
  - Community centers

Effective Strategies Program

<u>Goals</u>

- To promote independence
- Provide strategies for anticipating and coping with changes
- Provide emotional support
- Develop a support system

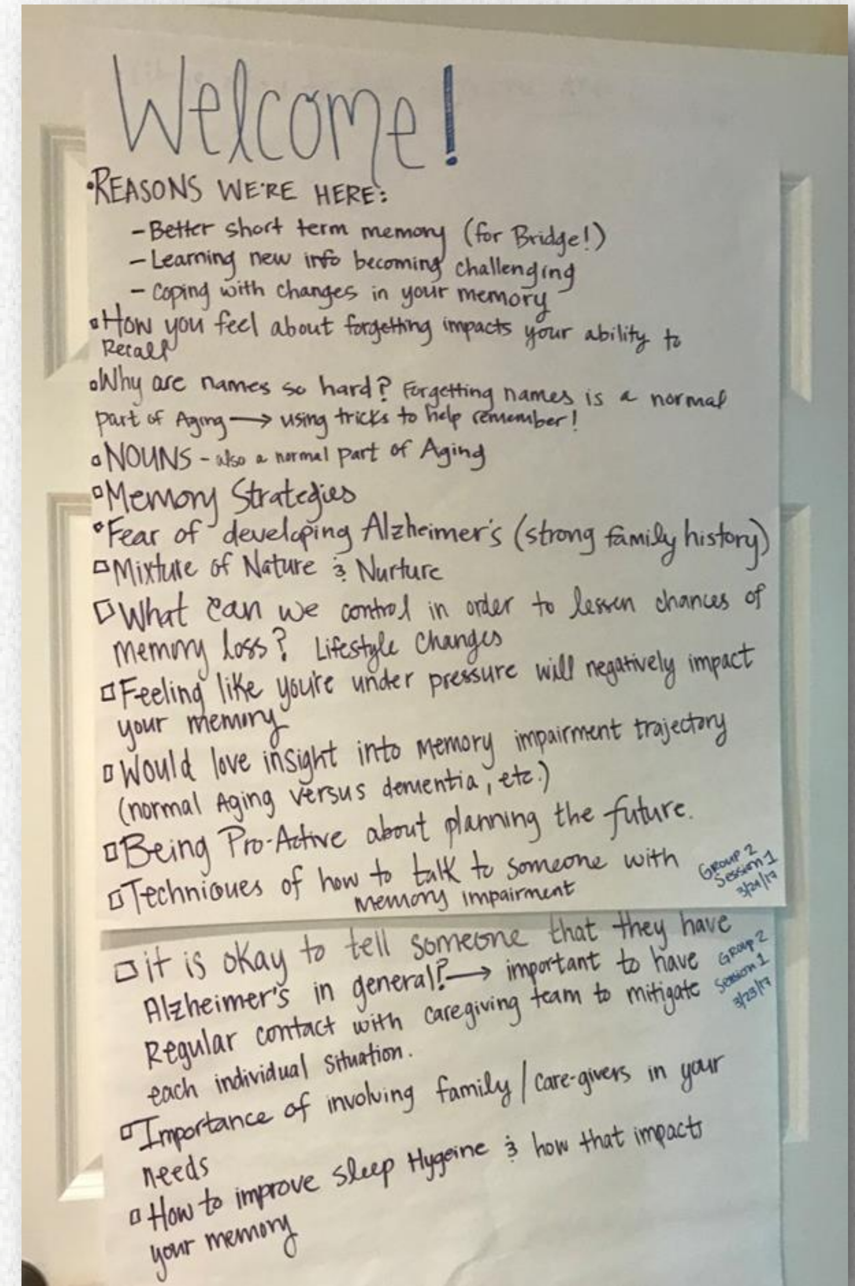
Effective Strategies Program

- 20 sessions over 10 weeks
- 1 hour of interactive presentations followed by ½ hour of socializing over snacks
- Sessions are led by experts in their respective fields
  - Neuropsychology
  - Nurse practitioners
  - Social work
  - Occupational therapy
  - Physical therapy
  - Speech therapy
  - Art therapy
  - Music therapy

Effective Strategies Program

<u>Topics include</u>

- Education about dementia and memory
- Speech, language, and memory strategies
- Developing and practicing an exercise program
- Home safety
- Planning and participating in outside activities
- Using art and music therapeutically
- Emotional adjustment to memory changes



Effective Strategies Program

Welcome!

- REASONS WE'RE HERE:
  - Better short term memory (for Bridge!)
  - Learning new info becoming challenging
  - Coping with changes in your memory
- How you feel about forgetting impacts your ability to Recall
- Why are names so hard? Forgetting names is a normal part of Aging → using tricks to help remember!
- NOUNS - also a normal part of Aging
- Memory Strategies
- Fear of developing Alzheimer's (strong family history)
- Mixture of Nature & Nurture
- What can we control in order to lessen chances of memory loss? Lifestyle changes
- Feeling like you're under pressure will negatively impact your memory
- Would love insight into memory impairment trajectory (normal Aging versus dementia, etc.)
- Being Pro-Active about planning the future.
- Techniques of how to talk to someone with memory impairment

Group 2 Session 1 3/21/19

- it is okay to tell someone that they have Alzheimer's in general? → important to have Regular contact with caregiving team to mitigate each individual situation.
- Importance of involving family / care-givers in your needs
- How to improve Sleep Hygeine & how that impacts your memory

Group 2 Session 1 3/21/19

Session 3 – Memory

Session 3 group 2 3:30 ①

- it is easier to Recall something when you hear parts first (triggers...)

Why is Memory Important?

- "Basics of Living"
  - helps with socializing (interacting with others meaningfully)
- How to Cook, How to Sew, Basics such as Social Security #
- Memory helps with being able to expand your knowledge
- Personal History (things that make you unique - sense of self)
- If you don't learn from the experience, you risk repeating mistakes

Different Types of Memory

- "How-to" Memory → cooking, Riding a Bike, tap-dancing, generally this type of memory is fairly stable
- Driving is Different due to the various types of memory & skills involved (directions, reading signs, reaction time)
- Long Term Memory - childhood memories tend to be easier to recall though more difficult to verify
- Repetion improves ability to Remember
- can be difficult to Recall more Routine items from short term –

try to make it unique to Remember!

Session 3 group 2 3:30 ⑤

FLASHBULB MEMORY (memory about events)

- Research shows that people are frequently not accurate with where they think they were at the time of a significant event

KNOWLEDGE

- you know it because you were there or you read about

Names ARE CHALLENGING TO REMEMBER
Name tags are great when there is a purpose

How does memory work?

① Learning
- you need to understand it & have it be meaningful

② Storing the Info
- Requires Repetion often (like recalling a phone # while walk to the phone)
- the more ways you rehearse it, the better off you will be - Reading, writing, talking...

③ Recalling & Retrieving Information
- Aging impacts how you recall – such as a list of... you need to organize it by category (i.e. a grocery list...)

Alzheimer's impacts your ability to store information, making it impossible

Session 3 group 2 3:30 ③

- Parkinsons
- Depression can limit your ability to remember because it takes energy to Recall

Know your Learning Style! Some people are more visual, or concrete, etc.

Things That Are Easy To Remember: childhood memories, unpleasant events – the birth of a sibling, something that you repeat often, important events like a wedding,

Things That Are HARD to Remember:
- dates / appointments → utilizing a calendar / date book & Keeping it in the same place → Have a system!

Iveagh's new goal = Streamline your system ☺
- use one calendar → move the phone to a spot that makes sense for you

Tricks to Remember Names (say it out loud)

ENEMIES OF MEMORY:
- depression, Fatigue, Stress, not feeling well, Alcohol
- As we age, our sleeping changes
- too much medications or certain combos can negatively impact your memory
- too much going on (can mean situational stress or generally having distractions around you)

Session 3 Group 2 3:30 ④

Friends of Memory:
- Repetition
- Peace & Quiet
- Cognitive Exercise → no one particular strategy is superior, do things you enjoy
- Healthy Diet → good for your heart & good for your brain!

BRING YOUR Med lists!

Session 4

1.) Exercise!
- make your ph...
- "Life is bett... mood.
- What is good... brain (& your...

2.) Socializing → ... opportunities f...

3.) Memory Medicat... Memory loss, ...
- Communica... (i.e. generic...

4.) Over the Co...
- use with cautio...

- Important to Act a... list
- Have Regular conversations with Medical team regarding the supplements you take

Session 4 group 2 3:30 ⑤

Suppliments Cont.
- use caution (not FDA regulated)
- Have a conversation with your MD before starting a suppliment

Meds that can negatively impact your memory
- "PM" meds (Sudafed PM, Advil PM, Tylenol PM, etc) → negatively impacts
  - have benadryl in them to help sleep
  - can cause additional confusion, Additional Risks such as Falls the memory

Be a Smart Consumer – Read the Labels & be careful.

Have a system for helping to Remember to take your Meds → pill box, Alarms, electronic med box
- Routines help Memory!

Session 5, 3:30 group

Cardio + M. End... Most day 4-5/7 — 30-40 min

Stretching 7/7

Strengthening 2/7

$10,00...

What's on your plate?

calendar / a lot of things to do / usually full / everybody's retired even busier / living a lie / we think they into retired idea that we came to retirement expecting & we overcommit b/c we want everyone to like us / fragmented, don't have enuf time, things I want to do + need to do / plate is overflowing / multitasking / Dr's appointment

Retirement isn't always what we expected /
A LOT OF HAVE-TOs
UNPREPARED FOR COMMUNITY LIFE
NOT A LOT OF TIME FOR RELAXATION
GUILT, STRESS, ANXIOUS, OPPORTUNITIES, FUN, SATISFACTION, SECURITY
MEDICAL STRUCTURE

ON	OFF
EXERCISE	Pressure
SKATING	Responsibilities
READ MORE	House Repairs
TIME	25 lbs
BETTER MEMORY	Being Scattered
SELECTIVE " "	Pain in HAND
SENSE OF Humor	PHYSICAL LIMITATIONS
GARDEN	EXERCISE

SOCIAL RESPONSIBILITY ⟷
" " CHOICES

Effective Strategies Program: Outcome Measures

Participants complete validated measures at the start and finish of each ESP course

Outcomes: (1) Increased knowledge of & ability to use memory strategies
(2) Improved mood & quality of life
(3) Satisfaction with the program

Effective Strategies Program

- 5 cycles, 40 participants
- 25% male; 75% female
- 18% veterans
- 100% Caucasian
- 64% married; 28% widowed

Effective Strategies Program: Participant Profile

- Basic ADLs: 5.82 (out of 6)
- iADLs: 7.3 (Range: 5-8)
  - Shopping: 13%
  - Food Preparation: 18%
  - Transportation: 10%
  - Finances: 15%

Effective Strategies Program

- Quality of Life: 42 (Range 30-50)
- Depression: 6.9 (Range 0-28)
- # Neuropsychiatric Symptoms: 4.5 (Range: 0-14)

Effective Strategies Program: Lessons Learned

- Participants feel isolated and fear for their future
- Setting/context matters
- Significant heterogeneity in patient profiles and groups
- Greater than expected (invisible) impairments
- Variable awareness/acceptance of decline
- Institutional/staff relationships matter

Effective Strategies Program: Preliminary Outcomes

- High participant satisfaction
- Cohesive group membership
- Improved understanding of memory
- Improved understanding of memory strategies
- Improved coping skills

Effective Strategies Program: Preliminary Outcomes

“This is a great interactive program.”

“Lots of fun & excellent input.”

“Everyone could benefit from this program. It is comforting to know you are not alone.”

Effective Strategies Program

Music and Memories

When I hear the Beguine
I always see your face
You were in your tux
And I was wearing lace

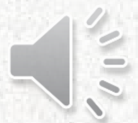
Love was in the air
When I danced with you
You tutored me in math
And taught me to be true

Music… brings back memories
Music… brings you back to me

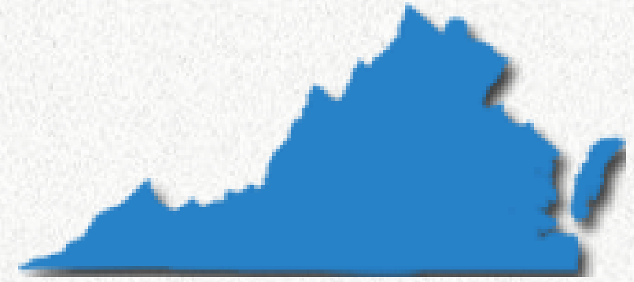
When I was in the dorm
I played my radio
My roommate complained
So I had to let it go

I played it in my heart
I held it close to me
The future held our love
As far as we could see

Music… brings back memories
Music… brings you back to me.



Future Replication



Manual for state- and nation-wide replication by end of three-year grant

- Documented comprehensive training program for Care Coordinators
  - Using on-line materials and in-person training supporting dementia capability
  - Community networking and outreach to enhance knowledge and awareness of available resources

- Fully-developed procedures and best practice for reproducing
  - Care Coordination Program
  - Effective Strategies Program

Thank you for your attention

Questions?