

Healthy Brain Initiative

Focus Group Report, April 2024



Three³



KNOX COUNTY
TENNESSEE

HEALTH DEPARTMENT

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Acknowledgements

This project was funded by the Healthy Brain Initiative. The Healthy Brain Initiative Road Map Strategists Program is supported by the Centers for Disease Control and Prevention and the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award. All views represented are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by the Alzheimer's Association¹, the CDC/HHS or the U.S. Government.

We would like to acknowledge the leadership of Mikaela Gass, Program Manager at the Knox County Health Department (KCHD). We would like to thank the many family members, care partners and individuals who have been diagnosed with Mild Cognitive Impairment (MCI) or Alzheimer's Disease and Related Dementias (ADRD) who contributed their time to data collection efforts. Herein, the collection of these disorders will be referred to as MCI/ADRD and family members or caregivers will be referred to as care partners.

Additional thanks to leadership from the First United Methodist Church in Oak Ridge, St. James Episcopal Church, KCHD staff, the Daily Living Center, and Knoxville's Community Action Committee who provided connections and locations to facilitate focus groups as well as assistance with recruitment of participants. We would like to further acknowledge the guidance from HBI Work Group, whose members are listed below.

David Compton, Retired Physician and Advocate
Sara Dickson, Alzheimer's Association
Amy French, Alzheimer's Association
Mikaela Gass, Knox County Health Department
Juila Holland, Knox County Health Department
Paige Huggler, University of Tennessee Brain and Spine Institute
Dottie Lyvers, Knoxville-Knox County Community Action Committee, Office on Aging
Laura Porter, Cherokee Health Systems
Amber Tayman, Tennessee Memory Disorders Foundation/Genesis Neuroscience Clinic
Morgan Vance, Pat Summitt Foundation
Kim Warnick, Dementia Care Solutions of East Tennessee

This report was developed by Three³ (pronounced ThreeCubed), a 501(c)3 research nonprofit located in Knoxville, TN, with a mission to foster equitable and sustainable futures.

¹Alzheimer's Association. (2024). *2024 Alzheimer's disease facts and figures*.
<https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>



Introduction

For those with MCI/ADRD and their care partners, the impacts of cognitive change, loss of independence and challenges of navigating resources are numerous. About one-third of people with MCI due to Alzheimer’s disease develop dementia within 5 years of diagnosis, but fewer than 1 in 5 Americans are familiar with MCI, which can be an early stage of ADRD.¹ Ninety percent of physicians say it is important to diagnose MCI due to Alzheimer’s, but over half say they are not fully comfortable giving the diagnosis. More than twenty-five percent of the overall workforce helping those with ADRD reported being “only sometimes” or “never” comfortable answering patient questions.¹ Additionally, more than ninety-five percent of people with ADRD have one or more other chronic conditions.

ACRONYMS

KCHD	Knoxville County Health Department
MCI	Mild Cognitive Impairment
ADRD	Alzheimer’s Disease and Related Dementias
EACD	Early Adult Cognitive Disorders
HBI	Healthy Brain Initiative
HHS	U.S. Department of Health and Human Services

Within Knox County, the overall population is growing older, and many of these individuals are doing so without support in the home. Twelve percent of the aging population also experiences ADRD while, simultaneously, almost a third of the aging population has 2 or more chronic diseases. Despite this, our understanding of the impacts that ADRD has on Knox County residents is lacking and would benefit from further research. Prior to this report, many of the experiences of persons with MCI/ADRD and their care partners within Knox County were undocumented.

The purpose of this project was to promote early detection and diagnosis of ADRD through workforce development. To inform these efforts, four key objectives were developed: community assessment, convening an interdisciplinary workgroup, conducting focus groups, and offering opportunities for interviews and surveys.

This report contains results from the project conducted by KCHD in collaboration with Three³ as part of the Healthy Brain Initiative (HBI) Road Map Strategist Program.



Background

To meet these objectives, KCHD and Three³ collaborated to gather existing data and conduct focus groups before presenting subsequent findings. First, the research team convened an HBI workgroup and developed interview questions and protocols between May and October of 2023. The workgroup reviewed the focus group questions and shared feedback. The workgroup also shared focus group questions with people living with MCI/ADRD for feedback on understandability, length and content. Three³ prepared a toolkit outlining best practices for conducting focus groups with individuals with MCI/ADRD, which is found in the appendices. After focus group protocols were finalized, Three³ conducted six focus groups composed of adults with MCI/ADRD and their care partners between October 2023 through January 2024. The final key themes were compiled and shared with community partners in February of 2024.

In total, Three³ hosted six focus groups, reaching 39 individuals. Twenty-one self-reported a diagnosis of MCI/ADRD and 18 were care partners to someone living with MCI/ADRD. Focus groups were held at four different locations: KCHD, First United Methodist Church in Oak Ridge, St. James Episcopal Church, and the Daily Living Center. At St. James Episcopal Church and the Daily Living Center, focus groups were held separately for care partners and for those with MCI/ADRD. At KCHD and First United Methodist Church, people with MCI/ADRD and care partners participated in focus groups together.

Facilitators asked ten open-ended questions for each group, allowing each participant to answer to whatever extent felt comfortable to them, ensuring at the beginning of each session that participants and care partners were aware of their rights to confidentiality and decisions on their personal level of engagement. At the end of each session, the facilitators provided participants with gift cards to compensate them for their time and investment in this project.

Included in this report are the observations obtained from these focus groups. Focus group questions and a link to Three³'s Focus Groups: Best Practices for Seniors with Cognitive Decline are provided in the Appendix.



Focus Group Observations

The following feedback obtained from six focus groups gives insight into the concerns, interests, and lives of care partners and patients diagnosed with MCI/ADRD, with a special focus on their experiences accessing medical services related to memory and cognition. The research team discovered ten themes from the data:



Early Observations and Response



Acceptance and Open Discussion



Care Partner Well-being and the Importance of Support Groups



Early Screening and Diagnosis



Practitioner Comfort in Early Detection and Diagnosis



Communicating Through Common Language and Clear Explanation



Quality Care and Treatment



Types of Treatment and Medication for Emotional/Physical Support



Family Support During Diagnosis and Decision-making



Resources and the Sharing of Knowledge

The observations section that follows is organized by themes. Direct quotes and observations that informed each theme are shared throughout this section.



Overarching Themes



Early Observations and Response

During the focus groups, many stories were shared of early observations about themselves or their loved ones that alerted them to possible memory or brain health issues, from shifts in personalities to behavioral changes. Some reported that when they would raise concerns with practitioners or people in their social networks, their concerns were often dismissed or even met with fierce denial.

- *“My memory had gotten to the point that, just normal stuff, phone numbers, street directions... I would go somewhere and forget where I was going. I’ve never had problems with remembering locations... It would come to me as I was driving that direction, but I would leave home not knowing which turn to take and all that. And I thought, ‘I’m getting old in a hurry.’ And I talked to my wife, and we decided it would be good for me to go to the doctor just to be sure. And I realized that my grandmother had dealt with it, and I had put it out of my mind.” – **Someone with MCI/ADRD***
- *“I would notice that she wasn’t cleaning and tidying as usual.” – **Care partner***
- *“I have been married for 50 years.” The couple had moved recently, and they noticed that the husband forgot a lot more and thought that he knew the directions to certain places, but they would end up lost. So, they went to go get him checked, and they found out that her husband has mild degenerate cognitive decline. She said that she has not been tested but her husband has. – **Care partner + Someone with MCI/ADRD***
- *He knew something was going on initially, but the first thing that he noticed was how people treated him. He said that he didn’t talk much. He figured he had something, but he thought he was alright, and he would deal with it. He wasn’t upset about it. Early drugs and finding the best support groups was important. He said there are so many now that you don’t have to worry about all the things going on. He said that he is as happy as he can be. – **Someone with MCI/ADRD***
- *“We are trying to change dementia from all kinds of singing, acting, skating on roller skates... people make assumptions about you years ago: they just knew that you were getting old, and some people still have that concept, so this just helps people know that life isn’t over. There are still things that you can do.” – **Someone with MCI/ADRD***
- *“When she started dealing with it, I hated leaving work because I didn’t know whose house I was going to walk into. I didn’t know where things would be. She would arrange the whole kitchen. The biggest sign something was wrong: the post-it notes. It wasn’t your normal post-it note. It wasn’t ‘get milk.’ It was ‘feed the dog,’ and it would be on the back of the*



*door in the bathroom. She worked in her field for thirty years, and then she couldn't pass the test she used to write. She'd study for the test for hours at home and then you'd ask her a question and she'd go through anger [...] then remorse, then sorrow. This was before the diagnosis. We went to the doctor, and he gave her a pill [for agitation]. It didn't take away everything, but I had my wife again.” – **Care partner***

Previous experiences with diagnosis of MCI or memory disorders (especially with other family members) seemed to help with both early detection and acceptance.

- *“We knew when we had signs with my mom's mom, so we knew and, when I noticed, I moved her in as soon as we found out, and I have support with family. My mom has dementia, but her mama had Alzheimer's.” – **Care partner***
- *“[I] saw [my] husband go through so much; Nobody helped me understand it better.” – **Someone with MCI/ABRD***



Acceptance and Open Discussion

For many participants, grief – or even shame – was a common part of their family’s acceptance of a memory disorder.

- *“I remember telling my brother that he has it, and he asked me to explain, and I told him, and he said, ‘So I have what Papa had.’... and he just cried. But for him to feel safe to cry, I felt it was an honor... He didn’t want to be on any medication, but we like to keep him informed in family life, and church helps him. He loves it.” – Care partner*
- *“It broke my heart as I saw him progress. It’s gotten worse to where he has shut down. I had a brother that passed a few months ago, and he wanted to know what was going on, but he didn’t want to come around anyone. He wanted to be alone, and now that it’s gotten worse, I think he just doesn’t want anybody to see him.” – Care partner*
- *“[It’s like] a long goodbye.” – Care partner*
- *“The first thing she wanted was a cigarette. Her first words were, ‘give me a cigarette.’ I sat on the steps of that clinic and cried, and she was out in the car smoking a cigarette.” – Care partner*

- “I wouldn’t tell people because there was shame.” – **Care partner**

The expression above exemplifies what many others talked about: the importance of being open and creating a culture of honest communication around brain health and memory disorders.

- *“It’s important to be open about this, I mean, I left work to come to this. It’s not something to be secretive or be ashamed, so we need to talk about this.”* – **Care partner**
- *“We need to change the terms we use and how we talk about it.”* – **Someone with MCI/ADRD**
- *“You have a lot of people who are very sensitive about it. My best friend’s dad won’t go to the doctor.”* – **Care partner**
- *“Be truthful about what you’re doing.”* – **Someone with MCI/ADRD**
- *“You know, I’m a marine, and my approach is: head on, let’s go, none of this namby-pamby stuff, let’s go get it.”* – **Someone with MCI/ADRD**

One participant reported being angry when she learned that her co-workers had noticed her memory issues but never told her. Other participants reported anger and denial from themselves and loved ones.

- *“Early on in my experience I was just chatting with a friend, another Social Worker, and she was furious that anyone would suggest that I have a disease, and early into the morning she was ranting about it...and you know what that means, that there’s anxiety about it, that they are anxious about it themselves. And the sad thing is that she has already died of it.”*
– **Someone with MCI/ADRD**
- *He said that he gets agitated because he cannot do the things he used to do.*
– **Someone with MCI/ADRD**
- *“It was difficult for people in the community to absorb that she was dealing with it. She was always top of the class. She was a leader, a pioneer, so it was hard for other people to accept it. But I know her now, probably better now than any of her siblings or kin. And I know it was hard because her mother died of it, and her first response was remorse, and then anger, and then dread, and then fear, and she said, ‘there goes our ideal retirement life together.’ We had had such great experiences after retirement, and this is like watching a death, a slow death.”*
– **Care partner**

And yet some participants living with cognitive impairment reported the importance of continued purpose and value.

- *“You learn to live with it. You learn to think about things in a different way. And I learned okay, this is how I can structure this and work with it. I went back to work. Not the same work, but I worked.”* – **Someone with MCI/ADRD**
- *“[People with Alzheimer’s] are more resourceful. People underestimate their intelligence and what they can do.”* – **Someone with MCI/ADRD**



Care Partner Well-being and the Importance of Support Groups

Both individuals living with cognitive impairment and their Care partners or loved ones underscored the importance of having social supports, in particular from others going through similar experiences. Several participants reported – and many others agreed – that humor and laughter help offset the emotional toll of the daily challenges associated with these diseases.



- *“This humor takes so much of a burden off. The world can laugh with me, I don’t care.”* – **Someone with MCI/ADRD**
- *“For support groups, they happen when I’m at work. Support groups are mainly for women as the Care partners, but I’m a man and I’m not going to go in and cry on another woman’s shoulder. It’s disrespectful to women.”* – **Care partner**
- *“Church has been so very important. It is so helpful for them to hear worship songs and engage with music and sing.”* – **Care partner**
- *“Some people don’t understand what you’re going through or don’t want to know what you’re going through... other people in your situation.”* – **Someone with MCI/ADRD**
- *“They can say anything to each other [here] and nobody gets mad. The world that we live in is very different. Down the hall [our] spouses are down there, and they have the same rules, and they have to say what they are upset about and things that aggravate them. It is a super blessing to have that ‘family’ therapy.”* – **Someone with MCI/ADRD**
- *“She comes here [support group], so for one hour of the week, I know she’s okay. She is with the people she needs to be with. She can come in here and laugh and there’s joking and exchanges of information. She can come in here and cry. This is what I wish I would have known at diagnosis: there are people who go through this that can help her. When she comes home, she’s at peace. She’s balanced. She has purpose.”* – **Care partner**

Support groups also appeared to be a place of sharing knowledge across a range of topics, from research, resources and events to experiences with different medical providers. One participant even shared information about an app that helps her and explained that her partner and she track each other so they don’t get lost.



Early Screening and Diagnosis

Focus group participants were asked about the importance of early screening and diagnosis.

- *“We found out late. When my wife found out, our starting point had passed by years.”*
– **Care partner**
- *“[At a local memory facility], I didn't like that they would be in the hallway—I don't know if it was just the time I was visiting—but I never saw anyone on staff interacting with them, but it wasn't the same time every day. The people with MCI were just kind of sitting there with no one talking with them and nothing to do.”* – **Care partner**
- *“We need more places that have short-term care and not a long minimum stay. The fewest days you can sign someone in for is one month.”* – **Care partner**
- *“I had a good experience, where she was always in good care: it's off Middlebrook... called Atria. It's expensive now, but it's big.”* – **Care partner**
- *“You have these places that have such high prices, and they don't even do anything with them.”*
– **Care partner**
- *“I care for two sisters, and August of 2021, we finally brought them from Florida. And the sisters worked in the system really good until they got UTI'S, and I don't know when it was diagnosed but at the point when we came down there, she was at the point where she couldn't make food for herself. We made 6 trips and the last 4 was sizing up the situation and helping them stay in the house, but that worked against it because it's like, ‘Why are taking them out the house?’”* – **Care partner**

For some, diagnosis was made alongside other diseases or disorders, suggesting the complexity of diagnosis.

- *“He was diagnosed with Parkinson's disease and was in memory care. Then he caught Covid. Then they said, ‘He is at a moderate stage of dementia.’”* – **Care partner**

Focus group participants expressed the desire for more information to help them distinguish between signs of cognitive impairment or memory disorders and general forgetfulness. The uncertainty appeared to cause some anxiety for both Care partners and people living with the impairment.

- *“Thinking of every time you forget something. Every time you forget something, you think, ‘is it finally happening to me?’”* – **Care partner**
- *Person with MCI/ADRD said they don't know what is going on; it is different for everybody. He stated that if someone has been around for ages, they say “this is part of the aging process.”*
– **Someone with MCI/ADRD**



Practitioner Comfort in Early Detection and Diagnosis

It seemed to many focus group participants that some practitioners (especially general practitioners) experience discomfort raising the need for healthy brain or cognitive screening and then, if there is an observation of early or mild cognitive impairment, they refer patients to a specialist. Participants expressed frustration and anxiety with the lack of information and understanding about what they or their loved ones are going through while they waited (sometimes up to a year) to see a specialist.

- *Earlier on, a couple of weeks ago at the time, they saw an Oak Ridge neurologist. They went to the wrong doctor first with long waits, and the doctor needed to see an MRI first. Then they had one year to Pat Summit, resulting in two years wasted. They stated diagnostic response and treatment should be right away. They stated that memory was not focused on, at first. After waiting for cancelation at Summit, the specialist didn't accept the insurance.*
– **Care partner**



- *“Optometrists should know more.” She stated that her husband first had a visual issue and couldn't count change. Vision was the first thing impacted. She went to Vanderbilt to get a diagnosis for him. The specialist there said it was too rare, but it wasn't really. They saw three neurologists before getting a correct diagnosis, but she knew three years before he got a diagnosis. She stated that her husband couldn't see the whole picture.*
– **Care partner**
- *“Her original diagnosis came from a psychiatrist where we lived. The first diagnosis was amnesia, which is my favorite. He said she has Loui Body. I asked what that was. He said, ‘look it up,’ and closed the door. After that, she experienced fear, anger, remorse, hurt.”*
– **Care partner**
- *“More doctors need to understand... dementia; they don't understand.”*
– **Someone with MCI/ADRD**



Communicating Through Common Language and Clear Explanation

- *When her sister came back from the practitioner, [Care partner] said, ‘do you all have anybody that can help?’ Monica Crain is who they sent her to. She said, “you do not get to see her first, you have to do all of these tests.” The doctor called and asked if she could come in. Her sister had had a stroke in the last month or two. The doctor said that she was responsible if she did not get her sister medical help. They went to the appointment that the doctor sent her to. So, the new doctor said that they could not help her because they do not have a treatment for her disorder. They told her that she needs to talk with her other doctor about it, that she is a good doctor. But the doctor had only specialized in what she did, so she could not help them with this. “Are we up to research on this stuff? How do we know when they need to go to a facility?” – **Care partner***
- *“We need to change the terms we use and how we talk about it.” – **Someone with MCI/ADRD***
- *There is more information about vascular dementia, but a medical provider said it was very little. – **Someone with MCI/ADRD***
- *“I [still] don’t know what the signs are of dementia.” – **Someone with MCI/ADRD***
- *“[It] changes you; it changes your personality. The doctors try not to speculate on when you need to stop driving or when you need help. It is like you just keep going and going.” – **Someone with MCI/ADRD***
- *“It seems like the word needs to be broken down. We need new terms to describe what we’re going through.” – **Someone with MCI/ADRD***





Quality Care and Treatment

When quality care and treatment were received, it appeared to make a critical difference in the overall experience living with or caring for someone with cognitive impairment.

- *She said that she learned all this research to help her mom through programs and education and the doctor. They have a good support system. – Care partner*
- *“Let’s also talk about what’s good around here. I really appreciate that there are doctors around here who know when to refer you, and they know what teamwork is, and doctors here referred us to other doctors who they knew who were really close to us (distance). They tell you what to watch for, even a gastrologist is right here in town. It’s remarkable that we have so many available resources.” – Care partner*

Across the focus group sites, many participants expressed frustration with waiting lists to see specialists. Frustration was also expressed if after waiting to see one specialist they were referred to another with an additional wait time.

- *“The doctor gave us a sheet of ‘brain food’ and said, ‘stay as active as possible,’ but there wasn’t anything said about support groups. If a doctor encourages something, it’s almost like listening to God in our culture. The medication was interesting. They said, ‘this is for malaise help and for settling your nerves,’ but I didn’t hear that they would reassess things. We need a medical reassessment (the original doctor’s appointment was too long ago and she needs prescriptions that match what she needs now). She’s having a lot of tremors, anxiety and fear, and we need a reassessment. But we’re waiting a long time.” – Care partner*
- *“For me with my dad, he was diagnosed 5 years ago so we were able to get him in assistant living. So, it was helpful because we were able to get him in a comfortable environment. We were able to plan because we knew it was coming.” – Care partner*

One participant with early cognitive decline expressed the importance of following through with promised care:

- *“Promises for older people: you don’t just tell people you’re going to do it and then don’t do it; that breaks their heart deep down.” – Someone with MCI/ADRD*

One individual with early cognitive decline expressed the importance of treating people living with these disorders with trust, understanding, and dignity:

- *“Learn to respect one another: people are growing old. And say things in a nice, pleasant way; don’t make people feel less than.” – Someone with MCI/ADRD*



Types of Treatment and Medication for Emotional/Physical Support

Focus group participants talked more specifically about different medications that work – or haven’t worked – for both treatment of the disease and assistance with mental, emotional, and behavioral health needs.

- *“We don’t have much confidence in medication. The doctor hasn’t given us much confidence in medication. The best medication is taking care of the head and heart, and we have that here.” – Care partner*
- *“They are seeing now that there are some things people can do to slow the development of it. Things like moving your body are important, and regularly walking and moving is even more important than exercising your brain. Stress and depression also play a major role.” – Care partner*
- *“I wish I’d known... How anxious I could be. It’s just...overwhelms me at times.” – Someone with MCI/ADRD*



Family Support During Diagnosis and Decision-making

Both Care partners and persons living with cognitive impairment reported the impacts of loneliness or isolation after a diagnosis-associated life change. Although in most instances the request was for more social supports, one participant reported making the decision for their loved one to receive residential care so they could be around more people dealing with similar experiences. This individual expressed how difficult this decision was and that it felt as though they were “abandoning” their loved one.

- *“[She] had a stroke a few years ago, and she just recently had a stroke, and it took us a year to see, which is horrible, but it is not the type of vascular dementia that is different from Alzheimer’s. She moved in 3 months ago.” The care partner helps her sister with dementia, and she works in social work. She said that she sees a lot of guilt and depression. She has 2 family members, a daughter, and a cousin. She feels like the past things that they have done have taken effect. She takes anti-anxiety medicine, and she said that if her sister lives alone, she will not eat. She said that her mother ran through the CVS on Cedar Bluff Road and that was when she started helping her and checking on her. She started looking into assistant living, and her sister stayed 2 days and moved back home because they do not do memory care. She works with the census bureau. She said it is frustrating because you feel like you are failing.* – **Care partner**
- *“I remember telling my brother that he has it, and he asked me to explain, and I told him, and he said, ‘so I have what Papa had.’ I told him it was early, and he just cried. But for him to feel safe to cry, I felt it was an honor. I was honored that he felt safe to cry with me. He didn’t want to be on any medication, but we like to keep him informed in family life and church helps him. He loves it.”* – **Care partner**
- *“With my grandmother, her person left her, and that’s when she began to decline.”* – **Care partner**
- *“We were asking ‘what is the best treatment?’ and they said it depends on what you’re dealing with, because each experience is different. My son... wants to dig at a problem until he has all the answers, and he said, “Dad, I want to do some research,” and he called back two weeks later and said, “you need to go to one of two hospitals, and you need to go to the best.” And then we went to Kentucky and met with one of the doctors, and we’re about to go to a doctor in Knoxville and we’ll bounce off some ideas... We’re kind of wading through the process at this point.”* – **Someone with MCI/ADRD**

When asked about the things or people that are most important to help get them through the day, participants reported family and other “people to talk to.”



Resources and Sharing of Knowledge

Importantly, focus group participants expressed frustration with the lack of available or affordable resources and the lack of communication about resources, including social supports. Some recommendations for structural supports included better access to day programs, resources in the evenings, respite for Care partners, and even legal support with estate planning or securing power of attorney. People living with memory disorders requested more in-home support as they age and progress through their disorders; especially if they live alone.

- *“I’m new to this game. Less than six months into the process.... My thing is, if you’re asking about awareness and stuff, I didn’t know. I didn’t know what dementia or Alzheimer’s was. When I dealt with memory issues, I didn’t know I could go to the doctor, and if I sit down and tell the doctor my story, they might say I need to get more sleep. The biggest thing in this process is not getting information out and when you see someone, they need to know how to help you.”*

– Someone with MCI/ADRD

- *“People don’t know about the resources. We found doctors through referral. The medical system isn’t the issue. I don’t know jack about Medicare. I don’t know where to start, so we called one office on aging, they didn’t know and said to call another. The person on that one sounded like a kid in high school and said, ‘go to the Medicare website and fill it out.’”*
– **Care partner**
- *“I think there should be an agency that has home health aide, just so caretakers could take a break.”* – **Care partner**
- *“[about the Choices program] They come to your house and have to see if it’s approved, but if you pay private then you don’t have to have your home approved for safety.”* – **Care partner**
- *“My husband is 83. I’m 74. She [the loved one] does go to [a day center], and she loves it. She’s happy there, but we need respite care. I’ve been 5 places so far, and they all have a minimum of 1 month! I’m not putting her away for that time. First of all, it would be a shorter time for me, but for her it would feel like such a long time. I just need somebody for some small periods of time, like overnight or weekends now and then. What if me or my husband had to be in the hospital? What if something happened to us where we couldn’t take care of her for a time? I don’t need a month. I don’t want it. We need short-term, and nobody is making that possible. But when my mama was here in 1997, those resources were available. She could stay in short term care.”* – **Care partner**
- *“I think what is challenging is finding Care partner support if you don’t [have anyone].”*
– **Care partner**
- *“Her husband [wasn’t able to] change lightbulbs, and it was dark and that was cognitive for him, and they were eating once a day and sharing it. So, they didn’t get resources, either. But he was not able to get people to come and do those things.”* – **Care partner**
- *“It would be helpful if earlier on I learned about resources for Care partners. I happened to learn about it because of a brochure in the doctor’s office that was a conference for Care partners. Why can’t we have a list of resources for the Care partners? Why couldn’t a doctor or a nurse or an assistant help you in that way?”* – **Care partner**
- *“If I could have one thing at the time of diagnosis, I wanted resources. I wanted that doctor’s phone number.”* – **Care partner**
- *“Early on, I had some learning, but I wish I knew right away about the Care partner conferences that Tennessee provides. I wish I’d known more about end-of-life preparation. We went to a lawyer that helped us along that line. I wish I’d known about a support group that was in place.”* – **Care partner**

Finally, one participant living with early cognitive impairment recommended the need to listen to people and provide what is requested versus assuming we know what is needed:

- *“Some people don’t even have food; but people aren’t asked what they need, they’re just given things they may or may not need.”* – **Someone with MCI/ADRD**



Summary

The focus groups revealed several important insights and findings that could help practitioners and professionals better understand experiences and needs of adults living with MCI or ADRD. The focus groups also provided opportunities for people caring for others with MCI/ADRD to share their experiences and recommendations for improving care and support. The following findings help summarize key insights gained from the focus group discussions:

The findings in this report aim to assist organizations and community leaders with the knowledge needed to advance population health approaches related to ADRD/MCI.

- *There appears to be a disconnect between existing resources and knowledge of available resources.*
- *With a shortage of providers, connection to resources is needed to support people with memory problems during long appointment wait times. Examples of opportunities for improvement can include development of resource hubs, integrating community health workers into existing systems, and promotion of existing materials.*
- *Focus group participants expressed that support groups provided great comfort and a sense of community. Support groups should be included in discussions about support for people with MCI/ADRD.*
- *There appears to be a need for grief support associated with new diagnoses of ADRD at the time of a diagnosis for the person receiving the diagnosis and their care partners.*
- *Focus group participants suggested that some practitioners appeared somewhat hesitant or fearful of offending patients by suggesting the need for cognitive tests or assessment. Additional training might help practitioners feel more comfortable initiating screenings and making a diagnosis, despite the sensitive nature of suggesting signs of a memory disorder.*



Appendix

Focus Groups: Best Practices for Seniors with Cognitive Decline

[Best practice guidance](#) for facilitating group discussions or focus groups with people living with MCI/ADRD was developed for this project and shared with KCHD and the advisory committee supporting this work.

Focus Group Questions for Care Partners of People Living with MCI/ADRD

1. At what stage were your loved ones diagnosed: early, mid, or late-stage dementia?
2. If your loved one were diagnosed with mild cognitive impairment in the early stages, what were the benefits of knowing sooner rather than later?
3. How did you and your loved one feel after receiving this diagnosis?
4. What was your loved one's experience with getting a medical diagnosis of MCI or dementia?
 - a. What was easy or challenging about the process?
 - b. What was the length of time between when your loved one first noticed cognitive changes and the diagnosis?
5. Tell me about a time when your loved one received medical care as a person living with MCI or dementia. What was easy or difficult about it and what type of care setting was it in?
6. What are some things you wish healthcare professionals understood about living with MCI or dementia?
7. What are the top three recommendations given for how to support your loved one's health after they received their diagnosis with MCI or dementia?
8. What programs do you and/or your loved one participate in or what resources do you use that are related to brain health? How did you hear about them?
9. What programs and resources would be helpful to you as a Care partner, but are not available?
10. Is there anything else you would like us to know?

Focus Group Questions for People Living with MCI/ADRD

1. What was your experience receiving a medical diagnosis of mild cognitive impairment or dementia?
 - a. Was it easy or challenging?
 - b. Was the diagnosis explained clearly?
 - c. Were other family members present?
 - d. Did you have your questions answered?
 - e. How did you feel when the diagnosis was made and explained to you?
2. If you were diagnosed early, what are the benefits of knowing sooner?
3. What was the length of time between when you first noticed symptoms to when you were finally diagnosed?
4. Did you receive information about how to live with this diagnosis including recommendations for lifestyle change, medication options, diet and exercise?
5. What information about programs and/or support groups were given to you?
6. Have you found any resources outside of those given to you by your provider?
7. What are your major questions and concerns you and your family have moving forward with this diagnosis?
8. What do you think healthcare professionals need to know about MCI and adult cognitive disorders?
9. What programs and resources would be helpful to you but are not available?
10. Is there anything else you would like us to know?

