

IMAGINE

YOUR BRAIN HEALTH GUIDE



INSIDE

The Best Days are Ahead / KC Proud: A Hidden Gem / The Super Six

IMAGINE

A DAY WITHOUT ALZHEIMER'S

At the KU Alzheimer's Disease Research Center, we're doing more than imagining that future.

We're doing the work to make it real.

Join us.

Be part of the progress.

What you do *TODAY* can change the future for *MILLIONS*.

With the help of people like you—research participants, patients, families—we're gaining insights on everything from brain scans to brain teasers.

We're reducing risk. We're improving lives.

KU ALZHEIMER'S DISEASE RESEARCH CENTER
The University of Kansas Medical Center

**IMAGINE
WHAT WE CAN
DO TOGETHER.**

PREVENTION WORKS,
AND A CURE IS OUT THERE.

HELP US FIND IT.

WWW.KUMC.EDU/KUADRC

913.588.0555

THE BEST DAYS ARE AHEAD

Fifteen years ago, if you mentioned Alzheimer's disease prevention, there was nothing going on. Now, there are large studies underway, including those at the KU Alzheimer's Disease Research Center (KU ADRC). Fifteen years down the road, we may well be postponing—or preventing—the changes created by Alzheimer's disease.

It's no longer a question of *if*.
It is a matter of *when*.

There is hope. There is progress. When it comes to the prevention and treatment of Alzheimer's, you are empowered. As you'll see in this guide, the earlier you get involved, the better.

Start here. Start now.

YOUR GUIDE ::

- /2/ KC Proud
- /4/ Dr. Jeff Burns: On Curing Alzheimer's Disease
- /6/ FAQs: Alzheimer's Disease
- /8/ Research Heroes
- /11/ The Super Six
- /13/ Take a LEAP!
- /14/ Dr. Russ Swerdlow: On Answering the Big Questions
- /16/ Opening Doors
- /18/ Changing Perceptions, Creating Possibilities
- /19/ How to be a Healthy Caregiver
- /20/ Improving Homes and Communities
- /21/ MyAlliance for Brain Health
- /22/ Spreading the Word
- /24/ Atypical Alzheimer's

KC Proud: Life-Changing *Research*, Game-Changing *Results*

2004

DR. JEFF BURNS ESTABLISHES THE KU ALZHEIMER'S RESEARCH PROGRAM.

2011

THE KU PROGRAM IS DESIGNATED AS ONE OF ONLY 31 NATIONAL INSTITUTES OF HEALTH (NIH) ALZHEIMER'S DISEASE RESEARCH CENTERS IN THE COUNTRY.

2016

NIH RENEWS KU ADRC STATUS AND FUNDING THROUGH 2021.

20??

WITH EFFECTIVE TREATMENTS AND PREVENTIONS, **Alzheimer's disease is curable.**

Nestled away in Fairway, Kan., the KU Alzheimer's Disease Research Center has been something of a hidden gem in the Kansas City metro area. No more. With studies that are making a difference and researchers respected worldwide, the KU ADRC is stepping into the spotlight.

Dr. Jeff Burns, who established the Center, directs the program along with Dr. Russ Swerdlow. Talk with either of these national experts and you'll find their optimism contagious.

"Someone is going to cure Alzheimer's disease," says Dr. Swerdlow. "We think it would be great if it was us. Even if we're not the ones who find the cure, we're going to make an important contribution to reaching that goal."

KU ADRC programs include research and direct care. The research division brings the latest clinical trials to KC and tests the newest medicines. The KU Memory Care Clinic provides patient and family care, from diagnosis through treatment.

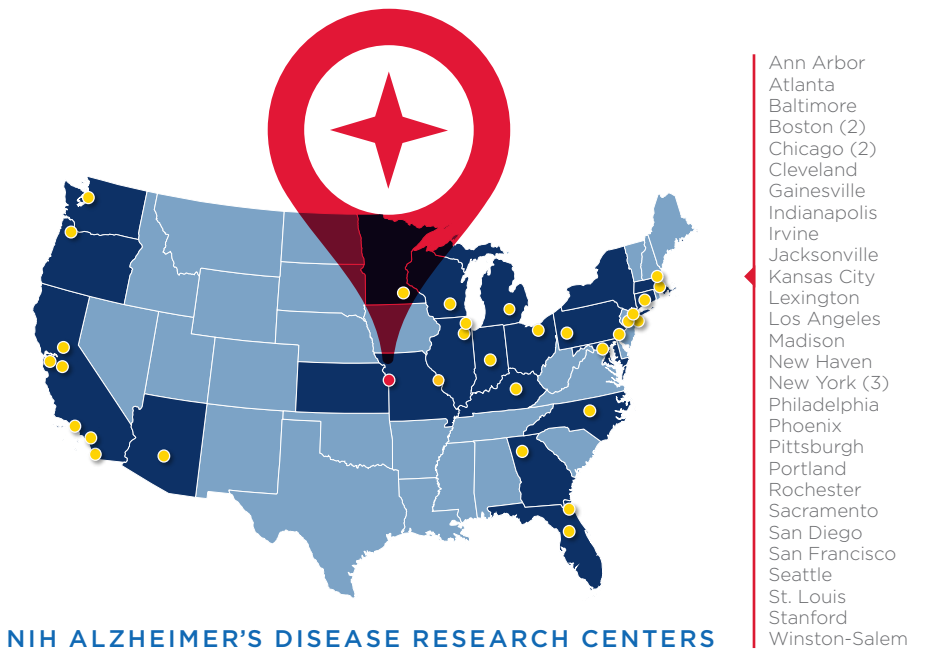
"The clinic gives me insights into the lab, and the lab gives me insights back into the clinic," says Dr. Swerdlow. "Most of my colleagues in this field are doing one or the other, so seeing patients in the clinic gives me a unique perspective as a physician-scientist."

According to Dr. Burns, gaining that "labs to life" perspective is a true advantage.

"It's important for our researchers to see patients who are living with Alzheimer's, so we can better understand the impact and see how the disease plays out in people," he says. "We're not just working with test tubes and petri dishes. We're working on how to deliver better patient care."

IMAGINE THAT

90% of what we know about Alzheimer's has been discovered in the last 20 years.



Moving forward with metabolism

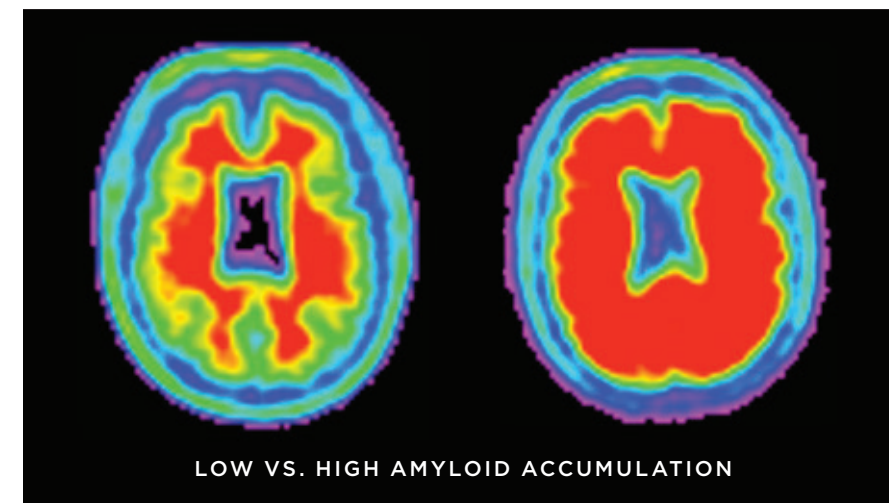
How do you break down food and transform it into energy? Could that process—including the food involved—impact Alzheimer's disease? Researchers at the KU ADRC believe there is a connection between diet, metabolism, and memory.

"We're trying to understand what is wrong with the

brain energy metabolism in Alzheimer's, and why it has gone wrong," says Dr. Swerdlow. "What are the consequences and how can we fix the problem?"

The Center's metabolism research includes studies on mitochondria, the powerhouse of our cells and tissues—including the brain.

Mitochondria produce the energy necessary to move and think. Because the brain uses about 20% of the energy we make per day, good mitochondrial function is critical to a healthy brain. Our researchers are studying how changes to mitochondria may increase or decrease the risk of Alzheimer's disease.



New views

With positron emission tomography (PET) scans like this, researchers at the KU ADRC can see wide red areas that indicate amyloid accumulation in the brain. This wide distribution of amyloid is common in people who have been affected by Alzheimer's disease.

Livingston et al., 2017

TOP 10

THINGS YOU SHOULD KNOW ABOUT THE KU ADRC

Dr. Jeff Burns leads the team at the KU ADRC, and another big crew at home: He and his wife Jennifer are the proud parents of 10 children! Naturally, they enjoy a good Top 10 list.

10 We've given KC another major league team: *There are only 31 nationally recognized NIH ADRCs across the country.*

9 We thought it would take 15 years to get the NIH funding. *We got it done in seven.*

8 We've written the book on brain healthy living. Literally. *SEE PAGE 13*

7 Top researchers from around the world turn to us for collaborative investigations.

6 Thoughtful, generous donors change lives. *SEE PAGE 23*

5 All research moves us forward: If the end result isn't what we hoped for, we still learn from it.

4 Diversity matters. *SEE PAGE 16-18*

3 Hope is pervasive here. And contagious.

2 Our support goes beyond patients and families. We help doctors too. *SEE PAGE 22*

1 What you do today can change the future for millions.

CURING ALZHEIMER'S DISEASE::

No Longer a Question of *If*, but *When*

DR. JEFFREY M. BURNS MD, MS
CO-DIRECTOR, KU ADRC

You might think that a doctor who is immersed, day after day, in the world of Alzheimer's disease—a man who has seen what this disease does to friends, family, and patients—might be weary. You'd be wrong.



Dr. Jeff Burns, a Kansas City native and co-director of the KU ADRC, radiates energy and optimism.

He's justifiably proud of the progress made at this NIH-designated center, and excited about the cure he is confident will be found. Will we have that cure in the next five years? Maybe not. *In 15 years?*

"Fifteen years down the road, we may well be spotting the changes of Alzheimer's before the onset of memory problems, and have interventions that postpone or prevent, reduce or stop, those changes," says Dr. Burns.

"Will we have a cure in 15 years? I don't know. I do know this: We will get there. I'm confident the day will come when doctors recognize the disease years before onset, and in time to start new and effective drugs. It's no longer a question of if we will be able to do this, it is a matter of when."

Dr. Burns says Alzheimer's is both the most feared disease

and the costliest disease. But, he adds, there's hope.

"We are empowered today, in ways that we weren't a few years ago. We can diagnose Alzheimer's and we can treat it. We have treatments that do help, and we are pushing hard to develop new drugs.

"We're also making progress with the care we provide. We've improved the delivery of care, and are better able to help families. We're talking about prevention, and we've come a long way in understanding the importance of lifestyle."

In addition, Dr. Burns says, having the KU ADRC in the metro area gives local and regional residents the rare opportunity to be part of the research that drives hope.

Dr. Burns attended the University of Kansas School of Medicine and completed his residency in neurology at the University of Virginia, a post-doctoral fellowship at the Alzheimer Disease Research Center at Washington University in St. Louis, and a master's of science in clinical research at the University of Kansas. He returned to Kansas City in 2004 to start the Alzheimer's disease clinical research program, designated as an Alzheimer's Disease Research Center in 2011. His research supports clinical trials testing new approaches to treating Alzheimer's disease, and a variety of research programs focused on how lifestyle issues, such as diet and exercise, can be used to prevent or delay onset.

Our research is a community and team effort. There is hope and there are things you can do. You are empowered. Join a study. The earlier you start, the better.

ALZHEIMER'S DISEASE::

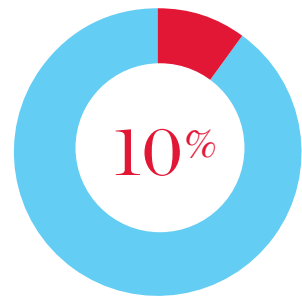
Frequently Asked Questions

IN 2020, NEARLY

6,000,000 Americans

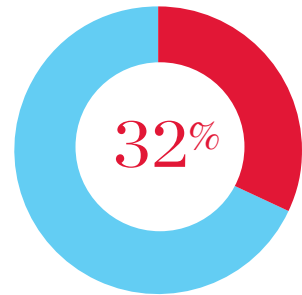
OF ALL AGES ARE LIVING WITH ALZHEIMER'S

AGE
65+



1 in 10
HAVE ALZHEIMER'S

AGE
85+



1 in 3
HAVE ALZHEIMER'S

EVERY 65 SECONDS...



SOMEONE IS DIAGNOSED WITH ALZHEIMER'S

FOR ALZHEIMER'S,
PREVENTION IS
PART OF THE CURE.

Postponing memory changes for five years will cut the incidence by 50%



- ◆ ALZHEIMER'S DISEASE
60% – 80%
- ◆ Other types of dementia include:
DEMENTIA WITH LEWY BODIES
FRONTOTEMPORAL DEMENTIA
MIXED DEMENTIA
VASCULAR DEMENTIA

What's the difference between Alzheimer's disease and dementia?

Dementia covers Alzheimer's disease and other conditions. It is an umbrella term used to describe memory loss and other cognitive decline that impacts daily life and activities. Alzheimer's is by far the most common type of dementia. Other types of dementia include: dementia with Lewy bodies; frontotemporal dementia; mixed dementia; and vascular dementia.

Am I at risk?

Alzheimer's can strike anyone. Age is a major risk factor, along with family history and heredity. If you had a parent or sibling with Alzheimer's, you are in a higher risk group, but that does not mean a diagnosis is inevitable.

There's a common misperception that Alzheimer's only targets the elderly. Not so. Some 640,000 Americans have early-onset dementia, most commonly related to Alzheimer's disease. An early-onset diagnosis is reached when the patient is younger than 65.

Can I do anything to reduce my risks?

Good news! Simple steps such as eating well and exercising regularly are proving effective. Check out our Super Six steps.

SEE PAGE 11

What can I do if I'm concerned about my memory lapses or a loved one's behavior?

We all forget things now and then, and it's not unusual to wonder if memory lapses are related to dementia. Review the warning signs. SEE PAGE 12

If even subtle memory changes are causing concern, don't assume it's a natural part of aging; it could be a sign of mild cognitive impairment, changes that sometimes precede more serious decline. The first step is to talk with your doctor.

The KU ADRC also offers research evaluations for mild cognitive impairment, and we have a number of studies underway in this area.

Call 913-588-0555 for more information or to schedule an appointment.

Why would I want to know the reason for memory changes?

First of all, while Alzheimer's might be your biggest concern, people experience memory changes for numerous reasons, including: mild cognitive impairment, depression, medication issues, low vitamin B levels, and poor sleep patterns. Identifying and addressing the primary reason is important.

If the memory changes are connected to Alzheimer's, the earlier you receive a diagnosis, the earlier treatment can begin. Current Alzheimer's treatments can slow the progression of dementia symptoms, and proper support and care navigation can improve life for patients and those who care about them. In addition, early diagnosis may open the door to participation in a research study that could benefit you, your loved ones, and countless others.

IMAGINE THAT

THE BIGGEST ROADBLOCK ON THE WAY TO A CURE IS NOT HAVING ENOUGH RESEARCH PARTICIPANTS.

JOIN A STUDY.

//////

Become a RESEARCH HERO

WANT TO DO SOMETHING TO HELP, BUT YOU'RE NOT SURE WHAT?

Check out the many groundbreaking research opportunities at the KU Alzheimer's Disease Research Center. Every study unlocks more clues about the mysteries of Alzheimer's disease, and much of what we know would not have been possible without study participants. Whether you have memory changes or not, joining a study will help find a cure for Alzheimer's disease. And we always have studies underway!

//////

DISCOVERY AND INNOVATION STUDIES

You can help without taking study medications or devoting much time to research. Our discovery and innovation studies explore how behavioral and environmental factors may play a role in the development and progression of Alzheimer's disease.

These studies are primarily observational, do not affect outcomes through intervention, and often require only a single visit.



INVESTIGATIONAL MEDICINE TRIALS

Our Clinical Trial Unit (CTU) specializes in studies that involve investigational medications for the treatment or prevention of Alzheimer's and related diseases.

These trials offer participants an opportunity to help us research medications not available to the general public.



EXERCISE AND LIFESTYLE INTERVENTION TRIALS

Our Physical Health Intervention Team (PHIT) conducts studies that involve interventions such as exercise, diet, and other aspects of lifestyle.

The PHIT team works closely with partners at the YMCA of Greater Kansas City and Genesis Health Clubs to conduct many of the prevention trials.



LEARN MORE. TODAY.

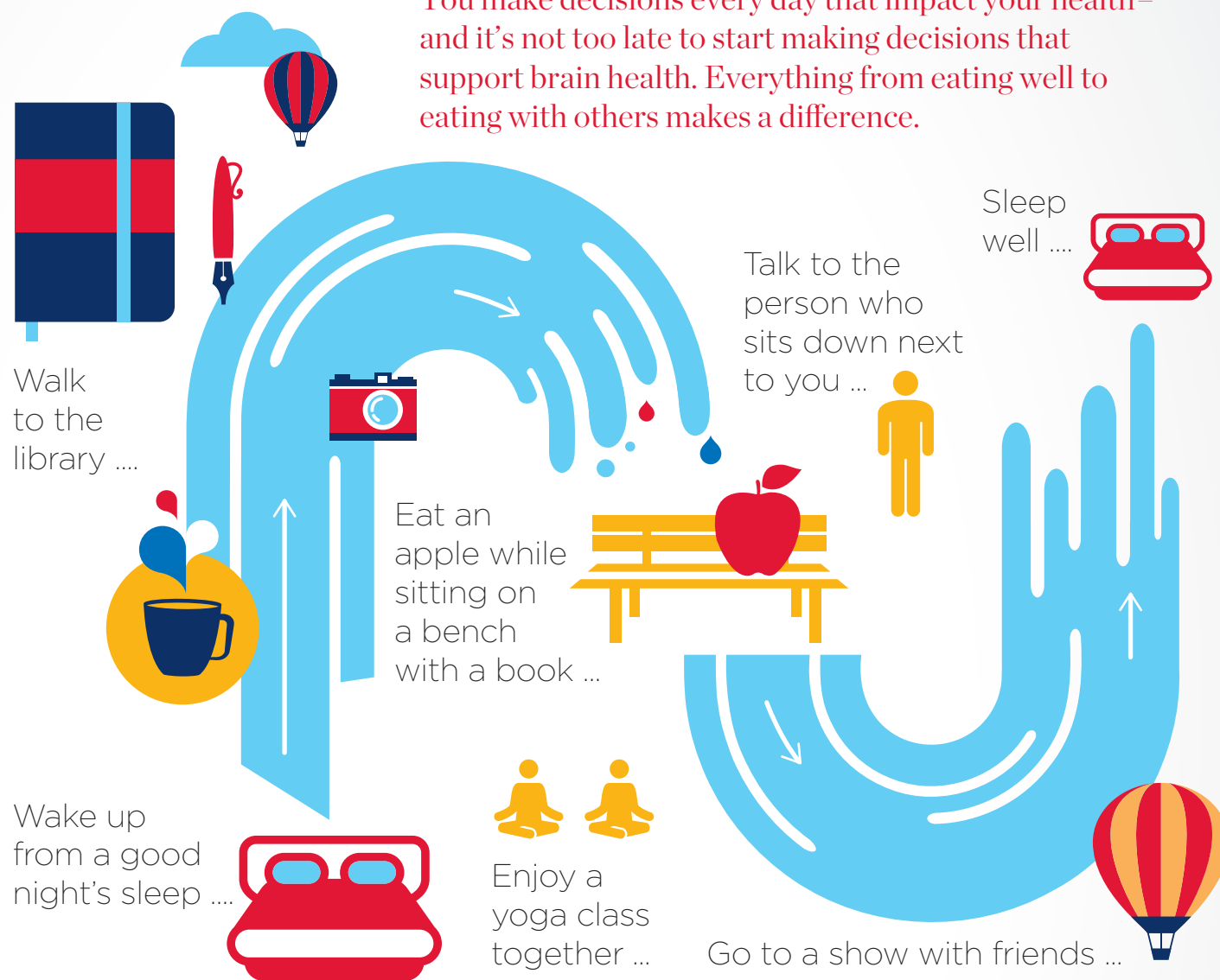
To find a study that's right for you, call **913-588-0555**.

////////////////////////////////////

BIG DIFFERENCE

SMALL STEPS

You make decisions every day that impact your health – and it's not too late to start making decisions that support brain health. Everything from eating well to eating with others makes a difference.



8			7	4	3	6	
	4	7		2		5	8
6	1	2					4
5	3	9	4	2			1
7	2			9	6	8	3
4	8	6				2	
		8		7	4		
9	6		2		8		7
			4	5			

NEW TO SUDOKU?

Fill each big square with the numbers 1-9. Don't repeat a number, vertically or horizontally. For more brain games, visit games.aarp.org.

IMAGINE THAT

DESPITE POPULAR BELIEF, DOING A CROSSWORD PUZZLE EVERYDAY WON'T PREVENT ALZHEIMER'S.

Learn something new!

//////

We're All IN THIS TOGETHER

Research and study participants help us unlock the clues that lead us closer to a cure. We're delighted that many of our KU ADRC study participants go on to become volunteers. Bob Deady in Johnson County, Kan., and Lois Edmiston in Clay County, Mo., followed similar paths to our door: They first heard about the KU ADRC at their local YMCAs, learned more, and got involved.

//////

Bob Deady



Bob Deady's first KU ADRC research study tested the theory that exercise helps memory. His initial connection grew into volunteer work at the KU ADRC; Deady also continues to participate in studies.

"I'm happy to do it and be part of something so important. We need more people to step up for research. The only way to slow down onset or make a cure or treatment is to have lots of people in these studies. And the studies they're doing at the KU ADRC are some of the best in the world.

"The studies point out that it's important to do new things. People tell me, 'I do the crossword every day!' And I tell them, 'Then let your husband do the crossword and you do the Sudoku. And don't do that Sudoku at your kitchen table. Go across the street and do it with your neighbor. The social interaction will be good for your brain.

"Risk reduction makes a difference. If you were to get Alzheimer's at 84 and you can delay that through lifestyle changes to 86 or even 90, well, statistically, that's almost like a cure."



Lois Edmiston

Lois Edmiston is a LEAP! champion. She first joined the KU ADRC's Lifestyle Empowerment for Alzheimer's Prevention program in Fall 2017. She's now preparing to be a LEAP! facilitator.

"I love LEAP!. I felt like I had a good food plan going on before, but I realized it was really mediocre, so I made improvements. I was also doing some exercising, but with LEAP! I zeroed in on exercises and physical activities that are good for brain health. The LEAP! module that is the toughest, for me, is finding good ways to manage stress and taking the time to do so.

"My sleep habits have also changed dramatically. I work at having a good sleep routine—no computer or iPhone before bed. Maybe some reading or a bath. And I try to go to bed at the same time every night and get up at the same time every morning."

Edmiston's LEAP! experience gives her a fresh perspective to share with people facing a difficult diagnosis. "There is hope. I want people to know that even with a diagnosis of Alzheimer's, or another type of dementia, that person can still Live. Life. Fully. It's not the end of the road. It's just a new path on their journey."

////////////////////

BRAIN HEALTHY HABITS:

THE SUPER SIX

////////////////////

1 Keep Learning

Give your brain something new to mull over.
Learn how to tango.
Try a different brain game.
Join a study at the KU ADRC!

Get 2 Moving

Movement is marvelous.
Go for a walk.
Join a gym.
Play pickle ball with friends.
Aim for 150 minutes of aerobic exercise per week.

3 Stay Connected

Eat a healthy meal with a friend.
Volunteer.
Talk to your neighbors.
Social interactions stimulate your brain.

Manage Stress 4

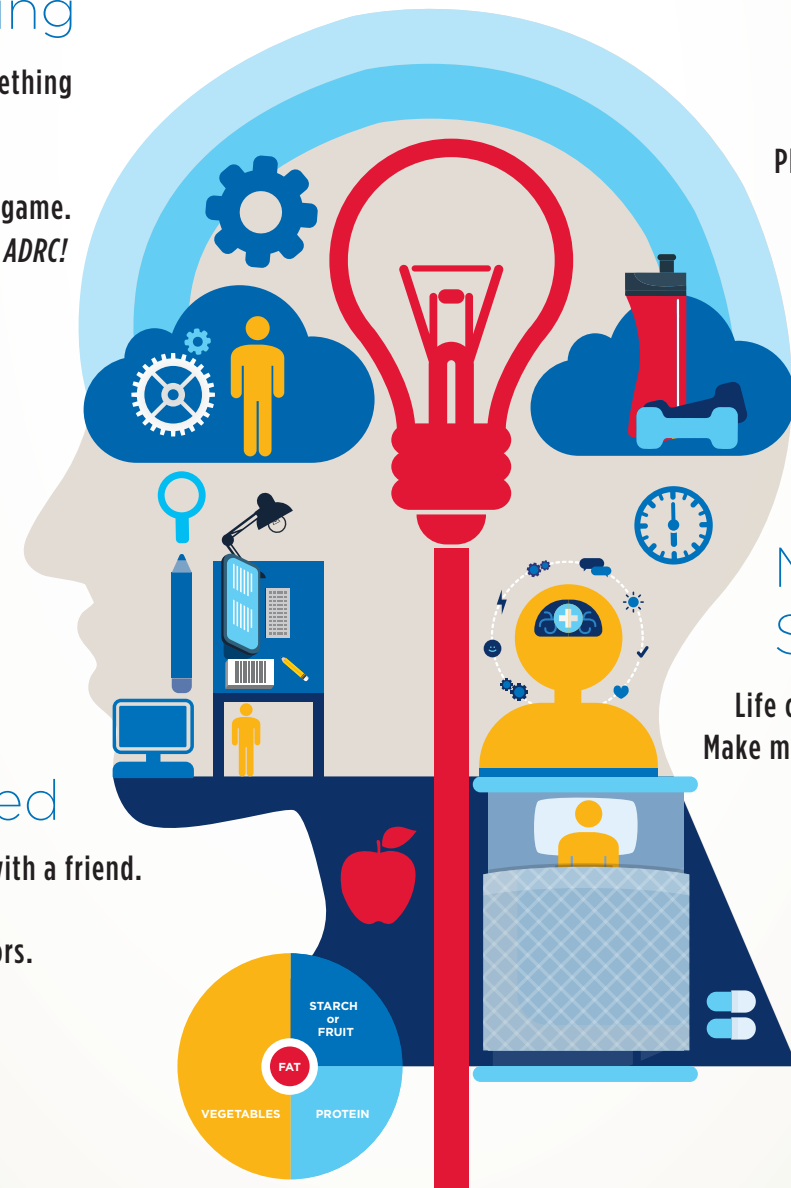
Life can be stressful at any age.
Make mental well-being a priority.
Set boundaries.
Try yoga.
Meditate.
Get professional help when needed.

5 Eat Well

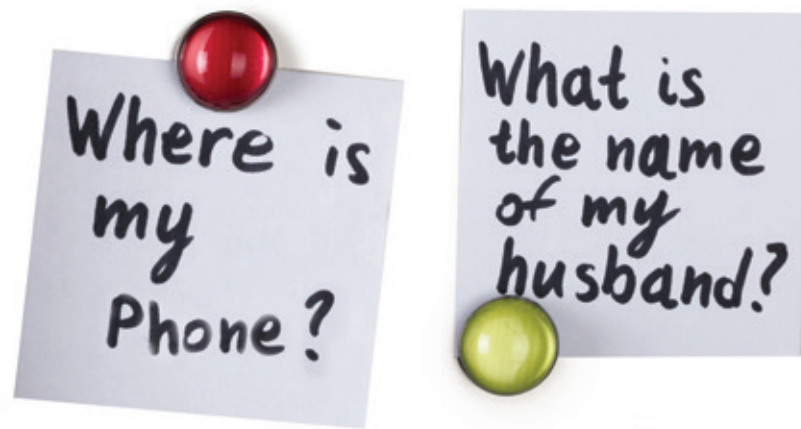
Want sweets? Eat fruit.
Crunch veggies instead of chips.
Forget the fryer and eat more fish and poultry.
Your brain and heart will thank you.

Sleep Tight 6

Give your brain a break.
Follow a calming nighttime routine.
Read a book; write in a journal.
Avoid TVs, phones, and computers for two hours before bed.



Worried Well —or— Concerning Changes?



Once we reach a certain age, it's understandable if misplacing our car keys or forgetting why we walked into a room sets off internal alarm bells. The "worried well" are people who worry that their forgetfulness is an indication of Alzheimer's, when it's not.

On the other hand, if someone has been driving to the same office for 20 years and can't remember the route, that's a concerning change.

How can you tell the difference?

While it's common to forget something occasionally and remember it later, watch out for:

- **MEMORY LOSS THAT CREATES CHALLENGES IN DAY-TO-DAY LIFE** such as frequently forgetting appointments or special dates like birthdays that you or your loved one always used to remember. When a person has trouble making decisions that would have been easy before, that's a warning sign.
- **REPEATING THE SAME INFORMATION OVER AND OVER AGAIN** or asking others to repeat something frequently.
- **UNUSUAL JUDGMENT PROBLEMS** such as making poor financial decisions, like giving money to online scams or unfamiliar telemarketers.
- **CHALLENGES WITH FAMILIAR TASKS OR TROUBLE LEARNING NEW ONES** can indicate an issue. If driving to the neighborhood grocery store or balancing a checkbook suddenly becomes difficult, that's a concerning change.

- **LESS INTEREST IN PEOPLE, PLACES, AND ACTIVITIES** that have mattered before, such as withdrawing from family events, hobbies, or work-related functions.
- **PERSONALITY AND MOOD CHANGES** such as becoming easily confused, anxious, or upset. Depression and fearfulness are also warning signs.
- **DIFFICULTY FINDING THE RIGHT WORDS TO USE** in a conversation, especially if the person is typically well-spoken. Watch for a new hesitancy to join a conversation, or the inability to keep one going.
- **CONFUSION WITH TIME** whether it's forgetting the correct month or year or understanding that dinner won't be served for another three hours.

IMAGINE THAT

Needles aren't necessary.

TALK TO US ABOUT THE KU ADRC
DISCOVERY AND INNOVATION STUDIES.

You're Empowered

AND WE'RE NOT JUST IMAGINING THAT.

KU ADRC experts frequently speak to the community, and typically get asked the same question:

“What should I do now to reduce my chances of developing Alzheimer's disease?”

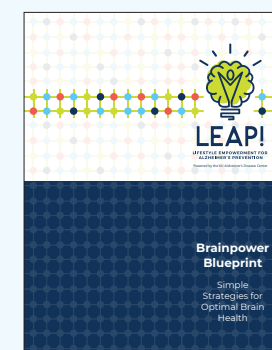
Fair question.
Here's one answer.



Take a LEAP!

Learn more about Lifestyle Empowerment for Alzheimer's Prevention (LEAP!):

- GET MOVING
- EAT HEALTHY
- SLEEP WELL
- STAY CONNECTED
- MANAGE STRESS AND MENTAL HEALTH



Brainpower Blueprint: Simple Strategies for Optimal Brain Health is an outgrowth of LEAP!, an innovative educational program developed by the KU ADRC in 2015 and inspired by more than 10 years of research. Rachel Sandoval, MS, RDN, and program manager, co-authored the book with Dr. Jeff Burns and Erin Blocker, Ph.D.

“With LEAP!, our goal is to take the existing science and turn it into something practical and applicable to daily life,” Sandoval says. “We are talking about real-life applications and daily strategies.” Sandoval says that even small changes—consistently applied—make a difference.

“Improving all the lifestyle variables you can is about risk reduction, rather than prevention,” she says. “The evidence supports that relatively quick changes and adjustments are beneficial, regardless of when you make them.”

When's the best time to make a positive change? Today.

“Your lifestyle matters, and you can influence your overall health, including your Alzheimer's risk, with lifestyle changes,” says Sandoval. “Making changes can be difficult. But if you make a handful of changes, small steps in the right direction, you can see improvement.”

Ready to leap? Visit leapbrainpower.com.

“Research tells us you'll do better if you make the lifestyle changes, but is it worth the effort involved? We certainly think so, but only you can answer that question.”

Answering the Big Questions

by DR. RUSSELL SWERDLOW, MD
DIRECTOR, KU ADRC

At the KU ADRC, we want to cure Alzheimer's disease. That requires tremendous resources and infrastructure: You have to start small and build the infrastructure.

That's exactly what we've done here.

We're now part of the National Institutes of Health, and the importance of that can't be over-stated. The NIH has identified the KU ADRC as a place where people hope the answer may be found.

Our Center collaborates with other NIH Alzheimer's Disease Research Centers across the country, and our investigators collaborate with other investigators worldwide. We also work with physicians, patients, community leaders, and caregivers.

This is a process, and it takes a village. It takes finances, intellect, and resources. It requires active stakeholders who embark on the journey with us.

I don't have Alzheimer's, so why should I get involved in research?

The question is: Why not be part of it?

If you don't have Alzheimer's now, you may in the future. If you don't know someone who has it now, you may in the future. Figuring out the cause and finding the cure can be a rewarding journey, and we can't do it alone.

Why is finding a cure so difficult?

Many reasons, including a very basic one: *Finding a cure requires us to take a new approach.* What are we good at with medicine? Destroy and remove. Antibiotics can cure strep. Chemotherapy can kill cancer cells. If something is broken, we can cut it out. Alzheimer's is a fundamentally different problem. We're not going to fix it by finishing off what's damaged. *We actually have to repair it.*



Dr. Swerdlow received his undergraduate and doctor of medicine degrees from New York University, and trained as a neurologist and Alzheimer's specialist at the University of Virginia. In addition to his work at the KU ADRC, he is a professor in the Departments of Neurology, Molecular and Integrative Physiology, and Biochemistry and Molecular Biology at the University of Kansas School of Medicine and is active nationally on Alzheimer's and aging issues. Dr. Swerdlow's research focuses on brain energy metabolism, the role brain energy metabolism plays in Alzheimer's disease and other neurodegenerative diseases, and how to manipulate brain energy metabolism.

What does a cure look like?

We want to take what's not working, and make it work again.

That's what the cure looks like.

When what's taking down the brain is no longer taking down the brain. When what wasn't working, now works. When people hold onto what they have.

That means we have to identify what's gone wrong, and figure out how to reverse it. The brain is like a set of fuses in a fuse box. With Alzheimer's, the fuses get screwed up. If we can restore them to the way they should be, that would be a cure to me.

For the patient?

They're able to do whatever they could do, and count on being able to do the same things just as well in the future.

IMAGINE THAT

82% OF SENIORS SAY IT'S IMPORTANT TO GET REGULAR COGNITIVE CHECK-UPS.

Only 16% do it.



I bought this bag the week I graduated from medical school. I carried my tools in there on house calls. It cost \$75—all I had at the time.

I still carry it with me every Wednesday to the clinic. I keep my cognition testing tools in there now. And, just in case I need a 24th century consultation, I take along Dr. McCoy from Star Trek.

In all seriousness, whatever it takes, I want to figure things out and solve this. Am I hopeful? Yes. This isn't the biggest challenge mankind has had to overcome. If the will is there, we will solve this.

HISTORY TELLS US: PROBLEMS GET SOLVED.

FROM THE DAY WE OPENED OUR DOORS...

KU ADRC has been an inclusive environment, dedicated to eliminating disparities in knowledge, treatment, and prevention.

Alzheimer's disease impacts everyone—and everyone can help us find a cure.

ASHLEY SHAW, PH.D., a postdoctoral fellow at the KU ADRC, runs the Aging with Grace program, with a special focus on Kansas City's African-American community. She shares everything from basic information on Alzheimer's disease to brain-healthy recipes during her presentations at churches and other metro area sites.

"In the African-American community, there's a feeling that memory loss is a normal part of aging: This is what God wanted, so let it be," she says. "Due to historical research events, there's a mistrust in research institutions which has impacted participation in research in the African-American community; people tell me they don't want to be a lab rat."

Shaw says she explains the ethical and legal changes made to protect study participants throughout the U.S. and clarifies the value of participating with the KU ADRC. "Being involved in research helps the African-American community as a whole.

We need more African Americans in clinical trials to ensure that the discoveries, treatments, interventions, and prevention strategies are going to be relevant to our community," Shaw says. "My role is to ensure that we are including our community so that when we do find a cure and make advancements in prevention and intervention strategies they are for everyone; everyone will be able to benefit."

Howard Pace, a longtime pastor in the African-American community, became involved with the KU ADRC after his wife Pearl was diagnosed with Alzheimer's disease. He encourages everyone to "get involved and help somebody else. Don't be fearful of it."

"People should be concerned—this disease affects everyone. It doesn't have a color to it," Pace says. "The people at the Memory Care Clinic feel like family. They want what's best for us. We're there to be a part and help others for the future, but it has been a blessing to us, also."

CARING SPIRIT::

Pearl Pace is also supported by her daughter, Cecille Swan. Since her mom was diagnosed several years ago, Swan has become both a caregiver and study partner.

"You can feel kind of lost when you get a diagnosis of Alzheimer's, and you don't know where to go," Swan says. "The clinic has been a wonderful support system. Beyond getting the diagnosis, they've helped teach us how to care for someone with Alzheimer's. It's a difficult process, but the clinic is like a family.

"Everyone there really cares about people," she says. "It's not just about the research and getting samples. Every person we've dealt with at the clinic really has a caring spirit."

"I'm hoping there's a cure for my mom. But if not, being part of these studies will definitely help someone else."



Dr. Shaw earned her Ph.D. in nursing, a master's degree in public health, and a bachelor's degree in nutrition and exercise physiology at the University of Missouri. Her main research interest areas include dementia prevention through culturally tailored dietary interventions, racial and ethnic health disparities in Alzheimer's disease, faith-based prevention and intervention programs, and health promotion in the African-American community. As a postdoctoral fellow, she leads the African-American outreach and education efforts at the KU ADRC and the African-American Cohort, in which she recruits and conducts clinical dementia assessments.

To schedule an Aging with Grace program, call **913-588-0555**.

Meet a Real Pearl

Pearl Pace is a research hero. Since her diagnosis with Alzheimer's, she has been meeting with the healthcare team at the KU Memory Care Clinic, and participating in research studies at the ADRC.

How did Mrs. Pace first get involved? Several years ago, her family noticed changes that concerned them. As a computer programmer and a pastor, she was known for her "really sharp" memory. Her family wondered what was wrong when she couldn't balance her checking account. The diagnosis of Alzheimer's disease was an explanation, and the start of a new journey.

“ Our family believes in the program. They want to help us and we want to help others.

"At first I thought, 'Whoa! What's happening to me?'" Mrs. Pace says. "This can come upon anyone, and the more information they have, they won't be as frightened. Someone else has walked this path, and they will be able to do the same thing."



Pearl Pace, Howard Pace, Kelli McRae, Camille Allen, and Cecille Swan. By the way, Camille and Cecille are twins!

IMAGINE THAT

Can soul food be brain food? Absolutely!

BRAIN-HEALTHY SOUL FOOD RECIPES ARE INCLUDED IN THE KU ADRC'S AGING WITH GRACE PROGRAM.

Changing Perceptions, Creating Possibilities

Latinos, like many in the African-American community, have traditionally seen Alzheimer's as a typical part of aging.

JAIME PERALES PUCHALT, PH.D., an assistant professor at the KU ADRC, is working to change that perception and expand Latino participation in research studies.

"If you don't know what Alzheimer's is, there's little motivation to try to prevent it or participate in a study," he says. "There's little motivation in looking for help, if you're thinking, 'Grandfather is just old and there's nothing we can do.' You need knowledge to take action. When knowledge increases, there's more motivation to participate in research.

"I want to increase understanding of Alzheimer's disease, reduce the disparities in care and prevention, and find a cure," Perales says.

“The first person to be cured will be a research participant.”

In his bilingual community presentations on Alzheimer's disease, Perales talks about the many research studies available at the KU ADRC, including those in need of more diverse participation. Current studies explore such topics as whether exercise can help maintain and improve brain health in older adults; the impact of following a Mediterranean diet vs. a low-fat diet; and whether sleep intervention and therapy for insomnia improves cognitive function. Want to learn more and see if you qualify? Visit www.kumc.edu/kuadrc and click on "Currently Enrolling Studies."

IMAGINE THAT

SOME FATS, INCLUDING THOSE OFTEN INCLUDED IN LATINO MEALS, ARE BRAIN-HEALTHY.

Avocados are on the good list, so enjoy!



Dr. Perales received his doctorate in biomedicine and a master's degree in public health at the Universitat Pompeu Fabra, Barcelona. He has conducted research in Spain, England, and the United States, and has collaborated with many international teams. His primary interest is understanding and reducing dementia disparities among Latinos and other vulnerable groups through intervention and epidemiological research. He has led the development of a dementia educational and recruitment tool for Latinos (Envejecimiento Digno) to increase Latinos' dementia literacy and representation in research. He has studied the risk of dementia and mild cognitive impairment among sexual and ethno-racial minorities.

HOW TO BE A...

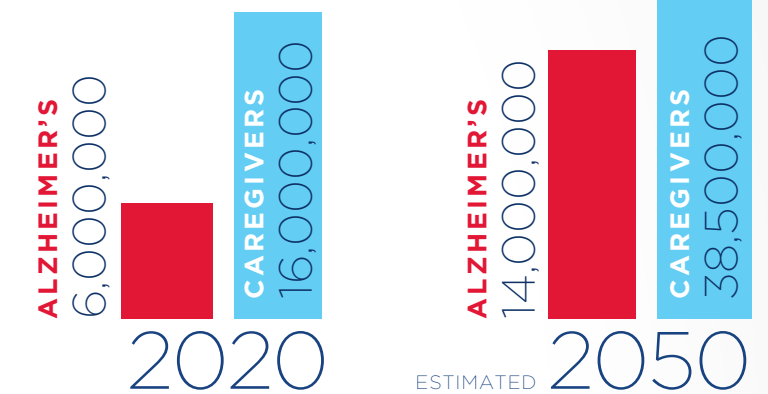
Healthy Caregiver

IN 2020, MORE THAN

16,000,000 Americans

WERE PROVIDING UNPAID CARE FOR PEOPLE WITH ALZHEIMER'S AND OTHER DEMENTIAS

As the number of individuals with Alzheimer's rises, the number of caregivers rises.



While every situation is unique, caregiving stress is universal. Managing life when a loved one has Alzheimer's disease can be overwhelming. If you're in this position, it's essential to take care of yourself. You need to be in good shape to help your family. *And remember: you matter, too.*

— MAKE PLANS EARLY ON.

Making financial and legal plans as soon after diagnosis as possible helps patients participate in that process. You'll know what your loved one wants.

— LEARN AS YOU GO.

There are different stages of Alzheimer's. Trying to comprehend it all at once can be overwhelming, and no one can predict the future. Take it step by step.

— ASK FOR HELP.

You are not in this alone. There are support groups and other valuable resources in the KC metro area. If you wonder where to start, call the KU ADRC and ask to speak with one of our social workers.

— ACCEPT WHAT YOU CAN'T CHANGE.

It can be a challenge to accept the changes you see in a loved one, but insisting that someone "must remember" something isn't helpful—to the person or you.

— DON'T MISS THE GOOD MOMENTS.

Even though things are changing, and they are different than you want them to be, there are still moments that you can enjoy. Try not to get lost in a comparison of what was.

— VISIT YOUR DOCTOR.

Make your annual check-up a priority and schedule other appointments when needed. Stress and exhaustion are real health dangers. If you're losing weight, not sleeping well, or experiencing other symptoms, call your doctor.

— GIVE YOURSELF A BREAK.

Caregiving is hard. Be nice to yourself: Make arrangements for someone else to provide care, so you can take a day off. Forgive yourself for any "mistakes" you make. Find time, every day, for something you enjoy.

LOOKING BEYOND::

Improving Homes *and* Communities



Along with making brain-healthy decisions for yourself, there are simple steps you can take to make your home and community more supportive for individuals with Alzheimer's disease and other dementias.

AT HOME::

- Store potentially dangerous items—such as medication, matches, firearms, sharp objects, cleaning fluids, etc.—in secure locations. A locked cabinet can prevent serious accidents.
- Remove locks on interior doors and consider installing deadbolt locks on external doors, above eye level.
- Look for tripping hazards, such as power cords and throw rugs, and remove them.
- Take advantage of technology available that can increase safety and independence.
- Install grab bars in the bathroom.
- Create a central place for a daily calendar and other notes, such as on a whiteboard.
- Simplify. Clear out unnecessary clutter.

IN THE COMMUNITY::

- Provide information (such as this guide) to leaders at your business, civic, and faith organizations, so people throughout the community can better understand Alzheimer's disease and how they can make a difference.
- Offer to run errands for neighbors who are caring for a family member with a dementia.
- Volunteer to take walks with family members, friends, and neighbors who have a dementia.
- Encourage caregivers to take care of themselves too.

SEE PAGE 19

IMAGINE THAT

Plans for the KCI New Single Terminal

INCLUDE SIGNAGE, RESTROOMS, AND PARKING DESIGNED TO MAKE TRAVEL EASIER FOR PEOPLE WITH ALZHEIMER'S AND OTHER DEMENTIAS.

JOIN::

MyAlliance for Brain Health

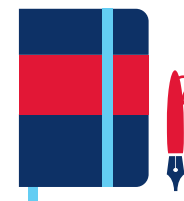
WANT TO STAY CONNECTED WITH RESOURCES OFFERED BY THE KU ALZHEIMER'S DISEASE RESEARCH CENTER, BUT YOU'RE NOT SURE HOW?

The KU ADRC outreach and engagement team has created a new communications program to keep you connected! Through weekly updates, we will provide easily accessible information and resources that support brain health and all those affected by Alzheimer's and other dementias.

MyALLIANCE / *Change the future. Start today.*
FOR BRAIN HEALTH

Make informed decisions that support brain health.

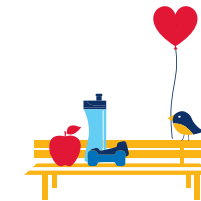
BY JOINING MYALLIANCE, YOU WILL RECEIVE WEEKLY COMMUNICATIONS THAT INCLUDE:



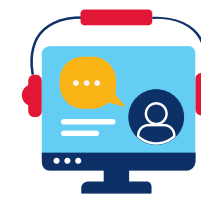
/ Useful information, customized to your needs



/ Caregiver advice and support



/ Tips on eating, exercise, and lifestyle



/ Special invitations to webinars and other events



/ Easy access to research study opportunities

Join MyAlliance for Brain Health

WWW.KUMC.EDU/KUADRC

SPREADING THE WORD::

Cognitive Care Network

Should the medical care you receive for Alzheimer's or other dementias depend on where you live? We don't think so.

And we're doing something about that.

To increase access and support across Kansas, the KU ADRC launched the Cognitive Care Network in 2019, a program that goes beyond the metro area, helping providers in Douglas, Barton, and Russell counties incorporate early-stage-sensitive screening tools into their practice.

MICHELLE NIEDENS, Lscsw, a clinical social worker, longtime aging advocate, and director of the Cognitive Care Network, says better tools and well-trained healthcare providers make a world of difference.

"Without the right tools and training, providers may ask a patient, 'Are you worried about your memory? Are you having any problems?'" Niedens says. "The answer often is, 'No.' While the person may not be having any problems that interfere in day-to-day life, they may indeed be experiencing cognitive changes."

Doctors miss an estimated 70% of early-stage Alzheimer's cases.

The Cognitive Care Network supports an earlier diagnosis, so patients and families receive essential support sooner.

It's good to understand at the front end that there's still life to live. Lots of times, with early Alzheimer's, the bigger issue is depression. We can treat that, and there are tools we can use when short-term memory or speech issues come up. There are ways to navigate those changes.

It's not about the proclamation of deficits. It's about the navigation of compensatory measures.

"I know of a woman in her mid-60s in rural Kansas, with a bubbly personality, articulate, still working," Niedens says. "She told two different providers that she was having problems, and that she and her husband thought she might have Alzheimer's or some issue. Both times, she was told she was fine. There was no further evaluation.

"She told a third provider, one who is participating in the Cognitive Care Network. He used an early-stage screening tool that triggered a concern. Then, he did a full dementia evaluation, and she was diagnosed with Alzheimer's disease."

The woman's response? *Relief.*

"She knew something was wrong," Niedens says. "The diagnosis allowed her to make informed decisions. She could start on medication and on a wellness plan, including exercise. She was able to include her children in a dialogue and planning. And she is interested in participating in research.



Michelle Niedens holds clinical social work licenses in Missouri and Kansas, and has worked with older adults and those with Alzheimer's disease for more than 30 years. She previously served as Director of Education, Programs and Public Policy for the Alzheimer's Association, Heart of America Chapter. Her work has included leading education and policy efforts; providing direct service to individuals and families; and providing mentorship and oversight to social work staff. She has a special interest in helping individuals with neuropsychiatric challenges and has spent significant time on developing and providing early-stage programs and services.

SUPPORTING THE CAUSE::

The tools, training, support, and service provided throughout the Cognitive Care Network are strengthened by the generosity of **LINDA AND RAY CARSON**, KU alumni who wanted to go beyond including the University in their estate planning.

"We asked ourselves, 'Why can't we do something now and begin to make a dent?' And that led to our work with the KU ADRC," Linda Carson says. "We want families to be educated on the issues of dementia and Alzheimer's, and know that they have a place in their community to go for services, diagnosis, and treatment. We want them to have a wellness plan, not just react in crisis—with a lack of planning and denial."

Carson knows firsthand what it's like to be a caregiver for a loved one with dementia: She and Ray took care of her beloved Aunt Jeanne, when the unexpected happened.

"In 2018, Uncle Jim fell, hit his head, and died," Carson says. "We were called, and confronted with the need to get Aunt Jeanne into short-term care, and then move her to be near us. Getting her the care she needed, and finding the right environment, was a family crisis. It was very difficult and very emotional for her and for us. That reinforced our decision and commitment to a program that would cover the disease, prevention, and support caregivers."

Carson says the launch of the Cognitive Care Network at the KU ADRC addresses all those critical issues. She is excited about its initial progress and the plans for future growth.

"For Alzheimer's patients and their families, we want to make this journey the best that it can be," she says. "With the Cognitive Care Network reaching out into rural Kansas, there's a place to go for information and treatment, and it's all in the best interest of the patient and their families. They can move away from crisis mode and move into prevention and wellness planning.

"From the perspective of a family supporting a loved one, the work of the KU ADRC brings hope."



IMAGINE THAT
Over 65 and on Medicare?

YOUR ANNUAL WELLNESS VISIT SHOULD INCLUDE SOME TYPE OF COGNITION TESTING.

Atypical Alzheimer's Disease: *Putting the Puzzle Together*

DR. RYAN TOWNLEY, MD, a cognitive neurologist and clinical researcher, was finishing training at the Mayo Clinic in Rochester, Minn., when Dr. Jeff Burns reached out to see if he'd be interested in making a move to the KU ADRC.

For Dr. Townley, it was an offer too good to pass up: Kansas City is home, Dr. Burns has been a longtime mentor, and the KU ADRC's focus on innovative Alzheimer's research is a perfect match for his work with atypical Alzheimer's patients.

"Atypical early onset disease isn't the same as what happens with older patients, and an MRI is often not diagnostic," says Dr. Townley. "Many times, these situations can be misdiagnosed as depression or anxiety. Losing a job, due to working memory impairment, can be the first clue. A patient can often maintain daily activities, like driving a car, but won't do well in detailed testing. There's a mismatch with the cognitive abilities, and people think, he's depressed and not trying."

At the KU ADRC, Dr. Townley has the rare opportunity to combine

his research with direct patient care, a blend with benefits for all.

"When the brain deteriorates, I see how the person changes. We want to learn why it happens and how to stop it. When I see patients in the clinic, I try to put the puzzle pieces together: the history, the exam, and the neuroimaging. Then, I can provide them with the best picture of what is going on," Dr. Townley says.

To complete his busy schedule, Dr. Townley serves as an assistant professor in the Department of Neurology at the University of Kansas Medical Center, is the director of the Cognitive and Behavioral Neurology Fellowship, and is an associate director and primary investigator of the KU ADRC's Clinical Trials Consortium.

It's a full plate, and he's excited to dig in and see what progress he and the KU ADRC team make in the years ahead.

"The KU ADRC has grown so much in the last nine years," he says. "What's going on here is really remarkable."



Dr. Townley joined the KU ADRC and KU Medical Center faculty in 2019, after completing a two-year cognitive behavioral fellowship at the Mayo Clinic School of Graduate Medical Education, where he also finished his neurology residency and an internal medicine internship. He is certified by the American Board of Psychiatry and Neurology. Dr. Townley graduated from the University of Kansas School of Medicine, where he earned the 2013 Dewey K. Ziegler Award for Excellence in Neurology and was honored with the American Academy of Neurology's Outstanding Neurology Medical Student Award. He also holds a bachelor of science in neurobiology from KU.

IMAGINE WHAT WE CAN DO TOGETHER

Our doctors and researchers work for the day when we can postpone—or prevent—the changes created by Alzheimer's disease. We firmly believe it is no longer a question of *if*. It is a matter of *when*. As we move forward, your contributions help patients and families today, and support progress for tomorrow.

JOIN A STUDY

VISIT: WWW.KUMC.EDU/KUADRC
CALL: 913.588.0555

HOW TO FIND US: KU CLINICAL RESEARCH CENTER
FAIRWAY OFFICE PARK
4350 SHAWNEE MISSION PARKWAY
FAIRWAY, KS 66205

TO MAKE A GIFT

VISIT: KUENDOWMENT.ORG/ADC
CONTACT: LINDSAY HUMMER
Development Director, Neurosciences
913.562.2717
LHUMMER@KUENDOWMENT.ORG

UNIVERSITY OF KANSAS ALZHEIMER'S DISEASE RESEARCH CENTER MISSION

To improve the lives of patients and families with Alzheimer's disease by eliminating the disease through its treatment and prevention.

 *The brain is who we are:
our memories, everything we are as humans.*

KU ALZHEIMER'S DISEASE
RESEARCH CENTER
The University of Kansas Medical Center



*What you do TODAY
can change the future
for MILLIONS.*

KU ALZHEIMER'S DISEASE
RESEARCH CENTER

The University of Kansas Medical Center



WWW.KUMC.EDU/KUADRC

913.588.0555