Jointly Provided by

33rd Annual Alzheimer's Disease Management & Research Symposium

August 15-16, 2019
The Clayton Center, Maryville College
502 E Lamar Alexander Parkway
Maryville, TN 37804

AGENDA

Schedule	Speaker and Topic
Thursday, August 15	
7:30 – 8:30 AM	**Continental Breakfast and Registration**
8:30 – 8:45 AM	**Welcome and Introductions** *Janice Wade-Whitehead* President/CEO, Alzheimer's Tennessee Knoxville, TN
8:45 – 9:45 AM	**Research Focus: Strengthen Brain Pathways for Attention and Implications for Improved Memory Study** *Xiaopeng Zhao, PhD* Associate Professor, Dept. of Mechanical, Aerospace and Biomedical Engineering University of TN, Knoxville
9:45 – 10:30 AM	**Symptom Management of Alzheimer's Disease** *Ginger Lovingood, MD* Knoxville Psychiatry Knoxville, TN
10:30– 11:15 AM	**Break / Visit Exhibits**
11:15 – 12:15 PM	**Traumatic Brain Injuries and Concussion in the Elderly and Impact on Dementia** *Wendy Ellmo, MS, CCC/SLP. BCNCDS* Brain Links Knoxville, TN
12:15 – 1:15 PM	**Lunch / Visit Exhibits**
1:15 – 1:30 PM	**Alzheimer's Tennessee: an Overview of Programs and Services** *Janice Wade-Whitehead*

1:30 – 2:15 PM	**An Overview of Alzheimer's Disease** *Bruce LeForce, MD* Clinical Assistant Professor University of TN, Knoxville
2:15 – 2:30PM	**Break / Exhibits**
2:30 – 3:15 PM	**Dementia and Driving: Determining Decision Making Capacity and Autonomy in Dementia** *Odacir Oliveria, PhD* Knoxville, TN
3:15 – 3:30 PM	**Wrap-up and Evaluations**
Friday, August 16	
7:30 – 8:30 AM	**Continental Breakfast and Registration**
8:30 – 8:45 AM	**Welcome and Introductions** Janice Wade-Whitehead
8:45 – 9:30 AM	**Finding the Pillars of Personhood: Keys to Living Well in Dementia** *Daniel Potts, MD* Tuscaloosa VA Medical Center Tuscaloosa, AL
9:30 – 10:30 AM	**Bringing Art to Life: Living Well Through Art and Stories** *Daniel Potts, MD*
10:30 – 11:00 AM	**Break / Visit Exhibits**
11:00 – 12:00 PM	**Early Onset Alzheimer's Disease: Early Diagnosis and Treatment Modalities** *Monica Crane, MD* Medical Director, Genesis Neuroscience Clinic Knoxville, TN
12:00 – 1:00 PM	**Lunch / Visit Exhibits**
1:00 – 1:30 PM	**Living Well with Alzheimer's Disease: A Panel Discussion with Persons Living with Diagnosis** *Janice Wade-Whitehead*
1:30 – 2:15 PM	**Clinical Characteristic of Lewy Body Dementia and Frontotemporal Lobe Dementia** *Monica Crane, MD*
2:15 – 2:45 PM	**Break / Visit Exhibits**
2:45 – 3:30 PM	**Palliative Care, Hospice and End of Life Decisions** *Cynthia Pearman, MD* Medical Director, UT Hospice/LHC Knoxville, TN
3:30 – 3:45 PM	**Wrap Up and Evaluation**

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Course Description and Educational Gap	This two-day live activity includes topics related to the diagnoses and management of Alzheimer's disease and related dementias. Both pharmaceutical and non-pharmaceutical treatment options will be discussed regarding the management of symptoms along with strategies for families. Following this program, learners will have improved recognition and diagnosis of pre-clinical, MCI, and early stages of dementia. Additionally, learners will have improved recognition and diagnosis of the more common variants of non-Alzheimer's dementia. Learners will increase level of support for individuals and families living with dementia. Finally, learners will have improved and appropriate levels of care for individuals in late stage dementia.
Target Audience	Primary Care Physicians, Advanced Practice Providers, Neurologists, Psychologists, Pharmacists, Nurses, Nursing Home Administrators, Social Workers and other Healthcare Providers.
Learning Objectives	*As a result of participating in this activity, the learner will be able to:* • Identify advances in technology, including imaging and biomarkers to improve diagnosis and monitor disease progression in Alzheimer's disease • Compare the pathophysiology of aging, Early Onset Alzheimer's, Alzheimer's, Non Alzheimer's dementia, delirium, depression and traumatic brain injuries and other syndromes associated with aging • Identify potential targets for treatment of dementia. Discuss recommendations for decreasing the risk of developing dementia • Discuss living well with Alzheimer's, with focus on early intervention and symptom management • Explain therapeutic breakthroughs in neurodegenerative disease • Cite the currently emerging research in the diagnosis and treatment of dementia • Provide improved and appropriate levels of care for patients with late stage dementia. • Define and describe appropriate action related to driving and dementia and legal issues experienced by individuals living with dementia and their families • Describe three problem solving strategies that can be used to deal with dementia-related behavioral expressions
Competencies Addressed	• Patient Care and Procedural Skills • Systems-based Practice

- Medical / Pharmacotherapy Knowledge
- Interpersonal and Communication Skills
- Professionalism
- Provide Patient-Centered Care
- Work in Interdisciplinary Teams
- Employ Evidence Based Practice

Course Director

Monica Crane, MD, Medical Director, Genesis Neuroscience Clinic: Clinical Assistant Professor, University of Tennessee

Disclosures

Potential Conflicts of Interest:

USF Health endorses the standards of the ACCME, ACPE and ANCC that requires everyone in a position to control the content of accredited educational activity to disclose all financial relationships with commercial interests that are related to the content of the educational activity. All accredited activities must be balanced, independent of commercial bias and promote improvements or quality in healthcare. All recommendations involving clinical medicine must be based on evidence accepted within the medical profession.

A conflict of interest is created when individuals in a position to control the content of an accredited educational activity have a relevant financial relationship with a commercial interest which therefore may bias his/her opinion and teaching. This may include receiving a salary, royalty, intellectual property rights, consulting fee, honoraria, stocks or other financial benefits.

USF Health will identify, review and resolve all conflicts of interest that speakers, authors or planners disclose prior to an educational activity being delivered to learners. Disclosure of a relationship is not intended to suggest or condone bias in any presentation but is made to provide participants with information that might be of potential importance to their evaluation of a presentation. USF Health does not endorse any products or services

Name	Company	Relationship
Monica Crane	Biogen, Axsome	Research support
Wendy Ellmo	None	
Bruce LeForce	None	
Ginger Lovingood	None	
O.H. Oliveira	None	
Cynthia Pearman	None	
Daniel Potts	None	
Xiaopeng Zhao	None	

All Planning Committee Members and Staff have completed conflict of interest disclosures, and all state that they all have nothing to disclose. The Conflict of Interest forms are on file in the Office of Continuing Professional Development at USF Health.

Accreditations

Physicians:
This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through a joint providership of USF Health and Alzheimer's Tennessee. USF Health is accredited by the ACCME to provide continuing medical education for physicians.

USF Health designates this live activity for a maximum of 9.50 *AMA PRA Category 1 Credits*. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Family Medicine Physicians:
This Live activity, 33rd Annual Alzheimer's Disease Management & Research Symposium, with a beginning date of 08/15/2019, has been reviewed and is acceptable for up to 9.50 Prescribed credit(s) by the American Academy of Family Physicians. Physicians should claim only the credit commensurate with the extent of their participation in the activity.
Activity # 85925

Nurses:
USF Health is an approved provider of continuing education for nurses through FBN 50-2970. This program has been approved for 9.5 contact hours. Florida Board of Nursing credit is accepted for certification by ANCC and by most Boards of Nursing nationally.

Florida Board of Psychologists:
USF Health is an approved provider of continuing education for Psychologists through the Florida Board of Psychology (provider number 2970). This program has been reviewed and approved for up to 9.5, continuing education credits. Licensee numbers are required prior to the issuance of certificates.

Social Workers:
This program was approved by the National Association of Social Workers – Tennessee Chapter (Provider Number: NASWTN 2018-0062) for up to 10.0 continuing education units.

Please Note: *Once you have followed the steps to claim credit, you will receive a Certificate of Completion. USF Health will upload your credit to the National Association of Social Workers-Tennessee Chapter on your behalf within 60 days after the conference.*

Long Term Care Administrators:
This program has been approved for Continuing Education for 9.25 total participant hours by NAB/NCERS—Approval # 20200813-9.25-A57635-IN.

Please Note: *In order for USF Health to provide credit, you must have a NAB number. You do not have to be a NAB member but you can register as a guest in order to obtain a NAB number. See registration desk for instructions on how*

	to register. USF Health will upload your credit to NAB with 30 days if you have provided a NAB number. **Case Managers:** This program has been pre-approved by The Commission for Case Manager Certification to provide continuing education credit to CCM® board certified case managers. The course is approved for 9.5 CE contact hour(s). Activity code: C00038355; Approval Number: 190002876. ***Please Note:*** *USF Health will provide Case Managers with a Certificate of Completion. To claim CEs for this activity, log into your CCMC Dashboard at www.ccmcertification.org and follow the instructions to upload your Certificate of Completion.*
Commercial Support	There is no commercial support for this activity.
Non Endorsement	USF Health does not endorse any product, material, or service mentioned in association with this activity.
Disclaimer	The information provided at this CME/CE activity is for continuing education purposes only and is not meant to substitute for the independent medical/clinical judgment of a healthcare provider relative to diagnostic and treatment options of a specific patient's medical condition.
EOE/ADA **For Questions**	USF is an Equal Opportunity / Affirmative Action / Equal Access Institution. Contact Charmagne Branch-Price
Educational Coordinator	Charmagne Branch-Price Education Coordinator Office of Continuing Professional Development USF Health 813-224-7859 cbranchp@health.usf.edu

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Research Focus: Strengthen Brain Pathways for Attention and Implications for Improved Memory Study

August 15
8:45 - 9:45 AM

Xiaopeng Zhao, PhD
Associate Professor, Dept. of Mechanical, Aerospace and Biomedical Engineering
University of TN, Knoxville

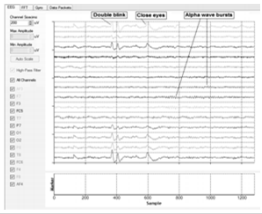
EEG-based Brain-Computer Interface for Dementia Diagnosis and Cognitive Training

Xiaopeng Zhao
Department of Mechanical, Aerospace, and Biomedical Engineering

THE UNIVERSITY OF TENNESSEE KNOXVILLE

What is EEG

EEG monitors electrical signals in the brain using electrodes placed on the scalp. EEG wave patterns characterize emotion, cognition, diseases, imagination, intention, and body kinematics.



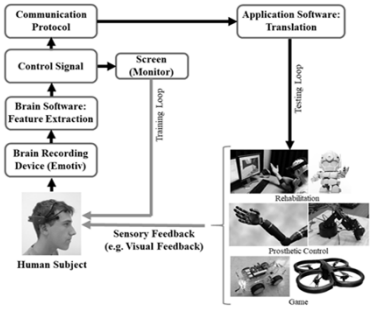
EEG Frequency Bands

- Higher frequencies: active processing, relatively de-synchronized activity (alert wakefulness, dream sleep).
- Lower frequencies: strongly synchronized activity (dreamless sleep, coma).

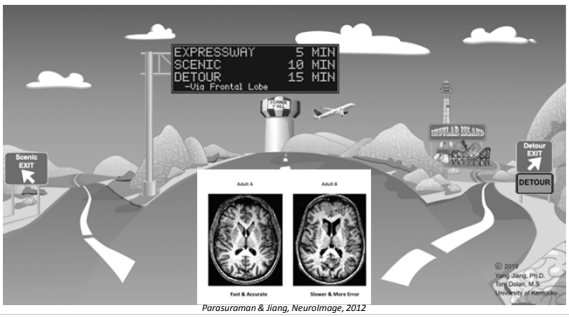
Name	Frequency (Hz)	Activity
Delta	<4	Deep sleep state/physical defects present
Theta	4-7	Emotional tensions, stress, frustration, disappointment
Alpha	8-15	Brought out by closing the eyes and by relaxation.
Beta	16-31	Brain is active, thinking, focusing
Gamma	>32	Conscious perception
Mu	8-12	Released with spontaneous nature of the brain like motor activities

Mind-controlled Robotics

Brain Computer Interface (BCI)



Currently No Effective Treatment for Alzheimer's Disease



Parasuraman & Jiang, NeuroImage, 2012

Courtesy of Prof. Yang Jiang, UKY

Noninvasive, Synaptic Neuromarkers

Dr. Collins, Director, National Institutes of Health

Dementia Diagnosis

Mild Cognitive Impairment (MCI), Alzheimer's Disease (AD)

Current Diagnostic Methods

- Self/family-reported behavior problems
- Task-based exams
- CT, fMRI, PET
- Biomarker proteins
- Limitations
  - Not available in primary care setting
  - Expensive and invasive
  - Time requirement

EEG-based Screenings

- Inexpensive
- Less invasive
- Usable in primary care settings
- May assist in dementia treatment/research
  - Early/annual screenings for abnormalities
  - Evaluation/monitoring
  - Drug discovery

Subjects

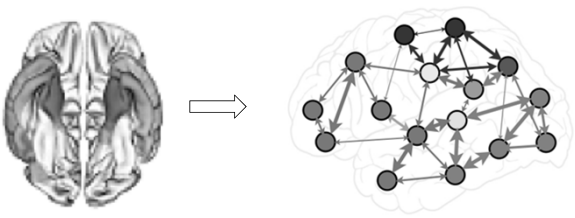
	NC	MCI	AD
Number	15	16	17
Age (std)	75.7 (5.5)	74.6 (8.8)	76.7 (5.2)
Gender	Male=6, Female=9	Male=12, Female=4	Male=7, Female=10
MMSE Median(range)	n=14 30 (28, 30)	n=16 27.8 (23, 30)	n=15 24.5 (19, 28)
Logic Memory I Median (range)	n=14 13.5 (9, 18)	n=15 9.5 (2, 39)	n=12 5 (1.5, 21)

Note: std = standard deviation. MMSE = mini-mental state examination. Logic Memory I is from Wechsler Memory Scale.

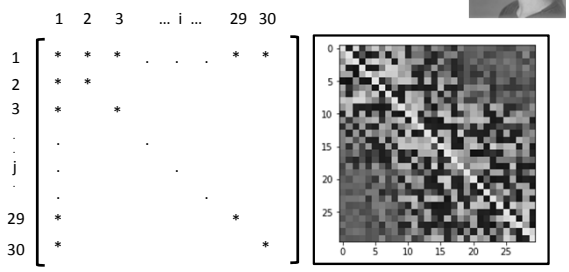
NC=normal control
MCI=mild cognitive impairment
AD=Alzheimer's Disease

Hypothesis

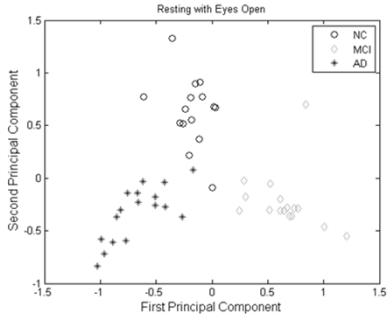
Brain thinning in early AD lead to functional change in EEG network.



EEG Causality Network



PCA: Resting Eyes Open

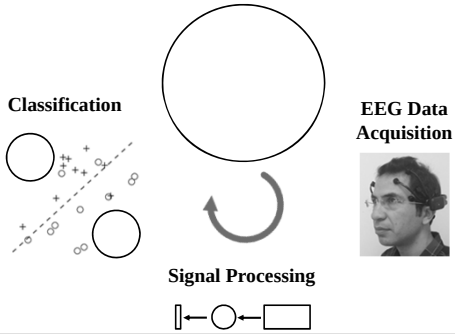


Results: Resting Eyes Open

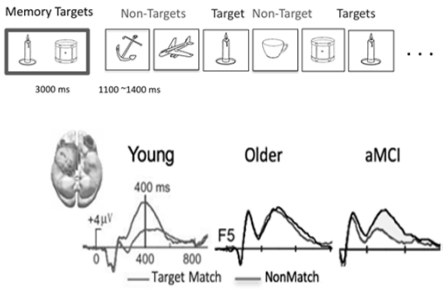
Machine Learning Classification

Confusion Table of 3-Way SVM Discrimination for Resting Eyes Open					
		Predicted Classes			
		NC	MCI	AD	
True Classes	NC	14	1	0	93.3%
	MCI	1	15	0	93.8%
	AD	0	0	17	100%
		93.3%	93.8%	100%	Overall Acc.: 95.8%

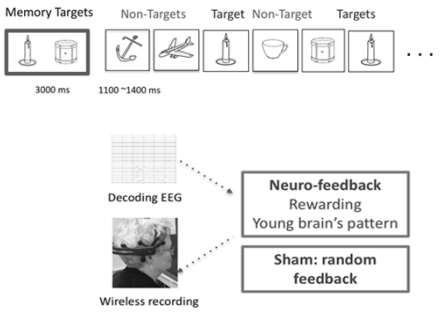
Neurofeedback: Enhancing Attention



Working Memory

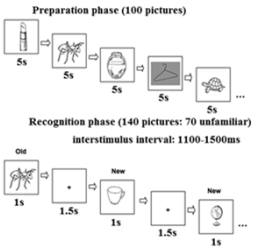


Neurofeedback: Enhancing Memory

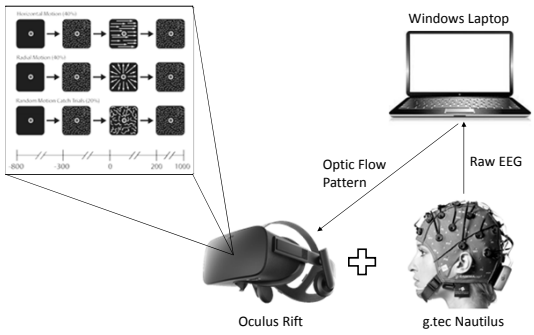


Other Application: Traumatic Brain Injury

- EEG recorded during working memory (WM) task
  - N=30 (15 NC, 15 TBI)
  - Avg. 13 yr (SD 7 yr) post-injury
  - Moderate/severe TBI
  - Well matched (age, extraneous factors)
  - 25 channels (32-chnl cap, some excluded)

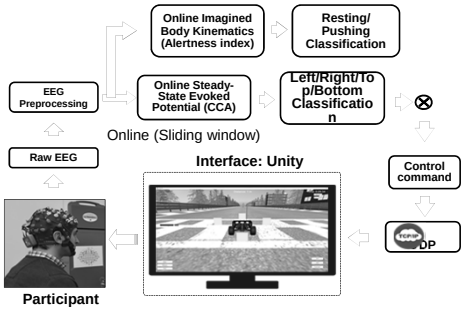


Other Application: Optical Flow

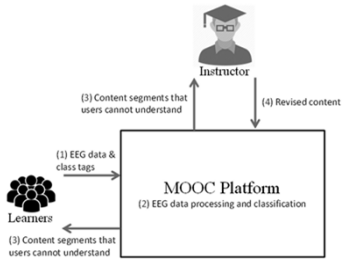


Courtesy of Dr. Fernandez, Pat Summitt Clinic

Other Application: Intelligent Driving

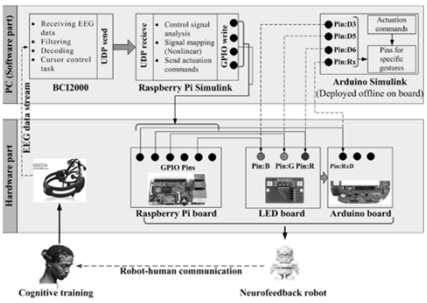


Other Application: Education



Massive Open Online Course
Lin & Kao, 2018, Computers and Education

Other Application: Communication



General Training: Chess etc.

BCI Community of Scholars

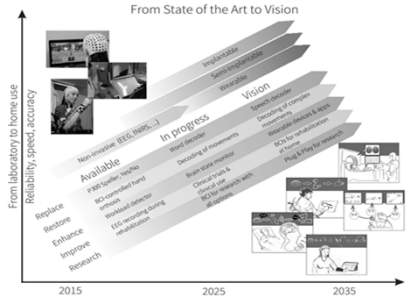
BME
ME
CS
Nursing
Sports
Psychology
Statistics

UTMC
ORNL
AFRL
UKY
AlzTN

BCI Community of Scholars

- Rehab for stroke and Parkinson patients
- Prosthetics
- Space searching
- Health monitoring
- Smart and connected vehicles
- STEM education
- Smart cities
- Artificial intelligence
- …

Paradigms and Applications



Muller-Putz et al. (2015)

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- National Science Foundation
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- National Institute for Computational Sciences
- NeuroNET
- UTK Office of Research and Engagement
- Alzheimer's Tennessee

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- Collaborators
  - Shuai Li (UTK)
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  - Kwai Wong (UTK)
  - Aaron Buss (UTK)
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  - Nancy Munro (ORNL)
  - Roberto Fernandez (PSC)
  - Eric Sellers (ETSU)
  - Yang Jiang (UKY)
  - Greg Jicha (UKY)
  - Luke Broster (UKY)
  - Karen Rose (OSU)

老吾老, 以及人之老

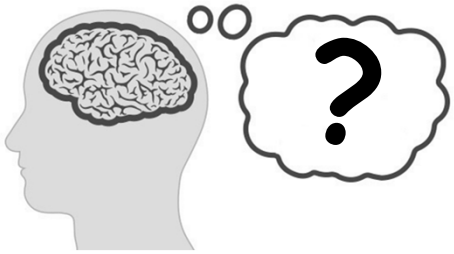
孟子Mencius

尊敬自己的老人，并由此推广到尊敬别人的老人

Caring for My Elders
Extending the Respect to the Elders of Others

Courtesy of Prof. Yang Jiang, UKY

THANK YOU



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Symptom Management of Alzheimer's Disease

August 15
9:45 - 10:30 AM

Ginger Lovingood, MD
Knoxville Psychiatry
Knoxville, TN

33rd Annual Alzheimer's Disease Management & Research Symposium

Symptom Management of Alzheimer's Disease

Ginger Lovingood, MD
Knoxville Psychiatry
8/15/2019

I have NO financial disclosures or conflicts of interest in relation to this presentation.

I will be discussing off label uses of several prescription medications.

Behavioral and Psychology Symptoms of Dementia (BPSD)

- Heterogeneous range of psychological reactions, psychiatric symptoms and behaviors that may be unsafe, disruptive or impair care in a given environment. [1]
- 4 categories: Affective, Psychotic, Sleep and Behavior
- An estimated 60-80% of patients living with dementia have behavioral symptoms [2]

BPSD Categories

- Affective–Depression, Anxiety, Irritability, Apathy, Mania
  - Affective symptoms are often the presenting symptoms of dementia which can precede the diagnosis by 3-4 years.
- Psychotic–Hallucinations, Delusions
- Sleep–Wake-sleep cycle disturbances
- Behavioral–Agitation, Aggression, Impulsivity, Wandering

Diagnosis

- Complete history to rule out premorbid psychiatric disorders including personality disorders
- Physical exam to rule out neurological or medical causes
- Labs and head imaging rule out neurological or medical causes
- Cognitive testing (screening or neuropsychological testing)
- Review medications and remove offending drugs
- If no other cause can be found then diagnosis of BPSD is likely.

Treatment Options

- Non-pharmacological treatments
- Anticholinergics or Memantine
- Antidepressants
- Mood Stabilizers
- Antipsychotics
- Others

Non- Pharmacological Interventions

- Psychoeducation for families and caregivers. Implementing patient centered care.
- Reduce boredom: increase daily activities, keeping a schedule, baby dolls
- Music and pet therapy
- Physical activities- walking, exercise programs
- Consider underlying personality types and tailor schedule to their needs (e.g. some patients are introverted and need more time alone)
- Learn the patient's social history and make accommodations (e.g. A patient with a trauma history will be more upset about someone coming into their room without invitation)
- Adding caregivers and/or changing level of care when a patient needs more assistance with redirection/structure
- Keep curtains open and lights on during the day, Lights off and quiet at night, decrease interruptions at night, adding nightlights in patients rooms to reduce confusion if they awaken

Things to consider

- There are many things that change as Alzheimer's disease progresses. Often these changes can lead to frustration and agitation for the patient and the caregiver.
  - Visual fields constrict, peripheral vision loss, blurred vision, loss of depth perception
  - Loss of language–cannot express pain, may not understand verbal instructions
  - Hearing Loss
  - Slowed movement and discoordination

Pharmacological Treatment

- There are no FDA approved treatment for BPSD
- Start with the lowest risk medications
- Think about side-effects and risk of medications
- Think about the symptoms and corresponding treatment (ie. Mania–Mood stabilizer, Depression–Antidepressant)
- Start with low dose and slowly increase
- Have a risk and benefits discussion with patient and family before choosing a medication

Pharmacological Treatment

- Antidepressants–Citalopram, sertraline, mirtazapine, and trazodone have the best indication for agitation in dementia. Antidepressants increase the risk of falls. [5] [14
- Anticholinesterase inhibitors—Evidence is limited but low risk of harm especially if already considering for modification of underlying disease state [9]
- Antipsychotics–Large RCT modestly better than placebo but significant risk associated
- Carbamazepine–1 positive RCT but several negative trials[6][7]
- Valporate–Ineffective [11]
- Gabapentin–A few positive case series and case studies [7]
- Prazosin–1 small positive RCT [7]
- Benzodiazepines–Only 1 positive study with multiple negative studies, all studies report adverse events associated with use, No RCT [8]
- Dextromethrophan/Quinidine–220 patients, 10 wk, placebo, controlled trail in 2015 [13]
- Pimavanserin–Initial studies pending

Black Box Warning

- April 2005, FDA announced the black box warning for atypical antipsychotics after 15 out of 17 placebo controlled trials involving atypical antipsychotics (aripiprazole, olanzapine, risperidone, and quetiapine) in patient with dementia resulted in an increase in mortality compared with placebo. [3]
- 1.6-1.7 times increased risk of deaths [3]
- June 2008, FDA extended this risk to typical antipsychotics as well though the evidence was not as strong (2 observational epidemiological studies) [3]

APA Guidelines for Antipsychotic Use in Dementia

- Only be used for severe, dangerous, or significantly distressing agitation or psychosis
- Explore non-pharmacological inventions first
- Assess and discuss the risk before starting antipsychotics
- Initiate low dose and use the minimum effective dose
- Review medication use if patient has a side-effect
- Taper or withdraw medication if no response after 4 weeks
- Taper or withdraw medications after 4 months unless patient has failed a taper in the past
- Monitor monthly when tapering medications and 4 months after discontinuation

CATIE- AD Study (2006)

- 36 week 42 site, double blind, randomized, placebo controlled trial of 421 outpatients with Alzheimer's disease with agitation and/or psychosis. [10]
- Goal was to assess the efficacy and safety of risperidone, quetapine, olanzapine versus placebo. [10]
- Primary Outcomes: [10]
  - Time to discontinuation for any reason (to assess safety and tolerability)
  - Clinical global impression of change scale (CGIC) at 12 weeks (to assess efficacy)

CATIE- AD Study (2006)

- Conclusions: [10]
  - Average dosages- Olanzapine: 5.5mg, Risperidone: 1 mg, Quetapine (56.5mg)
  - Discontinuation was equal between placebo and active drug (olanzapine, risperidone, quetiapine). Rates ranged from 77-85%.
  - EPS and weight gain were common with Risperidone and Olanzapine. Sedation associated with drug greater than placebo.
  - No change in the MMSE on antipsychotics vs placebo
  - Effects of antipsychotics are modestly more effective than placebo

Divalporex/Valporic acid

- Most well designed studies have shown no benefit for divalporex in the treatment of agitation in dementia [11]
- More concerning: 1 RCT in 2011 showed that using divalporex in dementia worsened cognition shown by more rapid decline in MMSE scores and hippocappal volume loss and increased ventricular dilation on MRI. [12]
- Another RCT showed increased agitation when divalporex was added.

Effect sizes [12]

- Small- <0.2, Moderate 0.2-0.8, Large >0.8
- Metformin for reducing blood sugars in DM2: 0.87
- Antihypertensives for HTN: 0.56
- Cholinesterase inhibitors for dementia: 0.41
- Antidepressants for depression: 0.38

- Non- pharmacological interventions for BPSD: 0.34
- Aripiprazole 2.5-10mg for agitation: 0.30
- Risperidone 0.25-2.5mg for agitation: 0.22
- Olanzapine 1-15mg for agitation: 0.19
- Quetapine 25-600mg for agitation: 0.05

- Aripiprazole for psychosis in dementia: 0.20
- Risperidone for psychosis in dementia: 0.19
- Olanzapine for psychosis in dementia: 0.12
- Quetiapine for psychosis in dementia: 0.13

Common Dose Ranges

- Citalopram 10-20mg daily
- Escitalopram 5-20mg daily
- Sertraline 25-200mg daily
- Trazodone 25-400mg daily
- Mirtazapine 7.5-45mg at bedtime

Common Dose Ranges

- Galantamine 8-24mg daily
- Rivastigmine 3-12mg daily
- Rivastigmine patch 4.5-9.5mg daily
- Donepezil 5-10mg daily
- Memantine 5-10mg BID

Common Dose Ranges

- Carbamazepine 200-400mg daily
- Divalproex 250-1000mg daily
- Gabapentin 1-1800mg daily

Common Dose Ranges

- Aripiprazole 2-10mg daily
- Risperidone 0.25-2mg daily
- Olanzapine 2.5-10mg daily
- Quetiapine 25-200mg daily

Non- Emergent Agitation Algorithm

- Start with a cholinesterase inhibitor
- Add Memantine if moderate or severe dementia
- If agitation persists, try a SSRI (citalopram, sertraline) or mirtazapine
- If fails SSRI, try trazodone or gabapentin
- If these strategies are unhelpful, try risperidone or aripiprazole
- If these fail, try olanzapine or quetiapine
- If antipsychotics ineffective, could switch to carbamezapine
- If monotherapy fails then use combination therapy. Avoid benzos.

Emergent Agitation Algorithm

- If patient is taking oral medications (PO):
  - Risperidone 0.25-1mg dose or Aripiprazole 2-5mg dose
  - Olanzapine 2.5-5mg dose or Quetiapine 25-50mg dose
  - May be repeated in 0.5-1 hour if agitation persists
- If patient refusing PO and is very aggressive/agitated:
  - Aripiprazole IM 1.875-7.5mg
  - Olanzapine IM 2.5-5mg
  - Haloperidol IM 0.5-2mg
  - Haloperidol topical compound, call pharmacy for compounding details
  - May need to repeat in 0.5-1 hour if agitation persists

Take Away Points

- Medications for BPSD are not as effective as we, patients, families, or staff would like and have significant risks including death, stroke, falls, worsening confusion. Limit use of medication if at all possible.
- Medication can often be the cause of agitation. Make sure you reconcile medications an look for possible offending agents.
- Non-pharmacological interventions work and are more effective than medications. They are difficult to implement but worth it.
- Psychosis in dementia is different than other psychosis, may not respond to antipsychotics. Consider antidepressants as an alternatives.
- Being angry, tearful, sad, scared is normal in many cases. Often we are too quick to pathologize the normal range of human emotions especially in people living with dementia.

Questions?

References

- [1] Kales H, Gitlin L, Lyketsos C. Assessment and Management of behavioral and psychological symptoms of dementia. *British Journal of Medicine* March 2015
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Jointly Provided by

33rd Annual Alzheimer's Disease Management & Research Symposium

August 15-16, 2019
The Clayton Center, Maryville College
502 E Lamar Alexander Parkway
Maryville, TN 37804

Symptom Management of Alzheimer's Disease

August 15
9:45 - 10:30 AM

Ginger Lovingood, MD
Knoxville Psychiatry
Knoxville, TN

33rd Annual Alzheimer's Disease Management & Research Symposium

Symptom Management of Alzheimer's Disease

Ginger Lovingood, MD
Knoxville Psychiatry
8/15/2019

I have NO financial disclosures or conflicts of interest in relation to this presentation.

I will be discussing off label uses of several prescription medications.

Behavioral and Psychology Symptoms of Dementia (BPSD)

- Heterogeneous range of psychological reactions, psychiatric symptoms and behaviors that may be unsafe, disruptive or impair care in a given environment. [1]
- 4 categories: Affective, Psychotic, Sleep and Behavior
- An estimated 60-80% of patients living with dementia have behavioral symptoms [2]

BPSD Categories

- Affective–Depression, Anxiety, Irritability, Apathy, Mania
  - Affective symptoms are often the presenting symptoms of dementia which can precede the diagnosis by 3-4 years.
- Psychotic–Hallucinations, Delusions
- Sleep–Wake-sleep cycle disturbances
- Behavioral–Agitation, Aggression, Impulsivity, Wandering

Diagnosis

- Complete history to rule out premorbid psychiatric disorders including personality disorders
- Physical exam to rule out neurological or medical causes
- Labs and head imaging rule out neurological or medical causes
- Cognitive testing (screening or neuropsychological testing)
- Review medications and remove offending drugs
- If no other cause can be found then diagnosis of BPSD is likely.

Treatment Options

- Non-pharmacological treatments
- Anticholinergics or Memantine
- Antidepressants
- Mood Stabilizers
- Antipsychotics
- Others

Non- Pharmacological Interventions

- Psychoeducation for families and caregivers. Implementing patient centered care.
- Reduce boredom: increase daily activities, keeping a schedule, baby dolls
- Music and pet therapy
- Physical activities- walking, exercise programs
- Consider underlying personality types and tailor schedule to their needs (e.g. some patients are introverted and need more time alone)
- Learn the patient's social history and make accommodations (e.g. A patient with a trauma history will be more upset about someone coming into their room without invitation)
- Adding caregivers and/or changing level of care when a patient needs more assistance with redirection/structure
- Keep curtains open and lights on during the day, Lights off and quiet at night, decrease interruptions at night, adding nightlights in patients rooms to reduce confusion if they awaken

Things to consider

- There are many things that change as Alzheimer's disease progresses. Often these changes can lead to frustration and agitation for the patient and the caregiver.
  - Visual fields constrict, peripheral vision loss, blurred vision, loss of depth perception
  - Loss of language–cannot express pain, may not understand verbal instructions
  - Hearing Loss
  - Slowed movement and discoordination

Pharmacological Treatment

- There are no FDA approved treatment for BPSD
- Start with the lowest risk medications
- Think about side-effects and risk of medications
- Think about the symptoms and corresponding treatment (ie. Mania–Mood stabilizer, Depression–Antidepressant)
- Start with low dose and slowly increase
- Have a risk and benefits discussion with patient and family before choosing a medication

Pharmacological Treatment

- Antidepressants–Citalopram, sertraline, mirtazapine, and trazodone have the best indication for agitation in dementia. Antidepressants increase the risk of falls. [5] [14
- Anticholinesterase inhibitors—Evidence is limited but low risk of harm especially if already considering for modification of underlying disease state [9]
- Antipsychotics–Large RCT modestly better than placebo but significant risk associated
- Carbamazepine–1 positive RCT but several negative trials[6][7]
- Valporate–Ineffective [11]
- Gabapentin–A few positive case series and case studies [7]
- Prazosin–1 small positive RCT [7]
- Benzodiazepines–Only 1 positive study with multiple negative studies, all studies report adverse events associated with use, No RCT [8]
- Dextromethrophan/Quinidine–220 patients, 10 wk, placebo, controlled trail in 2015 [13]
- Pimavanserin–Initial studies pending

Black Box Warning

- April 2005, FDA announced the black box warning for atypical antipsychotics after 15 out of 17 placebo controlled trials involving atypical antipsychotics (aripiprazole, olanzapine, risperidone, and quetiapine) in patient with dementia resulted in an increase in mortality compared with placebo. [3]
- 1.6-1.7 times increased risk of deaths [3]
- June 2008, FDA extended this risk to typical antipsychotics as well though the evidence was not as strong (2 observational epidemiological studies) [3]

APA Guidelines for Antipsychotic Use in Dementia

- Only be used for severe, dangerous, or significantly distressing agitation or psychosis
- Explore non-pharmacological inventions first
- Assess and discuss the risk before starting antipsychotics
- Initiate low dose and use the minimum effective dose
- Review medication use if patient has a side-effect
- Taper or withdraw medication if no response after 4 weeks
- Taper or withdraw medications after 4 months unless patient has failed a taper in the past
- Monitor monthly when tapering medications and 4 months after discontinuation

CATIE- AD Study (2006)

- 36 week 42 site, double blind, randomized, placebo controlled trial of 421 outpatients with Alzheimer's disease with agitation and/or psychosis. [10]
- Goal was to assess the efficacy and safety of risperidone, quetapine, olanzapine versus placebo. [10]
- Primary Outcomes: [10]
  - Time to discontinuation for any reason (to assess safety and tolerability)
  - Clinical global impression of change scale (CGIC) at 12 weeks (to assess efficacy)

CATIE- AD Study (2006)

- Conclusions: [10]
  - Average dosages- Olanzapine: 5.5mg, Risperidone: 1 mg, Quetapine (56.5mg)
  - Discontinuation was equal between placebo and active drug (olanzapine, risperidone, quetiapine). Rates ranged from 77-85%.
  - EPS and weight gain were common with Risperidone and Olanzapine. Sedation associated with drug greater than placebo.
  - No change in the MMSE on antipsychotics vs placebo
  - Effects of antipsychotics are modestly more effective than placebo

Divalporex/Valporic acid

- Most well designed studies have shown no benefit for divalporex in the treatment of agitation in dementia [11]
- More concerning: 1 RCT in 2011 showed that using divalporex in dementia worsened cognition shown by more rapid decline in MMSE scores and hippocappal volume loss and increased ventricular dilation on MRI. [12]
- Another RCT showed increased agitation when divalporex was added.

Effect sizes [12]

- Small- <0.2, Moderate 0.2-0.8, Large >0.8
- Metformin for reducing blood sugars in DM2: 0.87
- Antihypertensives for HTN: 0.56
- Cholinesterase inhibitors for dementia: 0.41
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Traumatic Brain Injuries and Concussion in the Elderly and Impact on Dementia

August 15
11:15AM - 12:15 PM

Wendy Ellmo, MS, CCC/SLP. BCNCDS
Brain Links
Knoxville, TN

Traumatic Brain Injuries and Concussions in the Elderly and Impact on Dementia

Alzheimer's Tennessee
August 15, 2019

Wendy Ellmo, M.S., CCC-SLP, BCN-CDS
Brain Injury Specialist, Brain Links

Brain Links

Conflict of Interest

Brain Injury Specialist for grant-funded program Brain Links.
Brain Links is a program of the non-profit Tennessee Disability Coalition.

I receive a salary from the TDC.
Neither I nor the TDC have any commercial ties to anything discussed today.

Our trainings are free.
Our resources are distributed for free.

Tennessee Disability Coalition

Brain Links

Objectives

Participants will

1. Understand how concussion and TBI impact the elderly
2. Learn similarities and differences between TBI and dementia
3. Learn the various components of a concussion/TBI toolkit for aging adults

ACL Administration for Community Living

TBI SPP Traumatic Brain Injury State Partnership Program

Brain Links is supported by the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services under Grant No. 90TBSG0024-01-00 and in part by the TN Department of Health, Traumatic Brain Injury Program.

Brain Links

Brain Links

Enriching the lives of Tennesseans with traumatic brain injury (TBI) by training and empowering the people serving them

- **Statewide team of brain injury specialists**
- **Evidence-based TBI trainings tailored to your discipline**
- **Family/patient-friendly educational materials**
- **Informative videos and podcasts at no cost**
- **Locate resources and referrals– specific to your population**
- **Provide training to your local providers**

We equip professionals to better serve people with TBI with current research-based training and tools.

TBI

A TBI is caused by a bump, blow or jolt to the head or body or a penetrating head injury that disrupts the normal function of the brain.

CDC.gov

Causes of Injury

- TBI : a leading cause of death and disability globally
  - 2.8 million people seek medical treatment in the US annually (Taylor et al, 2017)
- Older adults have the highest combined incidence of TBI-related ED visits, hospitalizations, and deaths (Taylor et al, 2017; Faul et al, 2010; Ramanathan et al, 2012)

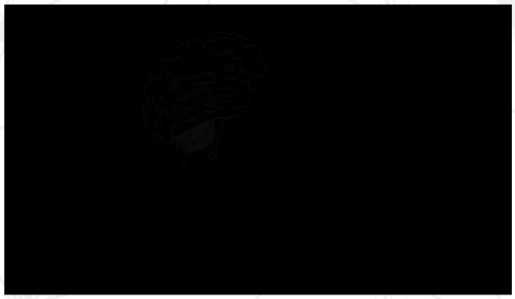
- Falls (walking, transferring, shower, from bed)
- Auto-related (accidents and pedestrian)
- Intentional injury (violence and self-harm)

TBI in Older Adults

- Higher morbidity and mortality
- Slower recovery
- Worse functional, cognitive and psychosocial outcomes

But a subset - even some with a severe TBI – do **really well**, so age and severity should not be the only factors we look at.

What is a Concussion?

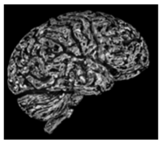


cdc.gov

Common Symptoms following Concussion

Cognitive/Communication
- Feeling dazed or in fog
- Word finding problems
- Slowed information processing

Emotional/Behavioral
- Irritability
- Quick to anger
- Decreased motivation
- Cries easily



Physical
- Headaches
- Changes in vision
- Sleep disturbance
- Fatigue
- Balance/Dizziness
- Sensitivity to light/sounds

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Danger Signs

- Rqh#sxslo#odujhu#wkdq#wkh#rwkhu1
- Gurzvlqhvv#ru#lqdelolw|#wr#zdnh#xs1
- D#khdgdfkh#wkdw#jhwv#zruvh#dqg#grhv#qrw#jr#dzd|1
- Voxuuhg#vshhfk/#zhdnqhvv/#qxpeqhvv/#ru#ghfuhdvhg#frruglqdwlrq1
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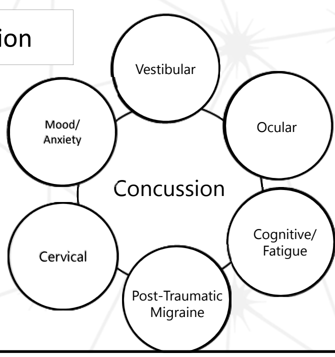
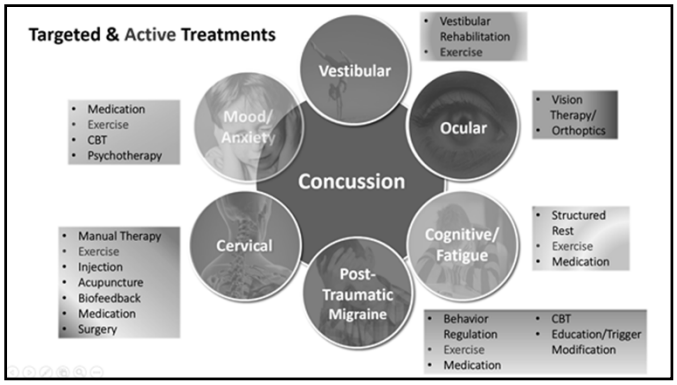
- Orvv#ri#frqvflrxvqhvv1#Hyhq#d#eulhi#orvv#ri#frqvflrxvqhvv#vkrxog#eh#wdnhq#vhulrxvo|1

CDC.gov

6 Types of Concussion



Collins MW, Kontos A, et al, KSST, 2014



Concussion in Older Adults

- More susceptible to concussions
  Even a fall to the knees or bumping heads with a grandchild
- Higher risk of intracranial bleeding
  Often signs are delayed
- Less likely to be diagnosed…and treated
  - Individual basis: need to question whether they will be able to participate in treatment
- Diagnosis is complicated by dementia and cognitive disorders

TBI and Dementia

- Can have similar symptoms (confusion, memory loss, speech problems, vision changes, personality changes)
  - With TBI, symptoms typically directly following event
  - Generally don't worsen over time, typically improve

TBI and Dementia

- TBI can increase the risk of later dementia

  But – always have to consider whether they sustained the TBI (fell) because of underlying pathology
- More likely if TBI occurs around age 55 or if the injury is severe
- Chances increase with other risk factors (like APOE gene)
- Many with concussion/TBI never develop dementia
- Repeated concussions **may** increase risk of developing dementia

"There's nothing wrong, they are just trying to manipulate."

- Any danger signs?
- Any obvious signs or report of symptoms?
- Any pain behaviors?
- Any change in functional status? (including exacerbation of pre-existing)*
  - behavior
  - cognition
  - emotions
  - motor skills

Exacerbation of Pre-existing Behaviors

Look for change:

- Used to focus for an hour before breaking, now breaks after 30 minutes.
- Balance was not great, but is falling more now.
- Behavioral outbursts were once a day, now they are 3 times a day.

Decisions

- If no, use positive supports and encouragement to engage in activity.
- If yes, use adaptive accommodations to engage in activity.
  - Wear a hat or sunglasses
  - Use earplugs
  - Take extra time
  - Shorten the workday/outing
  - Frequent breaks
- Rest if needed.
  - In the situation if possible
  - In a quiet space in the same environment
  - At home

Testing

Neuropsychological Testing:
Gold Standard for TBI Testing

- Brain-Behavior Relationships
- Academic Testing
- IQ Testing
- Specific Domains of Cognitive Function
  - Attention
  - Memory
  - Executive Functioning
  - Visual-spatial Function
  - Information Processing

Brain Links 2019

Healthcare Providers' Toolkit

Designed for use across the lifespan. We will highlight only those for older adults.

4 Categories of Documents

- Reference
- In-office Use
- Send home with Family – Recommended
- Send home with Family – Optional

HCPs' Concussion Protocol

Based on the gaps shown in the evidence

Asking Physicians to

- Think of Concussion as a 2-visit diagnosis
  - 1st visit: Give parent a symptom list to take home and observe
  - Return in 4 weeks if symptoms exist/persist
    - Referral for treatment
- Check in at yearly check-ups specifically about the concussion


CONCUSSION MANAGEMENT PROTOCOL

RECOMMENDATION: 2 VISIT MINIMUM

INITIAL VISIT

SYMPTOM EVALUATION AND PATIENT EDUCATION:

- ACE – Acute Concussion Evaluation (Physician/Clinician Office version)
- A Symptom Scale (Age-appropriate version)
- A Symptom Scale (Parent/Adult Patient – fill out in office)
- A Symptom Scale (Parent/Adult Patient – take home)
- ACE Care Plan (Return to school or work version)
- CDC Return to School Letter
- When Concussion Symptoms Aren't Going Away (Age-appropriate version)
- Any other educational materials or symptom tracker as needed

Send home an additional parent or adult version of a symptom scale to track symptoms over the next 4 weeks. This helps to understand what symptoms/behaviors to look for. Send home a letter to the school or work with recommendations. Research indicates that supports are more likely to be implemented if recommended by the healthcare professional.

With concussion diagnosis, recommend follow up visit in 4 weeks if any symptoms or any new behaviors since injury are present. Bring completed form to next visit.

4 WEEK POST-INJURY VISIT

IF SYMPTOMS PERSIST OR NEW BEHAVIORS ARE PRESENT, CONSIDER THE FOLLOWING REFERRALS:

- A specialized concussion treatment center
- A neurologist
- A symptom-specific specialist (e.g. neuro-ophthalmologist)
- A brain trauma rehabilitation center
- A neuropsychological evaluation
- TDSI (if child is under 7 years old)
- School -Based (5-6 years old)
- School- (5 years and over)

Note: Schools may not provide all the treatments needed. Research indicates that supports are more likely to be implemented if recommended by the healthcare professional.

YEARLY CHECK-UPS

ASK ABOUT:

- Any residual concussion symptoms
- Any changes in school or work performance

ACE: Acute Concussion Evaluation

Quick Screening Tool: 3-4 minutes


ACUTE CONCUSSION EVALUATION (ACE)

Physician/Clinician Office Version

Gerard Gioia, PhD* & Micky Collins, PhD*

*Center for Pediatric Brain Injury

Patient Name:

DOB: Age:

Date: ICD#/Dx:

A. Injury Characteristics: Date/Time of Injury: Reporter: Patient Parent Spouse Other

1. Injury Description:

1a. Is there evidence of a forcible blow to the head (direct or indirect)? Yes No Unknown

1b. Force of Blow/Impact: Direct Indirect Both Unknown

1c. Location of Impact: Frontal LF Temporal RF Temporal LO Parietal RT Parietal Occipital Neck Indirect Force

2. Cause: MVC Pedestrian-MVC Fall Assault Sports (specify) Other

3. Memory Before (Retrograde): Are there any events just BEFORE the injury that your person has no memory of (even brief)? Yes No Duration:

4. Memory After (Anterograde): Are there any events just AFTER the injury that your person has no memory of (even brief)? Yes No Duration:

5. Loss of Consciousness: Did your person lose consciousness? Yes No Duration:

6. EARLY SIGNS: Appears dazed or stunned Is confused about events Answers questions slowly Repeats Questions Forgetful (recent info)

7. Balance: Were seizures observed? Yes No Describe:

B. Symptom Check List: Since the injury, has the person experienced any of these symptoms any more than usual today or in the past day?

Indicate presence of each symptom: (0=No, 1=Yes) Scored in Clinic, Mild, or/Or

PHYSICAL (10)		COGNITIVE (4)		SLEEP (2)	
Headache	0 1	Feeling mentally "foggy"	0 1	Drowsiness	0 1
Nausea	0 1	Feeling slowed down	0 1	Sleeping less than usual	0 1 N/A
Dizziness	0 1	Difficulty concentrating	0 1	Sleeping more than usual	0 1 N/A
Balance problems	0 1	Difficulty remembering	0 1	Trouble falling asleep	0 1 N/A
Drowsiness	0 1	COGNITIVE Total (0-4):		SLEEP Total (0-4):	
Visual problems	0 1	EMOTIONAL (4)			
Fatigue	0 1	Irritability	0 1	Question: Do these symptoms worsen with	
Sensitivity to light	0 1	Sadness	0 1	Physical Activity: Yes N/A	
Sensitivity to noise	0 1	More emotional	0 1	Cognitive Activity: Yes N/A	
Numbness/tingling	0 1	Nervousness	0 1	Overall Rating: How different is the person acting compared to his/her usual self? (circle)	
PHYSICAL Total (0-10):		EMOTIONAL Total (0-4):		Normal 0 1 2 3 4 5 6 Very Different	
(Add Physical, Cognitive, Emotion, Sleep totals) Total Symptoms Score (0-22):					

C. Risk Factors for Protracted Recovery (check all that apply)

Concussion History? Yes No	Academic History? Yes No		Developmental History	Psychiatric History	
Previous # / M / Y / A	Prior treatment for headache		Learning Disorders	Anxiety	
Most recent: Date:	Current problems with headache		ADD/ADHD	Depression	
Days Weeks Months Years	Personal		Hyperactivity Disorder	Sleep Disorder	
If multiple concussions, was force caused isolated? Yes No	Family		Other developmental disorder	Other psychiatric disorder	

List other somatic/medical disorders or medication usage (e.g., hypothyroid, seizures):

D. RED FLAGS for acute emergency management: Refer to the emergency department with sudden onset of any of the following:

- Headaches that worsen
- Seizure
- Focal neurologic signs
- Loses any strength/can't be awakened
- Repeated vomiting
- Severe dyspnea
- Can't recognize people or places
- Increasing confusion or irritability
- Weakness or numbness in one/both legs
- Neck pain
- Unusual behavior change
- Change in state of consciousness

E. Diagnosis (ICD-10): Concussion w/o LOC S06.0X0A Concussion w/ LOC S06.0X1A Concussion Unspecified S06.0X9A Other (S06.)

No diagnosis

F. Follow-Up Action Plan: Complete ACE Care Plan and provide copy to patient/family.

No Follow-Up Needed

Physician/ Clinician Office Monitoring: Date of next follow-up:

Referral:

Neurological/Neuropsych Testing

Physician Neurosurgery Neurology Sports Medicine Physiatrist Psychiatrist Other

Emergency Department

ACE Completed by: MD DO NP PHD ATC

PCSI Adult

- Adult symptom inventory
- Recommended to give it at 1st concussion visit and send one home for 4 week follow-up


Post-Concussion Symptom Inventory

Adult

Pre/Post Version

Patient Name: Today's date:

Birthdate: Age:

Instructions: We would like to know if you had any of these symptoms before your injury. Next, we would like to know if these symptoms have changed after your injury. Please rate the symptom at two points in time: Before the Injury/Pre-Injury and Current Symptoms: Yesterday and Today.

Please answer all the items the best that you can. Do not skip any items. Circle the number to tell us how much of a problem this symptom has been for you.

0 = Not a problem 2 = Moderate problem 4 = Severe problem

		Before the Injury/ Pre-Injury	Current Symptoms/ Yesterday and Today
1	Headache	0 1 2 3 4 5 6	0 1 2 3 4 5 6
2	Nausea	0 1 2 3 4 5 6	0 1 2 3 4 5 6
3	Balance problems	0 1 2 3 4 5 6	0 1 2 3 4 5 6
4	Dizziness	0 1 2 3 4 5 6	0 1 2 3 4 5 6
5	Visual problems (double vision, blurring)	0 1 2 3 4 5 6	0 1 2 3 4 5 6
6	Move in a clumsy manner	0 1 2 3 4 5 6	0 1 2 3 4 5 6
7	Sensitivity to light	0 1 2 3 4 5 6	0 1 2 3 4 5 6
8	Sensitivity to noise	0 1 2 3 4 5 6	0 1 2 3 4 5 6
	Effort (Physical)	Total Pre=	Total Now=
9	Irritability	0 1 2 3 4 5 6	0 1 2 3 4 5 6
10	Sadness	0 1 2 3 4 5 6	0 1 2 3 4 5 6
11	Nervousness	0 1 2 3 4 5 6	0 1 2 3 4 5 6
12	Feeling more emotional	0 1 2 3 4 5 6	0 1 2 3 4 5 6
	Effort (Emotional)	Total Pre=	Total Now=
13	Feeling mentally "foggy"	0 1 2 3 4 5 6	0 1 2 3 4 5 6
14	Difficulty concentrating	0 1 2 3 4 5 6	0 1 2 3 4 5 6
15	Difficulty remembering	0 1 2 3 4 5 6	0 1 2 3 4 5 6
16	Get confused with directions or tasks	0 1 2 3 4 5 6	0 1 2 3 4 5 6
17	Answer questions more slowly than usual	0 1 2 3 4 5 6	0 1 2 3 4 5 6
18	Feeling slowed down	0 1 2 3 4 5 6	0 1 2 3 4 5 6
	Effort (Cognitive)	Total Pre=	Total Now=
19	Fatigue	0 1 2 3 4 5 6	0 1 2 3 4 5 6
20	Drowsiness	0 1 2 3 4 5 6	0 1 2 3 4 5 6
21	Sleep more than usual	0 1 2 3 4 5 6	0 1 2 3 4 5 6
	Effort (Sleep)	Total Pre=	Total Now=
22	In general, to what degree do you feel "different" than before the injury (not feeling like yourself)?	No Difference 0 1 2 3 4 Most Difference. Circle your rating with "0" indicating "Normal" (No Difference) and "4" indicating "Very Different" (Major Difference)	
PCSI Total Symptom Score (Effort Sum/Pre)		Pre (sum 4 domains) =	Post (sum 4 domains) =
		PCSI Total Adjusted Symptom Score (Post-Pre) =	

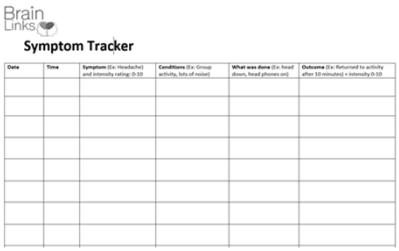
Adapted by Brain Links for use with adults from: Gioia, Janusz, Vaughan & Sady, 2011-2014.

Please do not modify without permission from the authors. 1/26/17

Acknowledgements: Dr. Gioia granted permission to Brain Links to use this document.

Brain Links is supported by the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services under Grant No. 90TBSG0003-01-00 and in part by the PA Department of Health. Tennessee Brain Injury Program.

Symptom Tracker



Brain Links

Symptom Tracker

Date	Time	Symptom (Ex: Headache) and intensity rating: 0-10	Conditions (Ex: Group activity, lots of noise)	What was done (Ex: head down, head phones on)	Outcome (Ex: Returned to activity after 10 minutes) + Intensity 0-10

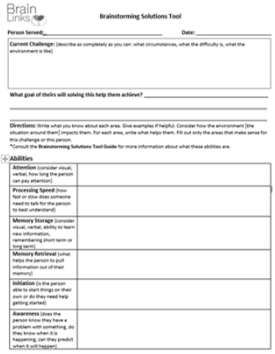
- Simple
- Quick
- List symptom
- Occurs during what
- What was done
- Outcomes

Over time, maybe only a few entries, you learn triggers and how to address them.

Problem Solving Tool

Tool for direct service providers to help develop solutions to a current issue/goal

- Helps them to incorporate
  - Cognitive, emotional and behavioral status; recent changes
- Provides structure for developing strategies (internal and external) and solutions
- Area to incorporate input of person served
- Area to evaluate how it went and follow-up plan



Brain Links

Brainstorming Solutions Tool

Person Served: _____ **Date:** _____

Current Challenge: (describe as completely as you can: what circumstances, what the difficulty is, what the environment is like)

What goal of theirs will solving this help them achieve? _____

Directions: Write what you know about each area. Give examples if helpful. Consider how the environment [the situation around them] impacts them. For each area, write what helps them. Fill out only the areas that make sense for this challenge or this person.
*Consult the **Brainstorming Solutions Tool Guide** for more information about what these abilities are.

Abilities

Attention (consider visual, verbal, how long the person can pay attention)	
Processing Speed (how fast or slow does someone need to talk for the person to best understand)	
Memory Storage (consider visual, verbal, ability to learn new information, remembering short term or long term)	
Memory Retrieval (what helps the person to pull information out of their memory)	
Initiation (is the person able to start things on their own or do they need help getting started)	
Awareness (does the person know they have a challenge with something, do they know when something is happening, can they predict when it will happen)	

6 Types of Concussion Infographic (UPMC) and Summary Information (Brain Links)

SIX TYPES OF CONCUSSION

1. Cognitive/Fatigue
2. Vestibular
3. Ocular
4. Post-traumatic Migraine
5. Cervical
6. Anxiety/Mood

FACTS

ACTIVE TREATMENT

RISK FACTORS (which may delay recovery)

CONCUSSION
CLINICAL TRAJECTORIES

A Model for Understanding Assessment, Treatment and Rehabilitation

COGNITIVE/FATIGUE

VESTIBULAR

OCULAR

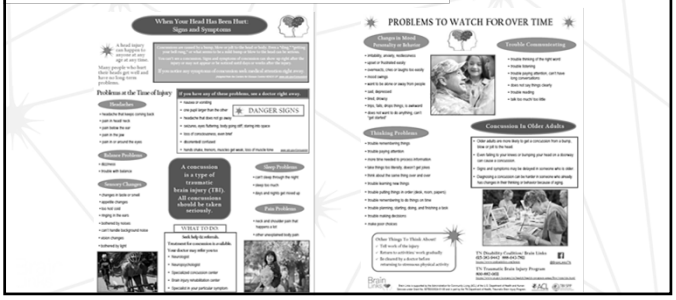
POST-TRAUMATIC MIGRAINE

CERVICAL

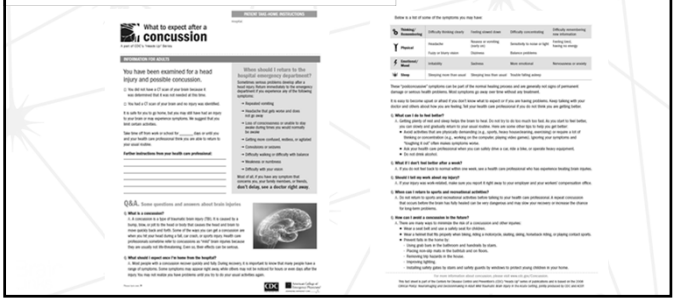
ANXIETY/MOOD

UPMC

Signs and Symptoms – Send Home



Send Home Information



Return to Services Letter

Recommendations for return to

- Adult Day Services
- Rehabilitation Program
- Assisted Living
- Nursing Facility

Nurse's Concussion Screening

DRAFT

Based on the CDC School Nurses Concussion Checklist, with some modifications.

For return to Adult Day Services, rehabilitation program, assisted living or nursing facility.

(see page 2)

Nurse's Concussion Screening Checklist

Brain Links

Name: _____ Age: _____ Date/Time of Injury: _____

Where and How Injury Occurred: (Be sure to include cause and force of the hit or blow to the head) _____

Description of the Injury: (Be sure to include information about loss of consciousness, how long, memory loss or seizures following injury, and previous concussions) _____

Directions:

Use this checklist to monitor patients with potential head injury. Monitor for a minimum of 30 minutes. Those who experience **one or more** signs or symptoms after a bump, jolt, or blow **should immediately be referred to a healthcare professional. Call EMS with any immediate concerns.**

For those being referred to another healthcare professional (including the ED), send a copy of this checklist with them.

See Danger Signs on page 2.

OBSERVED SIGNS	0 MINUTES	15 MINUTES	30 MINUTES	(MINUTES)
Appears dazed or stunned				
Is confused about events				
Repeats questions				
Answers questions slowly				
Can't recall events prior to the hit, bump, or fall				
Can't recall events after the hit, bump, or fall				
Shows mood, behavior or personality changes				
Forgets class schedule or assignments				
PHYSICAL SYMPTOMS				
Headache or "pressure" in head				
Nausea or vomiting				
Balance problems or dizziness				
Feels like "in a fog"				
Blurry or double vision				
Sensitive to light				
Sensitive to noise				
Feels sluggish, hazy, foggy, or groggy				
Does not "feel right"				
COGNITIVE SYMPTOMS				
Difficulty thinking clearly				
Difficulty concentrating				
Difficulty remembering				
Feeling more slowed down				
Feeling sluggish, hazy, foggy, or groggy				
EMOTIONAL SYMPTOMS				
Irritable				
Sad				
More emotional than usual				
Nervous				

This checklist is intended to be used by healthcare professionals.

Nurse's Concussion Protocol

Side 2:

Addresses basic medical issues that may be the cause of or outcome of the fall/concussion

Also includes Danger Signs

Symptom	Presentation
LOSS OF CONSCIOUSNESS (Note even if brief)	YES Length: NO
PUPILS	CONSTRICTED EQUAL, ROUND, REACTIVE TO LIGHT
PULSE _____BPM (Normal: 60-100BPM)	NORMAL HIGHER LOWER
BLOOD PRESSURE (Normal: 120/80 mm/Hg)	SITTING _____/_____ STANDING _____/_____
ORIENTATION	ORIENTED X4 (Person, place, time, events) CONFUSED
BLOOD SUGAR (Normal: 80L=115 mG/dL)	HIGHER LOWER
VOMITING/NAUSEA	YES NO
SYMPTOMS	NO SYMPTOMS IMPROVING DECLINING NO CHANGE
ALERTNESS	ALERT DROWSY OR CANNOT BE AWAKENED

Research Summary & References

- Summary of current research on best practices in TBI/Concussion diagnosis, management, treatment and referral practices.
- Also includes information on short and long term outcomes.

Adult Research

Follow Up and Education are important:

Findings from a study (Seabury, et al., 2018) of follow-up care that was provided to people at 11 level 1 trauma centers across the country:

- Less than half received TBI educational material at discharge or saw a health care practitioner within 3 months after injury.
- Only 27% were called by 2 weeks.
- Follow-up care varied by site, from 19% to 72%.

Same Study (Seabury, et al.)

- For those with a positive CT scan, over one-third had not seen a medical practitioner for follow-up.
- Even among those with 3 or more moderate to severe post-concussive symptoms, only about half saw a medical practitioner within 3 months.
    - Of those that did, 80% reported that it was helpful. The majority saw a general practitioner and 38% saw a neurologist. Only 15% reported visiting a clinic specializing in TBI care.

Conclusions from Seabury

- "Failure to follow-up with patients could have adverse consequences, as simply providing educational materials to patients with mTBI is associated with improved outcomes."
- "Our findings reveal the consequences that may result from the absence of systems of follow-up care for patients with mTBI and concussion. They also highlight an apparent lack of appreciation by many clinicians of the substantial symptom and life burdens experienced by a significant proportion of patients with injuries labeled mild."

Zuckerbraun, 2014

- Use of the ACE tools (screening tool and Care Plan) "increased patient follow-up and improved recall of and adherence to ED discharge recommendations (5-21 year olds)

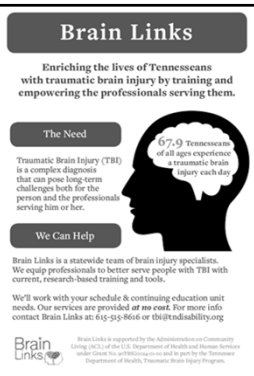
Job Accommodations

- Help in trying to work longer
- Accommodations for
  - Aging
  - Alzheimer's
  - Hearing Impairment
  - Brain Injury
  - Low Vision
  - Stroke

Brain Links Flyer

Give to family or directly to

- Adult Day Centers
- Home Care providers
- Rehab providers (PT, OT, SLP)
- Physicians
- Other providers

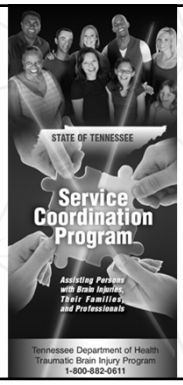


Service Coordination

TN TBI Service Coordination Program
The service coordinator works with survivors and their families to assess their current resources and needs. The service coordinator:

- •develops a comprehensive plan of care
- •provides referrals to available resources
- •coordinates services for individual client advocacy
- •bridges gaps in the service delivery system.

Free Service



Bibliography

Kontos, A.P., & Collins, M.W. (2018). Concussion: A clinical profile approach to assessment and treatment. Washington, DC: American Psychological Association.

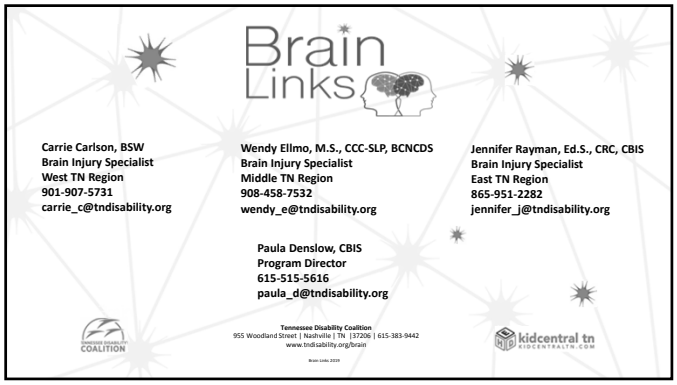
Seabury, S.A., Gaudette, E., Goldman, A.J., et al. (2018) Assessment of Follow-up Care After Emergency Department Presentation for Mild Traumatic Brain Injury and Concussion: Result from the TRACK-TBI Study. JAMA Network Open. 208;1(1)/jamanetworkopen.2018.0210

Zuckerbraun, N.S., Atabaki, S., Collins, M.W., Thomas, D., Gioia, G.A., Use of modified acute concussion evaluation tools in the emergency department. Pediatrics, 133(4). Doi: 10.1542/peds.2013-2600d

Handouts

- Brain Links Flyer
- Concussion Management Protocol
- Adult Signs & Symptoms

- Other documents discussed will be sent via email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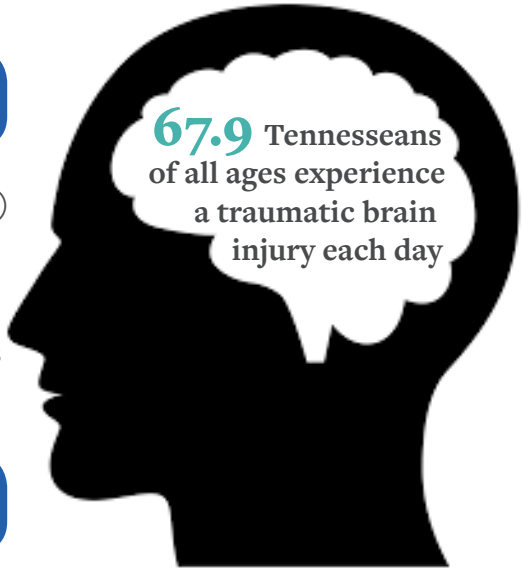
www.tndisability.org/brain
Brain Links 2019
kidcentral tn

Brain Links

Enriching the lives of Tennesseans with traumatic brain injury by training and empowering the professionals serving them.

The Need

Traumatic Brain Injury (TBI) is a complex diagnosis that can pose long-term challenges both for the person and the professionals serving him or her.



We Can Help

Brain Links is a statewide team of brain injury specialists. We equip professionals to better serve people with TBI with current, research-based training and tools.

We'll work with your schedule & continuing education unit needs. Our services are provided ***at no cost.*** For more info contact Brain Links at: 615-515-8616 or tbi@tndisability.org

Brain Links

Brain Links is supported by the Administration on Community Living (ACL) of the U.S. Department of Health and Human Services under Grant No. 90TBSG0024-01-00 and in part by the Tennessee Department of Health, Traumatic Brain Injury Program.

We Provide:

Evidence-based TBI trainings tailored to your discipline

Certificates for educational credits

Toolkits for screening, symptom tracking, reference, parent education and communication with schools

Assistance with goal writing and treatment plan development support for rehabilitation, direct service support and related services

Educational resources including parent-friendly educational materials

Resources for return to home, school or work settings

TENNESSEE DISABILITY COALITION

kidcentral tn
KIDCENTRALTN.COM

CONCUSSION MANAGEMENT PROTOCOL

RECOMMENDATION: 2 VISIT MINIMUM

INITIAL VISIT

SYMPTOM EVALUATION AND PATIENT EDUCATION:

- ACE – Acute Concussion Evaluation *(Physician/Clinician Office version)*
- A Symptom Scale *(Age-appropriate version)*
- A Symptom Scale *(Parent/Adult Patient – fill out in office)*
- A Symptom Scale *(Parent/Adult Patient – take home)*
- ACE Care Plan *(Return to school or work version)*
- CDC Return to School Letter
- When Concussion Symptoms Aren't Going Away *(Age-appropriate version)*
- Any other educational materials or symptom tracker as needed

Send home an additional parent or adult version of a symptom scale to track symptoms over the next 4 weeks. This helps to understand what symptoms/behaviors to look for. Send home a letter to the school or work with recommendations. Research indicates that supports are more likely to be implemented if recommended by the healthcare professional.

With concussion diagnosis, recommend follow up visit in 4 weeks if any symptoms or any new behaviors since injury are present. Bring completed form to next visit.

4 WEEK POST INJURY VISIT

IF SYMPTOMS PERSIST OR NEW BEHAVIORS ARE PRESENT, CONSIDER THE FOLLOWING REFERRALS:

- A specialized concussion treatment center
- A neurologist
- A symptom-specific specialist *(e.g. neuro-ophthalmologist)*
- A brain trauma rehabilitation center
- A neuropsychological evaluation
- TEIS *(if child is under 3 years old)*
- School district *(3-5 years old)*
- School *(5 years and over)*

Note: Schools may not provide all the treatments needed. Research indicates that supports are more likely to be implemented if recommended by the healthcare professional.

YEARLY CHECK-UPS

ASK ABOUT:

- Any residual concussion symptoms
- Any changes in school or work performance

Brain Links

https://www.tndisability.org/brain

@BrainLinksTN

Brain Links is supported by the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services under Grant No. 90TBSG0024-01-00 and in part by the TN Department of Health, Traumatic Brain Injury Program.

When Your Head Has Been Hurt: Signs and Symptoms

A head injury can happen to anyone at any age at any time.

Many people who hurt their heads get well and have no long-term problems.

Concussions are caused by a bump, blow or jolt to the head or body. Even a "ding," "getting your bell rung," or what seems to be a mild bump or blow to the head can be serious.

You can't see a concussion. Signs and symptoms of concussion can show up right after the injury or may not appear or be noticed until days or weeks after the injury.

If you notice any symptoms of concussion seek medical attention right away.

(Adapted from the Centers for Disease Control HEADS UP www.cdc.gov/Concussion)

Problems at the Time of Injury

Headaches

- headache that keeps coming back
- pain in head/ neck
- pain below the ear
- pain in the jaw
- pain in or around the eyes

Balance Problems

- dizziness
- trouble with balance

Sensory Changes

- changes in taste or smell
- appetite changes
- too hot/ cold
- ringing in the ears
- bothered by noises
- can't handle background noise
- vision changes
- bothered by light

If you have any of these problems, see a doctor right away.

DANGER SIGNS

- nausea or vomiting
- one pupil larger than the other
- headache that does not go away
- seizures, eyes fluttering, body going stiff, staring into space
- loss of consciousness, even brief
- disoriented/ confused
- hands shake, tremors, muscles get weak, loss of muscle tone

www.cdc.gov/Concussion

A concussion is a type of traumatic brain injury (TBI). All concussions should be taken seriously.

WHAT TO DO:

Seek help & referrals.

Treatment for concussion is available.

Your doctor may refer you to:

- Neurologist
- Neuropsychologist
- Specialized concussion center
- Brain injury rehabilitation center
- Specialist in your particular symptom

Sleep Problems

- can't sleep through the night
- sleep too much
- days and nights get mixed up

Pain Problems

- neck and shoulder pain that happens a lot
- other unexplained body pain

PROBLEMS TO WATCH FOR OVER TIME

Changes in Mood Personality or Behavior

- irritability, anxiety, restlessness
- upset or frustrated easily
- overreacts, cries or laughs too easily
- mood swings
- want to be alone or away from people
- sad, depressed
- tired, drowsy
- trips, falls, drops things, is awkward
- does not want to do anything, can't "get started"

Trouble Communicating

- trouble thinking of the right word
- trouble listening
- trouble paying attention, can't have long conversations
- does not say things clearly
- trouble reading
- talk too much/ too little

Thinking Problems

- trouble remembering things
- trouble paying attention
- more time needed to process information
- take things too literally, doesn't get jokes
- think about the same thing over and over
- trouble learning new things
- trouble putting things in order (desk, room, papers)
- trouble remembering to do things on time
- trouble planning, starting, doing, and finishing a task
- trouble making decisions
- make poor choices

Concussion In Older Adults

- Older adults are more likely to get a concussion from a bump, blow or jolt to the head.
- Even falling to your knees or bumping your head on a doorway can cause a concussion.
- Signs and symptoms may be delayed in someone who is older.
- Diagnosing a concussion can be harder in someone who already has changes in their thinking or behavior because of aging.

Other Things To Think About!

- ✓ Tell work of the injury
- ✓ Return to activities/ work gradually
- ✓ Be cleared by a doctor before returning to strenuous physical activity

TN Disability Coalition/ Brain Links
615-383-9442 888-643-7811
https://www.tndisability.org/brain

@BrainLinksTN

TN Traumatic Brain Injury Program
800-882-0611
https://www.tn.gov/content/tn/health/health-program-areas/fhw/vipp/tbi.html

Brain Links

Brain Links is supported by the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services under Grant No. 90TBSG0024-01-00 and in part by the TN Department of Health, Traumatic Brain Injury Program.

ACL Administration for Community Living

TBI SPP Traumatic Brain Injury State Partnership Program

Jointly Provided by

33rd Annual Alzheimer's Disease Management & Research Symposium

August 15-16, 2019
The Clayton Center, Maryville College
502 E Lamar Alexander Parkway
Maryville, TN 37804

Alzheimer's Tennessee: an Overview of Programs and Services

August 15
1:15 - 1:30 PM

Janice Wade-Whitehead
President & CEO
Alzheimer's Tennessee

Jointly Provided by

33rd Annual Alzheimer's Disease Management & Research Symposium

August 15-16, 2019
The Clayton Center, Maryville College
502 E Lamar Alexander Parkway
Maryville, TN 37804

An Overview of Alzheimer's Disease

August 15
1:30 - 2:15PM

Bruce LeForce, MD
Clinical Assistant Professor
University of TN, Knoxville

THE UNIVERSITY OF TENNESSEE MEDICAL CENTER
Wisdom for Your Life.

Overview of Dementia

Bruce R. LeForce, MD, FAAN
The Pat Summitt Clinic
The University of Tennessee Medical Center

Our Mission
To serve through healing, education and discovery

MAGNET RECOGNIZED AMERICAN NURSES CREDENTIALING CENTER

Tennessee Center for Performance Excellence 2016 EXCELLENCE AWARD

OVERVIEW OF DEMENTIA

THE UNIVERSITY OF TENNESSEE MEDICAL CENTER

- What is dementia?
- **Dementia** is not a specific disease. It's an overall term that describes a group of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities.

2

OVERVIEW OF DEMENTIA

THE UNIVERSITY OF TENNESSEE MEDICAL CENTER

- What about “mild cognitive impairment”?
- Mild cognitive impairment (MCI) causes a slight but noticeable and measurable decline in cognitive abilities, including memory and thinking skills. A person with MCI is at an increased risk of developing Alzheimer's or another dementia.

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OVERVIEW OF DEMENTIA

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- What do we mean by cognitive functions?
  - Orientation – personal, temporal, spatial.
  - Gnosis – visual, auditory, tactile, olfactory, gustatory.
  - Attention – sustained, selective, alternating, processing speed.
  - Executive Functions – working memory, planning, reasoning, flexibility, inhibition, decision making, multi-tasking.
  - Praxis – learned motor activity.
  - Language – expressive, receptive, reading, writing.

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OVERVIEW OF DEMENTIA

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- What about memory?
- Of course, memory is very important. Memory can be divided into:
  - Episodic memory – events and experiences.
  - Semantic memory – general knowledge.
  - Procedural memory – particular actions or sequence of learned actions.

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OVERVIEW OF DEMENTIA

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- What causes dementia?
  - Alzheimer's disease.
    - Most common cause of dementia, causing 60-80% of cases of dementia.
  - Vascular dementia, such as after a stroke or multiple strokes.
  - Lewy Body Dementia
  - Frontotemporal Dementia
  - Mixed Dementia

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OVERVIEW OF DEMENTIA

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- Less common forms of dementia:
  - Huntington's disease
  - Traumatic brain injury (traumatic encephalopathy syndrome)
  - Creutzfeldt-Jakob disease
  - Parkinson's disease

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OVERVIEW OF DEMENTIA

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- Possibly reversible causes of dementia:
  - Infections or inflammatory disorders.
  - Metabolic problems or endocrine abnormalities (vitamin B12 deficiency, hypothyroidism).
  - Nutritional deficiencies (dehydration, thiamine deficiency).
  - Medication side effects (anticholinergics).
  - Subdural hematoma
  - Tumor
  - Poisoning, anoxia, normal pressure hydrocephalus

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OVERVIEW OF DEMENTIA

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- Evaluation
  - History and neurological examination

- Cognitive screening
  - MOCA, Cognivue®, GDS, GAI, MCSI

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OVERVIEW OF DEMENTIA

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- Evaluation
  - –Laboratory screening
    - B12
    - TSH

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OVERVIEW OF DEMENTIA

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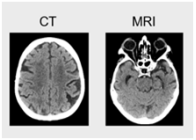
- Evaluation
  - – Anatomical brain imaging



  - – Functional imaging

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OVERVIEW OF DEMENTIA

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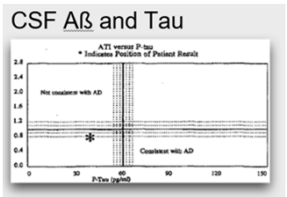
- Evaluation
  - – Biomarkers
    - Spinal fluid for amyloid and tau



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OVERVIEW OF DEMENTIA

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- Evaluation
  - Neuropsychological evaluation and testing
    - Highly detailed evaluation of different kinds of memory as well as executive functions, attention, and other domains of cognitive function.

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OVERVIEW OF DEMENTIA

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- Alzheimer's disease
  - Alzheimer's disease is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills, and eventually the ability to carry out the simplest tasks. In most people with Alzheimer's, symptoms first appear in their mid-60s.

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OVERVIEW OF DEMENTIA

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- Alzheimer's disease

  - Recent estimates indicate that the disorder may rank third, just behind heart disease and cancer, as a cause of death for older people.

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OVERVIEW OF DEMENTIA

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- Alzheimer's disease


Alois Alzheimer


Auguste Deter

  - Alzheimer's disease is named after Dr. Alois Alzheimer. In 1906, Dr. Alzheimer noticed changes in the brain tissue of a woman who had died of an unusual mental illness. Her symptoms included memory loss, language problems, and unpredictable behavior. After she died, he examined her brain and found many abnormal clumps (now called amyloid plaques) and tangled bundles of fibers (now called neurofibrillary, or tau, tangles).

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OVERVIEW OF DEMENTIA

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- Alzheimer's disease
  - These plaques and tangles in the brain are still considered some of the main features of Alzheimer's disease. Another feature is the loss of connections between nerve cells (neurons) in the brain. Neurons transmit messages between different parts of the brain, and from the brain to muscles and organs in the body.

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OVERVIEW OF DEMENTIA

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- Alzheimer's disease
  - Mild Alzheimer's disease.
    - As Alzheimer's disease progresses, people experience greater memory loss and other cognitive difficulties. Problems can include wandering and getting lost, trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, and personality and behavior changes. People are often diagnosed in this stage.

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OVERVIEW OF DEMENTIA

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- Alzheimer's disease
  - Moderate Alzheimer's disease
    - In this stage, damage occurs in areas of the brain that control language, reasoning, sensory processing, and conscious thought. Memory loss and confusion grow worse, and people begin to have problems recognizing family and friends. They may be unable to learn new things, carry out multistep tasks such as getting dressed, or cope with new situations. In addition, people at this stage may have hallucinations, delusions, and paranoia and may behave impulsively.

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OVERVIEW OF DEMENTIA

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- Alzheimer's disease
  - Severe Alzheimer's disease
    - Ultimately, plaques and tangles spread throughout the brain, and brain tissue shrinks significantly. People with severe Alzheimer's cannot communicate and are completely dependent on others for their care. Near the end, the person may be in bed most or all of the time as the body shuts down.

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OVERVIEW OF DEMENTIA

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- Alzheimer's disease
  - Treatment
    - A nutritious diet, physical activity, social engagement, and mentally stimulating pursuits have all been associated with helping people stay healthy as they age. These factors might also help reduce the risk of cognitive decline and Alzheimer's disease. Clinical trials are testing some of these possibilities.

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OVERVIEW OF DEMENTIA

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- Alzheimer's disease
  - Treatment
    - Medications
      - Donepezil (Aricept)
      - Rivastigmine (Exelon)
      - Galantamine (Razadyne)
      - Memantine (Namenda)
      - Donepezil plus memantine (Namzaric)

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OVERVIEW OF DEMENTIA

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- Alzheimer's disease
  - Clinical trials
    - clinicaltrials.gov

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OVERVIEW OF DEMENTIA

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- Vascular dementia
  - Vascular contributions to cognitive impairment and dementia (VCID) are conditions arising from stroke and other vascular brain injuries that cause significant changes to memory, thinking, and behavior. Cognition and brain function can be significantly affected by the size, location, and number of brain injuries.

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OVERVIEW OF DEMENTIA

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- Vascular dementia
  - Symptoms of VCID can begin suddenly and progress or subside during one's lifetime. VCID can occur along with Alzheimer's disease. People with VCID almost always have abnormalities in the brain on magnetic resonance imaging scans. These abnormalities include evidence of prior strokes, often small and asymptomatic, as well as diffuse changes in the brain's "white matter"—the connecting "wires" of the brain that are critical for relaying messages between brain regions.

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OVERVIEW OF DEMENTIA

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- Vascular dementia
  - Vascular contributions to cognitive impairment and dementia are often managed with drugs to prevent strokes or reduce the risk of additional brain damage. Some studies suggest that drugs that improve memory in Alzheimer's might benefit people with early vascular dementia. Treating the modifiable risk factors, such as high blood pressure, can help prevent additional stroke.

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OVERVIEW OF DEMENTIA

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- Lewy Body Dementia
  - Lewy body dementia (LBD) is a disease associated with abnormal deposits of a protein called alpha-synuclein in the brain. These deposits, called Lewy bodies, affect chemicals in the brain whose changes, in turn, can lead to problems with thinking, movement, behavior, and mood. Lewy body dementia is one of the most common causes of dementia.

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OVERVIEW OF DEMENTIA

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- Lewy Body Dementia
  - Diagnosing LBD can be challenging. Early Lewy body dementia symptoms are often confused with similar symptoms found in other brain diseases like Alzheimer's or in psychiatric disorders like schizophrenia. Also, Lewy body dementia can occur alone or along with other brain disorders.

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OVERVIEW OF DEMENTIA

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- Lewy Body Dementia
  - Lewy body dementia affects more than 1 million individuals in the United States. Lewy body dementia typically begins at age 50 or older, although sometimes younger people have it. LBD appears to affect slightly more men than women.

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OVERVIEW OF DEMENTIA

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- Lewy Body Dementia
  - Lewy body dementia is a progressive disease, meaning symptoms start slowly and worsen over time. The disease lasts an average of 5 to 8 years from the time of diagnosis to death, but the time span can range from 2 to 20 years. How quickly symptoms develop and change varies greatly from person to person, depending on overall health, age, and severity of symptoms.

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OVERVIEW OF DEMENTIA

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- Lewy Body dementia
  - In the early stages of Lewy body dementia, symptoms can be mild, and people can function fairly normally. As the disease advances, people with LBD require more help due to a decline in thinking and movement abilities. In the later stages of the disease, they often depend entirely on others for assistance and care. Some Lewy body dementia symptoms may respond to treatment for a period of time. Currently, there is no cure for the disease.

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OVERVIEW OF DEMENTIA

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- Frontotemporal dementia
  - Frontotemporal dementia (FTD) describes a clinical syndrome associated with shrinking of the frontal and temporal anterior lobes of the brain. Originally known as Pick's disease, the name and classification of FTD has been a topic of discussion for over a century. The current designation of the syndrome groups together Pick's disease, primary progressive aphasia, and semantic dementia as FTD.

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OVERVIEW OF DEMENTIA

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- Frontotemporal dementia
  - As it is defined today, the symptoms of FTD fall into two clinical patterns that involve either:
  1. Changes in behavior
  2. Problems with language.

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OVERVIEW OF DEMENTIA

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- Frontotemporal dementia
  - The first type features behavior that can be either impulsive (disinhibited) or bored and listless (apathetic) and includes inappropriate social behavior; lack of social tact; lack of empathy; distractability; loss of insight into the behaviors of oneself and others; an increased interest in sex; changes in food preferences; agitation or, conversely, blunted emotions; neglect of personal hygiene; repetitive or compulsive behavior, and decreased energy and motivation.

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OVERVIEW OF DEMENTIA

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- Frontotemporal dementia
  - The second type primarily features symptoms of language disturbance, including difficulty making or understanding speech, often in conjunction with the behavioral type's symptoms. Spatial skills and memory remain intact. There is a strong genetic component to the disease; FTD often runs in families.

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OVERVIEW OF DEMENTIA

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- Frontotemporal dementia
  - No treatment has been shown to slow the progression of FTD. Behavior modification may help control unacceptable or dangerous behaviors. Aggressive, agitated, or dangerous behaviors could require medication. Anti-depressants have been shown to improve some symptoms.

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OVERVIEW OF DEMENTIA

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- Frontotemporal dementia
  - The outcome for people with FTD is poor. The disease progresses steadily and often rapidly, ranging from less than 2 years in some individuals to more than 10 years in others. Eventually some individuals with FTD will need 24-hour care and monitoring at home or in an institutionalized care setting.

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OVERVIEW OF DEMENTIA

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- Mixed dementia
  - It is common for people with dementia to have mixed dementia—a combination of two or more types of dementia. A number of combinations are possible. For example, some people have both Alzheimer's disease and vascular dementia.

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OVERVIEW OF DEMENTIA

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- Mixed dementia
  - Some studies indicate that mixed dementia is the most common cause of dementia in the elderly. For example, autopsy studies looking at the brains of people who had dementia indicate that most people age 80 and older probably had mixed dementia caused by a combination of brain changes related to Alzheimer's disease, vascular disease-related processes, or another neurodegenerative condition. Some studies suggest that mixed vascular-degenerative dementia is the most common cause of dementia in older adults.

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OVERVIEW OF DEMENTIA

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- Mixed dementia
  - In a person with mixed dementia, it may not be clear exactly how many of a person's symptoms are due to Alzheimer's or another disease. In one study, researchers who examined older adults' brains after death found that 78 percent had two or more pathologies (disease characteristics in the brain) related to neurodegeneration or vascular damage. Alzheimer's was the most common pathology but rarely occurred alone.

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OVERVIEW OF DEMENTIA

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- Mixed dementia
  - Researchers are trying to better understand how underlying disease processes in mixed dementia influence each other. In the study described above, the researchers found that the degree to which Alzheimer's pathology contributed to cognitive decline varied greatly from person to person. In other words, the impact of any given brain pathology differed dramatically depending on which other pathologies were present.
  - Boyle PA, et al. Person-specific contribution of neuropathologies to cognitive loss in old age. *Ann Neurol.* 2017 Dec 15. doi: 10.1002/ana.25123.

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Clinical Trials

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Genentech	Anti-Tau therapy for treatment of moderate Alzheimer's
Eisai	Anti- Amyloid therapy for mild cognitive impairment (MCI)
Eisai	Open-Label for previous participants
Acadia	Treatment for psychosis associated with dementia.

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Collaborations

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- **UTK Biomedical Engineering**
  - Development of human-computer interfaces for diagnostics
- **UTK Audiology**
  - Effects of speech therapy on primary progressive aphasia
- **Oak Ridge National Labs**
  - Role of microbiome in neurodegenerative disease
- **UT Medical Center**
  - Effects of anesthesia on cognitive function

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OVERVIEW OF DEMENTIA

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Thank you!

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Jointly Provided by

33rd Annual Alzheimer's Disease Management & Research Symposium

August 15-16, 2019
The Clayton Center, Maryville College
502 E Lamar Alexander Parkway
Maryville, TN 37804

Dementia and Driving: Determining Decision Making Capacity and Autonomy in Dementia

August 15
2:30 - 3:15PM

Odacir Oliveria, PhD
Knoxville, TN

33rd Annual Alzheimer's Disease Management and Research Symposium

Dementia and Driving

- **Determining Decision-Making Capacity and Autonomy in Dementia**

- **O. H. Oliveira, Ph.D.**

- **August 15, 2019**

Overview

- In 2015 47.8 million people were 65 and older (about 15% of the total U.S. population
- In 2015 there were 6,165 people age 65 and older killed in traffic fatalities
- In 2015 there were 240,000 people 65 and over injured in motor vehicle traffic accidents

DOT/Bureau of the Census
2015

Overview

- **Nearly 10,000 baby boomers will turn 65 each day over the next 15 years, fueling the aging population explosion!**

Source: Census.gov

Overview

- **Fatal crashes per mile traveled increases by age 70 and peaks at age 85 and older.**
- **Dementia is most likely to be diagnosed after age 65**

Overview

- **In 2015, people 65 and over made up 18% of all traffic fatalities**
- **In 2015 people 65 and older increased by 29%**
  - **Males: 34%**
  - **Females 24%**

Overview

- **Since 2006 the fatality rate of the older population has steadily declined from 16.3 in 2006 to 12.9 in 2015 per 100,000 population of older people**
- **In 2015 there were 40.1 million licensed older drivers (a 44% increase since 2006**
- **In 2015 older drivers had the lowest percentage of drivers with blood alcohol concentration (BAC) of .08 gm/dcl or higher**

Overview

- **In 2015 most crashes involving older drivers occurred during daytime. Daytime crashes equaled 70%**
- **70% of crashes were on a weekday**
- **67% of crashes involved other vehicles**

Source: National Center for Statistics and Analyses

Driving is a Privilege

- **Physical capacity to operate a vehicle**
- **Mental capacity to follow directions, follow laws, rules, signs governing traffic**
- **Intact judgement for rapid decision-making and reflexes to act**

Significance of Driving

- **Independence**
- **Self-reliance**
- **Competence**
- **Self expression:**
  - **Small Car**
  - **Mid-size car**
  - **Truck**
  - **Luxury vehicle**
  - **Travel vehicle**
  - **Sporty and expensive**

Obvious Causes that Incapacitate Older Drivers

- Diabetes complications
  - Loss of limbs
  - Loss of vision
  - Hypoglycemia
  - Hyperglycemia
  - Neuropathy

Obvious Cause that Incapacitate Older Drivers

- **Visual Impairments such as cataracts, macular degeneration and blindness**
- **Cardiac Risks depend on physician recommendations depending on condition of the elderly driver**
- **Severe Hearing loss/deafness, vertigo**
- **Medications that impact alertness and cognition**

Not So Obvious Causes that Diminish Capacity/Autonomy

- **Depression**
- **Psychosis**
- **Anxiety (panic)**

Neurocognitive Disorders that Impair Driving

- **Alzheimer's Disease**
- **Frontal Lobe Dementia**
- **Lewy Body Disease**
- **Parkinson's Disease**
- **Cerebral Vascular Disorders**

Dementia Manifestations and Driving

- Short and long-term memory loss
- Impacts on the individual's ability to plan, organize and execute and review decision
- Causes mood, emotional and behavioral changes
- Causes slower reflexes
- Causes difficulties to comprehend vehicle instrumentation, distance to breaking timing
- Use of mirrors and judgement of depth perception misperception

Dementia And Driving

- **Causes cognitive limitations that impair understanding of traffic laws**
- **Makes logical planning of trips difficult**
- **Increases the chance of becoming lost even in once familiar places**
- **Puts others in vehicle and on the road at risk**

Dementia Workup to Evaluate Capacity Autonomy to Drive

Imaging Test (MRI)
CBC/CMP
Thyroid
B12
Cognitive Assessment (MMSQ, MOCA)
History

Cognitive Tests Used to Determine Capacity/Autonomy

- **MMSQ: for evaluation of long term and short term memory**
- **MOCA: Long and short term memory**
- **Orientation**
- **Visuospatial test (Trail-making)**
- **Abstract thinking (Similarities)**
- **Object naming**

Determining Capacity

- **Loss of 30% or less of cognitive capacity should restrict driving**
- **Avoid driving at night and in bad weather**
- **Driving only in familiar places**
- **Driving within a restricted radius of home**
- **Stay off of expressways**
- **Limit distractions such as radio, conversations,**
- **telephone**

When to Stop Driving

- **Loss of greater than 30% of cognitive loss should terminate driving**
- **When your family will not allow you to drive with children in the car it is time to stop driving**
  (Gary S. Kennedy, MD, Albert Einstein College of Medicine)

Jointly Provided by

33rd Annual Alzheimer's Disease Management & Research Symposium

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Finding the Pillars of Personhood: Keys to Living Well in Dementia

August 16
8:45 - 9:30 AM

Daniel Potts, MD
Tuscaloosa VA Medical Center
Tuscaloosa, AL

FINDING THE PILLARS OF PERSONHOOD

KEYS TO LIVING WELL IN DEMENTIA

ALZHEIMER'S MANAGEMENT & RESEARCH SYMPOSIUM - ALZHEIMER'S TENNESSEE - 8/16/2019
Daniel C. Potts, MD, FAAN
Cognitive Dynamics Foundation, Tuscaloosa VA and The University of Alabama

FINDING THE PILLARS - Objectives

- *At the conclusion of this activity, participants will be able to:*
  - Explore the fallacy of diminishing personhood as the root cause of stigma related to dementia.
  - Review the concept of pillars of personhood relative to individuals living with all stages of dementia.
  - Discuss the role of care partners and health care providers in bolstering personhood as a means of helping individuals with dementia to live well.
  - Summarize the lessons learned and subsequent changes in practice one neurologist has made based upon a personal care partnership experience, and upon subsequent meaningful interactions with persons living with dementia, including suggestions providers may offer toward the goal of living well.
  - Discuss some realistic expectations persons living with dementia and care partners should have of their healthcare providers.

DISCLOSURES

- Consulted gratis with Embodied Labs on the development of Virtual Reality dementia training modules
- Formed a not-for-profit foundation to benefit people living with cognitive impairment, Cognitive Dynamics (www.cognitivedynamics.org)
- With Ellen W. Potts, MBA, formed a dementia care partner education company, Dementia Dynamics (www.dementiadynamics.com) which published *A Pocket Guide for the Alzheimer's Caregiver*

FACES (*RELATIONSHIPS*) *Change Us…*

- *"The dimension of the divine opens forth from the human face."*
  - Emanuel Levinas
- *"Being touched by the vulnerable and injured face of the other…we no longer can remain indifferent…we are called to responsibility."*
  - Roger Burggraeve
- *"Touching that which causes us to weep can liberate the transforming fire of* ***hope*** *within us."*
  - Simone Campbell

"The true worth of a (person) is not to be found in (the person) him/herself, but in the colours and textures that come alive in others."
- Albert Schweitzer

MEET LESTER…

(A film by Corey Matthew Carpenter)

STIG·MA
/ˈSTIgMə/

The disapproval of, or discrimination against, a person based on perceivable characteristics that serve to distinguish them from other members of a society.

What is the root cause of the stigma associated with Alzheimer's and other dementias?

I BELIEVE THE ROOT CAUSE OF STIGMA IS…

- The belief, perhaps unacknowledged, that people living with dementia somehow embody less personhood than others who don't have dementia.
- That the diagnosis of dementia somehow renders one less a person than before receiving the diagnosis, as if personhood could be diminished by any circumstance or condition at all.

WHAT IS PERSONHOOD AND HOW IS IT AFFECTED BY DEMENTIA?

"IT MAY NOT BE DYING WE FEAR SO MUCH, BUT THE DIMINISHED SELF."

- ANATOLE BROYARD

DEFINITIONS OF PERSONHOOD

Legal

Philosophical

Psychological / Neurological

Ethical

Theological

Ontological

Relational

Societal

WHAT IS PERSONHOOD?

My 2 cents (a simple country Neurologist):

Personhood is the condition of being a person: a relational being created in the image of God (imago dei) and named by God, who is sustained and will be eternally remembered through God's Love and providence, with the potential to grow more in the likeness of God through an ever-expanding capacity for love, compassion and relationship.

PERSONHOOD

- Is imparted
- Cannot be gained or lost
- Is not earned
- Is sacred and carries inherent dignity
- Is not dependent on productivity, morals, or *cognitive ability*

PERSONHOOD

- This concept of personhood has profound implications for the way we, both as individuals and as a society, regard persons living with dementia.
- It should call forth our finest and most compassionate efforts as care partners.
- It means that we never give up on persons living with dementia, no matter how far the progression, severe the disease, misunderstood the behavior, etc.
- There are no human "shells."

AWARENESS OF PERSONHOOD AND SENSE OF SELF IN DEMENTIA

- Research suggests personal identity persists into late stage.
- "To have an identity is to know who one is, in cognition and in feeling; a sense of continuity with the past, and hence a 'narrative,' a story to present to others."
- Certain aspects of relational identity may be lost as a result of how persons living with dementia are viewed and treated by others.
- Due to declining cognition, persons living with dementia need others to "hold their story," and to respond as "thou, in the uniqueness of…being."

*Kitwood, Fazio, et al

AWARENESS OF PERSONHOOD AND SENSE OF SELF IN DEMENTIA

- *"I can give an authentic experiential account of dementia from an insider's perspective, which provides alternative insights into the idea of loss of self. I explore a continuing sense of self, in embodied relationships within the community, where I retain the ability to find a sense of meaning in the present moment. My aim has been, and continues to be, to project a new world of possibility and to 'redescribe reality,' so that people with dementia can be seen in a very different way."*

– Christine Bryden, PhD, a person living with dementia, from her book, *Will I Still Be Me?*

AWARENESS OF PERSONHOOD AND SENSE OF SELF IN DEMENTIA

"I'm still me…I know the face I and my family see in the mirror. We don't like it all the time but it is what it is. I have no choice but to accept it. My family chooses to accept it. I think it's why the one thing I DO REMEMBER is how much I love them and how very much they love me. I also appreciate the friends that have not deserted me, with hopes they NEVER go away…

I have Alzheimer's, but Alzheimer's doesn't have me."

– Brian LeBlanc, living with Alzheimer's disease

PERSONHOOD - RELATIONSHIPS

"Because you're not
what I would *have you* be,
I **blind** myself
to who, *in truth* …
YOU ARE."

- Madeleine L' Engle

PERSONHOOD – *DO WE EXPECT TO SEE IT?*

"The observing mind is absolutely crucial

in the actuality that emerges as our perceived reality."

- Eben Alexander, MD

"To be is to be perceived."

- George Berkeley

TAPPING INTO PERSONHOOD

- Relationships characterized by authenticity and compassion (supportive community)
- Faith and spirituality
- Expressive arts (especially music)
- Pets and other animals
- Intergenerational relationships
- Nature
- Imagination and Play
- Reminiscence
- Humor
- Present moment centeredness
- Giving back to others (generativity)
- Living in ways that add meaning and purpose

"PILLARS OF PERSONHOOD"

- Each individual possesses and retains self-defining attributes which are enduring, even in the face of dementia.
- These attributes may be more difficult to identify when cognitive faculties are lost, *but still remain,* nevertheless.
- Learning about and developing an appreciation for these "pillars of personhood" will aid in care partnerships and relationship building.

The Four Pillars

A New Approach Toward Healing

Alan Swindall, Birmingham: www.alabasterfamily.com
Bob Montgomery, Tuscaloosa: www.reflectiontherapy.com
Daniel C. Potts, MD, FAAN: www.cognitivedynamics.org

PILLARS OF PERSONHOOD

Physiological/physical

- Approach Mr. John from the right if there is vision loss on the left.
- Use non-verbal cues & communication tools w/Mrs. Bailey, who has aphasia.
- Place a shadowbox or storyboard at a lower level for Mrs. Vick, who is 4 feet 10 inches tall.
- Avoid offering (or discussing) sweets to Mr. B, who has brittle diabetes.
- Complement Mr. Potts on the appearance of his hair, knowing this is pleasing.
- Share football stories w/Coach S, a former college fullback & high school coach.
- Turn on music and dance with Mrs. Williams, a professional ballroom dancer.
- Acknowledging wandering tendencies, move Mr. Morris's room more centrally, and get Mrs. Washington a Project Lifesaver bracelet.
- Mr. L's family says he has always taken a nap after breakfast. Allow him to do so.
- Mrs. W speaks slowly; give her time to express her thoughts and don't interrupt.
- Let former drama teacher, Ms. Ann use her vivid imagination in group activities.

PILLARS OF PERSONHOOD

Psychological

- Tap into Mrs. Bright's joyful disposition on the way to breakfast and continue this encouraging discussion with other residents.
- Facilitate Mrs. Houston's trait of hospitality in letting her set the table or help to choose the guest list and prepare the meal.
- Engage Mrs. Love's sense of pride in her family by showing pictures of her grandchildren, telling her what a fine family she has.
- Let Mr. Sum, a former accountant, use an adding machine or calculator someone has donated.
- Engage Mrs. Oaks's love of flowers by letting her tend the courtyard garden.
- Knowing Mr. Layton is an introvert and needs private time, don't require him to stay in the common area too long.
- Offer art, music, poetry, drama and dance activities to your residents, and give residents some choice regarding which activities to participate in.
- Let your mother, the consummate housekeeper, fold sheets and towels, even though they have already been folded.

PILLARS OF PERSONHOOD

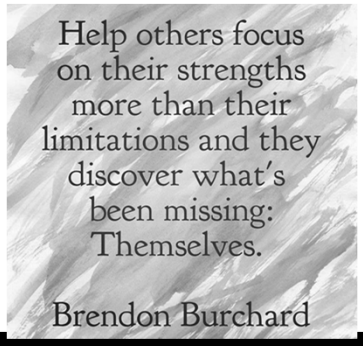
Spiritual/faith

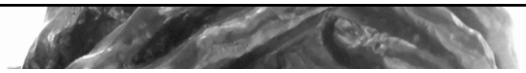
- Quote the 23rd Psalm to Pastor Jim if he is agitated at bath time.
- Ask Great Uncle Joe to return thanks at dinner, knowing this was his traditional privilege.
- Sing "Great Is Thy Faithfulness" to Mrs. Beasley, which you have learned is her favorite song.
- Offer different styles of dementia-friendly worship for those of different faith traditions.
- Lead residents/caregivers in mindfulness or meditation activities.
- Encourage Mrs. Jackson to use her well-known skills on the piano.
- Complement Mr. Lloyd, a former Professor of Voice, on his lovely singing.
- Let Dr. Thomas, a retired choral director, lead the group singing activity.
- Ask the Pastor if communion can be offered to your loved one in hospice.
- Invite the church youth group to come caroling for your Mother this year.

PILLARS OF PERSONHOOD

Relational

- Don't mention to Mrs. Hamlin again that her husband has passed away.
- Don't discourage Mr. Ball and Mrs. Joslin to hold hands if it makes them happy.
- When Mrs. James visits her husband, respect their privacy.
- If Mrs. Hathaway says that her grandmother visited her for breakfast, ask her what they ate, and if her grandmother was a good cook.
- Remembering that Mr. Arnold was a bird dog trainer, offer him opportunities to interact with dogs.
- Work with schools in the community to develop after school service activities at your center to promote intergenerational relationships.
- Challenge your residents to prepare gifts for children in need.
- Challenge yourself to act interested and eager to hear more, even though your grandmother has told the story of her pet horse 3 times today.
- You doubt your Great Grandmother knows you are there, yet you visit her, hold her hand, brush her hair, pray, and sing to her, and just be present with her.





"There is no greater agony
than bearing an untold story
inside you."

- Maya Angelou

STORY

"*Owning our story*

and **loving ourselves**

through that process

is the bravest thing

that we will ever do."

-Brene´Brown

THOMAS KITWOOD'S PHILOSOPHY

- Dementia is best understood as an interplay between neurological impairment and psychological factors (especially the social context of the environment of care).
- Persons living with dementia exist in a state of relative well-being or ill-being, based on not only neuropathology but also the degree to which the following needs are met in an affirming social context (personhood is in part maintained through relationships):

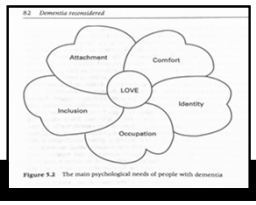


Figure 9.2 The main psychological needs of people with dementia

PRACTICE RECOMMENDATIONS FOR PERSON-CENTERED CARE

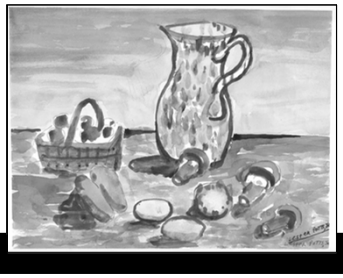
FAZIO, ET AL

- Know the person living with dementia.
- Recognize and accept the person's reality.
- Identify and support ongoing opportunities for meaningful engagement.
- Build and nurture authentic, caring relationships.
- Create and maintain a supportive community for individuals, families and staff.
- Evaluate care practices regularly and make appropriate changes.

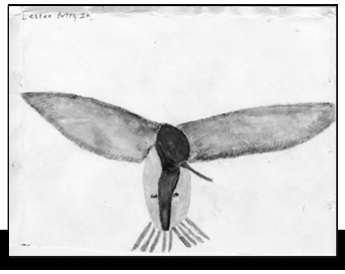
LESSONS LEARNED

From Lester and Other Persons Living with Dementia and Care Partners

Care partners are curators of another person's museum of life.



The innate value and dignity of human beings cannot be stolen by any condition or circumstance. To care with compassion, we must first believe that all people retain an incontrovertible identity.



The beauty, vitality and relational energies inside the very one living with dementia can provide the inspiration for the care partner's journey.

I should love and honor persons in their current state, rather than holding them accountable to be what my ego needs them to be.

Allow persons living with dementia the opportunity to express themselves as completely as they can.
"Please don't complete my sentences for me." – Bill, BATL Partner

Distractions must be minimized during interactions with persons who are living with dementia.
"I can't process two conversations at the same time." – Rev. Dr. Cynthia Huling Hummel

We should always look people in the eyes when they are sharing their stories. We should realize that they may be sharing their stories without using words.

One's story needs to come out. When words fail, art, in all forms, can be a vehicle for expressing one's story. Expressive arts and opportunities to explore creativity should be made available to everyone who is living with dementia.

Nothing stirs the soul more than a feeling of belonging. We must do everything in our power to promote this kind of experience daily in people who are living with dementia.

Always try to remember the silent struggles of others, which may lie buried beneath attitudes and behaviors that we don't understand.

Rich present moment experiences open the pages of a person's narrative, bolster identity and bring a sense of continuity to a person's existence.
"What's your favorite holiday, Bobby?" "A day like today." – Bobby, BATL Partner

Laughter is essential. It is the great equalizer. But listening rivals laughter as the best medicine. Listening requires use of all senses, not just hearing.
"I learned to listen a different way." – Cathie Borrie, author of *The Long Hello*

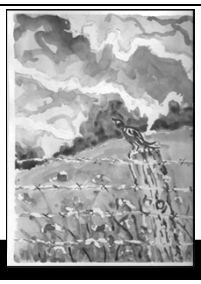
We must not take ourselves too seriously. Play is important at any age.

It is essential to develop the practice of self-compassion.
"The hardest part for me is learning to be independent in a dependent situation."
– Naomi Feil, author, *The Validation Breakthrough*

As a care partner, I should act as if my life is a mirror reflecting only the good and true image of personhood and none of the toxicity of dementia.

There is no greater privilege than to help someone find his or her true voice, and no greater crime than to silence it.

Culture change cannot occur if the voices of those who are living with dementia are not heard.

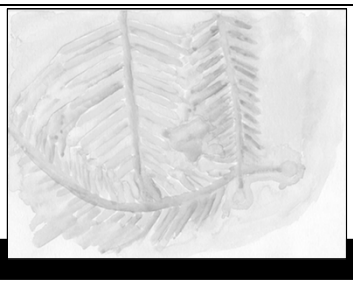


Don't take it personally if someone living with dementia offends you or hurts your feelings.

Empathy is the game changer in creating a culture of compassion in dementia care. Empathy increases when persons allow themselves to have meaningful relationships with those living with dementia. It is especially important to facilitate this process in young people.

Though the requirements of care partnerships can sometimes bring out our worst, they also can bring out our best human qualities.

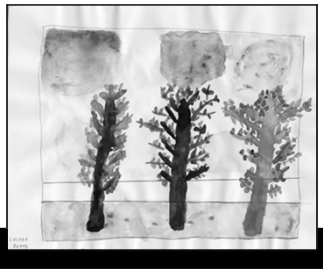
Cultivate spiritual intentionality. Get past denial and resentment to acceptance and gratitude. Choose to look for opportunities to love more deeply in each moment of the ongoing care partnership.
(Morgan and Thibault)



Reliance upon one's faith and spirituality can provide a deeper meaning to the journey through dementia for everyone involved.

Mindfulness is a very important practice to cultivate (for ones living with dementia, care partners and healthcare providers).

Meaningful relationships can be maintained with persons living with dementia even in late stages. Presence is the most important characteristic of these relationships.



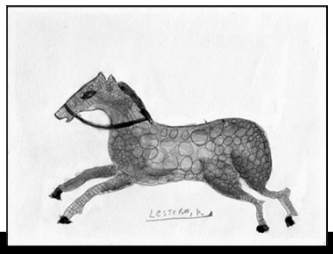
Brain pathology is not the only determinant of wellbeing; the relational qualities of one's surroundings play a major role. (Kitwood)

The strength of the ego's need to retain control often is proportional to the level of denial exhibited by a care partner.

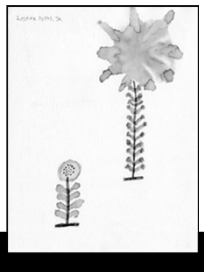
It is much better to be kind than to be right. When in doubt, default to kindness. When not in doubt, default to kindness.

The need for generativity never goes away.

Models of dementia care must address this need.



We would do well to remember the things we learn from old people, young people, wounded people and disabled people.



Life is about relationships. That doesn't change if someone has dementia.

Personhood, relationships, and empowerment promote living well.

Showing others back to the themselves may be the greatest gift we can give them.

SOME WAYS MY PRACTICE HAS CHANGED
Because of These Persons and Experiences:

- Having experienced burn-out, I learned ways to guard against it, including wellness practices, self-compassion, mindfulness, nature experiences, strengthened relationships, better sleep, a deeper faith/spirituality practice, exercise, photography, writing poetry, a healthier diet, gratitude and authenticity practices, etc.
- I address the person living with dementia 1st in all clinical interactions, care partners and family members 2nd.
- I spend as much time as I can and learn as much as possible from persons living with dementia.
- I try to do a better job with diagnosis disclosure, sharing resources/supports, opportunities for research participation, etc.
- After the initial diagnostic assessment, I make less use of routine formal standardized clinical assessments.
- I strive to always see the person, not the disease, while giving the disease its due acknowledgement.
- I strive to be non-judgmental of care partners and others unfamiliar with the concepts we have discussed.
- I try to share what I have learned with colleagues in practice and in training.

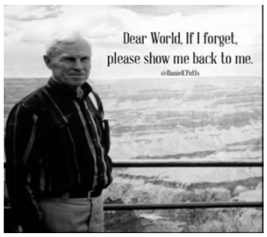
REALISTIC EXPECTATIONS OF A HEALTHCARE PROVIDER

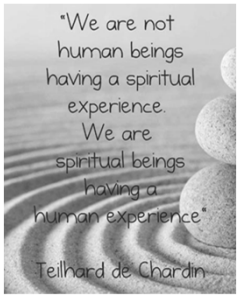
- Compassion and empathy
- Good listening skills
- Espouses person-centered care and the importance of maintained relationships
- Should interact with the person who is living with dementia
- Should listen to care partner concerns
- Should have a good understanding of treatment options and ongoing research
- Should have knowledge of available resources and supports
- Should have an accessible office staff

HELPING PATIENTS TO LIVE WELL
Some Suggestions for Providers

- Diagnosis should be delivered to the person living with dementia and care partner (s) accurately and in a timely fashion, unhurried, with compassion, empathy, education, resources, follow up, and an action plan of care and support.
- Evidence-based supports should be recommended, including such modalities as occupational therapy, caregiver supervised exercise programs, cognitive-stimulation sessions (eg, memory training, problem-solving, mnemonic devices, multisensory stimulation, word games, puzzles, and social activities), support groups, memory cafes, museum visits, expressive arts therapies and creativity, etc.
- Promote brain health
- Promote adequate safety, while supporting independence
- Recommend elderlaw services
- Offer guidance and support during transitions
- Inquire about care partner health and coping

"From mirror after mirror no vanity is displayed;
I'm looking for the face I had
before the world was made."
-William Butler Yeats





"When the face of the other (especially the suffering face) is received and empathized with, it leads to transformation of our whole being...We are mirrored into life, not by concepts, but by faces delighting in us, giving us the beloved self-image we can't give to ourselves. Love is the gaze that does us in.
How blessed are those who...receive it deeply."
- Richard Rohr

MY TRUE FACE

"Remember who you are, my child…"

THANK YOU!

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Jointly Provided by

33rd Annual Alzheimer's Disease Management & Research Symposium

August 15-16, 2019
The Clayton Center, Maryville College
502 E Lamar Alexander Parkway
Maryville, TN 37804

Bringing Art to Life: Living Well Through Art and Stories

August 16
9:30 - 10:30 AM

Daniel Potts, MD
Tuscaloosa VA Medical Center
Tuscaloosa, AL

Bringing Art to Life

Living Well
Through
Art and Stories

Alzheimer's Management & Research Symposium
Alzheimer's Tennessee
8/16/2019
Daniel C. Potts, MD, FAAN

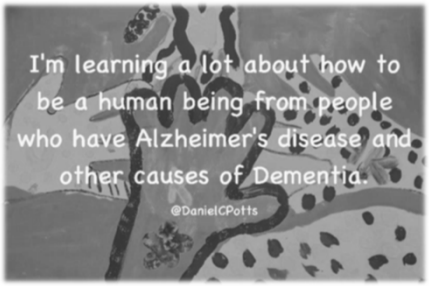
Disclosures

- Dr. Potts is not serving as a paid consultant for any pharmaceutical or medical device company
- Dr. Potts has consulted with GE Healthcare on the development of an expressive arts therapy app (MIND)
- Dr. Potts has formed a not-for-profit foundation to benefit people with cognitive impairment, Cognitive Dynamics (www.cognitivedynamics.org)
- Dr. Potts has formed a Dementia care partner education company, Dementia Dynamics (www.dementiadynamics.com) which published *A Pocket Guide for the Alzheimer's Caregiver*

Objectives

- Discuss the art and life story of Alzheimer's artist, Lester Potts, and give examples of the expression of personhood through artistic creativity in dementia
- Discuss some of the benefits of expressive arts therapies and creativity in persons with cognitive impairment
- Review *Bringing Art to Life*©, a program of art therapy, life story appreciation, and intergenerational relationship-building inspired by the life of Lester Potts, including relevant outcomes of the program
- Share the inspiration that has been gained through mindfully connecting with persons who have Dementia through artistic creativity
- *Celebrate the belief that nothing, not even Dementia, can steal identity or relationship*

I'm Learning…



My apologies, but…

- Physicians don't do a good enough job supporting psychosocial/spiritual well-being in our patients or ourselves.
- Appreciation for narrative is essential for supporting psychosocial/spiritual, and physical well-being.
- Our society increasingly is characterized by data inundation without the framework of depth, ethics, knowledge and narrative to provide meaningful interpretation.
- Efforts should be made to bring back appreciation for and use of narrative to inform, broaden and deepen our experience.
- Educational models which make use of personal, familial and cultural narrative should be developed, supported and implemented for all ages, particularly pertaining to health-related disciplines.
- We should stop, look each other in the eyes, and listen to one another's stories.

Deep connection is possible…

To people with Alzheimer's
and other causes of dementia at any stage
using the arts, story and spirituality,
keys that unlock the enduring Self

#CultureOfCompassion

And those experiencing this connection…

Can help us connect
to ourselves

The Connecting Power of Art

- Art, in all forms, is the purest medium of human connection, most truly promoting holistic communion between individuals
- Art's power lies in its ability to meld the heart and mind of the artist with that of the observer, calling into consciousness in another the depth of emotion, experience, spirituality and intellect behind the creation of the artistic work
- Among other things, art is a tool to honor and express personhood, make connections and build relationships

The Story Of A Man



And His Family

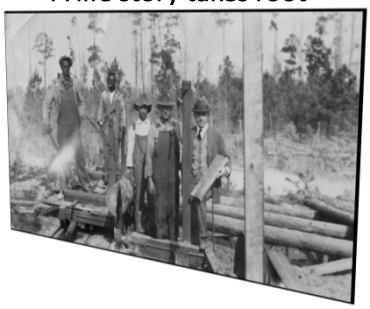


A Gift And A Place

A life story takes root

A life story takes root

A life story takes root



A life story takes root

A life story takes root

And grows…

And grows…

And remembers…

The art of living

And of loving

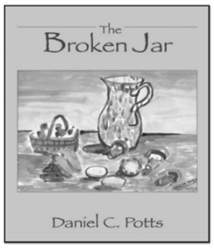
Meeting him in the "now"

Making a connection

Sharing, giving

"giving back his pride…"

And telling his story



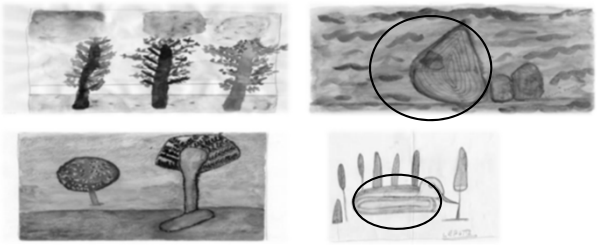
www.caringdays.org

Wood Grains and Bird Houses

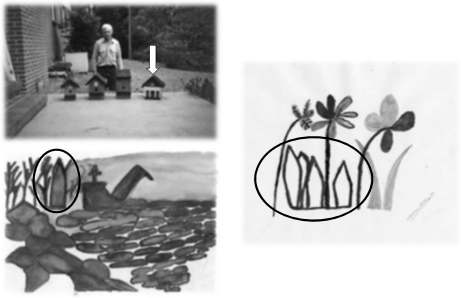
Lester spent many formative hours looking at logs on end, visualizing their rings of growth. As similar rings were laid in his own life, the imagery of youth framed his concept of self. In later years he built bird houses for townsfolk, fashioning them of the same timbers he had planed in the past. His late-stage artistic expression was rich in such imagery and creates a window through which to view the core of a person.



Wood



Birdhouses

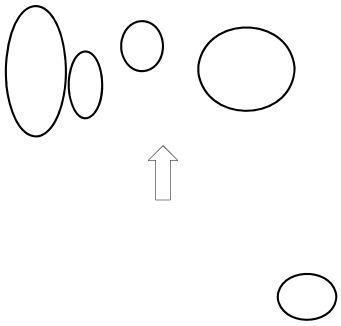


Fences

Brothers From Sawmilling Days

A life-long friendship was forged of sinews, sweat and sawdust between Lester and Albert Corder seen here in both life and art…

Lester and Albert



Lester's Last Painting…

"The true worth of a (person) is not to be found in (the person) him/herself, but in the colours and textures that come alive in others."
- Albert Schweitzer

Water color by Lester E. Potts, Jr., an artist with Alzheimer's

"Painting in Twilight: An Artist's Escape from Alzheimer's"

David Streets Galleries, Beverly Hills, CA 11/5/10

©Daniel C. Potts, M.D.

A Mission

Cognitive Dynamics

Cognitive Dynamics WORD · DRAMA · ART · MUSIC Bringing Art to Life

Mission: To improve the quality of life of persons with cognitive disorders (such as Alzheimer's disease) and their care partners through education, research, and support of innovative care models that promote human dignity, especially therapies employing the expressive arts and storytelling.

www.cognitivedynamics.org

Artistic Expression in AD

- Progressive loss of visuospatial skill would be expected to inhibit creation of visual art
- Some previously proficient artists have eventually lost the ability to paint with disease progression
- Art loses realistic precision and maintenance of spatial relationships but retains appealing color and form, though fewer colors may be used later
- Art may become more aesthetically appealing with disease progression
- More abstraction and use of symbolism; less depictive accuracy and realism
- Continuous urge to create, despite considerable cognitive impairment

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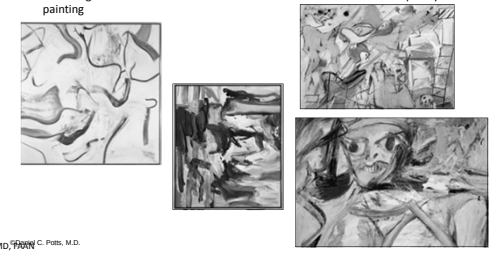
Artistic Expression in AD

Willem de Kooning (1904-1997)

- Alzheimer's diagnosed in his late 80's
- Painted more than 300 abstract paintings after the diagnosis, which art critics assess as among the finest and most sensitive artistic achievements in contemporary painting



Artistic Expression in AD

Carolus Horn (1921-1992)

- Alzheimer's diagnosed at age 58
- Distortion in perspective, "primitive" style, lack of individual characteristics in depicting his subjects, more schematic drawing, and a preference for using reds and yellows; no change in output

Artistic Expression in AD

William Utermohlen (1935–2007)

The Changing "Face" of Alzheimer's

"…extraordinary ability to express emotion… and originality: each is a new piece of work, not an attempt to copy a previous painting" (Marcus & Kaufman, 2009)

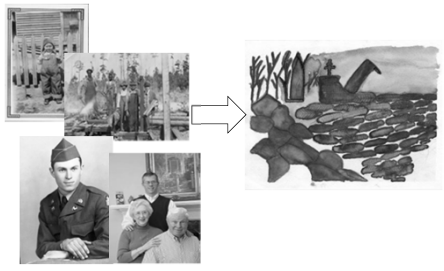
The Changing "Face" of Alzheimer's
Lester Potts (1928-2007)

1999

2007

"Saving Face"

"Saving Face"
(Dipping into the self to paint a life portrait)



Expressive Arts Therapies

- An emerging body of evidence suggests the expressive arts
  - Improve quality of life
  - Enhance perceived self-worth
  - Promote human dignity
- Expressive arts
  - Music, art, drama, dance, poetry and bibliotherapy
  - Incorporate reminiscence therapy, storytelling and cognitive/behavioral therapy in the treatment plan

©Daniel C. Potts, MD

Expressive Arts Therapies

- Expressive arts can
  - Improve an individual's ability to communicate his/her story
  - Stimulate memories
  - Foster community
  - Promote positive relationships with care partners
  - Help address issues underlying certain behaviors
  - Enhance cognitive abilities
  - Elevate and stabilize mood
- The end result is an **enlivened sense of self-worth, fostering of dignity, and the facilitation of living well**

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Arts and Creativity Benefits

- Creativity and Aging Study - 25 year study of arts and creativity in people 65 and older (Cohen 2009)
- Results indicated
  - ↑Physical health
  - ↓ Number of doctor visits
  - ↓ Medication usage
  - ↓ Depression
  - ↑ Morale
  - ↑ Activity levels

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Arts and Creativity Benefits

- Creativity (Cohen 2009)
  - Reinforces neuronal connections
  - Improves emotional resiliency
  - Enhances a sense of well-being
  - Improves memory

In a Mayo Clinic study of 256 people in their 80s, those who engaged in artistic activity (such as painting, drawing, and sculpting) both in midlife and later life had a significantly lower risk of mild cognitive impairment (16% vs 49%)

Creative Expression

- 2 distinct, interrelated and complimentary fields that connect arts to health (Sonke 2011)
- **Arts therapies**
  - Trained and credentialed therapists
  - Defined clinical relationship to clients, students or setting
- **Arts in healthcare**
  - Artists work as artists, not practitioners/therapists
  - Artists "in residence"
- Both work to promote the arts as health-enhancing

Creative Expression

Art Therapy

(painting by Lester E. Potts, Jr.)

- Mental health profession that uses the creative process of art making to improve and enhance physical, mental & emotional well-being
- Based on the belief that the creative process involved in artistic self-expression helps people to resolve conflicts & problems, develop interpersonal skills, manage behavior, reduce stress, increase self-esteem & self-awareness, & achieve insight – (American Art Therapy Association)

Creative Expression

- **Art Therapy**
  - From 1980-2013, 4 randomized controlled trials of art therapy reported clinically relevant outcomes in treating behavioral, social, cognitive, and/or emotional problems of dementia patients and/or their caregivers
  - Artistic engagement may improve behavioral symptoms and the quality of life in PWD
  - Provides safe ways to **express, process, and begin to make sense of traumatic experiences**, potentially turning the negative to the positive through art making

Creative Expression

- Memories in the Making, a fine arts program for people with early or moderate dementia –
  - Improved attention
  - Improved affect
  - Improved self-esteem
- Participants demonstrated more interest, sustained attention, pleasure, and self-esteem during art therapy than during the control activity

Creative Expression

- 2 small trials assessed the effects of art therapy to life outside the studio, finding diminished apathy and improved patients' quality of life
- In a UK study, over 40 weeks, the art group showed improvements in physical competency, mental acuity, sociability, and calmness
- **Meet Me at MoMA** – museum art appreciation program for PWD and caregivers – compared with controls, 55% of PWD showed ↑ mood and 27% showed ↑ self esteem that lasted several days in 9 month program

Creative Expression

Art therapy – why might it help PWD?

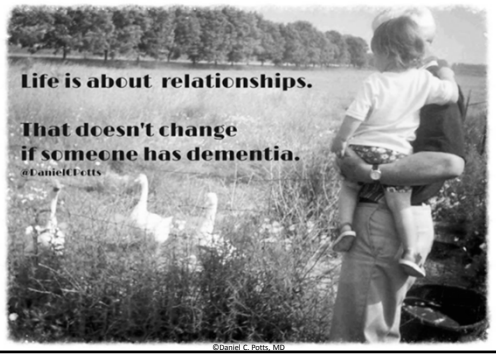
- Relies on preserved abilities rather than attempting to correct disabilities
- Provides a vehicle for emotional expression in people who have trouble communicating
- Can engender a state of 'flow', which is associated with a sense of well-being
- Promotes social interaction, combating isolation**,** giving a sense of ownership & belonging
- Helps overcome apathy and hopelessness and engages the senses; draws one into the present (mindfulness)

Expressive Arts Therapy And Story

- Person-centered, validating care is the standard
- Such care helps to preserve the sense of self
- Preservation of the self requires that an individual be cognizant of his/her life story, and be able to relate it in some way, to some extent
- ***Expressive arts therapies can help people maintain awareness of their life stories, and can aid in life story expression***

The Greatest Loss ?

- The ***loss of relationship***
- **This does not have to be so**



Bringing Art To Life!

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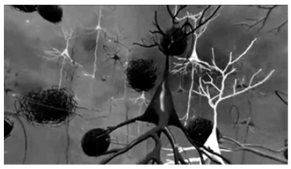
Bringing Art to Life

Giving back
Paying it forward
2011 - present

Bringing Art to Life Goals and Objectives

- To facilitate a dignifying experience for participants & families
- To elicit/preserve life stories of persons with Dementia
- To educate students on Dementia, including person-centered care
- To facilitate intergenerational communication, understanding & empathy
- To showcase the life stories & artistic accomplishments of the participants for their families, care givers and communities

Bringing Art to Life – The Virtual Dementia Tour & Embodied Labs



Bringing Art to Life – Art Therapy

Mindfulness: Being Present

Show up – mind, body, and spirit – engaged, actively listening, and fully attentive

We should always look people in the eyes when they are sharing their stories.
We should realize that they may be sharing their stories without using words.

"When the face of the other (especially the suffering face) is received and empathized with, it leads to transformation of our whole being…We are mirrored into life, not by concepts, but by faces delighting in us, giving us the beloved self-image we can't give to ourselves. Love is the gaze that does us in.

How blessed are those who...receive it deeply."

- Richard Rohr

Bringing Art to Life Credo:

Each person is born with and retains innate value and dignity despite conditions or circumstances.

Bringing Art to Life - Supporting Personhood

- We need to create, to be productive, to be independent, to be loved, and to be in community with others who understand us *(Relational identity) (interpersonal neurobiology)*
- We need to be able to share our own life stories and experience the life stories of others
- A kind word spoken, a gentle touch, smiling eye contact, the sharing of a story or song, and communicating in ways that affirm people in their present condition all validate personhood and foster its expression
- ***When personhood is strengthened, Dementia's hold is weakened***

Personhood

- For maintaining relationship with a person who has dementia, it is essential to preserve and validate elements of ***personhood*** upon which relationship can be preserved
- Searching for the inherent personhood within each individual is really about searching for the ***divine identity*** within each individual

Personhood

The light of personhood
always dispels the darkness
of any human condition

Dr. James M. Houston on Personhood

Tapping Into the Self

The beauty and relational energy ***inside the very one*** with the condition can often provide the fuel and inspiration for meaningful relationship

Did You Know Me Then?

Reminiscence
(Hartman-Stein et al., 2011)

- Reminiscence is core to human nature; we reminisce with an eye to the present and future
- For the young, reminiscence builds a continuous sense of identity and purpose in life
- For the old, it provides a source of comfort, closeness to others, and an opportunity for legacy

If You Would Know Me
You Must Know My Story…

- What's your favorite color?
- What do you like to eat?
- Let's sing your favorite song.
- Tell me about someone who loves you (you love).
- What does home look like?
- What are your hobbies?
- Do you like children and pets?
- What do you do for fun?
- "The Lord is my Shepherd…"

Reminiscence – Life Review
(Hartman-Stein et al., 2011)

- "I conceive of life review as a naturally occurring, universal mental process characterized by the progressive return to consciousness of past experiences, and, particularly, the resurgence of unresolved conflicts; simultaneously, and normally, these revived experiences and conflicts can be surveyed and reintegrated … "
- "The life review, as a looking-back process that has been set in motion by looking forward to death, potentially proceeds toward personality reorganization. Thus, life review is not synonymous with, but includes reminiscence… " – Robert Butler, 1963

Reminiscence
(Hartman-Stein et al., 2011)

- Life review core principles:
  - *Principle 1* – Older adults can handle the tough stuff
  - *Principle 2* – Telling the story is the most important part
  - *Principle 3* – Truth as fact is secondary in life review
- Reviewer - person telling his or her story
- Interviewer (therapeutic listener) – actively listens to the reviewer's story
- The power of story lies in the act of telling and the human interaction that surrounds it

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Do You Know Me Now?



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Do You Know Me Now?

Dipping into the well of the self and spreading those colors across the canvas of the now

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Denial

Has To Go

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The True Self

"Because you're not
what I would *have you* be,
I blind myself
to who, *in truth* …
YOU ARE."

- Madeleine L' Engle

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A Law for Relationships

- Less Ego. More **Empathy.**

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Shame and Story

- Alzheimer's may feed a sense of shame in those with the disease
- This must be countered with life-affirming, person-centered, compassionate care rooted in love and respect for humanity

Emotional Memory in Alzheimer's

- University of Iowa - September 2014 issue of *Cognitive and Behavioral Neurology*
- Individuals with Alzheimer's disease were shown clips of sad and happy movies
- Sustained states of sadness and happiness were observed despite not being able to remember the movies
- The less the patients remembered about the films, the longer their sadness lasted
- *"Caregivers have a profound influence—good or bad—on the emotional state of individuals with Alzheimer's disease. Patients may not remember a recent visit by a loved one or having been neglected by staff at a nursing home, but those actions can have a lasting impact on how they feel."*

How Do We Engage?

- Be present
- Be mindful
- Be quiet
- Leave behind the ego
- Be spiritually intentional
- Listen
- Be non-judgmental
- Join the reality – enter the world
- Focus on the pillars
- Laugh, cry, play, create

Engaging at a Spiritual Level

- If people are engaged at a spiritual level, meaningful relationship will result
- This is not dependent on the cognitive state of the ones participating in the relationship

What is Required of Us?

- Vulnerability, openness, acceptance, change and a willingness to see through the curtain of Dementia ***to find the person who still lives there***

Keeping Hope Alive On The Journey

Promotion of Living Well

- Laugh
- Reminisce and tell stories (and preserve them)
- Tap into creativity
- Honor personhood
- Stay in the Moment
- Start and end the day with gratitude
- Be spiritually intentional
- Allow your loved one (and yourself) some closure
- Practice forgiveness (self, others, and God)

Keeping Hope Alive On The Journey
Promotion of Living Well

- Reach out to others
- Love the one who is in front of you
- Care giving is not all about ***giving***
- Enjoy nature, children, pets
- Draw inspiration from the one with dementia
- Pass no judgements, have no expectations
- Know that we all are doing the best that we can under the circumstances
- Remember the good, forget the bad

Bringing Art to Life – Honoring Stories

"*Owning our story*
and **loving ourselves**
through that process
is the bravest thing
that we will *ever* do."

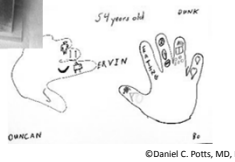
-Brene´Brown

Mindful listening and empathy are the most important gifts healthcare practitioners can offer to their patients.

@DanielCPotts

Bringing Art to Life – LifeBio.com Legacy Books

Bringing Art to Life Art



Bringing Art to Life Moments

"We love you."

"A friendly smile and a handshake don't cost a dime."

"I can't believe I can feel colors again."

Something special in a song…

Bouncing balloons at the end of art therapy

"What's your favorite Holiday?"
"A day like today."

Bringing Art to Life Research

Alabama Research Institite on Aging

- **Ivey, K. D.,** Allen, R. S., Gately, S., Westmoreland, J., Mayer, E., Myrick, J., Potts, D. C. (2016). *Intergenerational Service Learning with Individuals with Dementia: Outcomes and Principles.* Submitted for presentation at the Gerontological Society of America in New Orleans, LA and the Alzheimer's Association Conference in Toronto, ON, Canada.
- **Carden, K. D.,** Allen, R. S., Gately, S., Westmoreland, J., Mayer, E., Myrick, J., Potts, D. C. (April, 2016). *Bringing Art to Life (BATL) Preliminary Student Learning Outcomes: Experiential learning, didactic learning, and general principles.* Accepted for presentation at the Student Mentoring Conference in Pensacola, Fl.
- **Carden, K. D.,** Potts, D. C., Broman, E., Gately, S., Winton, E., Fields, M., Allen, R. S. (November, 2015) Bringing Art to Life (BATL) – A Mixed Methods Pilot: "…there is still a lot more to life even after the memories fade." Presented at the Gerontological Society of America Conference in Orlando, FL.
- Potts, D. C., **Carden, K. D.,** Broman, E., Myrick, J., Gately, S. M., Sanders, B., Allen, R. S., (July, 2015). *Cognitive Dynamics: Bringing Art to Life.* Presented at the Alzheimer's Association International Conference in Washington D. C.
- **Carden, K. D.,** Allen, R. S., Gately, S. M., McCrorie, C., Potts, D. C. (Invited talk: March 2015). *The Effectiveness of an Intergenerational Service Learning Course and Visual Art Therapy Intervention on College Students, Persons with Alzheimer's Disease and Dementia, and Caregivers.* Presented at Southeastern Chapter of the Association for Contextual and Behavioral Science conference in Lafayette, LA.

Bringing Art to Life Research

Keisha Carden Ivey, M.A, Dr. Rebecca Allen, Dr. Anne Halli-Tierney
Alabama Research Institute on Aging

Research Findings to Date:

- Students exhibited improved attitudes towards persons with Dementia
- Students' attitudes towards community service were improved
- Students showed greater increases in empathy

Qualitatively, Participants

- Enjoy being with the students, creating art & sharing stories
- Feel a sense of pride and accomplishment
- Exhibit improved communication skills
- Care partners report a lower burden of care, with uplifts

Building on Success

- ***Bringing Art to Life*** **Chicago**

Building on Success

- ***Art to Life*** **Outreach**

Bringing Art to Life – Lessons Learned

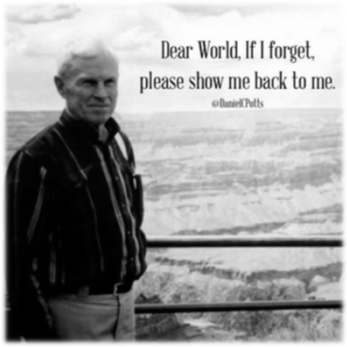
- Dignity and personhood are not affected by Dementia
- Openness, vulnerability, and non-judgement are required of us
- Enter the shared world and validate
- Leave behind ego, embrace empathy
- Be fully present
- Listen mindfully
- Search for pillars of personhood
- Practice patience and kindness
- Just be human
- Laugh, sing, dance, create, play and share stories
- Find joy in the journey

What is this really about?

- **The light of the human spirit burning brightly regardless of circumstances**
- **The kindling of that light in others**
- **The resulting gift of relationship**

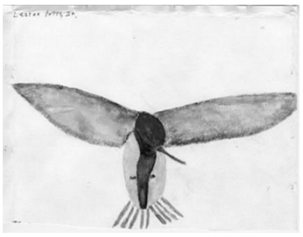
"Life is about relationships." – Dr. James Houston
Art to Life is about creating a culture of compassion

"We Became One Person"



Lester's Legacy

Finding the Artist Within



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Lester's Legacy – Dementia Care

- The arts & creativity are powerful tools that help people living with dementia share their stories
- Personhood is not diminished by the loss of cognition
- Relationships can be maintained with people who have dementia at any stage
- The beauty & relational energy inside the very one living with the disease can often provide the fuel & inspiration for meaningful relationship
- Validating, person-centered care utilizing creative expression should be made available to everyone who is living with dementia
- We must do our part to create a culture of compassion

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Lester's Legacy – The Greater Gift

- We are all artists, born to create beautiful & significant things (art)
- Our art is often discovered through hardship
- Beauty & truth in you begets beauty & truth in me (& vice versa)
- Authenticity is more beautiful than perfection
- Believing in one another enables us to become our True (best) selves
- Courage & vulnerability are required of us to be in relationships with people who have dementia, but empathic transformation results
- Resume Virtues vs. Eulogy Virtues – David Brooks, *The Road to Character*

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What Lester Gave to Me

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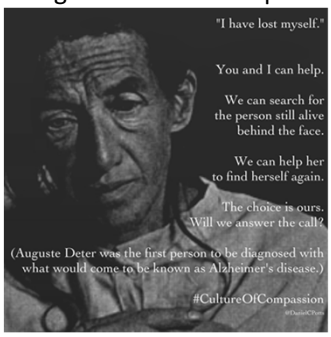
Relationships Never Die

Daniel C. Potts, MD, FAAN

Creating a Culture of Compassion



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Summary

- Expressive arts therapies and person-centered care enhanced Lester Potts's quality of life, promoted cognitive and functional stability, emotional and behavioral improvement, and delayed institutionalization
- The spirit and gifts of Lester Potts, a person with Alzheimer's, revealed through art and relationships, continue to inspire
- Expressive arts therapies and creativity have well documented benefits in the elderly and those with cognitive impairment
- Nothing, not even Dementia, can steal identity
- Life is about relationships. This doesn't change if someone has dementia
- We can mindfully connect with persons who have Dementia, at any stage, through artistic creativity

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- LifeBio.com - https://www.lifebio.com/
- Music and Memory Foundation - http://musicandmemory.org
- Cognitive Dynamics Foundation - www.cognitivedynamics.org

THANK YOU!

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*Member, Alzheimer's Association, Alzheimer's Foundation of America
*Architect of Change, MariaShriver.com

Jointly Provided by

33rd Annual Alzheimer's Disease Management & Research Symposium

August 15-16, 2019
The Clayton Center, Maryville College
502 E Lamar Alexander Parkway
Maryville, TN 37804

Early Onset Alzheimer's Disease: Early Diagnosis and Treatment Modalities

August 16
11:00 AM - 12:00 PM

Monica Crane, MD
Medical Director, Genesis Neuroscience Clinic
Knoxville, TNAL

Alzheimer's disease: a model of multiple system failure

Monica K. Crane, MD
Medical Director
Genesis Neuroscience Clinic
Assistant Professor, Dept. of Medicine, UTMCK and UTHSC

GENESIS Neuroscience Clinic

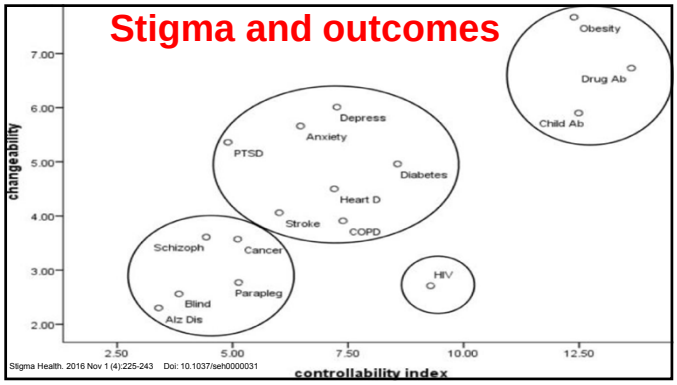
Disclosures

- Research support:
  - Biogen, Eli Lily, American College of Radiology
- Outreach:
  - Society for Nuclear Medicine and Molecular Imaging Outreach Workgroup
  - Alzheimer's Tennessee

Cancer or Dementia

Genetic or sporadic	Genetic or sporadic
Stages: Preclinical Early symptomatic Symptomatic phase	Stages: Preclinical Early symptomatic Symptomatic phase
Abnormal cell growth Spread from cell to cell	Abnormal protein aggregation Spread from cell to cell

Stigma and outcomes

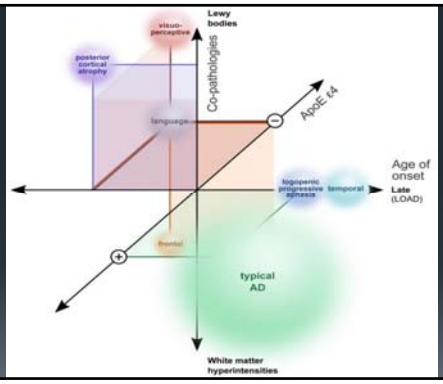


Stigma Health. 2016 Nov 1 (4):225-243 Doi: 10.1037/seh0000031

DEMENTIA SYNDROMES

Alzheimer's disease	Lewy Body Disease	Frontotemporal Dementia	Vascular dementia
Posterior Cortical Atrophy (PCA)Alz	Lewy Body Variant Alzheimer's disease (LVBAD)	Corticobasal degeneration	Behavioral variant FTD
Logopenic Aphasia	MIXED DEMENTIA	Progressive Supranuclear Palsy	FTD with MND
Parkinson's disease with dementia		Progressive Nonfluent Aphasia	Semantic dementia
			CTE

New Framework:



*Alzheimer's Research & Therapy*20135:1
https://doi.org/10.1186/alzrt155

The five subtypes of Alzheimer's Disease (AD)

AD(40-60%)

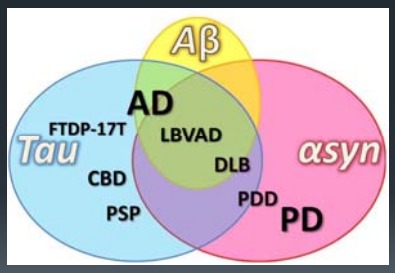
1. Typical Late Onset
2. Mixed
3. Logopenic PPA
4. Posterior cortical atrophy (PCA)
5. Frontal variant AD (nonamnestic)
6. Early Onset

Lewy Body Subtypes (15-25%)

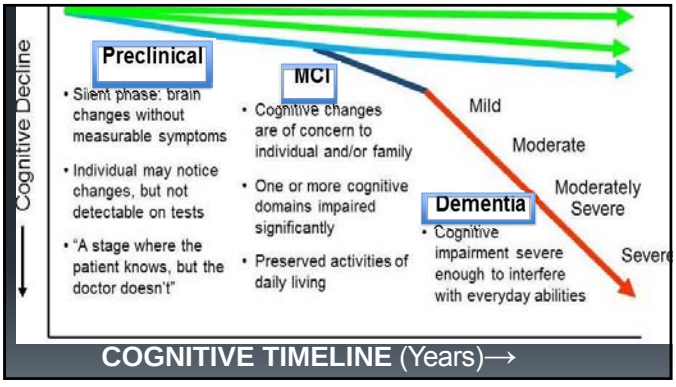
Frontotemporal dementias (5-10%)

Vascular subtypes (5-20%)

Alzheimer's is a mixed bag



Courtesy of Molecular Neurodegeneration 9(1):43 · October 2014

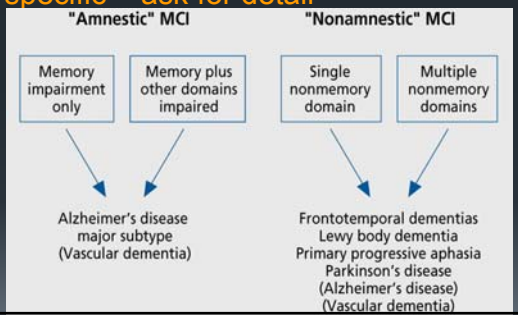


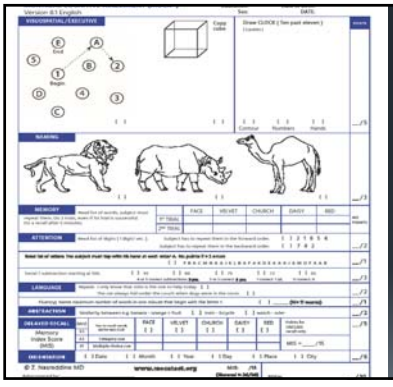
How do we screen for symptomatic cognitive impairment?

- Listen to the story and examine people
- Paper and pencil testing
- Imaging/ Biomarkers

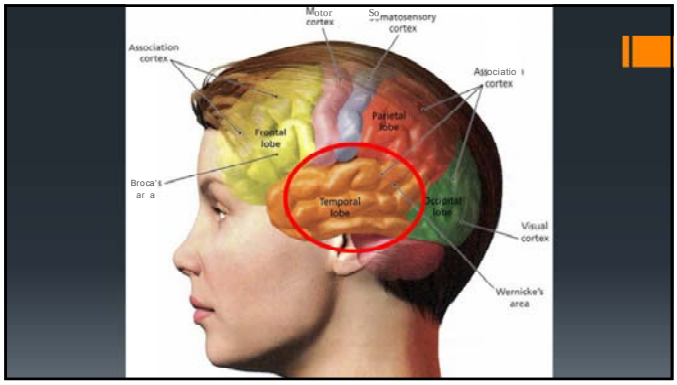
Dickerson. Advances in quantitative magnetic resonance imaging-based biomarkers for Alzheimer disease. *Alzheimer's Research & Therapy* 2010; 2:21
Meyer et al. Diagnosis-dent Alzheimer Disease Biomarker Signature in Cognitively Normal Elderly People. *Arch Neurol* 2010;67:949-955.

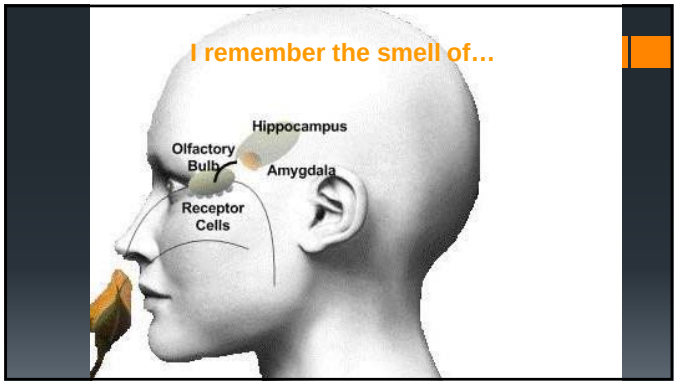
Memory loss or forgetfulness is not specific – ask for detail



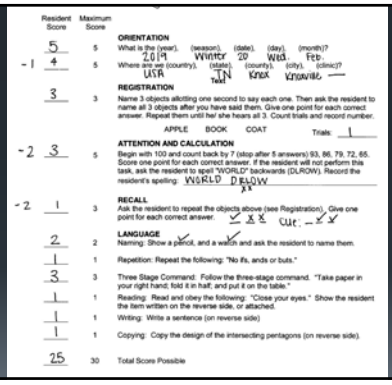


www.mocatest.org



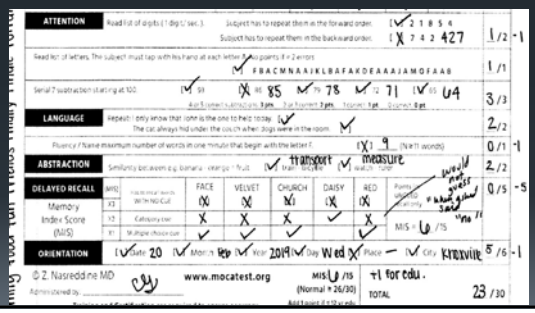


Case 1



Resident Score	Maximum Score	
5	5	**ORIENTATION** What is the (year), (season), (date), (day), (month)? 2019 Winter 20 Wed. Feb.
-1 4	5	Where are we (country), (state), (county), (city), (clinic)? USA TN Knox Knoxville —
3	3	**REGISTRATION** Name 3 objects allotting one second to say each one. Then ask the resident to name all 3 objects after you have said them. Give one point for each correct answer. Repeat them until he/ she hears all 3. Count trials and record number. APPLE BOOK COAT Trials: 1
-2 3	5	**ATTENTION AND CALCULATION** Begin with 100 and count back by 7 (stop after 5 answers) 93, 86, 79, 72, 65. Score one point for each correct answer. If the resident will not perform this task, ask the resident to spell "WORLD" backwards (DLROW). Record the resident's spelling: WORLD DELOW
-2 1	3	**RECALL** Ask the resident to repeat the objects above (see Registration). Give one point for each correct answer. ✓ X X cue: — ✓ ✓
2	2	**LANGUAGE** Naming: Show a pencil, and a watch and ask the resident to name them. ✓ ✓
1	1	Repetition: Repeat the following: "No ifs, ands or buts."
3	3	Three Stage Command: Follow the three-stage command. "Take paper in your right hand; fold it in half, and put it on the table."
1	1	Reading: Read and obey the following: "Close your eyes." Show the resident the item written on the reverse side, or attached.
1	1	Writing: Write a sentence (on reverse side)
1	1	Copying: Copy the design of the intersecting pentagons (on reverse side).
25	30	Total Score Possible

Case 1 diagnosis: Functional/ Mood disorder



ATTENTION — Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order. [✓] 2 1 8 5 4. Subject has to repeat them in the backward order. [X] 7 4 2 427. 1/2 -1

Read list of letters. The subject must tap with his hand at each letter A. No points if > 2 errors. ✓ F B A C M N A A J K L B A F A K D E A A A J A M O F A A B. 1/1

Serial 7 subtraction starting at 100. [✓] 93 [X] 86 85 [✓] 79 78 [✓] 72 71 [✓] 65 64. 4 or 5 correct subtractions: 3 pts; 2 or 3 correct: 2 pts; 1 correct: 1 pt; 0 correct: 0 pt. 3/3

LANGUAGE — Repeat: I only know that John is the one to help today. [✓] The cat always hid under the couch when dogs were in the room. ✓. 2/2

Fluency / Name maximum number of words in one minute that begin with the letter F. [X] 9 (Norm words). 0/1 -1

ABSTRACTION — Similarity between e.g. banana - orange - fruit: [✓] train - bicycle [✓] watch - ruler. transport ✓ measure. 2/2

DELAYED RECALL — Memory Index Score (MIS). Points for UNCUED recall only.

	FACE	VELVET	CHURCH	DAISY	RED
X3 Multiple choice cue	✓	✓	✓		✓
X2 Category cue	X	X	X	✓	X
X1 Free recall WITH NO CUE	(X)	(X)	(X)	(X)	(X)

MIS = 6 /15. 0/5 -5

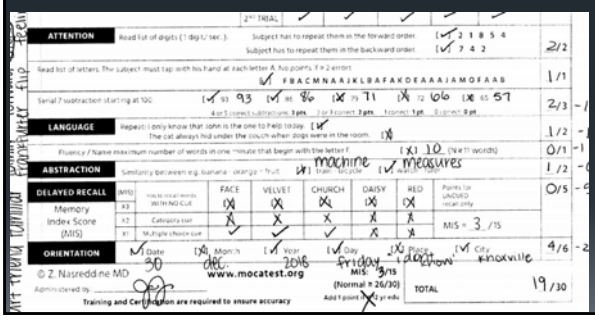
ORIENTATION — [✓] Date 20 [✓] Month Feb [✓] Year 2019 [✓] Day Wed [X] Place — [✓] City Knoxville. 5/6 -1

© Z. Nasreddine MD. Administered by: ____. www.mocatest.org. MIS 6 /15 (Normal = 26/30). Add 1 point if ≤ 12 yr edu. +1 for edu. TOTAL 23 /30

Case 2

Score	Score	
5	5	**ORIENTATION** What is the (year), (season), (date), (day), (month)? 2019 fall 30 Friday Nov. Where are we (country), (state), (county), (city), (clinic)? USA TN knox Knoxville Dr. Crane
3	3	**REGISTRATION** Name 3 objects allotting one second to say each one. Then ask the resident to name all 3 objects after you have said them. Give one point for each correct answer. Repeat them until he/ she hears all 3. Count trials and record number. APPLE BOOK COAT Trials: 1
5	5	**ATTENTION AND CALCULATION** Begin with 100 and count back by 7 (stop after 5 answers) 93, 86, 79, 72, 65. Score one point for each correct answer. If the resident will not perform this task, ask the resident to spell "WORLD" backwards (DLROW). Record the resident's spelling: dlrow
-3 0	3	**RECALL** X X X w/cues x book jacket. Ask the resident to repeat the objects above (see Registration). Give one point for each correct answer.
2	2	**LANGUAGE** pen/watch. Naming: Show a pencil, and a watch and ask the resident to name them.
-1 0	1	Repetition: Repeat the following: "No ifs, ands or buts."
3	3	Three Stage Command: Follow the three-stage command. "Take paper in your right hand; fold it in half; and put it on the table."
1	1	Reading: Read and obey the following: "Close your eyes." Show the resident the item written on the reverse side, or attached.
1	1	Writing: Write a sentence (on reverse side)
-1 0	1	Copying: Copy the design of the intersecting pentagons (on reverse side).
25	30	Total Score Possible

Case 2: Early onset AD



2nd TRIAL ✓ ✓ ✓ ✓ ✓

ATTENTION — Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order. [✓] 2 1 8 5 4. Subject has to repeat them in the backward order. [✓] 7 4 2. 2/2

Read list of letters. The subject must tap with his hand at each letter A. No points if > 2 errors. ✓ F B A C M N A A J K L B A F A K D E A A A J A M O F A A B. 1/1

Serial 7 subtraction starting at 100. [✓] 93 93 [✓] 86 86 [X] 79 71 [X] 72 66 [X] 65 57. 4 or 5 correct subtractions: 3 pts; 2 or 3 correct: 2 pts; 1 correct: 1 pt; 0 correct: 0 pt. 2/3 -1

LANGUAGE — Repeat: I only know that John is the one to help today. [✓] The cat always hid under the couch when dogs were in the room. [X]. 1/2 -1

Fluency / Name maximum number of words in one minute that begin with the letter F. [X] 10 (Norm words). 0/1 -1

ABSTRACTION — Similarity between e.g. banana - orange - fruit: [✓] train - bicycle [✓] watch - ruler. machine ✓ measures. 1/2 -1

DELAYED RECALL — Memory Index Score (MIS). Points for UNCUED recall only.

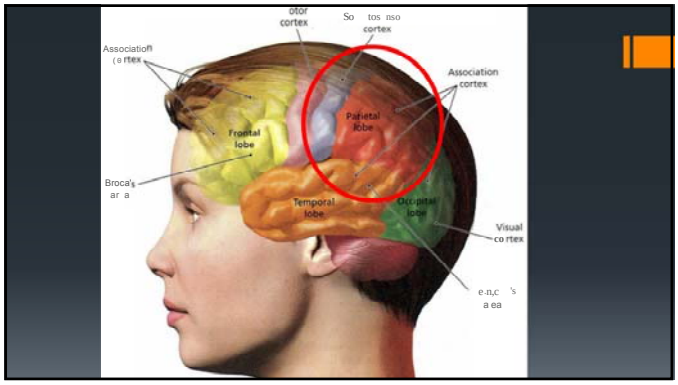
	FACE	VELVET	CHURCH	DAISY	RED
X3 Multiple choice cue	✓	✓	✓	✓	✓
X2 Category cue	X	X	X	X	X
X1 Free recall WITH NO CUE	(X)	(X)	(X)	(X)	(X)

MIS = 3 /15. 0/5 -5

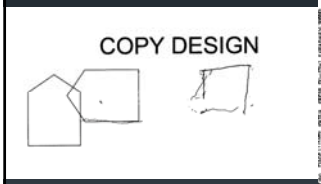
ORIENTATION — [✓] Date 30 [X] Month Dec [✓] Year 2018 [✓] Day Friday [X] Place Clinton [✓] City Knoxville. 4/6 -2

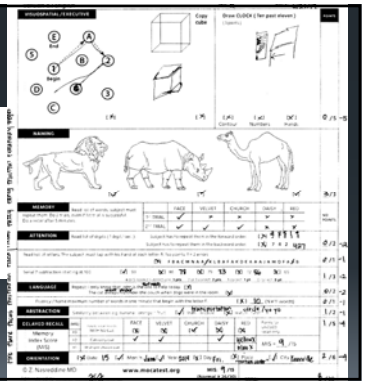
© Z. Nasreddine MD. Administered by: ____. www.mocatest.org. MIS: 3/15 (Normal ≥ 26/30). Add 1 point if ≤ 12 yr edu. TOTAL 19 /30

Training and Certification are required to ensure accuracy



Case 3: PCA

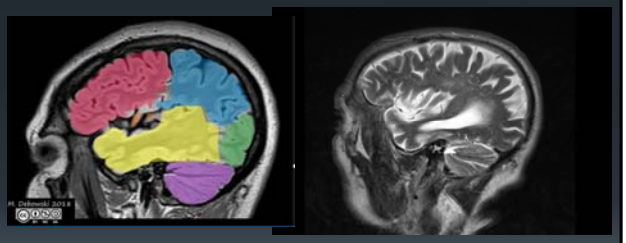




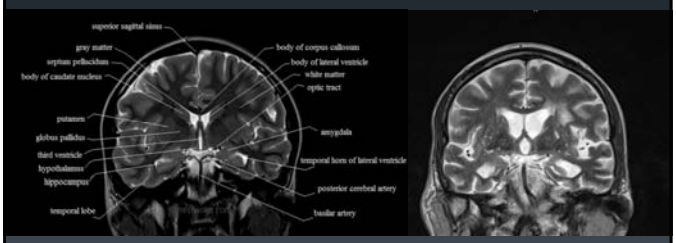
And ask radiologist to make 4 specific comments:

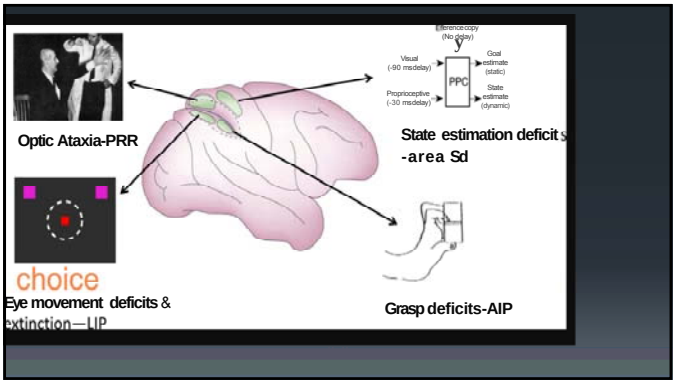
- **1. Global cortical atrophy (GCA scale)**
- **2. Medial temporal lobe atrophy (MTA score)**
- **3. Posterior atrophy score for parietal atrophy (Koedam score)**
- **4. Fazekas scale for white matter lesions**

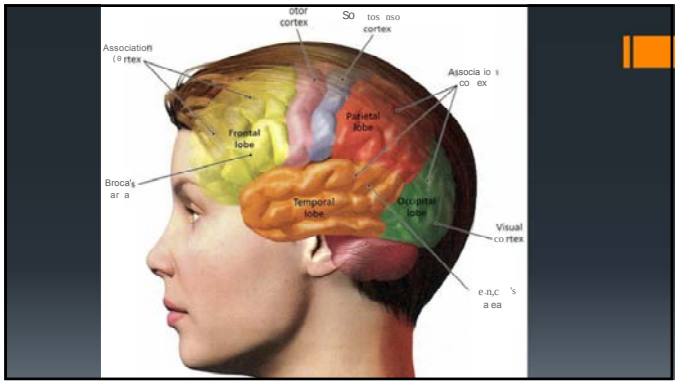
Look at your MRI sagittal views



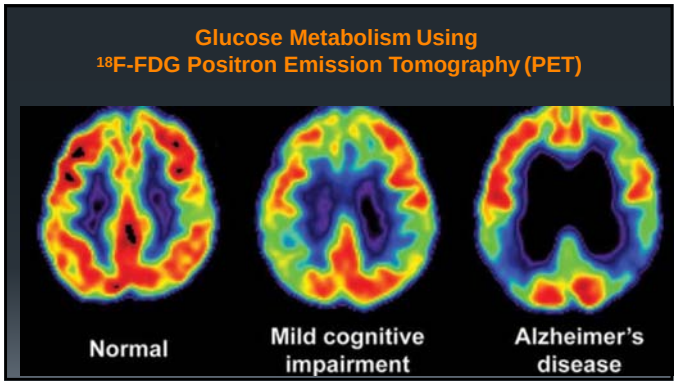
What is missing?







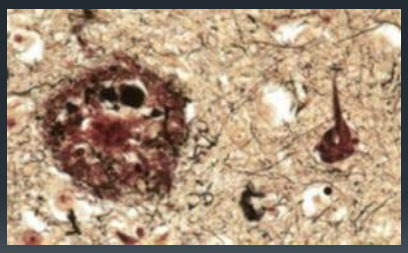
Glucose Metabolism Using ^{18}F-FDG Positron Emission Tomography (PET)



IDEAS Study

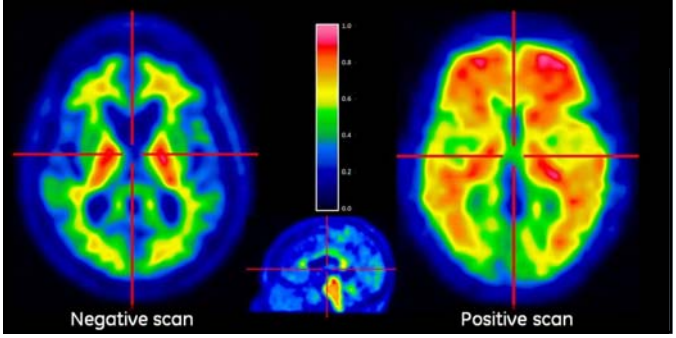
- Imaging Dementia-Evidence for Amyloid Scanning (IDEAS) Study:
  A Coverage with Evidence Development Longitudinal Cohort Study
- Directed by: Alzheimer's Association
- Sponsored & Managed by: American College of Radiology Imaging **(ACR)** American College of Radiology Imaging **Network (ACRIN)**
- Advised by: Centers for Medicare & Medicaid Services (CMS)
- Tracer Agnostic: All tracers can be used
  - florbetaben *(Neuraceq*, Piramal Imaging)
  - florbetapir *(Amyvid*, Eli Lilly and Company)
  - flutemetamol *(Vizamyl*, GEHealthcare)

Alzheimer 'Proteinopathy'

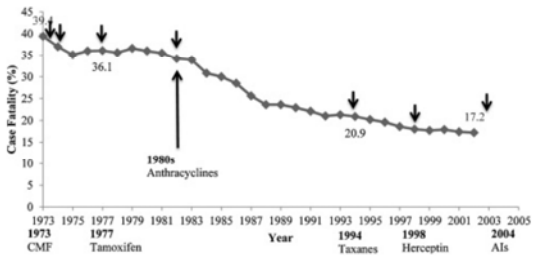


Serrano-Pozo **CSHPM** 2011

Amyvid (Amyloid scan) is a "virtual biopsy"

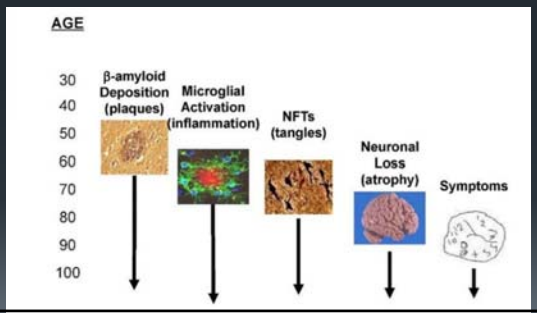


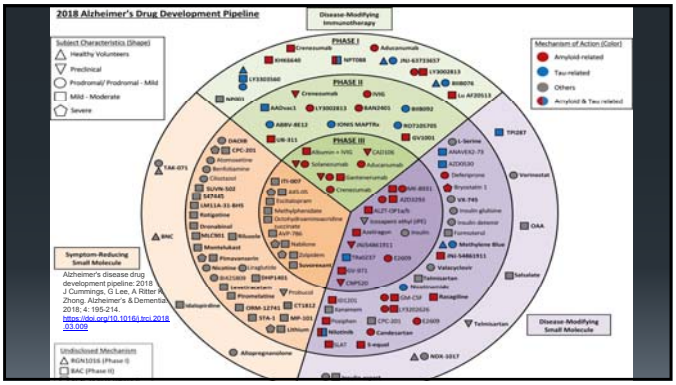
10-Year breast cancer case fatality and historical timeline of breast cancer chemotherapy.

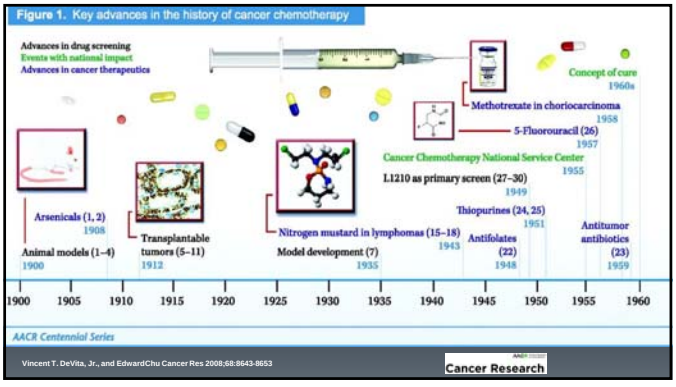


https://www.researchgate.net/profile/Anthony_Miller7/publication/277784730

Treatment: Depends on Age and Stage







1/3 of current Alzheimer's cases are from seven risk factors.

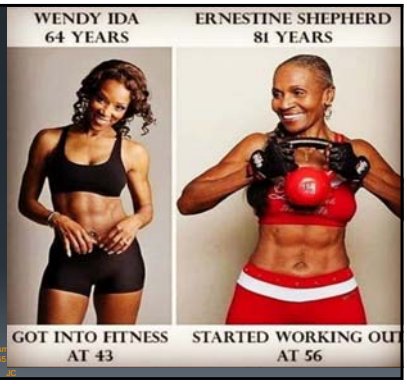
Fixable risk factors for MCI due to AD:

- Lack of exercise
- Midlife obesity & diabetes
- Low education
- Smoking, excess alcohol
- Hypertension, heart disease
- Depression
- Sleep Apnea

PAR, population attributable risk. Courtesy of Lancet Neurol. 2011 Sep; 10(9): 819–828.

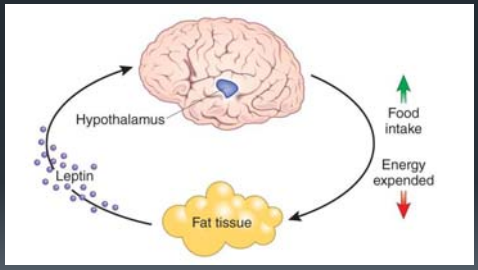
Exercise= brain health

- 4 hours per week minimum



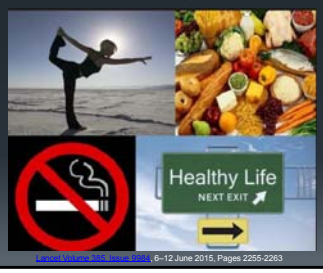
Exercise for cognitive brain health in aging Joyce Gomes Cem al. Neurology Clinical Practice June 2018 vol 8 no 3. 257-265 Smith et al.

"Midlife" adipose changes the brain



Gustafson DR, Bäckman K, Waern M, et al. Neurology. 2009;73(20):1559-66. Gustafson DR, Bäckman K, Joas E, et al. J Alzheimers Dis. 2012;29(1):163-71. Gustafson DR. J Alzheimers Dis. 2012;30 Suppl 2:S97-112.

FINGER study: Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability



Lancet Volume 385, Issue 9984 , 6–12 June 2015, Pages 2255-2263

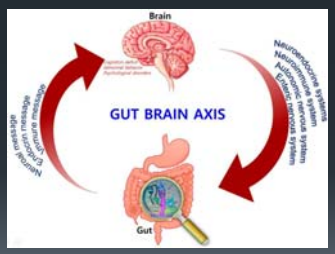
Mediterranean = GOOD BRAIN

www.rand.org Meta-analysis 1.5 million people, 35 studies

GENESIS Neuroscience Clinic

Food or edible things?

Gut microbiome



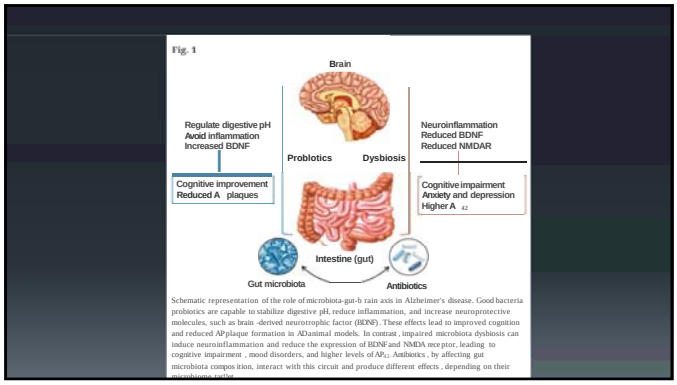
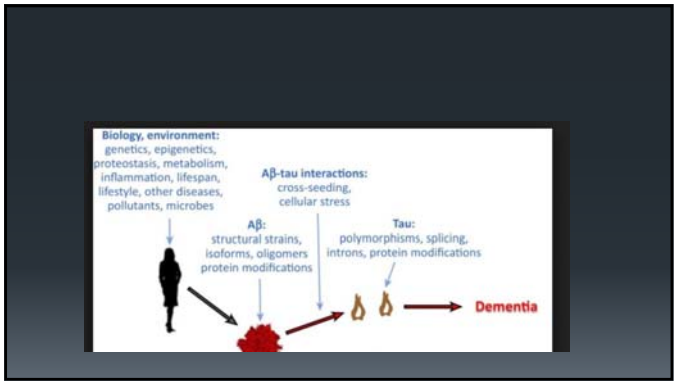
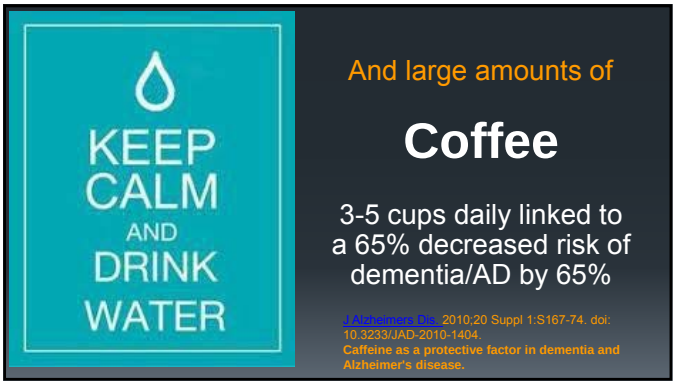


Fig. 1
Brain
Regulate digestive pH
Avoid inflammation
Increased BDNF
Cognitive improvement
Reduced A plaques
Problotics
Dysbiosis
Neuroinflammation
Reduced BDNF
Reduced NMDAR
Cognitive impairment
Anxiety and depression
Higher A 42
Intestine (gut)
Gut microbiota
Antibiotics
Schematic representation of the role of microbiota-gut-b rain axis in Alzheimer's disease. Good bacteria probiotics are capable to stabilize digestive pH, reduce inflammation, and increase neuroprotective molecules, such as brain -derived neurotrophic factor (BDNF) .These effects lead to improved cognition and reduced APplaque formation in ADanimal models. In contrast , impaired microbiota dysbiosis can induce neuroinflammation and reduce the expression of BDNFand NMDA receptor, leading to cognitive impairment , mood disorders, and higher levels of Ap42. Antibiotics , by affecting gut microbiota compos ition, interact with this circuit and produce different effects , depending on their


Biology, environment:
genetics, epigenetics,
proteostasis, metabolism,
inflammation, lifespan,
lifestyle, other diseases,
pollutants, microbes
Aβ-tau interactions:
cross-seeding,
cellular stress
Aβ:
structural strains,
isoforms, oligomers
protein modifications
Tau:
polymorphisms, splicing,
introns, protein modifications
Dementia


Coke
Diet
Coca-Cola
Classic



Statins decrease risk of Alzheimer's disease

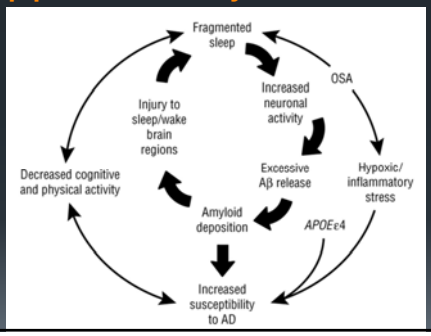
- Lipophilic statins decreased AD in white, Hispanics, and black women.
- Hydrophilic statins were associated with reduced risk of AD in white women.
- Review of ½ million UK patients, fungus derived and lipophilic statins were not associated with a decrease in AD as compared to synthetic and hydrophilic statins

Sinyavskaya L. Neurology 2018 Jan 16; 90 (3)
Zissimopoulos JM et al. JAMA Neurology 2016 Dec12.

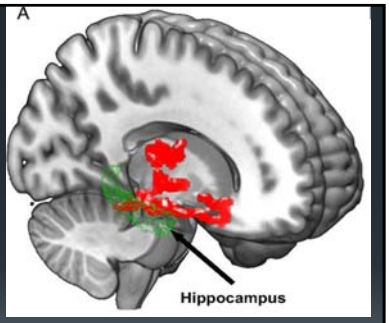
A wake-up call?

Neurology 2017; 89:419-420

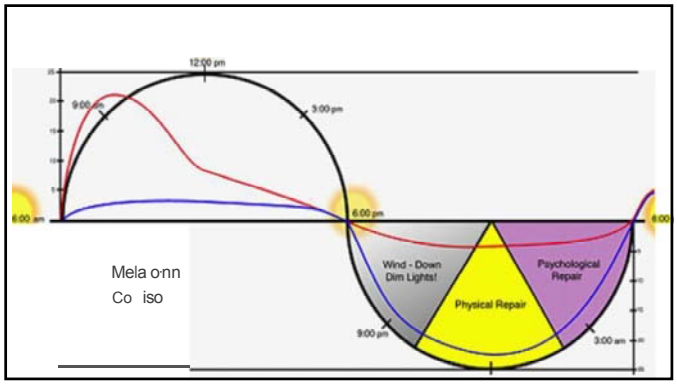
Sleep problems = amyloid= Alzheimer's



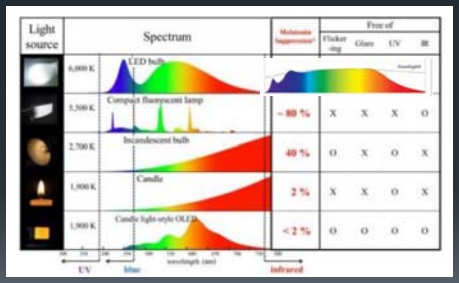
Increased beta-amyloid accumulation (red) after one night of sleep deprivation.



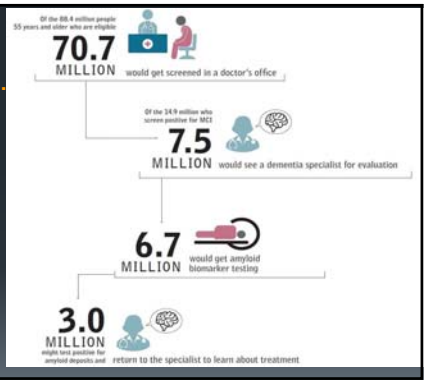
Courtesy of Proceeeding of the National Academy of Sciences.
Ehsan Shokri-Kojori et al. PNAS 2018;115:17:4483-4488
Effects of one-night SD on ABB. (A) Voxelwise paired t test between RW and SD conditions highlighting the hippocampus



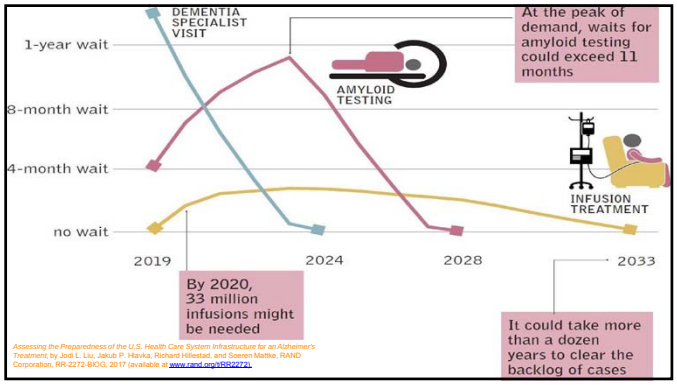
What about my Kindle, iPhone, TV, etc.?



If a cure was available today ... who will evaluate the millions?



RAND *Assessing the Preparedness of the U.S. Health Care System Infrastructure for an Alzheimer's Treatment*, by Jodi L. Liu, Jakub P. Hlavka, Richard Hillestad, and Soeren Mattke, RAND Corporation, RR-2272-BIOG, 2017 (available at www.rand.org/t/RR2272).



TODAY, we need at least 10,000 NEW healthcare providers to evaluate 7.5 million patients…

AND WITH ENOUGH CAPACITY FOR ALL ASPECTS OF CARE (DIAGNOSIS, TESTING, AND TREATMENT)

an additional

2.1 million people

might not develop

Alzheimer's dementia

You can't pour from an empty cup.

Take care of yourself.

GENESIS

Memory Assessment and Prevention Program (MAPP)

Jointly Provided by

33rd Annual Alzheimer's Disease Management & Research Symposium

August 15-16, 2019
The Clayton Center, Maryville College
502 E Lamar Alexander Parkway
Maryville, TN 37804

Living Well with Alzheimer's Disease: A Panel Discussion with Persons Living with Diagnosis

August 16
1:00 - 1:30 PM

Janice Wade-Whitehead
President & CEO
Alzheimer's Tennessee

Jointly Provided by

33rd Annual Alzheimer's Disease Management & Research Symposium

August 15-16, 2019
The Clayton Center, Maryville College
502 E Lamar Alexander Parkway
Maryville, TN 37804

Clinical Characteristic of Lewy Body Dementia and Frontotemporal Lobe Dementia

August 16
1:30 - 1:15 PM

Monica Crane, MD
Medical Director, Genesis Neuroscience Clinic
Knoxville, TNAL

The Tauopathies and Alphasynucleinopathies

Monica K. Crane, MD
Medical Director
Genesis Neuroscience Clinic

Clinical Assistant Professor, Dept. of Medicine, UTMCK and UTHSC

GENESIS Neuroscience Clinic

Disclosures

- Research support
  - Biogen, Eli Lily, American College of Radiology
- Community Outreach
  - Society for Nuclear Medicine and Molecular Imaging Outreach Workgroup
  - Provision Center for Biomedical Research
  - Alzheimer's Tennessee

GENESIS Neuroscience Clinic

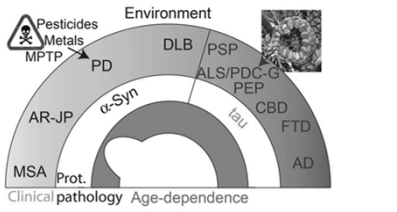
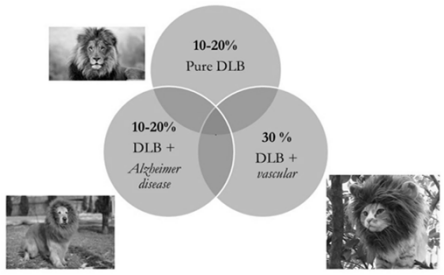
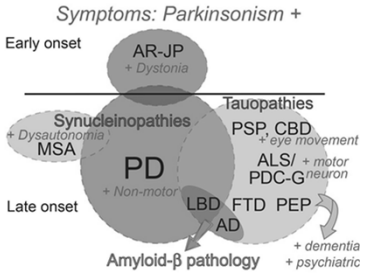


Figure 2 Visualisation of PD-related spectrum in a continuous arch. PD-related pathologies are arranged in an arch (orange) that shows subtle transitions in clinical symptoms. MSA is placed at one end of the spectrum because it is a unique systemic synucleinopathy with glial pathology. AD occupies the other end of the spectrum next to other dementias because parkinsonism is less common. The dominant protein pathology (α-syn or tau) is shown in the middle arch. In the centre (grey), the impact of age is shown, which is a strong determinant in all diseases, except for AR-JP. See figure 1 for abbreviations. α-syn, α-synuclein; MPTP, methyl-phenyl-tetrahydropyridine; Prot., protein.

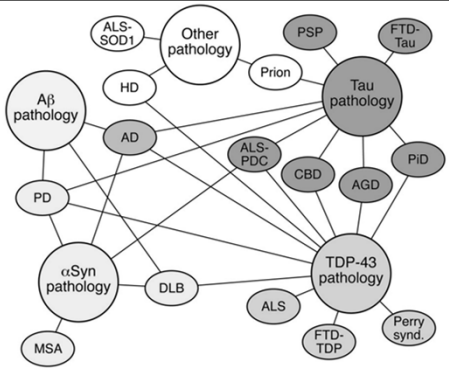


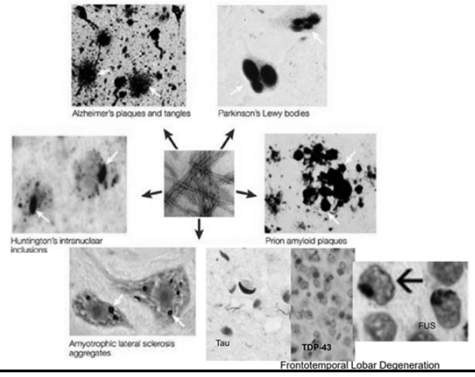
Symptom overlap among PD and related parkinsonian disorders. Parkinsonian disorders are represented as circles (not at scale) and the symptomatic overlap is shown.



Pei-Lan Zhang et al. J Med Genet 2018;55:73-80

JMG





Myths in movement disorders

These are:

- 1. Parkinson's Disease is one disease
- 2. Lewy Body Dementia is one disease
- 3. There is no overlap in dementia syndromes
-

Nomenclature of Lewy Body Disorders

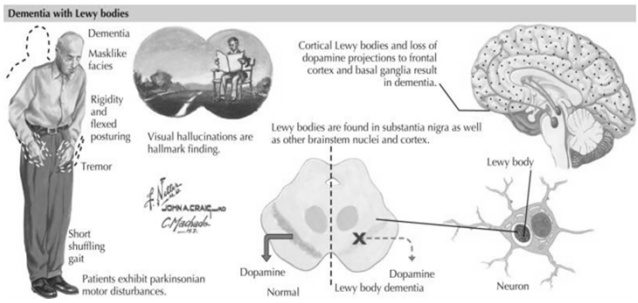
DLB/PDD Work Group (Lippa et al. 2007)

- Lewy body disorders
  - Parkinson's disease (PD)
  - Parkinson's disease with dementia (PDD)
  - Dementia with Lewy bodies (DLB)
- Distinction in temporal sequence of onset of motor symptoms and dementia in PDD and DLB retained in recent criteria (12 Month Rule)

(Does not really make sense)

Lewy Body Dementia

- Shuffling gait
- Axial rigidity
- May have a tremor (bilateral)
- Degeneration of autonomic system.
- Cortical atrophy similar to Alzheimer's disease.



Lewy Body Spectrum Symptoms

- Current visual hallucinations
- Visuospatial impairment (Stroop test, Clock face test)
- Executive function deficits (Nelson Card sort test)
- Parkinsonian motor features (mild gait impairments, resting tremor)
- Early extrapyramidal features (dystonia, akathisia, muscle rigidity, bradykinesia, tremor, tardive dyskinesia
- Fluctuating cognitive impairment (periods of coherence and alertness alternating with sequences of confusion and unresponsiveness)
- Attentional deficits
- Poor postural stability
- Neuroleptic sensitivity
- Orthostatic hypotension

Parkinson's disease (PD)

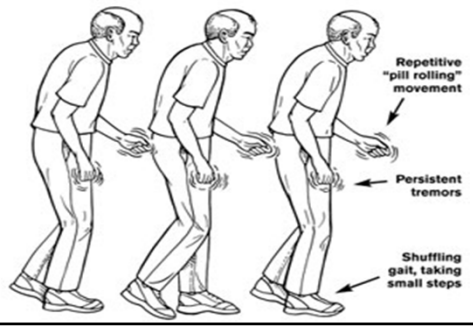
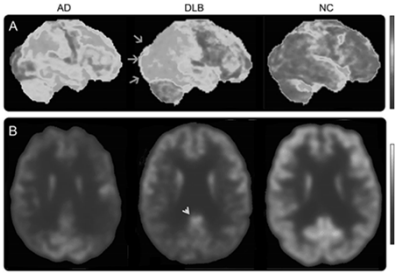
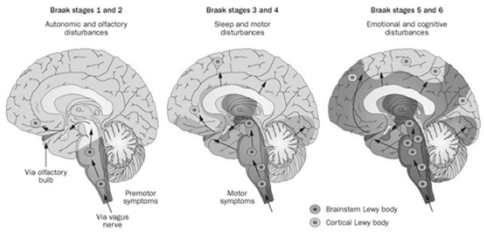


Figure 4 18F-FDG-PET images in Alzheimer disease (AD), dementia with Lewy bodies (DLB), and normal controls (NC)



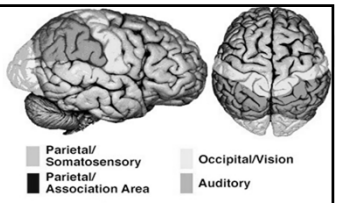
Ian G. McKeith et al. Neurology 2017;89:88-100

AMERICAN ACADEMY OF NEUROLOGY



The Spread of alpha-synuclein corresponding to the worsening of Symptoms in Parkinson's (Source: Doty et al. Nature Reviews Neurology 8(6) 329-39, doi: 10.1038/nrneurol.2012.80)

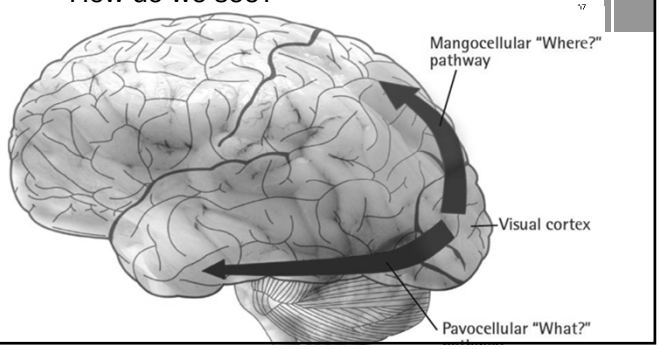
Balint's

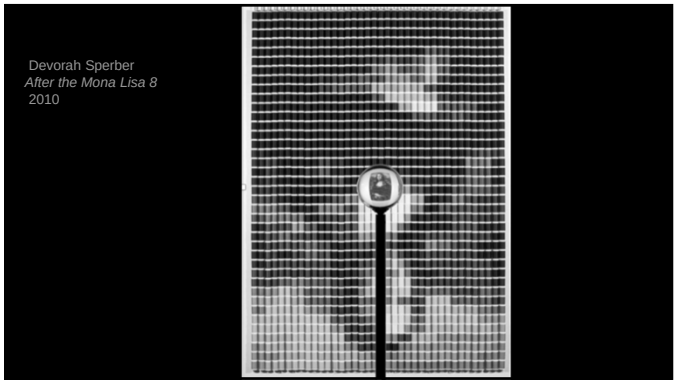


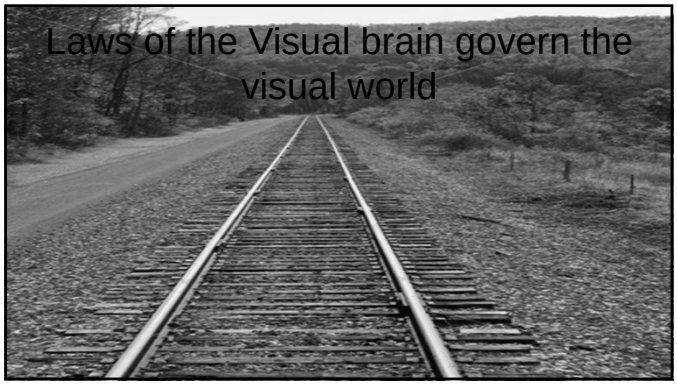
- Cautious gait
  - Hesitant, slow (looks shuffling)
  - With severe disease a gait apraxia occurs
- Visuospatial disorders
  - Visual misperceptions in AD, Lewy Body dementia, PDD

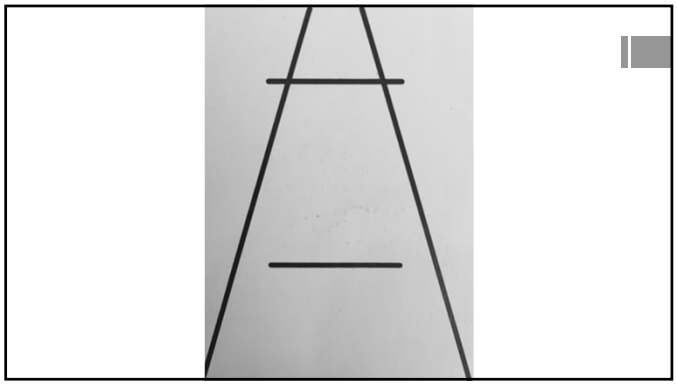
Vellas BJ, Wayne SJ, Romero LJ, Baumgartner RN, Garry PJ. Fear of falling and restriction of mobility in elderly fallers. Age and Ageing MB, Tinetti ME. Falls in community-dwelling older persons. JAGS. 1995;43:1146-1154.
Verghese J, LeValley A, Hall CB, Katz MJ, Ambrose AF, Lipton RB. Epidemiology of gait disorders in community-residing older adults. JAGS.

How do we see?

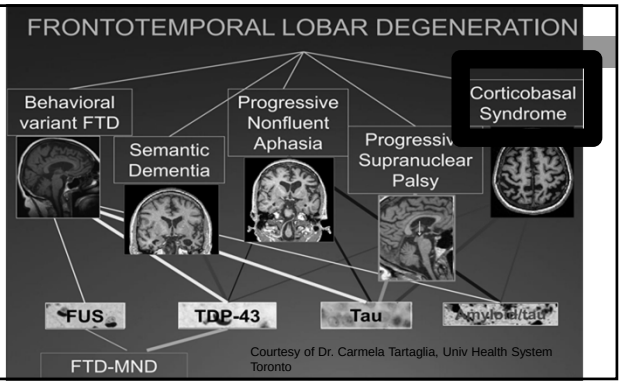





Laws of the Visual brain govern the visual world




LSVT BIG therapy
B. G. Farley and G. F. Koshland, "Training BIG to move faster: the application of the speed-amplitude relation as a rehabilitation strategy for people with Parkinson's disease," Experimental Brain Research, Vol. 167, no. 3, pp. 462–467, 2005.



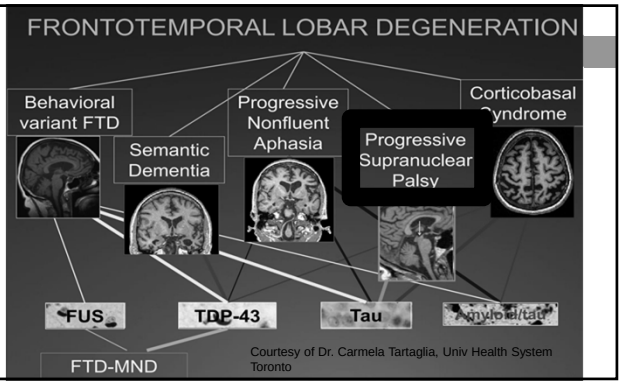
Corticobasal Degeneration (CBD) "Alien limb"

- Unable to use limbs for overlearned tasks (looks like stroke)
- Visual problems
- Muscle jerks (myoclonus)
- Asymmetric parkinsonism
- Speech problems

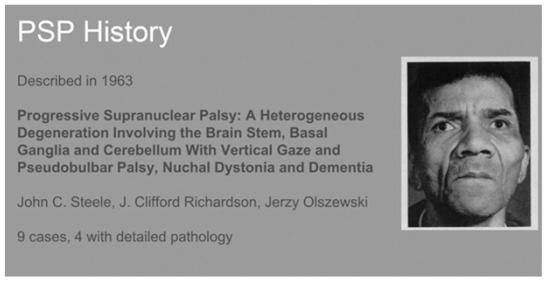
Dr. Strangelove (1964) actor Peter Sellars brought the alien limb syndrome to pop culture.

Corticobasal deneration (CBD or CBS)

- Gradual
- Asymmetric at onset (speech dyspraxia and dysphasia)
- Presence of:
- 1. Higher cortical dysfunction (apraxia, cortical sensory loss, or alien limb)
- AND
- Movement disorders (akinesia-rigidity, Levodopa reistant, limb dystonia or focal reflex myoclonus



Overview of The Lewy Body Spectrum, PSP and CBS

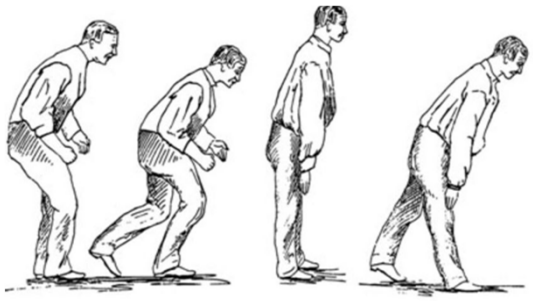


Progressive supranuclear palsy (PSP)

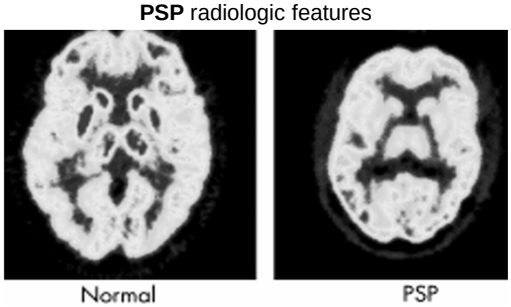
Dudley Moore (1935-2002)

PSP Symptoms:

- Falls
- Eye movement changes
- Parkinson's mimic
- Cognitive decline
- Personality changes

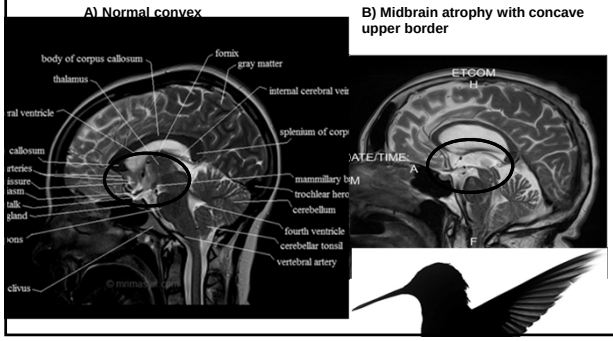


PSP radiologic features



- Hypometabolism on FDG-PET in basal ganglia, brainstem, and frontal lobes

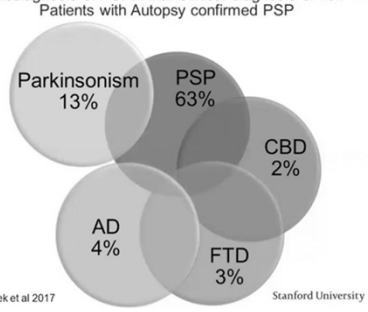
Hummingbird Sign in PSP



How often do we miss PSP

- Incidence: 5.3 cases per 100K in adults over age 50
- Often misdiagnosed (autopsy series)
- 5% of patients in Parkinson's disease clinics have PSP
- Patients that fall frequently are not evaluated for PSP – they become head trauma diagnoses.
- Cause: unknown versus (FTDP, TDP-43, PGRN, CMPB2 VCP)

Misdiagnosis of PSP: Final Clinical diagnosis of 181 Patients with Autopsy confirmed PSP



Respondek et al 2017

Stanford University

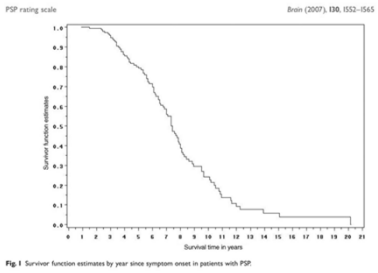


Fig. 1 Survivor function estimates by year since symptom onset in patients with PSP.

It's a spectrum and a complex web

A diagnosis of a frontotemporal dementia subtype or other neurogenerative dementia diagnoe

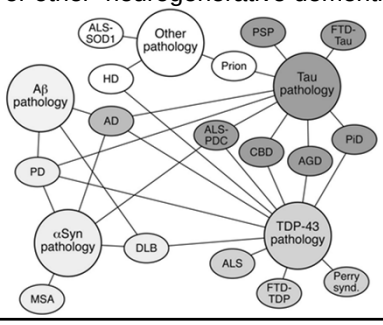
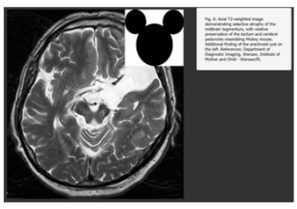


Figure Courtesy of Thinh

MSA



Jointly Provided by

33rd Annual Alzheimer's Disease Management & Research Symposium

August 15-16, 2019
The Clayton Center, Maryville College
502 E Lamar Alexander Parkway
Maryville, TN 37804

Palliative Care, Hospice and End of Life Decisions

August 16
2:45 - 3:30 PM

Cynthia Pearman, MD
Medical Director, UT Hospice/LHC
Knoxville, TN

Palliative Care and Hospice in Alzheimer's Disease and related dementias

Cynthia McClain Pearman MD

Medical Director, UT Hospice/Palliative Care/LHC

What is Palliative Care?

- Palliative means "to cloak"
- Palliative care is for control of symptoms and practical assistance at any point of a serious illness.
- Palliative Care is for people at any stage of a life-limiting or life-threatening illness
- Hospice is palliative care near the end of life

Where is palliative care done?

- In the hospital-
  - Patients with severe chronic illness may be seen by the palliative care hospital team to help with symptoms, to discuss goals of care, to help with planning for the future
- In the office-
  - Many aspects of palliative care are done by primary care and specialists when the focus on symptoms, comfort, planning for the future
  - Palliative care specialists may be located in offices in cancer centers, transplant centers etc.
- At home
  - especially when office visits become very difficult in later stages of illness

When might home palliative care help?

- When a recent illness or hospital stay has resulted in a decline in function
- When office visits are becoming very difficult
- When you are wondering if it is time to focus more on comfort
- When there are big decisions that you need help with
- When you are told that the disease is getting to the later stages

Who does Palliative Care?

- Physician, has to be board certified in Palliative Care/Hospice
- Nurse Practitioners/Advanced Practice Nurses
- Registered Nurses
- Social worker/MSW/MSSW
- Chaplain
- Administrative assistants

What does Palliative Care do exactly?

- Symptom control- pain, breathing, appetite, weight changes
- Sleep, depression, anxiety, mood problems
- Assistance with practical issues- equipment, home assessment, finding caregivers
- Assistance with advance directives, FMLA, living wills
- Goal setting for end of life
- Spiritual concerns and support

What can Palliative Care not do?

- Home Health aides (bathing, dressing)
- Pay for equipment, although may be able to help order it
- Pay for medicines, supplies
- Nurse visits with some exceptions
- Serve as your primary care physician
- After-hours coverage
- See persons in skilled/rehab facilities

Palliative Care- what to expect

- Intake phone call to assess needs, urgency of visit
- Wait for insurance approval
- Home visit- 90-120 minutes for initial visit
  - History, review of symptoms
  - meds
  - assess needs in home
  - Discuss advance directives/advance care planning/goals of care
- Follow-up phone call in 1-2 weeks
- Visits every 30-60 days depending on insurance approval (APN or RN)

Palliative Care- what to expect

- Social work/MSW visits- initial phone visit to assess needs
- If no needs then MSW will be available as needed
- If needed then will arrange visit
  - To discuss financial concerns
  - Funeral arrangements
  - Living arrangements
  - Legal issues and documents
- Follow-up visits as needed

Palliative Care- what to expect

- Chaplain services
  - Chaplains are specially trained to work in palliative care and hospice
  - Have usually completed a chaplain residency program
  - Are not representing or promoting any specific religion
  - Are trained to meet the needs of persons of all faiths
    - To discuss spiritual concerns of serious illness
    - To discuss concerns or changing roles in families
    - Listening ears
  - Beneficial even if the patient is nonverbal- they can read, play music, etc.
  - Life review

When is it time for hospice?

- Consider when dementia is at later stages/progressing rapidly (FAST 7A for Alzheimer's)
- When significant weight loss, especially if wounds
- Pain or other symptoms are hard to control
- Need for assistance with living will, advance directives
- If family members do not agree on advance directives
- If questions about feeding tubes, big decisions

Criteria for Hospice

- Life expectancy of approximately 6 months
  - Can be recertified after 6 months as long as they continue to meet criteria
  - Can be very difficult to predict life expectancy with dementia patients
- Alzheimer's disease and related dementias can be the most difficult for us to predict prognosis
- As with some other conditions, persons with dementia may have periods of stabilization when they start getting intense care in the home- "honeymoon period"

Criteria for hospice

- An increase in hospital and ER visits or frequent medical office visits
- Episodes of pneumonia or sepsis
- Frequent urinary tract infections
- Weight loss or dehydration due to reduced eating/drinking
- Problems swallowing, coughing and/or choking with food or drink, other signs of aspiration or known silent aspiration
- Wounds or skin breakdown related to weight loss or poor mobility

Criteria for Hospice

- Unable to sit upright in chairs, sliding out of chairs or falling forward or to the side when sitting
- Unable to walk without walker or human assistance or requires a wheelchair
- No longer able to smile
- Speech limited to six words or less per day
- Bowel and bladder incontinence
- Other significant medical problems- heart disease, diabetes, stroke, chronic lung disease, cancer
  - Usually hospice appropriate sooner if they have significant comorbid problems

Where is hospice done?

- In the person's own home
- In the home of family
- Assisted living ("aging in place") –will vary greatly according to the facility
- Nursing home
  - Regular nursing home bed (ICF), but not a skilled/rebab bed (SNF)
- Inpatient hospice facility
  - Except we do not currently have one in this area ☹
- In the hospital
  - If necessary for the safety or comfort of the person

Who is the hospice team

- Physician, preferably board certified in hospice/palliative care
  - Full board certification now requires fellowship training
  - Can be a certified medical director (HMDC) without fellowship
  - Many hospice medical directors don't have either one
- Nurse practitioners/Advanced practice nurses
- Registered nurses
  - RNs do the majority of the regular visits
- LPNs
  - help with Medicare paperwork, phone calls, some visits

Who is on the hospice team?

- Home Health Aides
  - Assist with bathing, bed linens, personal care
- Chaplains
  - Very important regardless of religious preference
- Social workers/MSWs/MSSWs
  - Final arrangements, finances, housing, legal issues, counseling
- Bereavement staff
  - Follow the family for 13 months after the loss
- Volunteer coordinators and volunteers
- A host of office people (!)

Hospice care- what to expect

- Admission visit
  - Done by RN, 1-2 hour visit to assess needs, sign paperwork, order meds and supplies
- RN visits
  - Minimum once a week, up to daily
  - To monitor symptoms, order meds and supplies, educate patient and family
- HHA visits
  - Usually 2-3 times a week if desired

Hospice care- what to expect

- Chaplain visits
  - Usually twice a month, more often if needed
  - Life review, discuss fears, concerns related to serious illness, death, changing roles in family
  - Not religion-based unless the patient wants it to be
- Social work visits
  - Once a month or as needed
  - To help with final arrangements, legal documents, financial concerns
  - Can do some counseling

Hospice care- what to expect

- Volunteers
  - Coordinator will make a visit to help determine needs
  - Volunteer is matched by location and needs of the person
  - Often visit once a week or as needed
  - Can do light housework, companionship, not personal care
- Bereavement staff
  - Can visit before the loss if needed, such as a very young patient, young children in home, special needs
  - Phone contact and/or visits bereaved family for 13 months after the loss
  - Special support groups available

Hospice perks- what is covered

- Medications- covered by hospice if related to the primary illness or if needed for comfort
  - *some exceptions*
- Supplies- disposable briefs, bed pads, wound supplies, etc
- Equipment- Hospital bed, wheelchair, oxygen, bed table, nebulizer
  - Not electric wheelchairs or lift chairs
- 5 day respite stays in nursing facility up to every 30 days
- 24/7/365 on call coverage- phone calls, on-call visits
- Not covered- 24 hour care, room and board in facilities

Who pays for all of this?

- Palliative Care
  - Limited coverage by traditional Medicare and some insurances
  - Medicare HMOs often do not cover or have very limited coverage
  - VA system has their own palliative care but will also cover some referrals
  - Many insurances require preauthorization/allow limited visits
- Hospice Care
  - Almost all insurance plans cover
  - If Medicare, falls under Medicare A (the hospital one)
  - Uninsured patients may accepted by many hospice agencies (!)

Advance Care Planning

- A road map for when a person is unable to make their own health care or living decisions
- Much more than just "code status" and feeding tubes
- It is never too early to start discussing
- Capacity vs competence: a person may still be able to make some medical decisions even when they are unable to make legal/financial ones
- The wishes of the POA should generally not overrule the wishes expressed by the patient

Advance Care Planning

- Most people want to have these conversations with their clinicians and families but are hesitant/afraid to bring it up
- Clinicians need to start these conversations early and encourage families to continue the discussions
- There are many good tools, free or minimal cost, that can help guide these discussions
- A palliative care provider can help you with this!
- Videos:
  - Ellen Goodman Does the Math (The Conversation Project)
  - ABC World News with Diane Sawyer: The Conversation Project

Palliative Care and Hospice Resources

- www.getpalliativecare.org CAPC
  - Includes info on finding Pall Care in your area
- NIA.NIH.gov- "What are Palliative Care and Hospice Care?"
- www.agingwithdignity.org/fivewishes
- www.caringinfo.org NHPCO
- www.prepareforyourcare.org
- Theconversationproject.org

Hospice and PC Resources, cont.

- Hard Choices for Loving People: CPR, Feeding Tubes, Palliative Care, Comfort Measures, and the patient with a Serious Illness, 6th Edition, by Hank Dunn
- A Beginner's Guide to the End: Practical Advice for Living Life and Facing Death, by BJ Miller MD and Shoshana Berge
- Courageous Conversations on Dying: The Gift of Palliative Care- A Practical Guide for Physicians, Healthcare Providers & All the People They Serve, by Shahid Aziz MD
- The Conversation: A Revolutionary Plan for End-of-Life Care, by Angelo E. Volandes MD
- Being Mortal, by Atul Gawande MD