

THE MINKA MONTHLY

Official Newsletter for the Minka Learning Lab for Living Well



CARE PARTNERS FOR PEOPLE LIVING WITH DEMENTIA - "NOW WHAT?"

By Leah Flake, Intern

Julia Benton's husband was a quiet man. As the years passed and he was diagnosed with dementia, he became quite the opposite. Julia said that he would strike up a conversation with almost anyone. Every year, Julia and her husband would go on vacation with family. One of Julia's family members expressed during vacation his frustration with Julia's husband and his talkativeness. After this, Julia and her husband stopped going.

Lisa Fournier's mother was diagnosed with dementia. Before she was diagnosed, Lisa started to pick up on clues of the impending diagnosis. Her mom began to show symptoms, and she'd brush it off as being "absent-minded," but Lisa could tell it was a different type of forgetting. When they received the diagnosis, Lisa turned to her doctor and said, "Now what?" to which he responded, "Well, you'll figure it out."

Julia and Lisa's experiences sum up a common occurrence for care partners for people living with dementia. As a society, we are underprepared to handle, and sometimes unwilling to address, neurological disabilities that occur later in life though 5-8% of people

will develop dementia after 60.

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EDITOR CORNER

GROWTH

By Thomas Engels, Intern



Most people in their early twenties do not think about becoming older because they are young and do not really think about the future. I would have put myself in that category a few months ago, but now my mindset on life has changed. During this semester, the Geriatric Workforce Enhancement Program has helped me broaden my perspective on what it means to be older, and the challenges that could happen trying to live-in-place.

Everyone knows that they will eventually become an older adult, but what does that truly mean? To me, becoming older means that I have grown as a person. It is important to learn from the past to create a better version of yourself. In my later stages of life, I want to look back and appreciate all the failures and success that I have had because those moments helped shape who I am. Becoming older in age is not terrible, horrifying or even sorrowful. I have learned that being an older adult can be wonderful because older people have a lot of knowledge and wisdom that they can provide for future generations.

Before being an intern at the GWEP, I have never heard of the term living-in-place. Now, I know that living-in-place is when older adults want to stay at their homes for the rest of their life. A lot of people probably want to live-in-place, but there can be many challenges in the process. Sometimes, people have inadequate living spaces, little access to food or healthcare and possible changes in health can occur. At the GWEP, exploring different possibilities with the Minka house can give people a model of what a living situation could be, which is very fascinating to me. Although this semester went by quickly, I have learned a lot about the topic of aging.

This month's newsletter contains articles about dementia, gardening therapy and interviews with Advisory Board members. Enjoy!

If interested in contributing to this newsletter, please contact Thomas Engels at teengels@eagles.usi.edu



Alzheimer's Association Virtual Event:

Wednesday May 12, 12 p.m. CT - Understanding and Responding to Dementia-Related Behavior To register for this free event, visit <u>USI.edu/alzheimerassociation</u>

Contact Thomas Engels at teengels@eagles.usi.edu for more information

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$3,691,706 million with zero percentage financed with nongovernmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.

DEMENTIA FRIENDLY COMMUNITIES

By Leah Flake, Intern

Dementia Friendly communities are cities, villages, towns or counties that take steps to make their area a safe space for people living with dementia. This includes adapting to the needs of those living with dementia, their families and their care partners. So far, there are five total Dementia Friendly communities in Indiana and two that have been initiated through the Geriatrics Workforce Enhancement Program (GWEP) in Rockport and Petersburg. These communities wouldn't be possible without the people who lead the way in establishing them. Read on to meet the coordinators of the Rockport and Petersburg DFCs!

Dementia Friendly Community Rockport

Meet Linda Wright, the Community Transition Supervisor for SWIRCA and Coordinator for Dementia-Friendly Rockport. Linda began working with Rockport's dementia-friendly community in August. In her position, she reaches out to people in the community to get them involved and holds Action Team meetings to develop a strategy for the DFC. Through her work, Linda hopes to establish a community in Rockport that has a greater understanding of people living with dementia and their care partners. Oftentimes, people living with dementia and their care partners isolate themselves because it can be difficult trying to explain the behaviors of a person living with dementia to those who don't understand it. By working with businesses, individuals and stakeholders in the community, Linda aspires to make Rockport more inclusive and a place where people living with dementia feel comfortable going out.

Dementia Friendly Community Petersburg

Meet Brenda Hancock, the Community Resource Coordinator for Generations – Area 13 Agency on Aging and Disability and the coordinator for Dementia-Friendly Petersburg. In the Petersburg dementia-friendly community, Brenda manages the Action Team meetings, reaches out to new stakeholders and expands the program. Right now, in the Petersburg's DFC, they are working on developing their platforms such as a Facebook page and creating a website to connect everyone involved. Petersburg is also looking at a May event to connect the various stakeholders in the community. Stay tuned for more details!

Dementia Friendly communities are a vital part of creating a more inclusive and accessible environment for people living with dementia in southwest Indiana. Some DFC activities include providing responsive legal and financial planning; adaptation of transportation, housing and public spaces to make them more inclusive; and providing options for community engagement, such as monthly dinners at local businesses. Are you interested in getting involved in Dementia Friendly communities or starting your own in your county? Go to www.dfamerica.org for more information

Continuation from page 1 The mission of the Geriatrics Workforce Enhancement Program (GWEP) is to improve health outcomes for older adults in southwest Indiana, but it is also a goal to change the conversation about dementia and how it is perceived in our culture. Dementia and other disabilities that come with older age are demonized, and when encountered personally, are disregarded. It doesn't have to be like this.

Lisa and Julia both took on the responsibility alone to be care partners for their loved ones with dementia. Other family members felt deterred from helping because they often felt embarrassed or afraid. In both Julia and Lisa's experience, they did recognize some positive outcomes after the onset of their loved one's dementia. For Julia, she noticed her husband become more talkative, and she got to see a whole new side of him she had not before. For Lisa, she got to know her mom on a very personal basis and see her outside of the parental bounds their relationship was based on up until then.

Care partnering is a difficult journey. Through education and support, the community partners of the GWEP are working to change the conversation to one of positivity and hope. It starts with all of us.



"Dementia Friendly communities are a vital part of creating a more inclusive and accessible environment for people living with dementia in southwest Indiana."



WHAT IS DEMENTIA?

By Paul Arthur, Chair, USI Occupational Therapy Program Assistant Professor of Occupational Therapy

Did you know that more than six million American's have Alzheimer's Disease or related dementias (ADRD)? The Alzheimer's Association's Greater Kentucky & Southern Indiana Chapter reports that more than 90,000 people with ADRD live in our community, making the likelihood of you and I being touched by the disease quite high. ADRD is a progressive disease that is not presently reversible. Disease onset is variable, beginning for some in their 30's, and others later in life. Persons with ADRD experience decreased cognition coupled with behavioral symptoms and physical decline that may last a few years, to many. With nearly 90% of the ADRD population residing in the community, much needed care is provided by family members and friends who are often facing life challenges of their own.

Significant scientific strides in the past decade have been made to confront ADRD. As the science has not yet led to disease reversal, pioneering work in prevention has been a significant priority. That is, can we delay disease onset by addressing modifiable risk factors?

A foundational 2020 report by the Lancet Commission identified 12 potentially modifiable risk factors that account for nearly 40% of ADRD diagnoses worldwide. Important factors included ensuring a full and meaningful education in early life. In midlife (45-65 years), addressing hearing loss, hypertension, alcohol intake and weight. Also being knowledgeable/aware of the link between prior brain injury (e.g. TBI) and ADRD. In later life (>65 years), preventing smoking, treating depression, preventing social isolation, remaining active, controlling diabetes and monitoring air quality.

In October 2020, the federal government approved support for ADRD research at a historic level of more than three billion dollars. This support is poised to identify further methods of prevention and, finally, lead to a cure.

GERO 101 GARDENING THERAPY

By Madeline Menke, Intern

Garden therapy is helpful in improving quality of life in older adults with dementia without the side effects of pharmaceuticals. It encourages autonomy, sensory stimulation and exercise. Garden therapy provides a way for older adults with dementia to regulate their behaviors and moods. Having therapies such as gardening is important now more than ever due to COVID-19 forcing isolation among older adults. COVID-19 has caused older adults to experience negative mood changes and increase agitated behaviors due to dementia from not having regular socialization.

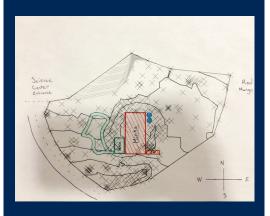
With the use of garden therapy, it can help those experiencing these negative effects find a way to reduce these behaviors. Aside from dementia, gardening helps improve moods no matter the situation. Interviewing an avid gardener on the Minka Advisory Board, the member mentions that she "feels at home and doesn't mind getting dirty and cleaning up." "It is a good experience for me, being able to do things outdoors after a cold winter."



"Disease onset is variable, beginning for some in their 30's, and others later in life."



"Garden therapy provides a way for older adults with dementia to regulate their behaviors and moods."



Future garden plans for the Minka

TECH & U

FUTURE POSSIBILITIES

By Thomas Engels, Intern

Often times, people in society view death as something that happens later in life. This is not always the case. Humans are not invincible, and death can happen at any moment, so it is important to be prepared. One way that people can prepare is by creating an advanced care plan which is a plan that people make medical decisions for themselves and others. For example, using a website like <u>prepareforyourcare.org</u> makes this process extremely easy for everyone.

PREPARE uses five steps to help people create a plan: choose a medical decision maker, decide what matters most in life, choose flexibility for your decision maker, tell others about your wishes and ask doctors the right questions. All of these steps are used to start a conversation about what an individual might want later in life or in a hospital environment.

For most people, they do not plan for potential medical problems or death. PREPARE is a way for people to start make decisions, but nothing is final. Any part of a PREPARE plan can be edited and changed. During a video on the website, a couple said, "We have started to talk about what is important to him. I feel so much better and more prepared." Since that couple started to use PREPARE, they feel more confident about the future. Start planning your future with PREPARE today.

To view the PREPARE website, visit prepareforyourcare.org



PROGRESS

By Thomas Engels, Intern

During the Month of April, the Minka had a couple of visitors to provide insight on future technology installations. Jerry from Quest4 Electronics in Evansville was able to give us a better idea on how to turn the Minka into a fully functioning smart home. He was able to explain how Quest4 Electronics can put in a smart home hub that controls most of the technology inside the Minka. Installing this system can help provide a person living with dementia the technology that could benefit them in many ways, such as temperature control and automating daily tasks.

Next, Rochelle from Illuminating Expressions in Evansville shared ideas on how we can improve the lighting and add a fan. Furthermore, Rochelle can provide the Minka with a circadian lighting system. Having circadian lights is important because light is one of the WELL building standards. For those not familiar, circadian lighting uses lights that can be dimmed to different percentages. Including these lights is perfect for people living-in-place because a care partner could have the lights automatically dim throughout the day and turn off in the evening. Research by Mariana Figueiro indicates using light therapy for dementia "demonstrates that timed light exposure can consolidate and improve nighttime sleep efficiency, increase daytime wakefulness and reduce evening agitation without the adverse effects of pharmacological solutions."

Please follow the Minka Instagram page @usiminkalearninglab to watch these future projects come to life.





Ouest4electronics.com



illuminatingexpressions.com

LET'S TALK ABOUT DEMENTIA

FORGIVE ME PLEASE!

By Dr. Lisa Fournier, DSL, MPM, Project Coordinator, Geriatrics Workforce Enhancement Program

When I was 5 years old, my Mom made me promise I would never put her in a nursing home. At that age, I couldn't even imagine not being with my Mom the rest of my life, so it was okay with me. This promise was extracted because we would go every week to visit the nursing home down the street. Nursing homes were like "wards" back in the day, so it was understandable Mom didn't want to be in one. I took my promise seriously. Fast forward. Mom developed Alzheimer's and lived with us for a while. Eventually, I had to put her in a nursing home. The guilt and shame washed over me. It took me years to forgive myself because my Mom deserved the best life and I couldn't give it to her.

Where does this unforgiveness come from? According to George Jacinto, researcher and author of *The Self-Forgiveness Process of Caregivers After the Death of Care-Receivers Diagnosed with Alzheimer's Disease*, a carepartner can experience helplessness and frustration throughout their care journey. These feelings are triggered from guilt and shame stemming from the current situation as well as past experiences with your loved one. As a carepartner, perhaps you weren't able to be with your loved one at all times of the day. Or, perhaps you feel like you let them down. Stemming from grief, unforgiveness sets in.

Carepartners experience a different type of grief called anticipatory grief. This means carepartners experience grief throughout the care journey with their person living with dementia. Most people grieve after the loss of a loved one. In their article, "An Assessment of Anticipatory Grief as Experienced by Family Caregivers of Individuals With Dementia," Drs. Ross and Dagley explain anticipatory grief as a "grief process of individuals who are losing someone slowly, expectedly and, many times, in stages." The carepartner is continuously "anticipating" and living with unending anxiety and stress. Carepartners are so busy, we forget to care for self throughout the care journey. And, once your loved one dies, unforgiveness is front and center.

There are four points to embrace self-forgiveness according to Jacinto and Edward's research article, "Therapeutic Stages of Forgiveness and Self-Forgiveness":

- Recognition: Confront you are in a cycle of ruminating about an incident or unfinished business. For me, I had to acknowledge I felt guilty for putting Mom in a nursing home. Not recognizing it kept me cycling on the "what-if" alternatives.
- Responsibility: Take personal responsibility and recognize you (and everyone else) has imperfections. For me, I did put Mom in the nursing home, even though I had promised not to do it. I wasn't perfect.
- Expression: Express feelings of self-blame with self or another person. Clarify the negative feelings and let go. For me, I blamed myself for not taking care of her the way she or I wanted. The reality is I couldn't keep her safe because I needed hip surgery. The nursing home kept her physically safe.
- Re-creating: Recreate your life by accepting your imperfection in the world
 of other imperfect humans and incorporate your past. Live in the present.
 Find a new direction for your future. She even made friends and developed a
 social circle! It was a blessing.



"Live your best life. Your mom would want you to."

HEALTHY LIVING EATING WITH DEMENTIA

By Elizabeth Ramos, Registered Dietitian
Instructor in Food and Nutrition

Dementia is not a part of normal healthy aging. Dementia is not benign; it is malignant and devastating and leads to dependence and death. Individuals suffering from dementia are at risk for malnutrition, simply because they do not eat, leading to decreased intake, weight loss and nutrient deficiencies. Age-related changes and diseases also play a role as dementia progresses. It is debatable whether additional energy calories and specific nutrient supplements can prevent or correct cognitive decline. The good news is that we can prevent malnutrition and maintain optimal nutritional status with a lifestyle that includes healthy eating. Eating well contributes to a good quality of life for individuals with dementia.

Nutritional care of a person with dementia requires screening for malnutrition as a first step, followed by close monitoring and recording of weekly body weights. Eating foods and drinking adequate fluids are the simplest ways to obtain nutrients. Preferred or favorite foods to "personalize one's plate" should be incorporated into simple recipes and menus. These can be further developed into easy meals and snacks that are enjoyable, adequate, prepared and served attractively in a pleasant and comfortable environment. Include vegetables, fruits, grains, protein and dairy foods. Any dietary restrictions should be avoided. A responsible caregiver can make this happen with guidance from food and nutrition professionals. Stress, however, can compound and aggravate any nutritional problems of the individual; stress should be eliminated.

Healthy eating then is the rule in nutrition and dementia. Specific supplements such as omega-3-fatty acids (fish oil), the vitamins B1, B6, B12, folic acid, E, D and the minerals selenium and copper in high doses will not prevent or correct cognitive decline. However, taking a multi-vitamin tablet will not hurt. There are no recommended special medical foods or nutritional products for persons with dementia. Artificial nutrition and hydration are medical treatments that require decisions to weigh the benefits and burdens is another topic for future discussion.

STUDENT ENGAGEMENT LET'S GET SOCIAL!

By Thomas Engels, Intern

This past month, the Minka has officially started an Instagram account and a Facebook community page. Each platform will have a different purpose for people to follow the type of content that they want to view. Facebook will primarily be used for information, updates and events, while Instagram will feature interactive content such as videos and stories.

In the future, the Minka social media will be able to provide people with a better understanding of our vision. After posting updates about innovations, events and education at the Minka, we hope to see more involvement from the greater Evansville community. Although this is just the start, we believe that the future for the Minka is bright.



"Healthy eating then is the rule in nutrition and dementia."



To follow the Minka Facebook page, visit facebook.com



To follow the Minka Instagram page, visit <u>instagram.com</u>

MINKA ADVISORY BOARD MEMBERS

By Leah Flake, Intern

The Geriatrics Workforce Enhancement Program (GWEP) has a lot of moving parts working together to advance the program towards its goal of improving health outcomes for the older population in our community. One of these key players in the GWEP is the MINKA advisory board that is made up of volunteers who advise and support the MINKA's mission to transform the environment for aging well in southwest Indiana to one that adaptive and personalized. Part of the advisory board's commitment is to help select technology before it is incorporated into the MINKA house. This is done by taking virtual technology assessment surveys to give feedback on technology. Read on to meet two of these all-star members who help to promote and better the program!

Meet Rebecca Neel

Rebecca is the Assistant Director at the USI Rice Library where she manages the library databases. Rebecca has two dogs, enjoys running and is pursuing her Doctorate in Education at USI. She currently has her master's in library science and bachelors in linguistics. Rebecca was influenced to join the GWEP advisory board by a former member who sparked Rebecca's interest when she mentioned the GWEP is focused on technology and improving the standard of life for the older population. Rebecca also took responsibility as a caregiver for her mother who had a life-long chronic condition. This introduced her to general accessibility issues and how standard housing and public spaces don't adapt to the older population. In the advisory board, Rebecca gives feedback and trains those in the staff and faculty about technology or research. Rebecca feels very fortunate to be a part of the program as important as the GWEP. Thanks for all you do Rebecca!

Meet Karen Hinderliter

Karen is a retired educator who is a two-time graduate of USI with a bachelors and a Master of Science degree in education. She is a wife, mother and grandmother to a wonderful family and enjoys reading, researching current topics of interest, boating with her family at Lake Barkley and volunteering in the community. Karen was invited to become involved with the advisory board through the MINKA MAGIC class she took in 2018. The class discussed ways to break down barriers through materials, took surveys on prejudices like agism and worked in small groups to come up with interesting ideas for inclusion. Karen first became involved in the dementia-friendly community when she began helping her mother's older sister who was diagnosed with Alzheimer's. Karen and her sister now care for their 85-year-old parents. Together, they try to incorporate technology into their parent's lives to improve the process of aging-in-place. In the advisory board, Karen reads referenced articles, participates in brainstorming sessions, gives feedback on devices and the PREPARE for Your Care website through surveys and volunteers to work with the GWEP interns. Thanks for all you do Karen!

Interested in being a part of the mission to create a better future for aging well in southwest Indiana? Email Lisa Fournier at Irfournier@usi.edu to get involved and learn more!



MINKA VISION STATEMENT

Aging well is personal. Each of us expects to live where we want and how we want as we go through life. Our homes are not always setup for aging well. In addition, our communities may be stifled by issues with access to healthcare, crime and violence, food insecurity, inclusion, age discrimination and more. The Center for Healthy Aging and Wellness wants to transform southwest Indiana by creating a Learning Lab for Living Well housed in the Minka house at USI. The Learning Lab for Living Well offers an interdisciplinary focus to involve students, faculty and campus stakeholders in research, healthcare leadership development, and simulations that address challenges for living-in-place and open health profession career opportunities. In addition, the Learning Lab for Living Well provides everyone in the local community a place to learn about and to adapt home innovations for living-in-place. Home innovations designed to integrate smart home technology, health coaching and learning workshops for a personalized, adaptable approach to aging well. The Center for Healthy Aging and Wellness at USI looks to offer a blueprint for other rural communities to address social determinants of health.