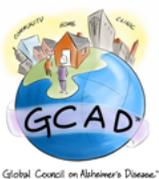


Hear Our Voices:

Expectations vs. Experiences
Living with Dementia and Agitation





Carrie Shaw



Terry Montgomery



Paulan Gordon



Ed Shaw



Regina Sofer

Dedication

This white paper is dedicated to all the courageous individuals who are speaking out and educating about their experiences of living with dementia. They are creating a better society in which to live fully with dementia.

Acknowledgments

The writing of this white paper was a collaborative effort by the Global Council on Alzheimer’s Disease (GCAD) and the Dementia Action Alliance that included the perspectives, insights, and experiences of the following individuals living with dementia and their care partners:

Cheryl Belleville,
care partner for husband

Terry Montgomery,
living with Alzheimer’s

Carrie Shaw,
care partner for mother

Mike Belleville,
living with Lewy body dementia

Barney Nelson,
living with Lewy body dementia

Edward G. Shaw,
care partner for wife

Paulan Gordon,
living with vascular dementia

Laurie Scherrer,
living with Alzheimer’s and
frontotemporal dementia

Regina E. Sofer,
care partner for mother and uncle

Cynthia Huling Hummel,
living with Alzheimer’s

Brian Van Buren,
living with Alzheimer’s



Cynthia Huling Hummel



Laurie Scherrer &
Brian Van Buren



Barney Nelson



Mike & Cheryl Belleville

Introduction

For years, dementia has been “hidden in the shadows.” As the spotlight shone on pink ribbons painted on football fields and heart-healthy icons on restaurant menus, dementia stayed in the dark.

But the shadows are lifting, thanks to tireless, creative, and undaunted advocacy efforts. Communities are becoming “dementia-friendly.” Books and movies are exploring the human side of living with dementia. At the highest levels of policy—at the G20, the World Economic Forum, and among dozens of national governments—plans are being created to confront this public health priority. This response is needed. Cognitive decline and dementia are the main causes for disability in older adults.

Yet, despite local and global progress, many aspects of dementia remain in darkness. Dementia continues to be one of the most misunderstood and stigmatized health conditions, particularly when it comes to living with the symptoms of the condition. Consider the circumstances that led to the recent suicide of Robin Williams. Two documentary films—*Spark* and *Robin's Wish*—report that autopsy results revealed that Robin had undiagnosed Lewy body dementia. It is a discovery that is both startling and revealing. Despite the actor's abundant resources and access to elite medical care, his dementia went undiagnosed.

There is urgent need to better understand the symptoms of dementia—particularly the highly stigmatized symptoms, like agitation.

Our Path Forward

In the 1990s, disability activism both embraced and popularized a belief that would change the course of living with disabilities: “Nothing About Us Without Us!” When people living with disabilities shared their first-hand narratives, it greatly improved understanding of the “lived experience” that accelerated practice and policy changes nationally.

We advocate that we must embrace and ingrain this culture of “Nothing About Us Without Us” to improve recognition and understanding of the symptoms of dementia and the lived experience. We need to not only create opportunities for the voices and perspectives of people living with dementia and their care partners to be heard, but to also value and encourage their first-person narratives.

This is why the Global Council on Alzheimer’s Disease (GCAD) and the Dementia Action Alliance (DAA) collaborated on a project to better understand the community voice. We wanted to hear from people living with dementia, and their care partners, in their own words, about their feelings and experiences. We wanted to create a space where they could share their voices.

When we began this project, we did not have a premise or a thesis. We began this wide-ranging interview series with open ears and open minds. We let the people living with dementia tell their own stories.

After hours of conversations, we realized a theme was emerging: from pre-diagnosis to diagnosis to living with dementia, there were gaps between what people *expected* and what they actually *experienced*. Because the symptoms of dementia are multifactorial, individualistic, and widely misunderstood, there are especially wide gaps between expected outcomes and outcomes experienced, particularly with agitation.

In the rest of this paper, we share with you, word for word, what we heard. And we arrange what we heard around this notion of what most people *expect* versus what they actually *experience*. Through these gaps, we offer first-person experiences and insights to help inform the broad and diverse dementia community: healthcare practitioners and their staff; long-term care service and support providers; researchers; policymakers; and hospital staff, among others.

We hope this paper is the beginning of a longer, broader collaboration to elevate the community voice of people living with dementia and engage in dialogue to instill a culture of “Nothing About Us Without Us.”

Signed,

Mary Michael

Chair,

Global Council on Alzheimer’s Disease

Vice President,

Patient Advocacy and Stakeholder Management

Otsuka America Pharmaceutical, Inc.

Karen Love

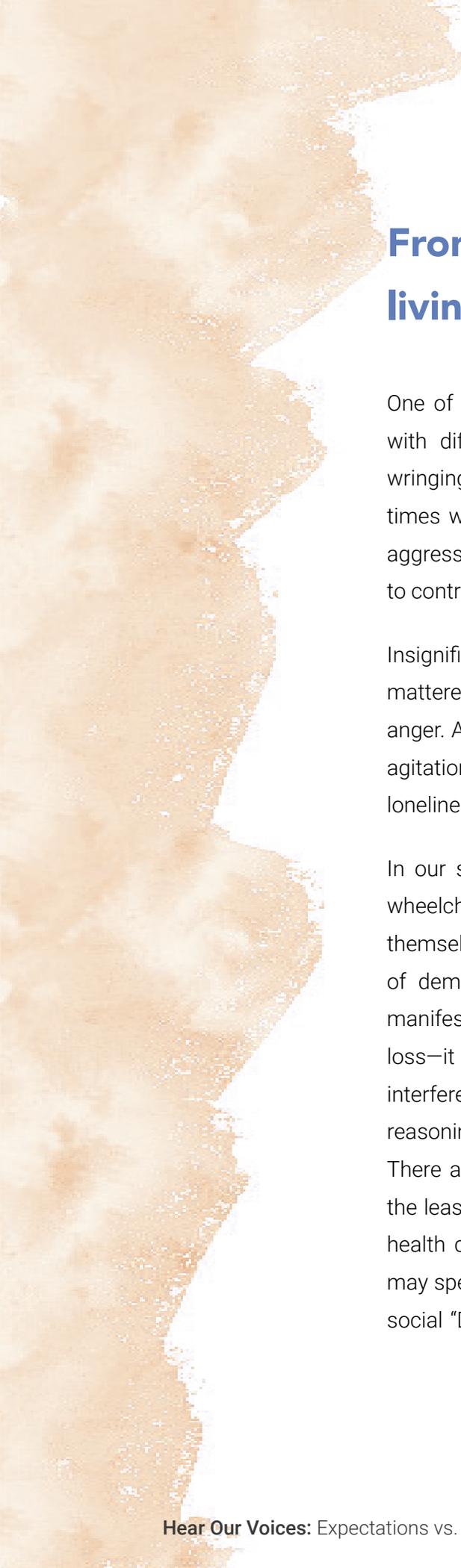
Co-Founder and Executive Director,

Dementia Action Alliance

Jackie Pinkowitz

Co-Founder and Chair, Board of Directors,

Dementia Action Alliance



From the perspective of a person living with dementia

One of our greatest challenges living with dementia is dealing with different forms of agitation, which can include pacing, wringing hands, uncontrollable anger, and restlessness. At times we are aware of personality changes which may include aggressive behavior and verbal outbursts, and yet we are unable to control our reactions.

Insignificant events or conversations that once would not have mattered can in our mind escalate into apprehension and even anger. Although we know some circumstances can increase our agitation (such as lack of sleep, changes in our routine, stress, or loneliness), the triggers are not always transparent.

In our society, dementia is stigmatized as elderly people in a wheelchair, unable to recognize their loved ones or care for themselves. Although that image may be the ending cycle of dementia, generally dementia is a slow process and can manifest over several years. Dementia is not just memory loss—it is the loss of cognitive functioning to the extent that it interferes with a person's daily living. This may include thinking, reasoning, executive skills, social skills, and behavioral abilities. There are many components to these symptoms, and perhaps the least recognized and understood by many people—including health care providers—is agitation. People living with dementia may speak and act inappropriately in part because their filters of social “Do’s and Don’ts” are compromised, making them unable



to decipher the messages of correct conduct.

Agitation and anxiety can lead to anger and in turn to verbal or physical abusiveness. Additional research on the impact agitation has on people living with dementia could be beneficial in recognizing a large component of dementia life and the portrayed behaviors.

Laurie Scherrer,

Living with Alzheimer's disease and
frontotemporal dementia

Blog Author,

Dementiadaze.com

Board Member,

Dementia Action Alliance

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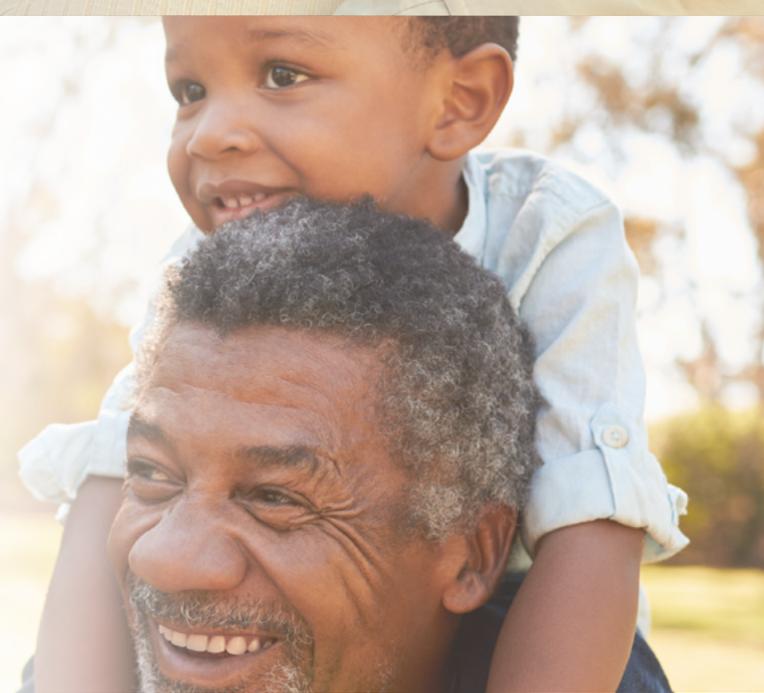
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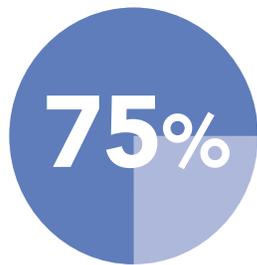


Prior to diagnosis:

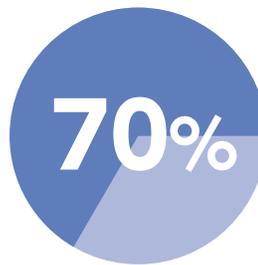
“One thing that people don’t understand is that when you’re diagnosed, it doesn’t mean that’s when the Alzheimer’s started.”

—Brian Van Buren, living with Alzheimer’s

In the U.S., 75% of adults think memory loss is a normal part of aging, and globally 70% of people do.^{1,2} These misconceptions may hinder the ability to recognize symptoms early. Common early symptoms can include difficulties multitasking; getting lost in otherwise familiar territory; repeating a request, question, or story; challenges with simple math calculations; word-finding difficulty; and agitation.³



of adults in the US



of adults globally

**think memory loss is a normal
part of aging**

Expectations Versus Actual Experiences: Before Diagnosis

Expectations:

Dementia is a disease of memory loss for older adults.

“

People think that dementia is just an 'old person's' disease. Or that it's just about memory issues.”

**—Mike Belleville,
living with Lewy
body dementia**

“

I didn't anticipate all the psychological issues that came with my Alzheimer's. But it's brought on paranoia, depression, and anxiety – and no one understands it's all part of the same disease.”

—Brian Van Buren, living with Alzheimer's

“

I didn't really expect to be diagnosed with dementia. I mean, after all, I was only 55.”

—Laurie Scherrer, living with Alzheimer's and frontotemporal dementia

“

I just thought of Alzheimer's in terms of *The Notebook*. It was something your grandma might get, and then she wouldn't remember who you are.”

—Carrie Shaw, care partner for mother



Expectations Versus Actual Experiences: Before Diagnosis

Actual Experiences:

Dementia is a condition of multiple and varying symptoms. Agitation often begins before diagnosis.

“ One thing that people don't understand is that when you're diagnosed, it doesn't mean that's when the Alzheimer's started. I look back and realize there were a lot of differences in my behavior and cognition, but I was in denial.”

—*Brian Van Buren, living with Alzheimer's*

“ In the time leading up to my husband's diagnosis, he wasn't acting like himself. He was easily agitated and getting very depressed and withdrawn. What brought us to the doctor in the first place was that we got into an argument – the sort that any long-time married couple may get into – but he said some things that were very out of character.”

—*Cheryl Belleville, care partner for husband*

“ I started having challenges at my job. At one point, I was looking at my laptop trying to find the 'text message' button so that I could send somebody a message. After about 15 or 20 minutes, I realized you can't do that from a laptop.”

—*Barney Nelson, living with Lewy body dementia*

“

I remember I was on a college visit with my mom before she was diagnosed, and she cried for 12 hours straight. Looking back on it, I realize that was probably a symptom of her disease.”

—*Carrie Shaw, care partner for mother*



Diagnosis

“I didn’t expect a diagnosis of dementia at all. But I know it should have been handled much differently.”

—Laurie Scherrer, living with Alzheimer’s and frontotemporal dementia

The road to diagnosis is often long and difficult. People living with dementia may not recognize symptoms as possible signs of the condition, or they may live in denial and avoid treatment.⁴ Additionally, families, friends, coworkers, and others might not recognize indications of the condition either. And among healthcare providers, research finds that nearly two in three consider dementia to be a normal part of aging, while half of health care practitioners think the condition is ignored by other healthcare professionals.^{5,6}



Nearly
2 out of 3
healthcare providers

think memory loss is a normal part of aging.^{4,5}

In our interview series with people living with dementia, the experience of diagnosis was typically summed up in five words: “Get your affairs in order.” Generally, no information is provided at diagnosis about how to live with the chronic condition of dementia, nor how to be proactive with the symptoms. The mindset that “nothing can be done” once diagnosed is far off the mark. There is much that can be done to support well-being while living with it.

Most people are surprised to learn that when individuals and their families are diagnosed with dementia, they typically are not provided with helpful information or connected with support. This lack of help and hope often plunge the newly diagnosed into depression, despair, and isolation.

People could be hugely helped if encouraged about how to live proactively with the symptoms of dementia, including reducing stress, being physically active, staying engaged in activities that are meaningful and of interest to them, eating nutritiously, getting enough good sleep, connecting with others living with dementia, and maintaining social supports.

It is also important to identify ways to manage symptoms to maintain function and well-being. For example, Laurie Scherrer was becoming agitated at dusk in her new house, because she didn’t know how to turn on various light switches. Laurie’s husband problem-solved the issue with her and now turns lights on in the house at dusk. This reduces Laurie’s frustration and agitation.

From our experience at the Dementia Action Alliance, we have found that agitation is often a sign of distress. And we therefore think it is important to understand the underlying cause of agitation in order to address the cause and implement an accommodation. Expressions of agitation typically do not come out of the blue. Some of the causes include pain, fear, frustration, lack of sleep, loneliness, boredom, overstimulation, too much sound/noise, and feeling useless.

While each individual is unique, some commonly helpful ways to address symptoms of agitation include responding compassionately, going to a less-stimulating area, playing soothing music, giving reassurances, using earplugs, and identifying meaningful and interesting ways to be engaged.

Expectations:

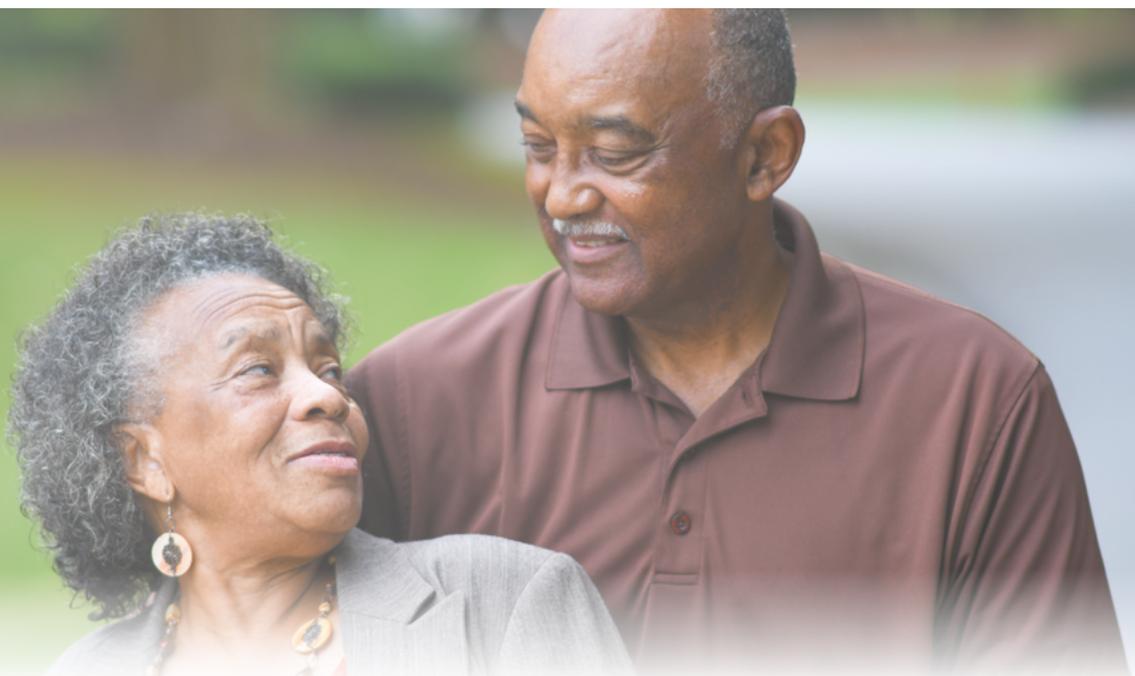
A doctor will deliver a timely diagnosis and help you understand what's next.

“ Whatever the diagnosis was, I expected the doctor to present it with compassion and support. I expected the same humanity we received when my mother was diagnosed with terminal cancer. She received such a different response: ‘put no limits on yourself.’ When I was diagnosed, I didn’t get that same treatment. Why do we treat dementia so differently from other terminal diseases?”

—Laurie Scherrer, living with Alzheimer’s and frontotemporal dementia

“ The diagnosis was given to me without hope or encouragement or any information about how to live with this condition that will continue for the rest of my life”

—Paulan Gordon, living with vascular dementia



Actual Experiences:

On the few occasions when a diagnosis is timely, little practical support is offered, particularly for agitation.

“ It took me eight years to finally get a diagnosis for the symptoms I was experiencing. I was relieved to finally find out what was going on with me.”

—*Cynthia Huling Hummel, living with early onset Alzheimer’s*

“ My doctors were not helpful one bit. I got no types of references, referrals, or articles. They just told me to go home and ‘get my affairs in order.’”

—*Brian Van Buren, living with Alzheimer’s*

“ The neurologist didn’t provide me with any information about how to live with Alzheimer’s. Since there is a lot of stigma about it and the societal narrative is gloom and doom, not being provided with information about how to live with dementia was like being dropped off a cliff.”

—*Terry Montgomery, living with Alzheimer’s*

“ **What we didn’t have was very good emotional support from the medical community and resources to deal with the issues, like agitation. That became a very front-and-center challenge.**”

—*Ed Shaw, care partner for wife*

After Diagnosis

“When you hit a bump in the road, you either can stay stagnant or move forward; I decided to move forward.”

—Brian Van Buren, living with Alzheimer’s

A diagnosis of dementia changes the course of people’s lives. Research shows that diagnoses prompt a wide range of emotions, including anger, relief, denial, depression, resentment, fear, and a sense of isolation.⁷ It is also commonly argued in the literature that people have expectations of losing agency and control over their own life, which undermine “one’s core sense of self.”⁸

Yet our interviews painted an alternative picture. It is certainly true that no one argued a diagnosis wasn’t life-changing, but we also heard stories of how people built a resolve to push forward and make the most of life in spite of living with dementia.

Expectations:

The disease will define my life, and the symptoms will be overwhelming.

“

I had a very dark view of the situation after my mom was diagnosed. I thought the whole thing was tragic and that her life was over. Now I know there are ways that people can really live with Alzheimer's.”

—Carrie Shaw, care partner for mother

“

If I had listened to the neurologist when I was diagnosed, I believe depression would have pulled me into a totally different life than I have now. Instead, after a bout of self-pity, I decided I was going to accomplish something with my life. And I have through my advocacy work.”

—Laurie Scherrer, living with Alzheimer's and frontotemporal dementia



Actual Experiences:

A dementia diagnosis is the beginning of a new story, and symptoms, including agitation, can be managed.

“ Dementia is a health condition, not a personality trait. And like any health condition, you still retain your personhood.”

—Mike Belleville, living with Lewy body dementia

“ It is important for people to know we may not respond quickly or understand everything the first time it is said. Our processing abilities have slowed down. Noises can be very hard on us as we often cannot filter out that distraction. It’s best when people face us when they are speaking to us. We need to see your face to best understand what you are saying. Everyone is different, but each of us needs to figure out how to adapt, make accommodations, and work with our strengths.”

—Terry Montgomery, living with Alzheimer’s

“ I am committed to not let dementia dictate how I will live my life, nor cede control of my life to it. I see myself as Barney—not Barney with dementia, and ultimately I know this is an attitude decision I can make and live by.”

—Barney Nelson, living with Lewy body dementia



Expectations Versus Actual Experiences: After Diagnosis

“ I met 8-10 people with a similar diagnosis of Lewy body. There were light bulbs going off. They were experiencing similar things that were happening to me. I came away saying, ‘I’m not crazy.’ By meeting others, I felt I wasn’t alone.”

—Mike Belleville, living with Lewy body dementia

“ There are ways that my mom would express herself with agitations. Care partners need to be aware of these nuances. That’s how you see symptoms expressed and develop ways to manage them. One thing that calmed my mom down was listening to Elvis. She loved Elvis and drinking Coca-Cola.”

—Regina Sofer, care partner for mother and uncle

“ **Dementia is a health condition, not a personality trait. And like any health condition, you still retain your personhood.**

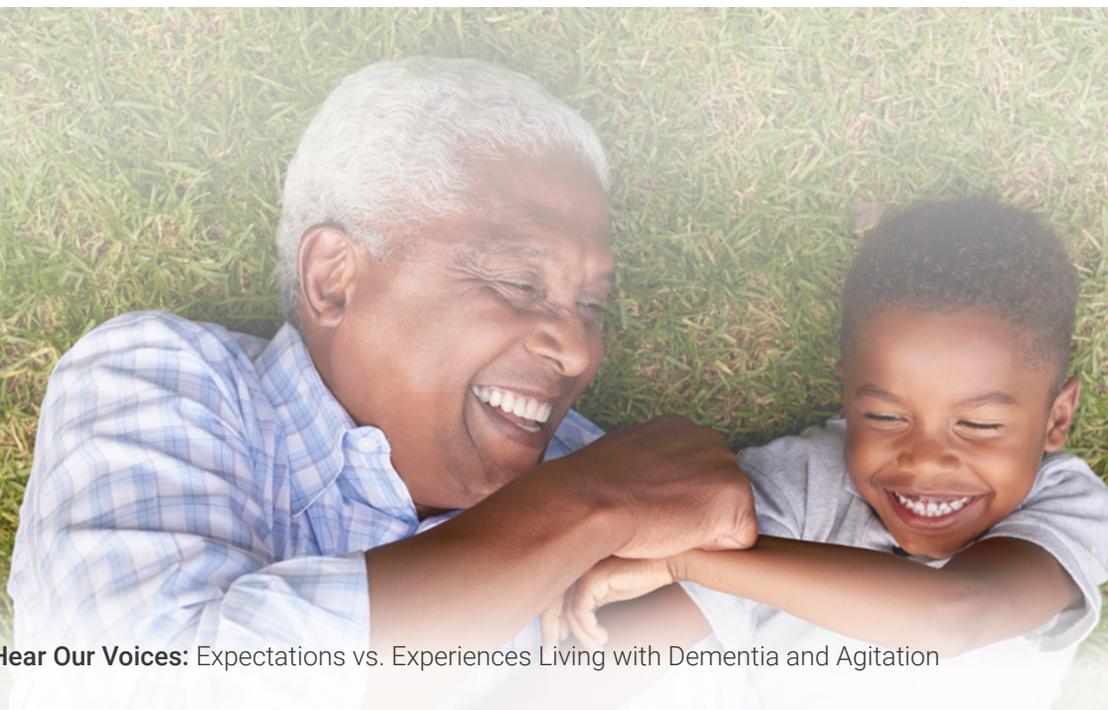
—Mike Belleville,
living with Lewy
body dementia

Spotlight on Experiences in the Black Community

Voices of Black Americans with Dementia

Black Americans develop dementia at a higher rate than any other group, and they develop dementia at about twice the rate as non-Hispanic whites. Black Americans bear a third of the cost of dementia, despite making up only 13.6% of the U.S. population,⁹ and the condition's costs to the Black community are projected to double by 2050.¹⁰

America's legacy of medical racism has led to higher levels of distrust in the healthcare system from the Black community.¹¹ This may discourage some from the Black community to share their experiences and seek care.



Spotlight on Experiences in the Black Community

“ Black people don’t talk about medical issues or family history. There’s a shame involved for a lot of people. I run a support group for Black people, there’s 20 people in it. They’re all retired, they’re all caregivers, and the majority have never told any friends or relatives that their loved one has Alzheimer’s. It’s always like that with Black people – you don’t put your business out there on the street.”

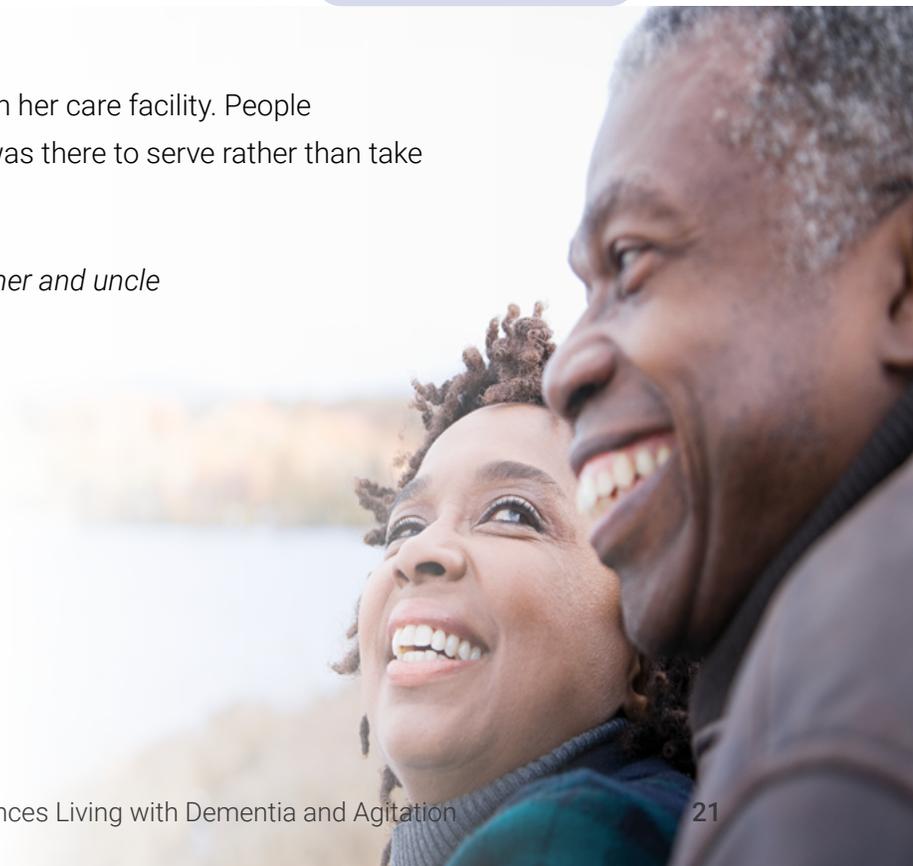
—Brian Van Buren, living with Alzheimer’s

“ **In communities of color, there is more of a sense of keeping people at home. There is a lack of trust and a lack of resources that might lead people to keeping their loved ones at home.**

—Regina Sofer,
care partner for
mother and uncle

“ I would visit my mom almost daily in her care facility. People sometimes saw me and thought I was there to serve rather than take care of my mom.”

—Regina Sofer, care partner for mother and uncle



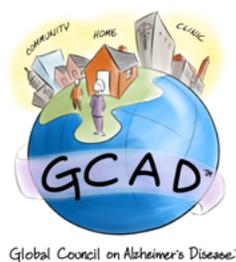
Conclusion and Next Steps

This paper shows that significant differences exist between people's expectations and their actual experiences, and it puts a spotlight on the societal need to improve understanding and practices about dementia. But it is also the goal of this paper to reveal how much can be learned through the experiences and insights of people living with dementia and their care partners.

As with the disability community's Nothing About Us Without Us activism in the 1990s, we believe it is time to embrace this culture to advance improved understanding and practices about living with dementia.

We recognize that much work remains to be done. On behalf of both the Dementia Action Alliance and the Global Council on Alzheimer's Disease, we hope this paper can serve as the foundation going forward for more work to include and amplify the voices of people living with dementia and their care partners.

We look forward to new opportunities to share the community voice, and we welcome thoughts, ideas, and collaborations as we do.



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