OUR VOICES

Brain Health Wisdom for Indigenous People

Ukwaw^na?shuha
August 2023/ No. 4

Wisconsin Alzheimer's Disease Research Center
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

Shekoli! (Hello)

Welcome to our newsletter "Our Voices." This quarterly publication is designed to inform you of future events, brain health resources, celebrations, and other helpful news.

We want to connect with our community and welcome any suggestions or comments. Please get in touch with us.

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Our Voices Purpose

- **Provide support and information**
- **Help with motivation**
- **Highlight accomplishments**
- **Announcements and updates**

Researchers Speak Out About Caregivers

By Cassie Thomas, AMICA Community Researcher

Bringing attention to providing more care by supporting elders and their caregivers, as well as understanding the benefits of traditional foods and their effects on brain health, was highlighted at the Great Lakes Native American Elder Association (GLNAEA) meeting held in June.

Dr. Nick Lambrou, Dr. Melissa Blind, and the community researchers of the Indigenous Cultural Understandings of Alzheimer's Disease and Related Dementias (ICARE) project shared key points from interviews with caregivers across four tribal nations. The Red Lake Nation of Minnesota started a caregiver support group for dementia-friendly community building and coping strategies. They work alongside their community advisory board to encourage cultural sensitivity training about Alzheimer's disease and related dementias.

Amber Hoon, the Tribal Dementia Program Director for the Great Lakes Inter-Tribal Council's (GLITC) "Together Strong" Program, shared personal stories of working with elders struggling with dementia and the trainings she found useful for communication and connection. Amber presented the importance of caregiver trainings for Indigenous communities, helping elders utilize their gifts, and creating care teams centered on patience, socialization, education, and safety.

The Q&A portion echoed that caregivers require more support, such as respite nurses and adult day services in our communities.

Blake Offers Compassionate Caregiving and Cultural Immersion to Help Cope

Interview recorded by Sacheen Lawrence, Outreach Specialist

Violet Blake is an enrolled member of the Oneida Nation. She was a caregiver to her mother, Shirley Thomas, who was diagnosed with dementia at the age of 73 and passed away at the age of 85 last year.

Q: When your mom was diagnosed with dementia, were you aware of this illness?

A: When I started taking care of her, we went through a lot of therapy because she wasn't verbal. So we went to Sid White, to behavioral health, she cried a lot. Oneida Elder Service's caregivers would come over and teach me how to give her showers. Her thoughts started coming out. Little by little she started to know everyone again; yelling at the grandkids which meant she was getting better. We were like, "Yay, she's coming back to us." We had a really good five years between therapy and the decline. Then, she started to talk to people that weren't alive anymore or see things no one else could see. I just let it go. But it then kind of progressed.

I talked to Carol RedHail, my mom's elder service's rep. She said let's bring her in for cognitive testing, and my mom couldn't do a clock. Her numbers were all mixed up and she didn't remember her address. It just declined from there. It took five years from the onset of symptoms to get diagnosed with dementia. Doctors contributed her memory problems to the stroke.

I felt like they wanted to treat everything by sending her to therapy or with prescriptions. I felt this wasn't working. So, I took her off the pills. Going to the dementia program, that's when we got some results. But to be aware makes it easier, and to know that we were not crazy and she wasn't either.

Q: What are ways you coped with caregiving; how did you make sure you were okay?

A: Carol has a caregiver program and she taught us a lot of different coping methods. If I seen a red horse running past me and I'm like, "That was a red horse!" and you say, "No, it's not," you're just telling me I'm crazy." You come to grips with that fact your loved one is not crazy, that this is what they are really seeing. And so, you just say, "Oh man I missed it," that kind of thing. You try to go around it and don't make it an argument.

Did I cry? I cried a lot, seeing your parent that way was hard, but I would just go in the bedroom and shut the door and just to have that little bit of time which helped a lot.

My husband would take over, kick me out of the house, and he would deal with it. To watch that person, the one that you relied on all your life, not be that person that you rely on anymore. Now they rely on you; you change those roles.

But, just to have a supportive partner, the classes with Carol, and just realizing that this is what it is and knowing that your person is not crazy. You can choose to join their reality or just be like, damn I missed it, because you have to let them have their reality. Like when they get angry, they get angry like you have never seen.

Like my mom was so meek when we were growing up. But when you see the anger of Alzheimer's come out, it was a different kind of thing.

Story continues on page 8

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VIRTUAL WEBINAR

WISCONSIN DEMENTIA RESOURCE NETWORK

Financial Scams and Fraud:

The Relentless Targeting of Older Adults

This webinar was held on June 29, 2023, and discussed the details of common scams that target seniors, the warning signs of a scam, and what to do if you or someone you know falls victim to a scam or fraud. The presenters explained the comprehensive facets of the Wisconsin Bureau of Consumer Protection, the role of adult protective services in financial exploitation cases and fraud, and shared helpful resources and prevention tools.

Watch the recording for free at: go.wisc.edu/y53zp2

Questions? Please contact Jody Krainer at jkrainer@wisc.edu

Oneida Aging and Disability Presents

ONEIDA

Wisconsin Alzheimer's Disease Research Center
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

ELDER EXPO 2023

Aug 28-29, 2023

at Radisson Hotel and Conference Center

Watch for Educational Speakers from 1-4pm Mon. August 28

Join us for Annual Elder Expo from 11am-2pm Tues. August 29

FOR MORE INFORMATION CONTACT CRYSTAL METOXEN AT (920)-869-6849 OR CMETOXE4@ONEIDANATION.ORG

Food Class with UW-Extension

Our team has organized cooking classes to engage our Oneida participants and to create healthy dishes such as venison stew, squash soup, and stuffed walleye – all from scratch! They even received an educational lesson on vital food ingredients and got to take some food home, as well as sample some of their work in class.

Liliana Ramirez, FoodWIse nutrition coordinator for the UW-Extension, shared some tips regarding whole grains. She explained whole grains, like fiber, act like a "brush" on the inside cleaning your intestines. High fiber foods like oats, quinoa, wild rice, brown rice, chia seeds, and corn chips are helpful, while crackers and some breads are not.

We Can Be a Friend to Those with Dementia

The Purple Angel Initiative

Dementia impacts us all. You may not know someone personally, but chances are someone you work with is impacted by dementia in someway.

Did you know 70% of people living with dementia live in the community?

Most live in their own homes.

The goal of the Purple Angel Initiative is to improve the experiences people with dementia have in the community when doing everyday things.

Taking the time to learn more about dementia and how to be dementia friendly can help support your neighbors, friends, and community.

Together we can help those who experience dementia live productive lives in our community!

What's in it for the community?

- People with dementia and their caregivers feel welcome and supported.
- Maintain social networks and a feeling of belonging. People with dementia can remain in their communities and maintain their connections.
- Purple Angel training is for businesses and organizations.
- Currently comprehensive health and governmental services division are trained.

Dementia Friends USA

A Dementia Friendly America Initiative

This training is meant for community members.

Dementia Friends is 1-hour presentation aimed at raising awareness and reducing the stigma of dementia.

The session includes education on the basics of dementia, activities that help people understand what it might be like to live with dementia, and tips on how to better communicate with someone with dementia.

Contact Debbie Miller, Tribal Dementia Care Specialist, at 920-869-4854 or dmiller4@oneidanation.org to schedule a training on either topic.

Learn more at:
dementiafriendsusa.org

What about Dementia?

F	M	L	I	N	R	T	M	O	N	P	G	N	E
O	E	C	G	P	D	A	J	C	E	R	M	S	C
A	M	F	N	O	I	N	J	O	M	S	I	U	N
M	O	N	I	O	O	G	M	N	W	E	S	P	A
E	R	E	R	R	L	L	E	C	G	T	P	P	L
T	Y	U	E	J	Y	E	F	E	A	W	L	O	A
I	T	R	D	U	M	S	L	N	I	O	A	R	B
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I	O	E	E	N	T	N	C	I	I	L	E	P	Y
T	N	T	G	T	R	N	E	L	C	B	S	A	G

MEMORYTEST
SUPPORTGROUP
POORJUDGEMENT
INSOMNIA
MISPLACING
TAU
CONCENTRATE
RESPITE
NEURONS
BALANCE
AMYLOID
TANGLES
WANDERING
BLOODFLOW
SAFETY

Tips To BOOST Your Health as You Age

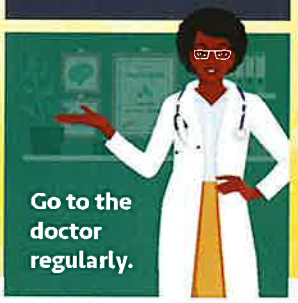
Did you know that making lifestyle changes can help you live longer and better? Try these tips to get started.

Get moving — try gardening, biking, or walking.

Choose healthy foods rich in nutrients.

Manage stress — try yoga or keep a journal.

Learn something new — take a class or join a club.



Go to the doctor regularly.

Connect with family and friends.

Learn more about steps you can take to promote healthy aging at www.nia.nih.gov/healthy-aging.

NIH National Institute on Aging

Save The Date

ONEIDA CARS AND GUITARS

Wisconsin Alzheimer's Disease Research Center
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Drive to End Alzheimer's Open House
September 23, 2023

What Does the ADRC, Oneida Nation, and CAB Do?

The Wisconsin Alzheimer's Disease Research Center (ADRC) has an ongoing partnership with the Oneida Nation. This partnership was formed with the goals of providing outreach and education for Native Americans affected by Alzheimer's Disease and Related Dementias (ADRD), in addition to ensuring that American Indians are included in research.

Presently, American Indians are more likely to develop ADRD than non-Hispanic whites but are drastically under-included in research focused on treating, curing, and preventing dementia.

The Oneida Nation guides the ADRC's multiple endeavors to ensure the work is culturally tailored and responsive and carried out with accurate and respectful communication. This guidance is provided by the Oneida Alzheimer's Community Advisory Board, or CAB. The CAB meets monthly to review and guide the work led by the outreach and research groups who have received BC approval to work with the Nation.

The ADRC research arm of the effort involves annual or bi-annual memory and brain check-ups. We learn about brain health with the help of individuals who have a family risk for the disease and those who do not. So, if your memory is healthy, you can help us learn how to maintain brain power. But if you are worried about your memory, we can provide a memory screening. As you know, we offer these visits at two locations in Madison, one at UW Hospital and one in a community location known as the UW South Madison Partnership (UWSMP) office.

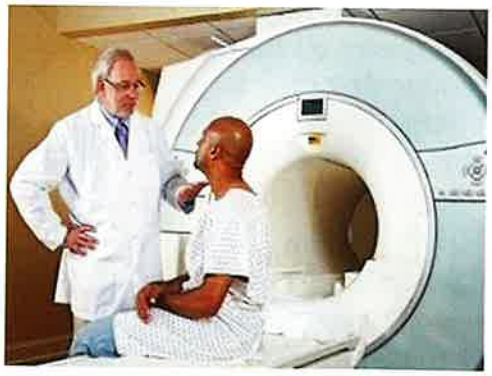
What Can Biomarkers Do?

Biomarkers are measurable indicators of what's happening in the body. These can be found in blood, other body fluids, organs, and tissues. Biomarkers can help doctors and researchers diagnose diseases and other health conditions, and identify health risks in a person. For example, an increased level of cholesterol in the blood is a biomarker for heart attack risk.

Previously, the only sure way to know whether a person had Alzheimer's disease or another form of dementia was after death through autopsy. But thanks to advances in research, tests are now available to help doctors see biomarkers associated with dementia in a living person.

Several types that are used to help diagnose dementia include CT, MRI, and PET scans.

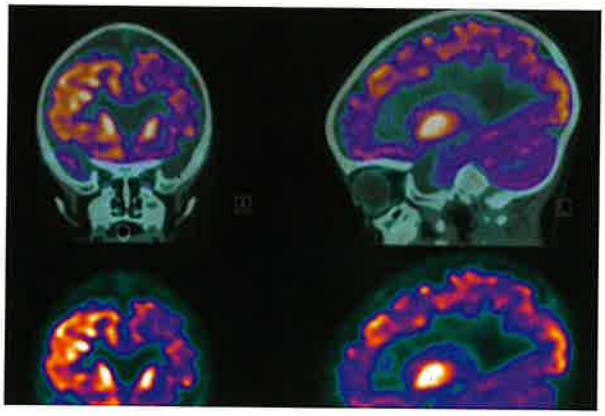
Computerized tomography, also known as a CT scan, is a type of X-ray that uses radiation to produce images of the brain or other parts of the body. A head CT scan can show shrinkage of brain regions that may occur in dementia.



Biomarker tests are only available through a medical research facility like the Wisconsin ADRC. Physicians like neurologists, geriatric psychiatrists, neuropsychologists, and geriatricians offer these state-of-the-art options for our participants.

MRI uses magnetic fields and radio waves to produce detailed images of body structures, including the size and shape of the brain and brain regions. MRIs can show whether areas of the brain have shrunk. Repeat scans can show how a person's brain changes over time. Evidence of shrinkage may support a diagnosis of Alzheimer's, but cannot indicate a specific diagnosis.

PET uses small amounts of a radioactive substance, called a tracer, to measure specific activity, such as energy use or a specific molecule in different brain regions. PET scans take pictures of the brain, revealing regions of normal and abnormal chemical activity.



Cerebrospinal fluid (CSF) is a clear fluid that surrounds the brain and spinal cord, providing protection and insulation. CSF also supplies numerous nutrients and chemicals that help keep brain cells healthy. Proteins and other substances made by brain cells can be detected in CSF. Measuring changes in the levels of these substances can help diagnose neurological problems.

Doctors perform a **lumbar puncture** (spinal tap) to get CSF. The most widely used CSF biomarkers for Alzheimer's disease measure beta-amyloid 42 (the major component of amyloid plaques in the brain), tau, and phospho-tau (major components of tau tangles in the brain, which are another hallmark of Alzheimer's).

Blood tests

Proteins that originate in the brain may be measured with sensitive blood tests. Levels of these proteins may change because of Alzheimer's, stroke, or other brain disorders. These blood biomarkers have historically been less accurate than CSF biomarkers for identifying Alzheimer's and related dementias.

Reproduced from: nia.nih.gov/health/how-biomarkers-help-diagnose-dementia#brain_imaging

Cont'd from page 2: Blake Offers Compassionate Caregiving

I think those were my saddest points cause I was like, that's not my mom. And to see the face and to know that's not the person is really confusing in your own head, and you have to recognize that's what it was.

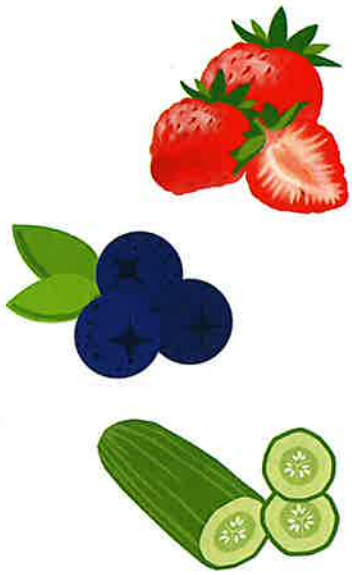
Q: As an Indigenous caregiver, do you feel like your spirituality has brought you closer to your mother while caring for her?

A: I think that my happiest moments with my mom with dementia was when we went to ceremony. My mom loved ceremonies. She always said my grandma was there. She was always at peace; she didn't have angry or confusing moments. We'd go ceremonies with the rattles going, it's just loud in there and everybody is dancing, she was in a place I think she has never been, still and content and just happy. She would be waving at all the dancers and she embraced it. We went for the naming ceremony; it was packed but she was sitting next to people and talking to them like she knew them forever. When we danced, she went by the singers, and that was her place. She didn't grow up with it but once she got to the longhouse, it was her spot; a safe place for her. She wanted to stay and wait for the feast. She loved the food and wild rice, and she would not leave until she got her wild rice.

Q: What's the biggest difference between your life now and then?

Try These Tasty, Healthy Foods During the Summer Months!

Cucumbers
Use this healthy vegetable in your meal plan because it is made up of 95% water to help keep you hydrated. Cucumbers are a low-calorie food – only 16 calories for a full cup! They are also packed with essential vitamins A and K, magnesium, potassium, and manganese.



Fresh Fruits
Great fruits that are in season are strawberries, raspberries, blueberries, melons, tomatoes, grapes, and apples. All these fruits are packed with vitamins, minerals, and fiber. Many of these fruits are great on their own as a snack! Use melon and berries together for a tasty fruit salad.

Zucchini
This ultimate vegetable is a zip to grill! Brush with olive oil and season with your favorite seasonings and cook until tender for tasty kabobs. Serve it with grilled chicken or hamburgers. Zucchini are high in antioxidants and have a high-water and fiber content so they will help keep you feeling full for longer.

Source: info.totalwellnesshealth.com/blog/7-healthy-summer-foods

A: Theres a big void. That's the hardest part. I tried to fill it with a job, doing different things but I always find myself doing the things that me and my mom used to do together. My mom was so much of my life for the last 18 years, it was harder to get over her death because it was like, now what do I do, who am I today? Now, I have to be a different person. I have to figure out that I'm not that caregiver anymore. I have to stop taking care of everyone else.

Everything I did revolved around my mom, so I had to figure out how to move on with life. For the first part of it, I think I tried to pack in so much to stay busy, that I was too busy, so now I'm burned out. So, then I wanted to do nothing but then I did too much of nothing. But I'm still trying to find that balance. Now, I am learning to say no and I've decided to just go full time with my job and learn to be a regular person, something I don't know how to do just yet.