NATIONAL COUNCIL OF DEMENTIA MINDS

TRANSFORMING LIFE WITH DEMENTIA

A Groundbreaking Needs Analysis Report on Support and Services by Persons Living with Dementia

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In formulating this groundbreaking report, we as individuals living with dementia and members of the National Council of Dementia Minds, joined forces with Dr. Daniel Vélez Ortiz, an esteemed Associate Professor at Michigan State University. Alongside us, a dedicated support team, led by Brenda Roberts, MA, Executive Director of the National Council of Dementia Minds, and John Williams, BA, Project Consultant, provided invaluable guidance and assistance.

In the spirit of inclusivity, authors are listed in alphabetical order as each person contributed equally to this report.

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We would like to express our heartfelt appreciation to the project management team for their dedication and guidance throughout the research project. Additionally, we extend our sincere thanks to the support team for their invaluable contributions and unwavering support.

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Expert Advisors

We are immensely grateful to our expert advisors for their invaluable guidance at the project's outset, specifically in promoting inclusivity and diversity. Their early insights have profoundly shaped our approach.

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Executive Summary

Pioneering a revolutionary movement, the National Council of Dementia Minds stands as the first national nonprofit organization founded and governed by persons living with dementia. Comprising individuals dedicated to support, education, advocacy, and research, we champion the cause of reshaping the landscape for persons living with dementia.

Amid our endeavors, a stark reality emerged: information and education are predominantly directed toward care partners (individuals who provide support for the person receiving a dementia diagnosis – typically a spouse or family member), neglecting the pressing need for persons living with dementia to be educated about our diagnosis. This inequity must be rectified. Our mission is to amplify the voices of persons living with dementia, advocating for our right to be informed, empowered, and actively engaged in decisions regarding our health.

Revolutionizing Research: Persons Living with Dementia Take the Lead

Our research project, driven by the voices of 65 individuals living with dementia from diverse backgrounds, including black, Latino, LGBTQ+, rural, urban, and an age range from 47 to 92, seeks to address a pervasive lack of support and information. This systemic issue persists, hindering individuals from leading fulfilling and hope-filled lives post-

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diagnosis, exacerbated by prevalent myths, misconceptions, and societal stigma surrounding dementia**.**

Our groundbreaking research defies convention by placing individuals living with dementia at the forefront. With 65 diverse participants driving the process, we are more than subjects; we are co-researchers and co-authors. From selecting topics to crafting recommendations, our voices shape every aspect of the study. This pioneering approach challenges the status quo by demonstrating that individuals living with dementia can be active agents of change instead of passive recipients of care.

Compassionate Diagnosis and Holistic Disease Management

Our vision extends beyond mere diagnosis—we advocate for a transformative disease management program, mirroring successful models for diabetes, cancer, and cardiovascular diseases. Recognizing the proven efficacy of such programs in improving health outcomes and reducing costs, we call for compassionate diagnosis and follow-up through integrating chronic disease self-management education. We are recommending comprehensive care including peer support, financial resources, legal guidance, and emotional support.

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Our Message

In the aftermath of our groundbreaking research, the National Council of Dementia Minds stands as a beacon of transformative movement, advocating for a paradigm shift in dementia care. Our study, a collaboration of 65 diverse individuals, reveals the pressing need for an inclusive, holistic, and person-centered approach to dementia care.

Our call for compassionate diagnosis and follow-up is coupled with a steadfast assertion that persons living with dementia deserve access to chronic disease self-management education and support. However, at the heart of our advocacy is the transformative power of peer support. Peer support, financial guidance, legal navigation, and emotional and practical assistance emerge as cornerstones of our revolutionary initiative.

The potential healthcare savings associated with early intervention, underscored by our report funded by the Michigan Health Endowment Fund, present a compelling case for investing in a future in which persons living with dementia can thrive.

Our research is not merely a report; it is a manifesto for change. It is a collective declaration that persons living with dementia deserve to be active participants in our care, equipped with the resources and support necessary to lead lives of purpose and dignity. The National Council of

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Dementia Minds invites stakeholders, policymakers, grant makers, and healthcare providers to join us in this revolutionary journey, fostering a world where every person, regardless of a dementia diagnosis, can live their best life.

More detail is provided below regarding the categories of support identified through our research with and by individuals living with dementia.

Living Well with Dementia

Support in many areas is critical for living well with dementia.

Peer Support

At the heart of our advocacy is the transformative power of peer support, an invaluable resource that individuals living with dementia have reported learning more from than traditional healthcare providers. Beyond fostering camaraderie, peer support serves as a lifeline for managing the emotional and practical challenges associated with dementia. Our fervent call is for tailored peer support groups which are based upon age, ethnicity, living situations, and personal circumstances. **I**nclusivity in dementia care is of paramount importance**.**

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Financial Empowerment for All

Our report identifies a crucial gap in services, urging the establishment of immediate guidance for individuals with dementia facing various financial challenges. Recommendations cover Americans with Disabilities Act (ADA) workplace accommodations, disability insurance, strategic financial planning, and clear, age-inclusive steps for navigating the complex financial landscape associated with dementia. The call is for measures that promote financial empowerment for all individuals living with dementia.

Legal Guidance

In the current landscape**,** the legal issues related to a dementia diagnosis are often unclear. Our advocacy recommends proactive engagement with elder law attorneys from the outset, bringing clarity to this complicated terrain. We propose a comprehensive approach, recommending both initial preparations and reviews throughout the dementia journey. This proactive strategy empowers individuals with the knowledge and support for informed decision-making and legal preparedness.

Emotional and Practical Support

Our participants have articulated the vital need for emotional and practical support. Access to knowledgeable counselors, life coaches,

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and professionals experienced in dementia-specific challenges is essential. Practical guidance on disclosing our dementia diagnosis to family, friends, and employers is imperative for managing the impact of a dementia diagnosis. We advocate for comprehensive emotional and practical support systems integrated into the healthcare journey.

Healthcare Savings and Excess Disability

Our report, funded by the Michigan Health Endowment Fund, underscores the potential healthcare savings associated with early intervention. By providing the resources and support individuals need from the beginning, excess disability can be prevented, contributing to healthier lives both physically and emotionally. It's not only about costs; it's about investing in a future where persons living with dementia can thrive.

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Study Objectives

National Council of Dementia Minds (NCDM) embarked on a mission funded by the Michigan Health Endowment Fund to enhance the health and wellness of individuals living with dementia. Our goal is to narrow the healthcare disparities faced by persons diagnosed with dementia by promoting person-centered support from healthcare providers and social service agencies.

For this project, our objective was clear: to conduct a thorough analysis of the current post-diagnosis support landscape, pinpointing the gaps and deficiencies in resources and services available to individuals like us living with dementia. Through engaging focus group discussions with diverse ages and backgrounds, we **as** fellow individuals living with dementia, shared our lived experiences post-diagnosis. Our intent was to shed light on the challenges we face and the areas where information, resources, and support fall short.

Furthermore, we set out to develop actionable steps to address the immediate post-diagnosis needs, focusing on empowering individuals like us with the knowledge and resources to navigate life with hope and confidence. Specifically, we crafted recommendations and resources tailored for individuals newly diagnosed with dementia, by individuals like us living with dementia. These resources will be accessible on the

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NCDM website (www.DementiaMinds.org), ensuring easy access for individuals navigating this journey and their families as well as healthcare providers, mental health professionals, community-based organizations, and communities.

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Our Needs Analysis

Methodology

Our target population for this project included individuals newly diagnosed with dementia, spanning both older adults and persons diagnosed before the age of 65. Our teams, comprised of 65 persons living with dementia, had roles as project managers, researchers, focus group participants, and report authors, with the invaluable support of professionals not living with dementia.

In this study, we endeavored to gather insights and recommendations from a diverse group of individuals living with dementia. This approach included individuals from various demographic backgrounds, such as underrepresented communities like Black, Latino, LGBTQ+, young onset, and former physicians living with dementia. Alongside general or mixed population groups, we engaged 65 individuals across 10 focus groups facilitated by the National Council of Dementia Minds (NCDM). Each focus group comprised three to nine collaborators per group, fostering rich discussions on various topics, including:

1. Resources Received from Diagnosis to 1 Year After: We shared the information and resources we received during this critical period following our diagnosis.

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2. Desired Resources at Diagnosis: We identified the resources which would have been beneficial at the time of our diagnosis and within the first year afterward.

3. Review and Refinement of Recommendations: We meticulously reviewed and refined the recommendations from our discussions to ensure accuracy and comprehensiveness.

Additionally, the physicians living with dementia group convened for a fourth session to further refine our recommendations.

To identify the gaps in resources and information needed for newly diagnosed individuals, we conducted a needs analysis through surveys and interviews with fellow individuals living with dementia. Each of our focus group sessions was held via Zoom and was recorded. Our dedicated facilitation teams transformed these recordings into written summary transcripts containing our recommendations for resources (see appendix).

Overall, our participant demographics reflect a broad spectrum. With an average age of approximately 75 years and ages ranging from 47 to 92 years, the participants represent a wide array of experiences. Most of us (49) reside in our own homes with others, while some live alone (8), in assisted living (2), in the homes of others (3), or in nursing homes (1), with two participants' living arrangements undisclosed.

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The most commonly reported diagnoses among us were Alzheimer’s Disease (22) and Mild Cognitive Impairment (20), followed by Frontotemporal Dementia (12), Lewy Body Disease (10), Vascular Dementia (6), Posterior Cortical Atrophy (2), Chronic Traumatic Encephalopathy (2), and unspecified dementia (5).

Regarding marital status, the majority live in married/domestic partnerships (53), with some being separated or divorced (9), single/never married (1), or having undisclosed marital status (2). Education levels vary among us, with the highest number of participants having completed a Master’s degree (23), followed by a Bachelor's degree (13), Doctoral degrees (12), while others completed High School (7), or obtained an Associate’s degree (4), or other/unknown qualifications (6).

Our racial composition reflects that the majority identify as White (54), followed by Black or African American (9), Hispanic or Latino (2), with one participant declining to disclose. Most of us (38) were diagnosed at age 65 or younger, and the majority reside in urban areas (45), followed by rural areas (18), with two participants' locations unknown. Eight of us are U.S. Veterans. In addition, three participants identify as LGBTQ+.

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In terms of Medicaid beneficiaries, most of us are not beneficiaries (57), while two are beneficiaries, and six are unsure. Almost all participants receive Medicare.

General Recommendations

One of the key aims of our study is to propose transformative recommendations that will profoundly impact the current approaches and experiences of individuals diagnosed with dementia. These recommendations, comprising 131 insights distilled from focus group discussions, are rooted in the lived experiences shared by individuals living with dementia. The insights gathered during these discussions have guided the development of recommendations aimed at enhancing the management of the disease.

1. **Advocacy:**
    - Advocate with medical insurers to ensure individuals newly diagnosed with dementia can access clinicians such as occupational therapists, cognitive speech therapists, and others who provide essential assistance in adapting everyday living skills.
    - Develop stigma reduction strategies to help families and the public understand that each dementia diagnosis is unique,

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countering the misconception that everyone with dementia experiences the same symptoms.

2. **Ancillary Services:**
    - Implement a coordinated interdisciplinary approach with all necessary services for specific diagnoses from the time of diagnosis, as individuals are often told they are not "bad enough" to receive these services.
    - Identify specific websites with diagnosis-specific information focusing on individuals with dementia, providing essential information and resources. This information should be provided at the time of diagnosis.
3. **Coach, Guide, Case Coordinator:**
    - Access to a case coordinator for medical and clinical services is crucial for all individuals diagnosed with dementia. While some have been fortunate to access this service through various channels, it's imperative to ensure universal availability. This arrangement enhances care coordination and allows team members to access the electronic medical record (EMR) efficiently.

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- Offer contact information for individuals with the same diagnosis to provide peer support and guidance, either directly from the doctor's office or through trusted facilitators.

4. **Counseling:**

    - Ensure access to psychologists or counselors at the time of diagnosis to assist with acceptance and the grieving process.
    - Ensure a multidisciplinary approach by involving professionals such as psychologists, social workers, or nurse practitioners in delivering **diagnostic** news and providing comprehensive support for associated emotions, including referrals to community-based services and peer support groups.

5. **Dementia Progression:**

    - Offer hopeful and comprehensive information about the progression of dementia at the time of diagnosis, highlighting potential fluctuations in abilities and emphasizing ongoing support and education throughout the individual's journey with dementia.

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- Establish an interdisciplinary team of clinicians and professionals to support individuals as dementia progresses.

6. **Financial Recommendations:**
   - Equip newly diagnosed individuals with resources regarding the Americans with Disabilities Act (ADA) and financial planning to address potential impacts on employment and benefits.
   - Provide guidance on organizing financial affairs in collaboration with legal, employer, and government benefit reviews, with assistance from an elder law attorney if needed.
7. **Government Benefits:**
   - Offer information on government benefit programs such as Social Security Disability Insurance and Medicare, along with the implications for employer **provided** benefits.
   - Educate veterans on resources and support from the United States Department of Veterans Affairs for healthcare services and benefit programs.

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8. **Information/Education:**

    - Provide basic written information and videos about specific forms of dementia at the time of diagnosis, including a brochure connecting individuals with resources.
    - Develop conversation guides to assist individuals in discussing the dementia diagnosis with various stakeholders, including employers, children, family members, and friends.

9. **Legal:**

    - Provide referrals or assistance with organizing legal affairs, including wills, powers of attorney, and advance directives, from the time of diagnosis.
    - Conduct regular legal reviews at specific intervals to accommodate changing perspectives and needs.

10. **Physicians:**

    - Enhance information provided about specific forms of dementia at the time of diagnosis and subsequent appointments, covering topics such as clinical trials, nutrition, exercise, sleep, and strategies to maintain cognitive functioning and well-being.

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- Train doctors to deliver information sensitively and effectively, ensuring that individuals living with dementia receive clear and understandable communication about the diagnosis and its progression.

11. **Population Specific:**

    - Establish culturally specific peer support groups and peer support groups for underrepresented communities such as African American, Latino, and LGBTQ+ individuals.
    - Address the unique needs of people living with dementia in rural areas, where access to experienced clinicians and resources may be limited.

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Current State of Dementia Care and Support

The emotions shared in this section resonate deeply with the firsthand accounts of individuals living with dementia, encapsulating the multifaceted experience of receiving a diagnosis, from the initial encounter with healthcare professionals to the subsequent journey characterized by a notable absence of essential information, resources, and support. Through our voices, insights are gained into the challenges faced by many in the absence of the necessary support and guidance outlined in this report.

For most, the diagnostic journey has been fraught with difficulty, with a range of emotions stemming from the clinical encounters during the diagnostic process. It is essential to convey these experiences, including the negative emotions, to humanize the diagnostic process. By sharing these stories, we hope to foster new awareness and practices that prioritize inclusivity and compassion. These narratives underscore the current-day reality of a dementia diagnosis, yet they also illuminate a pathway forward. Through the recommendations provided in this report, developed by individuals living with dementia, we can strive to transform this experience into one marked by support, understanding, and empowerment.

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Loss and Confusion: Before and during the diagnosis, confusion often prevails due to the changes and symptoms prompting the diagnostic journey. This period can be marked by conflicting dynamics, where the absence of a diagnosis is as frustrating as receiving one without empathy or accuracy. Many have experienced profound feelings of hopelessness and a loss of personhood due to the lack of inclusion and support at the time of diagnosis. The following quotes exemplify the loss and confusion felt by individuals facing a dementia diagnosis:

"…it's like losing a family member, except you're losing yourself. I was in denial, I kept thinking, in 6 months I'm going to go back, and they're going to say we had it all wrong. The grieving process was a big deal for me."

“...anytime you are diagnosed you grieve. You have to be able to understand it. There needs to be a process of how to work through that.”

Anxiety and Overwhelm: In the aftermath of diagnosis, many experience a profound sense of anxiety and overwhelm, exacerbated by a lack of guidance and information about dementia. Basic information that may seem routine to medical professionals can be overwhelming for individuals navigating a new diagnosis. The absence

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of such information can intensify feelings of uncertainty and disempowerment. The following quote reflects the anxiety and overwhelm experienced by many:

"I was given absolutely nothing. I went into my neurologist's office. I had a bunch of tests done. I had to fight for the appointment to even get in back to see her. She told me what the tests did not show. I said, then what do I have? And she said, you have Lewy body disorder. My daughter was with me, and my husband. My daughter said, is that the same as Lewy Body Dementia? When I heard that word, I totally shut down." "I really needed some help at the beginning of diagnosis to deal with my anxiety, and the discomfort of the things that I noticed were not the way they used to be."

Fear and Isolation: Coupled with anxiety, the diagnosis often brings a profound sense of fear and isolation. Many feel abandoned by the medical system, confronted with a grim prognosis and little guidance on how to navigate the uncertain future. Stigma and misinformation about dementia further contribute to feelings of isolation and alienation. The following quotes illustrate the fear and isolation experienced by individuals confronting a dementia diagnosis:

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“I was diagnosed in 2014, I was 59 years old...He recommended that we go home and get our affairs in order, because the prognosis was usually 7 years until death. So, at 59 that was a real gut punch.”

“…when I was given the news as far as what was like given at that time, I didn't get anything...Well, at least I left the Doctor's office, assuming that I would be dead within 5 to 7 years.”

“I feel really isolated, like there is really nobody I have to talk to. I don't have family where I'm at, it's just me and my partner.”

Doubt and Vulnerability: Throughout the diagnostic journey for individuals with dementia, doubt and vulnerability often loom large, exacerbated by a pervasive lack of recognition of individual worth and resilience in navigating life with this condition. Many find themselves feeling marginalized and dismissed by healthcare professionals, forced to confront the complexities of dementia on their own. The following quotes poignantly illustrate the profound doubt and vulnerability experienced by many during this challenging process:

“Once they give you the diagnosis, some primary care physicians kind of ignore it...if you have something in your hand, you can say, I want to talk to you about this. This information they should give you can be

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used as a starting point, instead of you sitting there trying to think of questions."

"I was diagnosed with MCI, and they advised you 'need to quit your job.' So, I was off for a couple of months, and I thought, well, I think I can work...There was no discussion of how's it going at work. Do you think you could go part-time?"

Frustration: Frustration permeates every step of the diagnostic journey, especially during interactions with medical professionals, where misdiagnoses and inadequate support often exacerbate the ordeal. The dearth of resources and guidance compounds this frustration, leaving many overwhelmed and disheartened by the monumental challenges ahead. The following quote vividly **depicts** the moments of frustration and disappointment shared by countless individuals confronting the complexities of dementia.

"Yup! Looks like you're moving along, you're doing fine...I've been very disappointed in the neurologists." "Saying, okay, go home and get your affairs in order. What the heck is that?"

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Living Well: Implementing Our Recommendations

While frustration often characterizes the current landscape of the diagnostic journey, there exist individuals who have navigated this challenging terrain with resilience and determination. These stories serve as beacons of hope, demonstrating that with the right support and resources, a fulfilling quality of life is possible even in the face of dementia. These individuals, though not plentiful, have found solace in a network of supportive professionals and community resources, enabling them to confront the complexities of dementia with confidence and grace. These experiences stand as a testament to the transformative power of access to comprehensive care and compassionate support. As we strive to improve dementia care for all, let these stories inspire us to create a future where every individual living with dementia can experience the same level of hope, resilience, and fulfillment.

Hope

Embracing a shift in perspective, we advocate for a renewed focus on the potential for a fulfilling life while living with dementia, moving beyond the narrow lens of disease progression. Within our grasp are resources that offer pathways to hope, enabling us and our loved ones to cultivate lives rich in meaning and wellness. The quotes that follow

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bear witness to our enduring pursuit of purpose and joy. Yet, the journey toward wellness could be profoundly enhanced if it commenced with a foundation of hope at the moment of diagnosis, bolstered by the guidance and support of knowledgeable professionals.

"This is not 1955, and you got cancer. Go home and get your affairs in order. You can mitigate the course of this illness with proper treatment on the front end."

[About a peer support group] "…*other people's stories of getting diagnosed and their journey with dementia. This was the place I found hope for the first time and has been helpful in not feeling alone."*

"I'm still learning after 7 years. I was told 7 years ago, I had 8 years left, and I think they might have been wrong."

Compassion

Receiving a dementia diagnosis can trigger a profound sense of isolation, not only due to limited engagement within the medical community but also among the wider public. To us, compassion transcends mere sympathy, embracing our inherent humanity beyond superficial appearances and pervasive stigma. This is particularly crucial within the medical sphere, where professionals serve as gatekeepers to accurate diagnosis and vital resources. The quotes that follow

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poignantly illustrate our encounters with compassion throughout the **diagnostic** journey and beyond.

"I had a very positive experience. I did have counseling and she's the one that gently brought it up [getting affairs in order], and how to go about it. Things I needed to think about, were discussed in a much more compassionate, understanding way."

[regarding telemedicine appointments] "He would say I know you've got a lot of questions. Why don't you ask me your questions first and tell me what has been going on. I'll address those questions, and if you leave anything out, I will fill in any other information. That's how our telemedicine appointments went, I also keep a medical diary."

"I think doctors need to be a little bit more sensitive to your feelings and share with you the fact that this isn't going to happen overnight. You're not going to end up in a nursing home the day after tomorrow."

Resilience

In the face of a diagnosis and the pursuit of a meaningful life, we embarked on various paths in search of information to guide us forward with dementia. Our approaches and sources varied, but each reflected our resilience in striving for wholeness despite the lack of information

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at the time of diagnosis. The following quotes exemplify our resilient efforts to navigate the diagnostic process independently. However, our resilience could be harnessed more effectively with access to proper sources of information and support, both during diagnosis and throughout our journey toward a meaningful life

“I found acceptance through my friends living with dementia at [a peer support group]. We're getting the word out there. A lot of people have joined and are benefiting. We're different than other peer-to-peer support groups, we’re educators, advocates, we are speaking out loud, and changing the way people see us.”

“Today I can tell you I'm living with it in peace. I had a very good counselor early on; she had an excellent background with dementia. She told me, don't worry about this. You have got to work on it, but you have got 10 to 20 years at least. So, sit back and try to figure out how you're going to accomplish doing the things that you really want to do.”

Guidance

In addition to mere access to information, it is crucial that we receive guidance on discerning credible and reliable sources relevant to

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understanding a dementia diagnosis. Moreover, transparency about the diagnostic process and the purpose of tests administered are essential for empowering individuals. The following quotes exemplify the impact of having such guidance on our overall well-being. From comprehensive reports on dementia to connecting with individuals successfully navigating the diagnosis, early guidance can significantly influence our journey toward understanding and coping with dementia."

"There's no cure. It's like saying you have stage 4 cancer, you don't know when it's going to get you, but it's going to get you. It would feel more respectful to have had someone say, okay, so let me guide you through the process of accepting this so that you can learn more about it and deal with the challenges that are going to come up."

"Just having somebody else that you can hug that has the same disease. That got me hooked up with several other different activities."

Security

Security includes various elements when it comes to navigating life with a dementia diagnosis and beyond. It encompasses financial stability, employment security, physical safety, and psychological well-being.

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Addressing these aspects of security is vital for laying the groundwork to live well with dementia. The following quotes highlight significant anecdotes concerning these crucial facets of security.

"…because most long- term and short-term disability is through your work, there's no medical questions… That was one of the things my social worker advised strongly. Talk to your employer, fortunately I had been diagnosed 2 years before I retired, I barely made it under the wire, and I got short- term, and then long- term. We need a checklist of what to talk to your employer about."

"I think it would be very helpful to all of us to know how to find the social security website that estimates your benefits."

"I know for me the more I learned about my disease, the less scary it became."

Engagement

While neurologists and other medical professionals may lack the comprehensive training needed to address all aspects of a dementia diagnosis, there are other health professionals available to provide crucial support. It is essential to involve these professionals from the beginning to address the diverse needs of people living with dementia. The following quotes illustrate the positive impact of early engagement with professionals such as social workers during the diagnostic process.

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"…when they gave me my diagnosis, they actually connected me with a social worker that was a specialist in dementia. They are very important to help you get your affairs in order… she walked us through benefits that were available. She looked at our insurance. She helped with financial kinds of stuff; she was a resource. Also, I've been able to go through several research projects because she got me registered."

"…the neurologist may not be the person that gives us the help that we need necessarily. But then he needs to know about the resources available so that he can say to us who you should get in touch with, or like our family doctor did, let me get in touch with them, and they will contact you."

"We have to name names. I think there's no way of getting around it. We have to talk about which programs and which people at these programs meet our needs. When we talk about the multi-disciplinary approach, I think this needs to be strongly emphasized for everybody."

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Support

Quality of Life

We are dedicated to surpassing mere existence and striving for the highest possible quality of life despite living with a dementia diagnosis. This encompasses not only our own lives but also the lives of our family members and care partners who accompany us on this journey. Our aim is to serve as sources of inspiration for individuals facing similar challenges. The quotes below exemplify the diverse approaches each of us has taken to enhance our quality of life while living with dementia:

“I finally found there are other people living well and they're happy. I want to spend time with these people more than anybody else. All of these different agencies serve a vital purpose, but it was [a peer support group] where I found my friends. People that can bear witness to my journey, and that doesn't mean that my spouse and other people that care about me are not bearing witness. It means that only other people living with dementia and I know what each other is experiencing, because it's a similar journey.”

“[regarding case coordinators] For me to get into the palliative care clinic where I am now, and having every type of doctor I need in one place is very helpful. If I need to see my general doctor, I see my general doctor. I always see my neurologist when I need to. My

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neurologist gives up his lunch hour when we go up every 4 months. It just has made it so much easier having my care in one place. If I need something, I just email my doctor directly, and then by the end of the day I have an email or whatever I need. Having that option for health care, even though we have to drive a couple of hours, that has made everything so much more streamlined and so much easier. The past couple of years things are so much more manageable."

Community

One of the most powerful ways we have discovered to enrich our lives and learn effective strategies for living well with dementia is by connecting with others who share similar experiences. Joining or forming communities with fellow individuals on this journey has been invaluable. Through these communities, we have encountered peers who offer creativity, compassion, and valuable knowledge, contributing significantly to our quality of life. However, finding the right community can be a challenge. Below, we share our experiences and frustrations in navigating this process of finding supportive peers:

"I began attending a support group every week. I know that was the most valuable thing I found. I didn't have another appointment with my neurologist for 3 months. When I was ready to go back to this neurologist, I had 3 pages of questions to ask. I asked in the support

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group, what am I going to do? It's a 2-hour long support group, and they spent most of an hour just with ideas of how to go about getting these questions answered. That was probably the best information they could give me. I told my neurologist I had 3 pages of questions, and she said, go ahead and ask them, the one thing she did right. I read every single one of them off, and she answered them and waited while I took notes on every one of them. So that was good."

"I had contacted [an organization] to see about getting into a support group, that was a dismal affair. They had nothing for vascular dementia."

[about a peer support group] "It was the best thing ever, because now I've got people with all different dementias, and in particular, I have certain people specifically with my type of dementia that I can reach out to, this has been so informative."

Validation/Inclusion

We have all encountered stigma surrounding dementia, whether it stems from misinformation or a lack of empathy. It's crucial to normalize the understanding that individuals living with dementia are equally deserving of compassion and respect, just like individuals with any other illness. Creating opportunities for listening to and sharing diverse experiences can help break down these barriers. Fear often

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accompanies us and our care partners on this journey, but open dialogue and inclusion can transform the experience into one of growth and support. Below, we share some of the ways in which validation and inclusion have shaped our interactions.

“It would have been extremely helpful to be invited to share what I was experiencing right away, what was challenging, and what helped in that first year with providers. To be invited to share with providers, staff, family members, and other people living with dementia.”

“That would have been ideal for us to sit down, the person diagnosed and the care partner, to talk about what that feels like for each of us. That should be an immediate, this is your diagnosis, and I suggest that you go do this.”

“I just would have loved to have a buddy. To say, I've been there, I understand it's a lot, and we can survive.”

Courage

Following diagnosis, we were faced with the task of transitioning from the initial shock to the practicalities of living with dementia every day. This journey required courage to reframe our perspectives and accept difficult decisions to prioritize our well-being. It also involved recognizing and leveraging our strengths to support our pursuit of a

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fulfilling life. Below, we recount some of the courageous steps we took after receiving our diagnosis.

"I started getting these invitations to talk to these companies, executive people that have been in this field of dementia care for decades. And here I am, little Joanna. I was telling them about my experience. That interest in hearing what I had to say from the lived experience, those 4 and a half years prior, my early symptoms and connecting with this community that serves me and my husband. That's been a huge blessing to be able to connect with these folks."

"Giving up my car was very difficult. It was rough, and I understood that it had to be done."

"I really got interested in meditation. That helped me to reflect on the quality of my life. What was the quality of my life? The first thing I had to address was what am I responsible for? What do I own? I'd always been a person that felt like they were in control of their life, and I knew what I wanted, and I knew where I wanted to go."

Purpose

Irrespective of a dementia diagnosis, finding purpose is paramount to leading a fulfilling life. Interestingly, receiving a dementia diagnosis offers an opportunity to reassess one's purpose with renewed focus and therapeutic benefits. We discovered a multitude of activities that

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imbued us with a sense of purpose, ranging from familiar pursuits to exploring new experiences. Below, we share examples of the diverse activities that have brought meaning to our lives.

"I've been given so many different opportunities to share my story, to show that just because you have Alzheimer's doesn't mean that you need to go sit in the corner and cry. You know there's so much that we can do. I just want to do as much as I can, while I still can."

"I continue to sing and it's kind of interesting. I'm singing at that second organization, the continuing care facility. I volunteer in the memory unit. I sing with and for the residents there. It's really a special thing that I do with them."

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Findings of Underrepresented Groups

While the journey of a dementia diagnosis and living with the condition unites individuals in shared experiences, it is crucial to recognize the diversity within underrepresented communities. Stigma affects everyone with a dementia diagnosis, yet individuals diagnosed at a younger age (young onset) may encounter distinct hurdles. Furthermore, individuals from various racial and ethnic backgrounds**,** as well as the LGBTQ+ community**,** confront unique challenges in finding community and navigating familial dynamics.

Young Onset Stigma

While dementia is commonly linked with older adults, a significant number of individuals are diagnosed at younger ages, challenging stereotypes and uncovering a pervasive stigma during the diagnostic journey and in everyday existence. We emphasize the importance of heightened education and awareness among medical professionals and the public alike, as we believe this can profoundly improve our quality-of-life following diagnosis. Furthermore, we deeply appreciate the support and validation provided by individuals living well with dementia, underscoring the significance of peer solidarity in navigating this journey.

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"When I was first diagnosed, the very first reaction was shock. There is no way it can be, I'm too young. I've lived a fairly healthy lifestyle. So, they've made a mistake. That led to anger. How could this possibly be? Now, I'm getting mad because I know I didn't do anything to deserve this…"

"In 2016 I made an appointment with my neurologist, and I was lucky to get in. Just 4 months earlier I had gone to him for acupuncture. He gave me an MRI which showed some white spots on my brain, and at that point he thought maybe seizures, but I was given no suggestions. They thought perhaps depression, as I was too young for dementia or Alzheimer's, because I was just 56."

"I was 48, I thought they're not going to help me. They're not even probably going to believe me, and I was wrong."

Family & Community (Latino and Black)

Being part of a community deeply rooted in family and faith can offer both positive and challenging aspects when living with a dementia diagnosis. While we encounter many situations that evoke emotions similar to individuals outside our communities, our experiences are

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often uniquely influenced by our cultural backgrounds. We firmly believe that increased education about dementia within our families can significantly enhance the support we receive from our tightly knit networks of family and friends. Moreover, connecting with individuals who share our cultural experiences has proven to be immensely impactful. Below, we offer insights into our experiences of living with a dementia diagnosis within the Black and Latino communities.

"…all I know is, with the support group I got connected with- [peer support group] and through them, Black [peer support group], people who also are suffering from cognitive disorders. It's made a huge difference. You feel like you are with your own, and if you say or do something that you'd be understood."

"It was never discussed in my family until my first aunt started acting very, very oddly, and that was really my first entree into Alzheimer's. My parents came over from Cuba, it could be that it just wasn't well known in Cuba."

"Black [peer support group] educated me about Alzheimer's being just one of the forms of dementia. How different people feel about being diagnosed with dementia, which helped me. It really helps to be with others who have the same issues. I guess, this is a school. One of the things that I've done in my life is share information. When I was in

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undergraduate school, my black studies department said, take what you hear and share."

LGBTQ+

Much like other marginalized groups, individuals within the LGBTQ+ community encounter distinct challenges when navigating life with a dementia diagnosis. Within our community, where stigma and isolation are already prevalent, our culture fosters support and validation. We are firm advocates for increased opportunities to connect with fellow LGBTQ+ individuals and for greater education about dementia within our communities. Our diverse and vibrant culture places a strong emphasis on finding community, which is especially vital for our identities and well-being, particularly in the context of living with a dementia diagnosis. Below, we share some of our personal experiences in seeking and finding community.

"The LGBTQ community resources are different in every community. There's no national organization that I'm aware of that puts all of those things together…All those resources we have to find on our own. We haven't found a happy middle ground. Either we don't get enough information, or we're getting too much. We're all trying to process the experience of this information starting off with a baseline. We're

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either inundated or left to our own devices, and either one is not great for us partners, or as a person with the diagnosis.”

*“…**there's a gay and lesbian center [where I live] that's big. They don't have a lot of services for dementia. In fact, as far as I know, they don't have any.”***

“There is a support group that meets twice a month for an hour and a half each time. There's also an LGBTQ group that meets twice a month through [an organization]. Those are both zoom groups.”

Physician’s Group

Experiences

One of the most enlightening revelations in our inquiry has emerged from the firsthand experiences of physicians living with a dementia diagnosis. It's paradoxical that despite possessing the most scientific knowledge and familiarity with the medical system, we encountered similarly isolating and detached treatment from our colleagues during and after diagnosis. We discovered that regardless of one's academic and professional background, the human experience of a dementia diagnosis remains consistent among all members of our community living with such a diagnosis. Below, we candidly share our personal experiences and reflections on the diagnostic journey and its aftermath.

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"I did the research before I went too. So, they probably figured they didn't need to tell me anything, but there's a lot of things that they should have done."

"Really, I again experienced no particular information given and I'm not sure if that's because with my history (professional background) they said, you know all this, and of course I found I didn't know much of it at that point."

"I really needed some help at the beginning of diagnosis to deal with my anxiety, and the discomfort of the things that I noticed were not the way they used to be. I think part of the discomfort that I had for some time was how to live with myself with it. People would say, oh, we don't notice anything, but I sure noticed things."

"What I found out basically after I was diagnosed, and it was somewhat on my own until I got to the right neurologist is that I needed more support than just from physicians. As things progressed, I needed a speech pathologist, and audiologist."

Recommendations

As medical professionals, we have access and training that allows us to reach deeper and further into the medical system. We reflected upon what is needed and what we have found through our own resources.

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Below are critical recommendations based on our lived experiences with a dementia diagnosis.

"One, a realistic discussion of what is to come, but not a fatalistic one. Focus on the things that you can still do. Not just the things that you can't do anymore."

"…at a local level, I think an office team leader is my proposal for getting this wrap around care that's needed. For people who are living in rural areas it's unrealistic to think that they're going to spend the time and money to travel, leveraging the telemedicine experience is needed. A video session is not as nice as an in-person session. But sometimes there are physical things that keep people from going to the doctor. How can we make these services available to everybody, no matter what their abilities and where they live. I think that should be a priority of this organization. Personalized medicine is my final pitch. We can talk about universal care, but when it comes to human brains and dementia it's got to be personalized care."

"My comments apply to those diagnosed with dementia who are aware or have insight into their situation. This would not apply for those with no awareness at the time of diagnosis. It would really help to have someone, a social worker, or the type of person or persons who are trained in dementia diagnosis and follow through. These

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professionals could work with neurologists or family practice doctors. They need to be able to meet with the patient and family at the time of diagnosis, and afterward as follow up. Under no circumstances should this group be referred to as a" Palliative Care team."

"I think it's real important to have a phone follow up. A week later. More of an organized follow up from the diagnosing doctor about, did you get the information we offered? Is there anything else you need? And have a closer follow up within a month before you get into your routine. It needs to be more of an organized approach to this, because it's not that easy. And you are kind of left out there doing your own research looking things up. What would really be helpful is just to have someone to talk with, that is experiencing your same thing. There is a need for support groups."

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Conclusion

This needs analysis was guided by the lived experiences and voices of 65 diverse individuals living with dementia, shaping this groundbreaking initiative, and providing a window into their realities while challenging stereotypes and promoting active participation. It underscores significant gaps in post-diagnosis information, resources, and support, particularly for those newly diagnosed with dementia, while also showcasing our collective resilience and accumulated resources throughout our journey.

While we shared our stories and emotions to illustrate how dementia has impacted our lives, we also offer critical recommendations for enhancing the diagnostic experience and fostering quality living with dementia. Our inclusive focus groups generated recommendations spanning advocacy, financial planning, and peer support, with a special emphasis on the pressing need for tailored services and support for newly diagnosed individuals.

A primary recommendation is an urgent call to physicians and healthcare providers to recognize the crucial need for personalized support for the recently diagnosed, including improved information sharing and referrals to case management. Another vital gap lies in the

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fact that current resources predominantly serve care partners, neglecting the unique needs of the newly diagnosed.

We urge stakeholders, policymakers, healthcare providers, and communities to heed our collective voice, acknowledging the pivotal role of the immediate post-diagnosis phase and the necessity for tailored resources and comprehensive support. As pioneers of this study, we advocate for a paradigm shift, recognizing persons with dementia as active contributors in shaping their journey.

These recommendations serve as a roadmap for transformative change, highlighting the power of inclusive collaboration and calling for a revolution in dementia support. The time for action is now, emphasizing our collective effort to ensure that no one faces the challenges of dementia alone. Our journey has taught us that timely access to information, resources, and support could significantly reduce disease management expenses.

For more information visit our website at www.DementiaMinds.org or contact:

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