

## Re-Thinking Dementia:

From Novel Prevention Strategies to Better Models of Care



### Dementia: A Brief Overview

#### What is dementia?

Contrary to popular belief, dementia is not a specific disease. Dementia is a term used to describe a wide range of symptoms that impact older people's ability to perform daily tasks independently.<sup>1</sup> There are a number of specific diseases that can cause dementia symptoms. While Alzheimer's disease is the most common cause,<sup>2</sup> Parkinson's disease, Huntington's disease and cardiovascular issues can also lead to dementia. In fact, the word "dementia" simply refers to the *effects* that various brain syndromes can have on our memory, thinking, behavior and emotion. <sup>3</sup>

#### Who does dementia affect?

While the condition can affect younger people, advancing age is the greatest risk factor for dementia. Genetics, family history, smoking and alcohol usage, artery plaque buildup, high cholesterol levels and diabetes can also contribute to or increase risk of dementia. Every individual's experience with dementia and expression of dementia symptoms is different and likely to change with time.

More broadly, however, we cannot forget that dementia also impacts those in caregiver roles – family members of loved ones affected by dementia and professional caregivers. While lack of education around dementia care is an issue that has gained traction in recent years, there is still much work to be done to better empower care providers and care communities.

Data shows that dementia is a condition that disproportionately impacts women globally. More women live with dementia than men, more women are at risk of developing dementia than men and dementia symptoms appear to be more severe amongst women. Women also occupy both formal and informal care positions significantly more than men. There is still little research around the gendered impacts of dementia, signaling a serious need for better knowledge about the longterm effects of dementia on women.<sup>5</sup>

#### What are the long-term, broader impacts of dementia?

Today, around 57 million people worldwide are living with dementia. It is estimated that this number will almost double every 20 years. By 2030, there will be 78 million people affected by dementia related syndromes. And by 2050, the number of people affected by dementia will sit close to 139 million.6

The annual global cost of dementia – including unpaid care, paid care and medical care - lies above 1.3 trillion US dollars and is expected to rise to 2.8 trillion US dollars by 2050. Dementia is one of our greatest public health challenges with worldwide implications. To blunt the scale of its future impact, global efforts must be made to prioritize dementia-related research and public health initiatives.<sup>7</sup>

With an eye to the future, Sodexo set out to study novel approaches to dementia prevention and care strategies. The result is this report - a collated guide of the thought leadership changing the industry of dementia-related care. Dementia will, no doubt, become a crucial public health issue in the next 20 years. Conscious of the enormous difference that everyday actions can make in the face of such looming issues, we hope to integrate the promising practices and preventative health measures listed in this report across our range from services – from nutrition to facilities management.

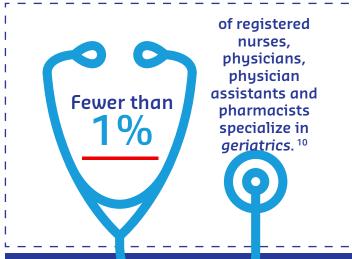
In implementing these novel strategies, Sodexo hopes to not only impact the older adults and care communities we serve, but to pave the path to a better tomorrow.



### **Facts and Figures**









primary care. 11

An estimated 6.2 million
Americans aged 65 and older are living with Alzheimer's dementia today.
By 2060, this number could grow to 13.8 million. 12

### Did You Know?

A surprising wealth of misinformation surrounds dementia. Although the science says otherwise, almost 62% of healthcare practitioners worldwide believe that dementia is a normal part of aging.<sup>13</sup>

In truth, many older adults go their entire lives without ever developing dementia, and while there is yet no cure, up to 40% of dementia cases can be prevented or delayed. According to the National Institute on Aging, "changes in the brain can occur many years before the first symptoms of Alzheimer's appear. These early changes point to a possible window of opportunity to prevent or delay debilitating memory loss and other symptoms of dementia."<sup>14</sup>



Dementia can be a scary and frightening condition – for those affected and for their loved ones. But we are not powerless in our capacity to address it. Indeed, studies show that promising strategies for dementia prevention and intervention do exist, including vascular risk factor control, cognitive and physical activity, social engagement, diet and recognition of depression. We need to empower our care communities with an understanding of the underlying conditions of dementia so that may adopt better, holistic practices to deliver more effective, compassionate forms of care – the type of care that older adults deserve.

### Introduction

## What is the purpose of this report?

Dementia is not *just* a memory problem. Memory helps shape our entire identity – our whole sense of self. This is precisely what makes dementia such a uniquely challenging condition. Living with dementia can mean experiencing jarring, distressing emotional and behavioral changes that impact one's entire personality. And these changes do not simply affect those living with the condition. They also directly impact informal and professional care-providers and family members of loved ones living with dementia.

Many older adults, families and careproviders lack a basic understanding of dementia's underlying conditions and expressions, and most caregivers are not properly equipped to deliver appropriate forms of care. We need to empower our care communities by bridging the gaps between research, policy and frontline service. The purpose of this report is to raise awareness around emerging research on dementia prevention and care, with the goal of improving the everyday lives of those living with dementia and the individuals surrounding them.

## What is included in this report?

This report was created in conversation with seven experts, each of whom are contributing to changing how we think about caring for older adults and those living with dementia. Each expert's unique framework teaches how to install practices, strategies and supports that ensure a better culture of care throughout the whole life course – from pre-diagnosis, early-stage interventions, to improved quality of care for people living with advanced dementia.

Our report is thus divided into two sections, the first of which outlines pre-diagnosis and early-stage strategies, and the second of which provides innovative approaches to improving the quality of care available around aging and memory care services.

- I. Pre-diagnosis and early-stage intervention: Proactive lifestyle changes to adopt upstream of the condition
  - a. Jeremy Spencer, MD
  - b. Mindi Manuel, MS, RD, CSG, LDN, CDP
  - c. Gary Small, MD
  - d. Miia Kivipelto, MD
- II. Living well with dementia:

  Approaches to improving the quality of aging, dementia and memory care services
  - a. Lori Stevic-Rust, PhD, ABPP
  - b. Robyn I. Stone, DrPH
  - c. Emi Kiyota, PhD



# Pre-Diagnosis and Early-Stage Intervention:

Implementing Proactive Lifestyle Changes to Mitigate Dementia Risk

#### Does our diet affect our brain health?

According to the World Health Organization (WHO), dietary factors may contribute to dementia development directly and through their role on other risk factors. Indeed, a balanced, healthy diet carries significant preventive potential for cognitive impairment. We spoke with Dr. Jeremy Spencer, whose research focuses on the relationship between diet and brain function, to learn more about what innovative types of dietary interventions show promise in preventing and delaying the onset of dementia.



Jeremy Spencer, MD Professor, Department of Food and Nutritional Sciences, University of Reading, UK

Dr. Spencer is the Programme Director for MSc Nutrition Food Science, leader of the Food Chain and Health sub-theme "Plant Bioactives and Health" and seminar coordinator for the Nutrition Research Group. His research team is one of the leading groups in the world currently dedicated to mapping out the relationship between dietary phytochemicals and brain function.



Whatever your dietary strategy is, it should be coupled with other strategies like social eating. Social interaction has proven benefits on the brain. Physical exercise also helps to keep the brain healthy as it supports blood flow which brings oxygen and nutrients while draining toxins. " - Jeremy Spencer

### How did Dr. Spencer arrive at his field of research?

With a background in biochemistry, Dr. Spencer's initial interest in the human brain function and the prevention and cure of different brain pathologies led him to pursue a Ph.D. on Parkinson's disease at King's College London. At the time, the scientific community generally accepted that oxidative stress in the brain could lead to neurodegenerative diseases like Parkinson's.

Dr. Spencer's decision to work on antioxidants was inspired by a desire to learn how to counteract this phenomenon. During his PostDoc, he began focusing on natural antioxidants, like flavonoids. He spent five years at King's College studying how these naturally occurring compounds have an antioxidant effect on the brain, until an opening at the University of Reading –

**Polyphenols** are antioxidants found in fruit and vegetables.

**Flavonoids** – part of the polyphenol class of phytonutrients – are the plant compounds responsible for the vivid colors in fruits and vegetables.

renowned for its Psychology department – presented itself. To date, Dr. Spencer has been a professor at the University of Reading for over fifteen years, and he is continuing the work he first began during his PostDoc. He works with his research teams, conducting clinical trials involving foods that are rich in flavonoids and measuring their short- and longer-term impacts on cognition.

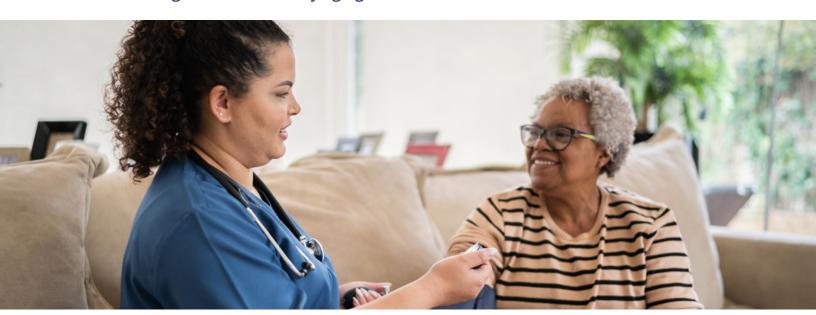
## How is Dr. Spencer's work changing the landscape of research around neurodegenerative diseases?

Dr. Spencer notes that while there is a promising exploration of surgical techniques that involve implanting cells to re-establish connections in certain parts of the brain, there is still no cure for any of the major brain degenerative diseases. Therefore, current research focus is primarily aimed at prevention. The state of the science is that prevention through diet over long periods of time – years – is most effective.

Currently, Dr. Spencer's research teams are tracking the impact of foods rich in flavonoids and other polyphenols on brain health by studying how flavonoids interact with specific cellular signaling pathways in the brain. These pathways are crucial in prevention against neurotoxins and neuroinflammation and in controlling memory, learning and neuro-cognitive performance. The team is

also exploring how the effects of good flavonoid levels on the vascular system may stimulate blood flow and neurogenesis in the hippocampus.

Dr. Spencer is also keeping a close eye on the upcoming, ancillary results of the COcoa Supplement and Multivitamin Outcomes Study (COSMOS) – a clinical trial that randomized 21,442 men and women across the United States. The study has investigated whether taking daily cocoa extract supplements containing 500 mg/day cocoa flavanols or a common multivitamin reduces the risk for developing heart disease, stroke, cancer, and other important health outcomes.<sup>17</sup> The study is promising, in that it will allow Dr. Spencer and his research teams more insight into the role of flavonoids on cognition and healthy aging.



### According to Dr. Spencer, what dietary strategies may help maintain good cognitive functioning?

No single food has all of the nutrition that the brain needs. When it comes to maintaining good cognitive functioning, a good, balanced diet including B vitamins, plant flavonoids and Omega 3 oils remains the way forward. It's also important to note that dietary interventions have a compound effect over time, just like exercise. It's not enough to do a lot in one sitting and nothing for an extended period of time. The body needs good, steady nutrition over a long period. People need a varied diet that includes fruits and vegetables throughout the whole life course, coupled with regular exercise. Intermittent fasting also appears to have an effect on neuronal growths in the short-term memory area of the brain, which is what dementia affects.

#### Key takeaways:

- A varied, balanced diet that includes B vitamins, plant flavonoids and omega-3 oils is best for cognitive health
- Consistency around healthy eating habits is key to long-term cognitive functioning
- Exercise plays a vital role in preserving brain health
- Social eating and social interaction have proven benefits on the brain
- Intermittent fasting shows promising impacts on preserving short-term memory



### Are there specific diet plans proven to promote brain health?

The MIND (Mediterranean-DASH Intervention for Neurodegenerative Delay) diet combines the aspects of the Mediterranean diet and the Dietary Approaches to Stop Hypertension (DASH) diet. Extensive research on the MIND diet shows that certain eating plans may, in fact, help to prevent dementia and age-related cognitive decline. The MIND diet encourages the consumption of the following foods: vegetables, especially green, leafy ones; berries; nuts; olive oil; whole grains; fish; beans; poultry; and a glass of red wine. Those adhering to the MIND diet should also limit their consumption of butter and margarine, cheese, red meat, fried food and pastries and sweets.<sup>18</sup>

We spoke with Mindi Manuel to learn more about leading research on the MIND diet and how exactly the eating plan helps to protect our brains.



Mindi Manuel, MS, RD, CSG, LDN, CDP Senior Clinical Area Support Manager, Sodexo

As a Sodexo Senior Clinical Area Support Manager and Registered Dietitian, Manuel supports all dietitians dedicated to the older adults we serve. She is a certified dementia practitioner and board-certified in gerontological nutrition. Manuel provides training and all regulatory and professional guidance as it relates to resident care, from food preparation to the assessment of resident malnutrition.





Certain nutrients may play a part in delaying or even preventing the onset of cognitive decline, but it is the synergistic effect of a variety of nutrients that have the greatest impact."

– Mindi Manuel, MS, RD, CSG, LDN, CDP

### How did Manuel arrive at her field of work?

Manuel has had a definitively non-linear career path. With a degree in finance from Butler University, she worked in corporate settings for about eleven years. In 2009, when the recession hit. Manuel was laid off. At the same time, she was also diagnosed with cancer. Her diagnosis drew her to research around nutrition - on how nutrition can both treat and prevent conditions. She felt herself growing passionate about nutrition and eventually questioned whether she wanted to go back to working in corporate finance at all. Her journey finally led her back to school, where she received her Master's in nutrition. Today, Manuel is a Registered Dietitian, working as a Senior Clinical Area Support Manager for Sodexo, providing training, guidance and care-related support to dietitians who serve older adults.

## According to Manuel, can dietary interventions help mitigate risk of dementia?

According to Manuel, while dietary changes may not prevent dementia, they may help delay the onset and mitigate symptoms and expression of the condition. A 2021 study found that those who followed the MIND diet had better cognitive functioning, independent of brain pathology. The study used data from the Rush Memory and Aging Project (MAP) to study 569 decedents with cognitive testing

proximate to death and complete autopsy data. Findings showed that many participants who strictly followed the MIND diet were diagnosed with Alzheimer's disease postmortem, and yet, showed no symptoms or expression of dementia, at all.<sup>19</sup>

#### What dietary strategies does Manuel recommend to maintain and promote long-term brain health?

Manuel notes that the latest research around the MIND diet holds compelling promise for cognitive benefits. Following the MIND diet has been shown to lower one's risk of developing Alzheimer's by 53% by curbing four of the known modifiable risk factors of dementia (excessive alcohol intake, obesity, hypertension and diabetes).

Even less strict adherence to this diet may lower Alzheimer's risk by up to 35%. We are learning that certain nutrients in this diet – antioxidant vitamins, polyphenols, flavonoids, B vitamins, etc. – help to protect the brain from cognitive decline. The MIND diet is also rich in long-chain omega-3 fatty acids, nutrients shown to improve brain function in older adults by reducing the formation of amyloid plaques and neurofibrillary tangles – formations in the brain believed to define Alzheimer's disease.

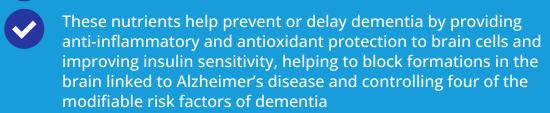


The MIND diet also helps balance blood pressure and cholesterol, thus protecting against vascular forms of dementia as well. Adherence to the MIND diet may also improve insulin sensitivity amongst individuals with diabetes, a significant finding, given that diabetes is a critical risk factor for dementia.

#### Key takeaways:







It is the synergistic effect of all these nutrients that affords the greatest benefit to cognition.

## Can physical health and other positive lifestyle changes help to prevent dementia?

Studies show that aerobic exercise can improve thinking, memory and reduce rates of dementia amongst middle-aged and older adults.<sup>20</sup> We spoke with Dr. Gary Small, whose research focuses on age-related cognitive decline, about how a combination of physical exercise, healthy diet and social engagement can work to protect our brains and promote long-term cognitive functioning.

#### Gary Small, MD

Chair of Psychiatry, Hackensack University Medical Center, Physician-in-Chief, Behavioral Health, Hackensack Meridian Health; H. Hovnanian Family Foundation Endowed Chair in Behavioral Health, Hackensack Meridian Health

Dr. Small is the Parlow-Solomon Professor on Aging at the David Geffen School of Medicine at UCLA and Director of the UCLA Longevity Center. He is the author of over 500 scientific publications, including the New York Times bestseller, The Memory Bible.

Dr. Small carries the distinction of numerous awards and honors, the most noteworthy of which are the Jack Weinberg Award from the American Psychiatric Association and the Senior Investigator Award from the American Association for Geriatric Psychiatry.

In 2002, Scientific American magazine named Dr. Small one of the world's top 50 innovators in science and technology. His research focuses on early detection and prevention of age-related cognitive decline, Alzheimer's disease and related conditions.



### How did Dr. Small arrive at his field of research, and how has his work impacted the field?

Following the advice of his physician father, Dr. Small entered medical school, where he was captivated by the role of the brain on physical health. Following his research interests, he specialized in psychiatry and eventually, geriatric psychiatry. At the start of his career, there were no medicines for dementia, no genetic risk discoveries and the focus largely remained on accurate diagnoses.

Early in his work, Dr. Small's conviction was that prevention was the best way to proceed when it came to addressing dementia.



The most compelling evidence around dementia prevention shows that physical exercise protects the brain. For example, research at the University of Illinois has shown that our brain actually grows if we walk a certain amount daily. A bigger brain is a better brain!" – Dr. Gary Small

His research has investigated the role of brain inflammation as a strong contributor of dementia; a 1990's study showed that people taking anti-inflammatory drugs were less likely to develop dementia. When his book, The Alzheimer's Prevention Program, was first published in 2011, there was a lot of initial pushback from the scientific community because everyone believed that dementia simply could not be prevented. Many studies have since been changing minds, and today, he notes, the dementia prevention strategies he has long touted are finally taking hold. Because of people like Dr. Small, we now know that we can address dementia not just through medication, but also through lifestyle changes.

A member of the research team at Duke University responsible for discovering the major genetic risk for Alzheimer's disease, Dr. Small has also played a significant influence in shaping our understanding of the relationship between genetic factors and dementia risk. During his time with the research team, he conducted PET scans to detect certain glucose patterns on people living with dementia.

## What strategies does Dr. Small recommend to promote long-term cognitive health?

Physical exercise increases blood flow to the brain and stimulates your body to produce mood-lifting endorphins. This is important because depression is not good for cognitive health as we age. There's no escaping that cognitive health is really about lifestyle changes: a combination of good diet and exercise. In 2018, Dr. Small and his colleagues published the results of an 18-month trial that found that daily oral curcumin intake led to significant memory and attention benefits.

Dr. Small's book, titled *Two Weeks to a* Younger Brain, explores how a mere two weeks of lifestyle changes can make an immense difference on our bodies and our brains. Of course, he reminds us that one needs to keep positive lifestyle changes going over the long term to truly reap benefits. He notes that public health behavior initiatives that encourage people to exercise, eat better, balanced diets and manage hypertension and diabetes more effectively can go a long way in impacting general cognitive health.

According to Dr. Small, technology may also play a significant role in maintaining good cognitive health. MRI scans of older adults' brains show that the act of searching online actually stimulates neuronal activity, helping to promote fluid intelligence, multi-tasking,

etc. A smart phone, it turns out, can help develop a person's brain power. But Dr. Small reminds us that today's older adult population has not grown up with this kind of technology, and thus, may struggle to adopt it quickly. But there is hope for future generations. Social engagement is incredibly important in maintaining a healthy brain. There are, however, ways in which social media can actually contribute to loneliness, so we still need to make some headway in understanding how to leverage technology for better and more social interaction when face-to-face interaction is difficult.

#### Key takeaways:

- Physical, cardiovascular activity is imperative to maintaining and increasing cognitive health
- It takes only two weeks of lifestyle changes to increase brain health
- Physical activity must be paired with a good diet for optimal effects
- Daily oral curcumin intake may have significant memory and attention benefits
- Social engagement is necessary for good brain health
- Leveraging social media, smart phones and other technology in the right ways can stimulate neuronal activity



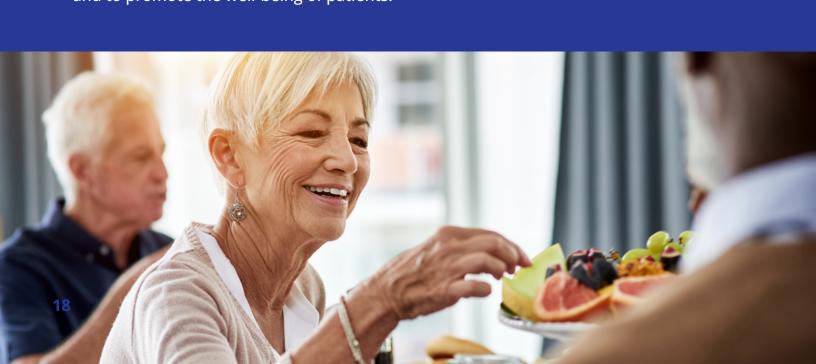
## What exactly is the relationship between our lifestyle choices and dementia risk?

While research has found that genetic risk and lifestyle factors act independently of one another, both do play a role in and are associated with dementia risk. <sup>21</sup> We spoke with Dr. Miia Kivipelto, the person behind the first randomized control trial showing that a multi-domain lifestyle intervention program can prevent cognitive decline, to learn more about the leading research on lifestyle and long-term cognitive preservation.

#### Miia Kivipelto, MD

Professor of Clinical Geriatric Epidemiology, Department of Neurobiology, Care Sciences and Society, Karolinska Institute, Sweden

Dr. Kivipelto is the Director for Research and Development of Theme Aging at Karolinska University Hospital. She led the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability clinical trial, which demonstrated that a multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring may preserve cognitive functioning in elderly people with high dementia risk. She also currently leads the World Wide FINGERS initiative, which aims to replicate multi-domain dementia prevention trials and share data internationally. In 2018, the Brain Research Society of Finland selected Prof. Kivipelto as the Neuroscientist of the Year in recognition of her outstanding work to increase our understanding of Alzheimer's disease and to promote the well-being of patients.





Today we know that more than 30% of cases of Alzheimer's are related to lifestyle factors like obesity, diabetes, smoking, depression and low education." - Dr. Miia Kivipelto

## How has the field of geriatric epidemiology evolved since Dr. Kivipelto began her career?

Twenty years ago, when Dr. Kivipelto started her research career, dementia was considered an inevitable part of the aging process, casting a relatively fatalistic attitude around the condition. Today, we know that a considerable amount of Alzheimer's cases are related to multiple lifestyle factors. The multifactorial nature of the condition proves that there is promising potential for prevention.

During her career, Dr. Kivipelto has witnessed much progress in terms of increased awareness around the impact of lifestyle factors on cognitive health. Much of this evolution has been paved by Dr. Kivipelto herself. In May of 2019, her team contributed to an important milestone in dementia prevention: the World Health Organization's publication of the first set of prevention guidelines, titled "Risk Reduction of Cognitive Decline and Dementia." The guidelines, she explains, establish a strong foundation for future research around lifestyle choices that may help reduce the risk of dementia.

Dr. Kivipelto also developed and led the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability, the first randomized control trial to show that it is, indeed, possible to get positive results by modifying lifestyle factors. The model is being replicated globally to include populations from a variety of geographic and cultural backgrounds.

The Finnish Geriatric
Intervention Study to Prevent
Cognitive Impairment and
Disability trial is the first
randomized controlled trial showing
that it is possible to prevent cognitive
decline using a multi-domain lifestyle
intervention among older at-risk
individuals. The results highlighted
the value of addressing multiple
dementia risk factors as a strategy
to protect brain health and promote
overall health and functioning.

## According to Dr. Kivipelto, what's next for the future of research around dementia prevention?

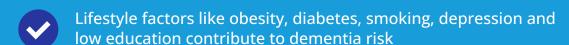
Because we now know that Alzheimer's is linked to inflammation and oxidative stress in the brain, there appears to be a holistic perspective developing around prevention strategies. Given this, Dr. Kivipelto is optimistic about the future of Alzheimer's care and prevention. In the long run, she sees a care model much like oncological care, for which there is no single pill to cure the disease, but rather a careful combination of medical and lifestyle interventions.

With regards to her own work, Dr. Kivipelto aims to combine different geriatric intervention study models into a new version, which would be more personalized and include disease-modifying tracks. She hopes to start implementing some of the results seen from trials. It normally takes 15 years for research results to be implemented, but we clearly need to be faster in addressing lifestyle change interventions. She urges that a holistic approach is required to address dementia.

### What strategies does Kivipelto recommend to reduce the risk of cognitive impairment?

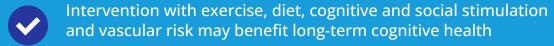
Results from the geriatric intervention study indicate that multidomain intervention with exercise, diet, cognitive and social stimulation and management of vascular risk factor may benefit cognition in those at risk of dementia. According to Dr. Kivipelto, understanding the complete risk profiles of individuals is very important. Only then can we move to changing lifestyle behaviors. Positively changing lifestyle behaviors not only reduces the risk of a variety of cognitive diseases, but also holds promising positive outcomes for our bodies. For at-risk populations, she advises, it is important to introduce positive lifestyle changes as early as possible.

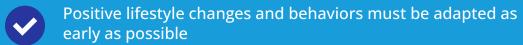
#### Key takeaways:











The best approach is a holistic one



## II. Living Well With Dementia

Approaches to Improving the Quality of Aging, Dementia and Memory Care Services



### What does a holistic approach to dementia care look like?

As we discover more about the value of social engagement and interaction in mitigating cognitive decline, we are recognizing the need for person-centered, holistic dementia care. We spoke with Lori Stevic-Rust – responsible for changing the landscape of care service for older adults and those living with dementia – to learn more about how she is working to redefine the care experience through a compassionate, person-centered lens.

### **Lori Stevic-Rust, PhD, ABPP**Clinical Health Psychologist and Dementia Care Consultant

Stevic-Rust is a board-certified Clinical Health Psychologist who holds a doctoral degree in psychology and earned a Diploma from the American Board of Professional Psychology. She completed an internship at Henry Ford Hospital with specialty training in geriatrics, cardiac care and integrative medicine. She has written six books on topics ranging from depression, heart disease and wellness, to a personal memoir on the art of ageing with gratitude. Her infectious enthusiasm, wealth of knowledge, engaging style and warm sense of humour has afforded her the title of "best speaker" by many organizations. Stevic-Rust consults across the US to hospitals, post-acute care facilities and assisted living facilities on clinical issues of care including anxiety/depression, caregiver stress and the creation of innovative programmes for the care of those with dementia.





We have an opportunity to shift how we think about providing healthcare: we are a collaborator in somebody's life; we are a part of a team with them. As a health psychologist, a holistic approach is critical. I care as much about the fact that you are feeling depressed as I do about the fact that you can't remember what you had for breakfast. We are recognizing the need for a team when it comes to care. Our patients and caregivers are coming to us better educated, pushing us to be better, too."

- Dr. Lori Stevic-Rust

## How did Stevic-Rust arrive at her field of research, and how has the field evolved since?

During her internship at Henry Ford Hospital in Detroit, Stevic-Rust gained vast exposure to older populations struggling with cognitive decline. At the time, experts had begun taking a deeper look into disorders like Alzheimer's disease, but the right language and underlying constructs of the disease had not yet been explored. Caregivers were struggling, and attention on deeper issues around healthcare systems and post-acute care was lacking. Those coming into the hospital with comorbid dementia were often the ones falling through the cracks. The culmination of these issues was what initially sparked Stevic-Rust's passion and interest.

For the past thirty years, Stevic-Rust has been a Clinical Health Psychologist working in acute and post-acute care facilities and studying comorbid conditions. While she currently has a private practice, people of all ages and with other medical and emotional struggles often come to Stevic-Rust to benefit from her holistic, integrated approach to care.

As we learn more about the brain, dementiarelated research is getting increasingly sophisticated. We are getting better at recognizing early cognitive symptoms that may or may not be a precursor to dementia. Stevic-Rust is hopeful that advances in research around neuroplasticity may help people living with the pathology in the brain by implementing a protective barrier that keeps them from experiencing symptoms. We are learning that even when one has the condition, there are things we can do to protect ourselves, potentially against the experience of the symptoms and the demonstration of dementia itself.

#### How is Stevic-Rust changing the standard of dementia care and care-work more generally?

There is a glaring lack of education around dementia in both medical schools and nursing programmes. Stevic-Rust frequently encounters family members and patients that do not fully understand the condition or what they can do about it. We simply do not offer caregivers an adequate amount of support or knowledge to effectively help those they care for. For the past year, she has been working closely with training entities to help give the condition a better understanding.

As part of this work, she created the Holistic Dementia Care® certification training programme. The program works to address the translation between the great bench research being conducted and the practice of care. Stevic-Rust views the lack of connection between research and care planning - between assessment and treatment - as glaring issues that stand in the way of effective care practices. She notes that we have a great deal of work to do when it comes to highlighting the importance of dementia care.

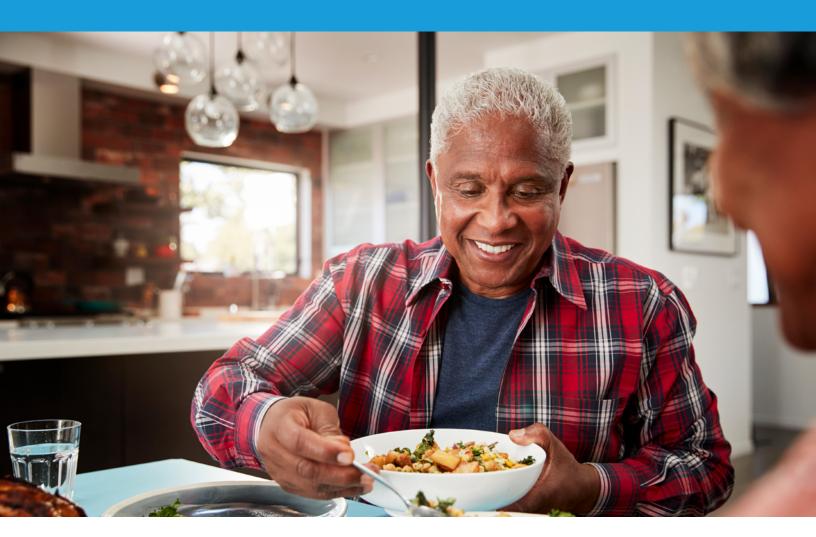
#### According to Stevic-Rust, what can we do to increase the standard of dementia care and promote long term brain health?

The most effective approaches to brain health are holistic strategies adopted upstream of disease. Stevic-Rust has been working with Sodexo to build holistic frameworks that address each of the core elements of brain health. To best promote long-term cognitive functioning, we need to encourage a good, balanced diet and an increase in physical activity, social engagement and activities that boost cognitive stimulation. Emerging research shows that learning new information can both strengthen and rebuild the neuroplasticity of the brain. Good gut health, too, can have significant positive impact on the brain.

Finally, we need to increase public awareness of and knowledge around dementia conditions. Dementia is not just a memory problem; it is a condition driven by diseases of the brain. The brain is the organ that controls everything, so reducing dementia to a memory problem obscures other effects of the condition. According to Stevic-Rust, a deeper understanding of dementia conditions may help family members and professional caregivers better address personality changes, behavioural changes and emotional changes in far more effective and compassionate ways. When we start to talk about things in a holistic way, we start to treat people in more holistic ways.

#### Key takeaways:

- A holistic approach to boosting and maintaining brain health is most effective
- Good long-term cognitive functioning is best achieved through the combination of a healthy diet, physical activity, social engagement and cognitive stimulation
- Gut health is connected to brain health
- Consistently learning new information may help strengthen and rebuild the brain's neuroplasticity
- We need to promote dementia awareness and understanding through training and research



# What changes must be made to deliver better standards of care for aging adults and those living with dementia?

Given the broad scale and impacts of the condition, dementia is a public health priority. We spoke to Robyn I. Stone to learn more about imminent issues facing the sector of older adult care services, the urgent need to bridge gaps between the world of research, policy and frontline services and the necessity of professionalizing the frontline.



Robyn I. Stone, DrPH Senior Vice President of Research at LeadingAge, Co-Director of the LeadingAge LTSS Center at the University of Massachusetts, Boston

Stone was a political appointee in the Clinton Administration, serving in the U.S. Department of Health and Human Services as Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy. She also served as assistant secretary for aging. Stone's widely published work addresses long-term care policy and quality, chronic care for people with disabilities, the aging services workforce, affordable housing and family caregiving. She is a fellow of the Gerontological Society of America and the National Academy of Social Insurance and was elected to the National Academy of Medicine in 2014. Stone received an MA in public policy from the University of Pittsburgh Graduate School of Public and International Affairs, and a DrPH from the University of California, Berkeley.



I'd love to see a shift from talking about our frontline workforce as low-wage workers to professional caregivers with liveable wages and a lot of potential for career growth. And I care about all low wage workers – we have so many professions that are so totally undervalued – but this is one where it affects the entire industry because 60-80% of all the services are provided by this frontline." – Dr. Robyn I. Stone

### How did Stone arrive at her field of research?

From a young age, Stone had an affinity for older people – a trait she attributes to the close relationship she shared with her grandparents as a child. Growing up in the 1950s and 1960s, she became captivated by public service and helping others. Because her initial interest was in working with disadvantaged populations, much of the work that Stone has done and is doing within the field of older adult care and aging services has focused on lower income individuals and the systems in place to support them.

Striving to be the trusted voice for aging in America, **LeadingAge** represents more than 5,000 non-profit aging services providers and other mission-minded organizations that touch millions of lives every day. The LeadingAge community – comprised of members and 38 state partners – uses applied research, advocacy, education and community-building to make the U.S. a better place to grow old. Stone is the senior vice president of research at LeadingAge. <sup>22</sup>

Her strong research and social science backgrounds provide Stone with a unique edge in her field of work. But she has also occupied policy positions and currently works in a provider position. Her agile framework allows her to effectively bridge the gaps between academic research, policy, and frontline workforce issues. During her time at the Department of Health and Human Services and as the deputy assistant secretary for disability, aging and long-term care policy, Stone focused on applied research and improved practice and policy to help older adults and their families. Her opportunities have allowed her to continually work in the service of improving systems of care, support and living for older adults, with a special emphasis on disadvantaged populations.

## How is Stone changing the standard and quality of care services for older adults?

Currently, Stone is on a National Academy of Medicine Committee that is looking at non-pharmacologic interventions around improving quality of care and quality of life for persons living with dementia, their families and their formal caregivers. But questions remain as to how to get these practices out to people and help them implement them on the ground. Moreover,

how can we implement policies that support good practice?

Much of Stone's work is also focused on workforce and staff development. The focus is on developing services and supports that meet the needs of those living with dementia. But it can be challenging to get good practice implemented and sustained in organizations. At LeadingAge, one of the strategic plan goals is to professionalize the frontline – nursing assistants, dietary aids, etc. Stone believes that we need to better value diet and nutrition-related professions so that they are recognized as viable careers that make a difference in the health, lives and longevity of people. To accomplish better quality outcomes in the sector, we need to focus on wages and compensation and better-quality training.

LeadingAge is also exploring how to promote cultural competence – the ability to acknowledge cultural differences, celebrate them and build them into training. Stone notes that we have a very diverse frontline staff in the US with very white mid-level management and C-suite. LeadingAge is committed to changing this. We need to have serious conversations about how to develop a more diverse leadership so at to untangle issues of racial inequity in aging services.

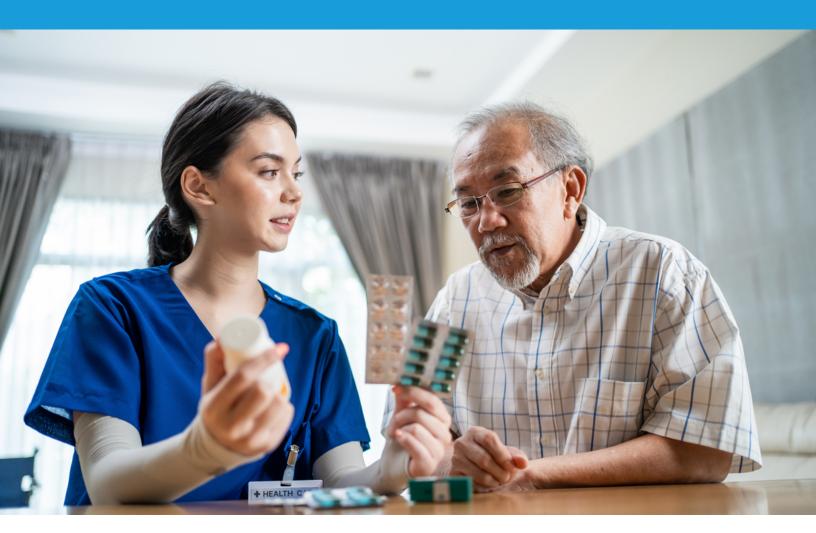
#### What imminent challenges does Stone see with regards to the aging care services sector?

Alongside colleagues, Stone has been focused on exploring new options around affordable models of housing and care for lower income older adults to help them age successfully in community. According to Stone, these individuals do not have access to assisted living or other types of residential options because they are too expensive in the US. Most of them end up in Medicaid facilities, which are not great options for them.

For the past decade, Stone and others in her field have been putting together innovative models comprised of service coordinators and wellness nurses to work closely with lower income older adults on a voluntary basis. These teams have become incredibly valuable in the work they perform, but there are limited avenues towards funding this type of infrastructure. There are about 3 million older adults currently living in existing affordable housing. The goal down the road is to achieve investments in affordable housing options and service teams that link with the health and social service supports in these communities.

#### Key takeaways:

- We need to better empower the professional caregiving workforce through education and other training resources
- The quality of training available matters profoundly
- Cultural competence is a valuable tool in the sector of aging care services
- There is an urgent need for affordable models of older adult housing and care





## How does the environment affect older adults and those living with dementia?

When we consider older adult care services, we do not often prioritize environmental design. But, as Emi Kiyota's work shows, environment can have an immense impact on quality of life for older adults. We spoke with Kiyota to learn more about creating socially integrated and resilient communities where older adults are engaged and able to actively participate in their communities.

**Emi Kiyota, PhD**Environmental Gerontologist, Consultant, Founder and Director of Ibasho

Kiyota is the founder and director of Ibasho, an organization that facilitates the co-creation with elders of socially integrated, sustainable communities that value their elders. She holds a Ph.D. in architecture from the University of Wisconsin-Milwaukee and has over 20 years of experience in designing and implementing person-centred care in long-term care facilities and hospitals globally. She has published journal articles and book chapters and serves on the board of directors of the Global Ageing Network. Kiyota has been awarded fellowships to investigate this topic, including the Loeb Fellowship at the Graduate School of Design at Harvard University, the Rockefeller Bellagio Residency Fellowship, and the Atlantic Fellowship for Equity in Brain Health at the Global Brain Health Institute at University of California, San Francisco.



I have spent the last three years as a fellow exploring what designing for older people means. I have found that they tend not to be included in the design process and wonder: when do older people lose their entitlement to be listened to? Could it be that the design field for dementia is influenced by pre-conceived notions of what dementia actually is?" – Dr. Emi Kiyota

#### How did Kiyota arrive at her field of interest?

Kiyota's initial interest in environmental gerontology was sparked during a visit with her grandmother, who was living with dementia in a long-term care community in Japan. Kiyota was shocked to see her loved one – an accomplished woman in her 80s – having to share a room, as if she were living in a hospital. She wanted desperately to improve her grandmother's quality of life.

In her mid-20s, she moved from Japan to the US to study gerontology and got her first degree in horticulture therapy. She grew new interest in creating environments that would allow older people to do their gardening in a safe way. She began exploring how to design spaces that empowered older adults to sit outside, how to create high quality experiences in safe environments.

With an initial Master's thesis on plants and environments, Kiyota committed to a second Master's degree, focused on the relationship between architecture, environment and behaviour. Her education taught her how to evaluate the impact of environment on people's behaviour, especially older people in institutional care settings. During her Ph.D. in architecture, Kiyota studied the meaning of person-centred care, leading her to found her NGO, Ibasho, and allowing her to dive into the world of practice. Recently, she was awarded a fellowship to study brain health at UCSF's neurology department, where she had the opportunity to learn about the latest research around Alzheimer's diagnosis.

### According to Kiyota, what's next for the future of research in environmental gerontology?

While there is quite a lot of evidence-based research on how to design environments for older adults and those living with dementia in relation to long term care communities (LTCs), Kiyota shares that there is little in relation to hospital environments. Systems and environments have not really evolved other than in relation to LTCs and human carer resourcing. Given that in the US, more than 85% percent of people living with dementia live in a community, not in LTCs, we need more research around other systems and environments. Kiyota is herself interested in neighbourhood design for older adults, including those living with dementia.

### What can Kiyota teach us about caring for older adults and those living with dementia?

Older adults living with dementia do not always need a registered nurse with them; they might just need company – a person to watch over them. Social isolation has been exacerbated by the pandemic, for older adults and for the young. From a physical environment perspective, Kiyota notes, older adults living in LTCs already felt restricted. We need to explore what we can do as community members to tackle social isolation. How can we extend LTCs concepts of care outside the walls of LTCs? What can we do in existing communities to integrate care?

Older adults can also benefit from non-professional care, which would be much easier in the context of better adapted communities that are interjected with the right knowledge to create ecosystems of care. Kiyota's World Bank Group report entitled, "Elders Leading the Way to Resilience" describes the experience of Ofunato, Japan, which was devastated by the 2011 Great Eastern Japan Earthquake. With some help, elders and other community members planned and built the Ibasho Café, which acted as a hub that is restoring the fabric of a badly damages community. The space helped to strengthen social capital and resilience, while at the same time changing people's mindsets about aging. Older people were empowered to become active contributors within their communities rather than care recipients. Kiyota believes we must take a closer look into what happens to people's sense of trust, belonging and agency through different changes in environment.



#### Key takeaways:

- We need to design environments to empower older adults and those living with dementia
- Care can mean empowering older adults to become active contributors within their communities
- Social interaction and integration can greatly benefit older adults and those living with dementia
- More research is necessary around designing systems and environments outside LTCs



### Acknowledgements

Sodexo would like to acknowledge the contributions of each expert who willingly participated in the curation of this report. In addition, warm thanks to former Sodexo colleagues Thomas Jelley and Daphne Carthy who helped bring this project to life. Transfer of knowledge is no trivial matter, and it has been a privilege to collaborate and partner so closely with those working to change how we perceive and understand dementia. While there is still much work to be done when it comes to expanding our knowledge of the underlying condition, there is also much hope in how far we have come.

As part of our vision to enhance quality of life for all, Sodexo is committed to working toward long-term solutions that raise the standard of care for dementia related syndromes. Our goal is to empower our care communities with the right knowledge and resources to deliver effective support, whether in the form of preventative health measures or alternative models of care. Much of the research gathered within this report points toward the numerous opportunities that exist for joy and meaningful connection, even while living with dementia. As we continue to grow and evolve in how we think about dementia, Sodexo remains dedicated to nurturing and prioritizing holistic models of care that center and value the human beings affected by this condition.

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