The Brainiac

August 2017
Volume 1, Issue 2

Cognitive & Mental Health SIG

Updates from Our Chair

Lise McCarthy, PT, DPT, GCS

In this second issue of *The Brainiac* newsletter, we present information to help answer the question: How can our physical therapy profession affect the quality of life (QOL) of people living with dementia? Here is how some of our Cognitive and Mental Health (CMH) SIG members are doing this.

To start, Janice Bays, PT, and CMH SIG Public Liaison, has written about her experience attending the first North American Dementia Conference, "Re-Imagine Life with Dementia" in Atlanta, Georgia. If you are interested in participating in next year's conference, it will be held in Canada. More details will be published later this year.

Other CMH SIG members have, for the second year in a row, collaborated with the faculty and students from the University of Slippery Rock to help develop Tests and Measures summaries for PTNow. This year's CMH SIG PTNow contributors were: Evan Prost, Anne Reicherter (PTNow Senior Practice Specialist, APTA), Mary Ann Holbein-Jenny (Professor, Slippery Rock University), Margaret Danilovich, Michele Stanley, Mary Fischer, Jena Harb, Kristine Josef, and Lise McCarthy. At this time, three measures have been completed and can be found on the PTNow website by going here: http://www.ptnow.org/Default.aspx.

- Quality of Life in Alzheimer Disease (QOL-AD)
- Functional Assessment Staging Tool (FAST)
- Pain Assessment in Advanced Dementia tool (PAINAD)

Many, many thanks to the students of the University of Slippery Rock for their significant efforts in researching and authoring these PTNow measures. These student leaders are: Cortney Marotto, BS, SPT; Mackenzie McElhaney, BS, SPT; Jennifer Picot, BS, SPT; David Reinhardt, BS, SPT; Leah Anne Wirfel, BS, SPT; Amanda Fairman, SPT, ATC, LAT; Justin Kostyo, SPT; Brandon Shotter, SPT; and Brandon Weaver, SPT.

So, once you are a little familiar with these measures, you may want to review the A Club Documents on the CMH SIG webpage to find case scenarios demonstrating how to use the FAST and PAINAD. These documents were created as a means to help promote discussions among you and your colleagues and students about measurement and assessment of complex and basic ADL and functional mobility deficits, and pain in your patients with dementia. *(Continued on page 2)*

NEWS AT A GLANCE:

ACADEMY OF GERIATRIC PHYSICAL THERAPY

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Then when you have a better understanding of how to measure and assess quality of life, function and pain in people living with dementia, what can you do? Go back to this issue of the *Brainiac,* and under the section entitled "Enhance Your Practice" read about key principles to consider for incorporating cognitive therapy approaches and rehabilitation-based models of positive support. The open access article referenced is written by Linda Clare from the Center for Research in Ageing and Cognitive Health, University of Exeter, Exeter, United Kingdom.

In closing, I want to share with you this quote by Teepa Snow: "Dementia does not rob someone of their dignity; it's our reaction to them that does." We hope you will share this issue of the Brainiac with your colleagues and students, as well as explore our CMH SIG webpage. And if you like what we are doing, show us by joining our SIG here: https://geriatricspt.org.

Updates from Our Vice Chair

Christy Ross, PT, DPT, GCS, CDP, MSCS

As we celebrate our 3rd year as a special interest group, we welcome our 2nd issue of *The Brainiac*. It remains our goal to continue to disseminate information, motivate and enhance practice, and promote the building of partnerships. Within this issue, we welcome Beth Black, PT, GCS and Heidi Moyer, PT, DPT who share their experiences as coordinator and state advocate, respectively. They invite us all to contact our state advocates who serve as the bridge between AGPT and those in our care to increase our awareness and knowledge of PT interventions for aging adults. Networking and building partnerships helps us learn from experts in the field such as Michele Stanley, PT, DPT, GCS, CEEAA who is featured in this issue's Clinician Corner. And finally, as the technology moves forward to seek diagnoses for cognitive diseases, we discuss Amyloid PET imaging and the criteria physicians used to correctly identify candidates for this newly developed imaging. We hope you enjoy this issue of *The Brainiac*!

Public Liaison Corner

Re-Imagine Life with Dementia

Janice Bays, PT
CMH SIG Co-Public Liaison

Last month I had an experience that I would wish for each of you. I attended the 1st North American Dementia Conference, "Re-Imagine Life with Dementia" in Atlanta, GA. The conference was a unique gathering of the dementia community including people living with dementia, care partners, support and service providers, community organizers, health care practitioners, researchers, policymakers from federal and state agencies, educators and students.

My colleague, Natalie Scott, M.A. CCC-SLP, and I represented the rehab professions and led a session titled "*Living* with Dementia: PT, OT, ST Roles in Optimizing Well-being"….or Getting What You Need from Therapy. In preparing for this session, we learned so much about the relationship and partnership needed to get the best outcomes from therapy and how we can help people living with dementia thrive.

The Dementia Action Alliance (DAA) partnered with colleagues in Canada to provide an opportunity for the dementia community to come together and give voice to those living with dementia and those who are partnering with them. The "partnering with" is a significant thing here. The DAA follows the mantra "Nothing About Persons Living With Dementia Without Persons Living With Dementia". Persons Living With Dementia (PLWD) were integral in planning, presenting and participating in this conference.

Brian LaBlanc, a DAA Advisory Council Member and Dementia Alliance International Board Member who is living with early onset Alzheimer's Disease, was the keynote speaker for the opening session. Brian's tagline is "I have Alzheimer's, BUT it doesn't have me". He gave a poignant description of what it is like to live with Alzheimer's Disease. He likened it to driving down a road with alternate patches of dense fog and clear sunny spots. He said, "I'm not suffering, I'm struggling."

G. Allen Power, MD, Schlegel Chair in Aging and Dementia Innovation, Schlegel-U, Waterloo Research Institute for Aging, (He may be better known to you as advocate and educator for dementia beyond drugs.) followed Brian with a global perspective of recognizing dementia as a disability condition and the implications for addressing well-being for PLWD.

This is a segue to the wellness that we advocate as members of the Academy of Geriatric Physical Therapy. I refer you to the article "Rehabilitation for people living with dementia: A practical framework of positive support"(https://doi.org/10.1371/journal.pmed.1002245).

Rehabilitative therapists of all disciplines can play a significant role in supporting PLWD to thrive. This was the focus of our session on therapy. Both PLWD and their Care Partners have told me that their experiences with therapists have been some of their most valuable. It is important that people understand how therapy can support them through the course of dementia.

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It is also important that people demand the "right therapy" based on respect and relationship to get the desired outcomes. Goals of PLWD are not always in line with those of medical management. This was a topic we explored. Here are the goals for living with dementia provided by Robert Bowles, a retired pharmacist, who is living with Lewy Body Disease:

- Stay strong in my faith.
- Enjoy time with family.
- Engage my brain through multiple ways: exercise; brain games of speed, memory, attention, flexibility, and problem solving; read books and scientific abstracts.
- Maintain socialization individually and through Dementia Mentors and Virtual Memory Café. Keep my mind positive. Continue my purpose of helping others though my advocacy.
- "Dementia will no define who I am. I'll fight this disease and focus on helping others."

A course of physical therapy should be focused on supporting those goals.

Robert also shared with me his expectations of the *right* therapy. I want to share them with you.

Foundational:
Respect, Dignity, Kindness, Tenets of Communicating and Interacting with Someone with Dementia

Expectations:

- Clear and concise explanation of my situation
- Purpose of my treatment
- Consideration given to my cognitive decline and other medical conditions
- Treat me as an individual not a textbook. Meet me where I am.
- Therapist Goals
- Do not set me up to fail.
- Set me up to succeed based on your assessment. It's better to go beyond the therapist's expectations than to fall below them.
- Explain the reason and expectations of success with each modality.
- Continue to guide me through the process of the therapy.
- Be kind but honest.

This is invaluable information to guide us in our interactions with people living with dementia.

Sherry Dupuis, PhD, professor from the University of Waterloo and Co-Lead for Partnerships in Dementia Care Alliance (Canada) rounded out the program with an exploration of relationships that shape the dementia experience and re-imagining new possibilities for support thriving.

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Continued from page 4, "Re-imagine Life with Dementia"

The North American Dementia Conference was an opportunity to learn about the experience of living with dementia from the real experts: people living with dementia. Dr. Power moderated a panel of Advisory Council Members of DAA and Ontario Dementia Advisory Group both at the beginning and the end of the conference. Panel members shared their experiences and perspectives and engaged conference participants in discussion about re-imagining life with dementia. PLWD were also integral in concurrent sessions and special interest group discussions. The dementia community came together to listen and learn from one another in Atlanta for those three days.

As Public Liaison for the Cognitive and Mental Health SIG, I felt that I was in the right place during this conference. I was proud to represent The Academy of Geriatric Physical Therapy and share with this important population, how therapy can be instrumental in their quest for quality of life, and how to advocate for the therapy that they need. I am also honored to share with you the needs and expectations of PLWD and their care partners.

Marissa Cruz, Jackie Madsen, and Mary Ann Wharton are my Co-Public Liaisons for the Cognitive and Mental Health SIG. We look for and share with you noteworthy publications about dementia and mental health issues. We are currently working on a community outreach presentation that should be available for your use this Fall, and we are working on a project reviewing videos for teaching PTs and PTAs about how to work more effectively with PLWD. We also represent The Academy at events like the North American Dementia Conference. Our goal is to bring information about the practice of physical therapy in the realm of dementia and mental health to the general public and to bring information that can impact our practice to members.

**Janice Bays serves as a Co-Public Liaison for the Cognitive and Mental Health SIG.*

Rehabilitation for people living with dementia: A practical framework of positive support March 2017 - Linda Clare

Awareness of the need to improve accessibility of services and opportunities for people with disabilities is growing, but people with "hidden" disabilities such as dementia can be excluded from these developments. Conceptualizing dementia in terms of social disability highlights the way in which symptoms such as memory problems—and the secondary effects of these, such as loss of confidence or negative reactions from others—affect the possibility of engaging in activities and participating in society . (WHO 2001) It also suggests some practical solutions that can support participation and inclusion and promote the ability to live well. (IoM 2012) Activity limitation and participation restriction can be tackled from two directions. From a community perspective, the focus is on dismantling external barriers to participation by changing public attitudes and creating accessible, dementia-friendly environments. A growing social movement led by people with dementia, Alzheimer associations, and supporters promotes acceptance, inclusion, and awareness of rights. (Alz Soc 2015) From a personal perspective, the focus is on enabling people with dementia to participate in everyday life, and in their families and communities, in a way that is meaningful to them. This is the aim of rehabilitation. (WHO 2016)

Clare continues to discuss the following:

- How can cognitive rehabilitation benefit people with dementia and carers?,
- Where do other non-pharmacological interventions fit in?
- How could services adopt a rehabilitation model?
- Why should we acknowledge the right to rehabilitation?

<u>To continue reading the above research article with open access, please see:</u>

Clare L (2017) Rehabilitation for people living with dementia: A practical framework of positive support. PLoS Med 14(3): e1002245. https://doi.org/10.1371/journal.pmed.1002245

Enhance Your Practice

Amyloid PET Imaging

The Alzheimer's Association Amyloid Imaging Taskforce (AIT) and The Society of Nuclear Medicine and Molecular Imaging have jointly published the first criteria to assist in the diagnosis of people with suspected Alzheimer's Disease and when to use brain amyloid imaging technology. Here's what the AIT concluded:

- When completed according to standardized protocols, Amyloid imaging could potentially be helpful in diagnosis of people with cognitive impairment.
- Amyloid imaging should only be used after a comprehensive evaluation completed by a physician experienced in the assessment and diagnosis of cognitive impairment, and if the presence or absence of amyloid would increase certainty in the diagnosis or modify the treatment plan.
- Candidates for Amyloid PET imaging include:
  - Those who complain of persistent or progressive unexplained memory problems or confusion, and demonstrate impairments on standardized tests
  - Individuals undergoing tests for people Alzheimer's Disease whose clinical presentation is unusual
  - Individuals who are younger than 65 and an atypical presentation of progressive dementia
- Amyloid PET imaging can cost $3,000 - $6,000 or more. However, Medicare and often most private insurers deny reimbursement for this procedure.
- However, anecdotal data indicates that the ability to predict amyloid status is poor:
  - 25% of clinical trials with individuals with Alzheimer's Dementia have negative amyloid scans
  - 50% of clinical trials with individuals with mild cognitive impairment due to Alzheimer's Dementia have negative amyloid scans
  - 80-90% preclinical studies of people without cognitive impairment symptoms have negative scans

For more information on Amyloid Imaging:

Johnson KA et al. Appropriate use criteria for amyloid PET: A report of the Amyloid Imaging Task Force, the Society of Nuclear Medicine and Molecular Imaging, and the Alzheimer's Association. *Alzheimer's & Dementia*. 2013; 9, e1 - e 16.

CLINICIAN CORNER

INTRODUCING...
MICHELE STANLEY, PT, DPT, GCS, CEEAA

One of the beauties of our profession is that endless possibilities exist for reinventing your career if you are willing to commit to endless learning. In various incantations I have done just about every kind of physical therapy imaginable, partially because of life circumstances moving around the US with a young family. I have been a pediatric therapist specializing in home and day center based care of fragile and complex littles as well as working in public schools. I have worked in acute inpatient rehab centers and outpatient sports/neurology/pain practices. A private practice and home care agency that I incorporated 30 years ago is still going strong (although I am no longer associated with it). I started a physical therapy and rehab department in a county hospital that grew to a staff of 40 within 5 years, one of several administrative positions that populates my resume. In general, figuring out the puzzle of movement and function impacted by the complexity of multiple comorbid conditions, trauma, and physiologic disturbances has always fascinated me so I gravitate to acute and subacute practices including SNF, hospital, and home health. Currently I work in a large acute care hospital, rotating between orthopedic, cardiac, oncology, neurology, emergency department, and general medical/surgical floors. My interest in cognition and behavioral health is a natural tie between all the areas in which I practice but it was really the experience of living with a spouse with traumatic closed head injury that led me to intensify my knowledge and educational passion for this area of physical therapy. Part of that journey included privately studying with Claudia Allen and earning my transitional DPT degree, then becoming board certified in Geriatrics.

I have been a volunteer EMT for many years and used to be a trainer/coach for dance and soccer teams when my children were participants. My 3 daughters are all adults now, 2 still in graduate school and no grandkids in sight so I've been "grand fostering" rescue puppies...thinking about fostering pups on the guide dog/ therapy dog career path and planning a B&B that will be adapted/friendly to those wanting to vacation with a disabled family member.

The APTA has always been important to me and I have held numerous positions in various states. Nationally, I am an editorial board member for GeriNotes, a co-moderator for the Academy of Geriatric PT listserv, and contribute information regularly to the Cardiovascular & Pulmonary newsletter.

**Michele Stanley currently serves on the Cognitive and Mental Health SIG Nominating Committee.*

HIPPOCAMPAL HIGHLIGHTS

Upcoming Conferences:

American Geriatrics Society Orlando - May 2018

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7th International Conference on Dementia & Care Practice

August 14-16, 2017

Toronto, Ontario, Canada

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CSM 2018 - February 21-24, 2018 New Orleans, LA featuring:
"Dementia Care Cognitive-Based Assessment Strategies: This is How We Do It" and
"Dementia Care Cognitive-Based Treatment Strategies: This is How We Do It!"

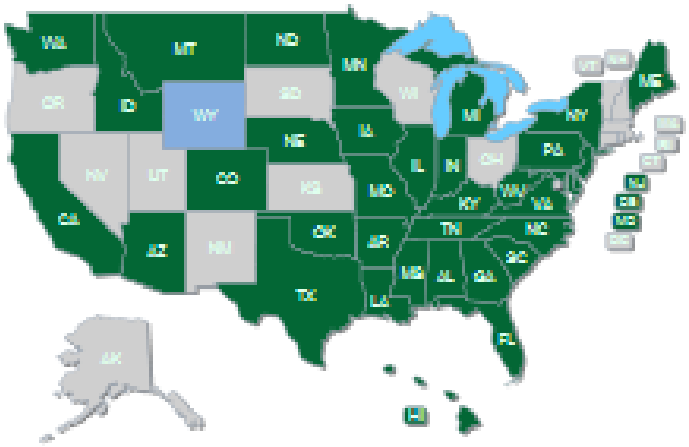
AGPT State Advocates Program

Beth Black, PT, GCS

Did you know that AGPT has State Advocates working locally in many states, advocating for older adults, promoting geriatric-related issues, courses, meetings and AGPT SIGs (including the CMH SIG) and being a liaison between AGPT and state chapters?

You can find our AGPT State Advocate contact information online at www.geriatricspt.org/ , then select the "Members" tab, and choose "Contact Your State Advocate" or http://geriatricspt.org/members/state-advocates/index.cfm .

We are actively looking for new State Advocates in the following areas: Alaska, Connecticut, DC, Kansas, Massachusetts, Nevada, New Hampshire, New Mexico, Ohio, Oregon, Rhode Island, South Dakota, Utah, Vermont and Wisconsin. We are also looking for co-chairs in the following states: Hawaii, New York, South Carolina.



If you are interested in being your State Advocate, or want more info about the program, contact the AGPT State Advocate Coordinator, Beth Black, PT, GCS, at BBlackPT@gmail.com

Partnerships:
An Update from the AGPT State Advocate Program

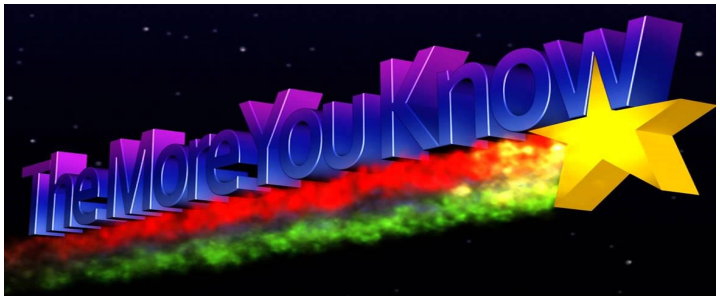
Heidi S. Moyer, PT, DPT

The AGPT State Advocate Program serves to improve the connection between AGPT members in each state and the national AGPT branch as well as to local SIG chapters and interest groups (where available). As Illinois co-State Advocates, my co-chair Jaime Fortier-Jones and I have had the pleasure of not only keeping our state members connected and engaged, but also facilitating other programs within the state. What keeps things dynamic and fun are the ideas for projects we get from our state members. Within the Illinois constituency, some of our members have come forward with ideas without the knowledge on how to put it into action; and that is where we come in. We have been able to connect AGPT members within Illinois to larger organizations to get their ideas and projects moving. The effort and participating from within our state is riveting, but it all stems from you, the members. As a Illinois co-state advocate, I charge you to reach out to your local state advocate to improve your connectivity not only to the AGPT, but to the physical therapy field as a whole. By utilizing your resources, you can help to frame a better healthcare system for our aging and older adult community.

* As written on the AGPT website, the State Advocates work at the local level to advocate for older adults. Some of the responsibilities of an AGPT State Advocate are:

1. Provide two-way communication between AGPT and the chapter.
2. Communicate with AGPT members in your state when there are geriatric-related issues, courses, meetings, etc. in your chapter.
3. Hold at least two activities each year to promote increased awareness and knowledge of PT for the older adult in your chapter.

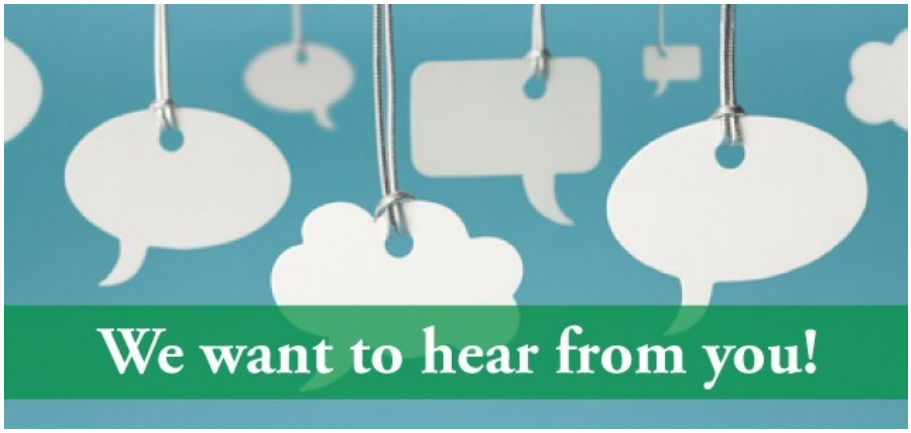
- *Dr. Moyer is a member of the Cognitive and Mental Health SIG and serves as an Illinois AGPT Co-State Advocate*



Cognitive and Mental Health Special Interest Group Webpage

On our wonderful webpage you will find…

- Past SIG Meeting Minutes
- "A" Club Documents
- Functional Assessment Staging Tool
- PAINAD
- Mini-Cog
- Research Resources
- SIG Links of Interest
- AGPT State Advocate Program Information



We would love to hear about your good news, too!

To be included in the next edition of *The Brainiac*, please send your information to:

RossC5@ccf.org or *lise@mipt.us*

Have a great next few months and
stay tuned for the next issue of *The Brainiac* in **November**!