

# 2024

# Impact Report



NATIONAL COUNCIL OF  
**DEMEN**TIA MINDS

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## MESSAGE FROM THE PRESIDENT

On behalf of the National Council of Dementia Minds Board of Directors, it is my honor to share our 2024 Impact Report with you.

This year, we proudly celebrated our third anniversary as the nation's first 501(c)(3) nonprofit organization founded and governed by persons living with dementia.

Together, we are delivering hope, challenging stigma, and empowering people everywhere to live well with dementia—with meaning, purpose, and connection.



Our success would not be possible without the incredible support of people like you. We extend our deepest gratitude to:

- Every person living with dementia who participates in our groups, meetings, research, and special projects;
- Our dedicated volunteers who generously share their time, talent, and expertise;
- Our donors whose financial support sustains our mission;
- The organizations that host our presentations and invite us to speak at conferences;
- The professionals who engage with our educational events;
- The colleges, universities, and students who welcome us into their classrooms;
- And most importantly, our friends, families, and care partners, whose unwavering support means everything.

Thank you for being part of NCDM as we continue this important work.

A handwritten signature in black ink, appearing to read "Bonnie".

**Bonnie Erickson**

President 2021-2024

National Council of Dementia Minds

# MISSION AND VISION

The National Council of Dementia Minds is proud to be the nation's first 501(c)(3) organization founded and governed by people living with dementia. We include individuals with all types of dementia or mild cognitive impairment, including younger-onset dementias.

Our groundbreaking mission is to develop and support a national corps of Dementia Minds groups—composed of people living with dementia—who foster education and dialogue among individuals with neurocognitive disorders, families, care partners, healthcare providers, researchers, and policymakers.

NCDM stands out by challenging stigma and offering hope-filled strategies and resources to support living well with dementia. Along with peer support, we provide education led by people living with dementia and create resources that empower individuals, care partners, and others by demonstrating that life with dementia can be lived fully—with meaning, purpose, connection and joy.

We believe in the principle "Nothing about us without us," because we are *Lived Experience Experts*.



**Steven**  
living with CTE dementia

"Thanks to Dementia Minds, I've found friends who truly 'get me' as a person living with dementia. Together we are changing the world for the better, not just for each other, but for people with dementia everywhere."



**Nia**  
living with young-onset Alzheimer's and CTE

"Being a part of Dementia Minds has given me a sense of belonging. This group understands the unique challenges of living with young onset dementia, and we encourage each other to face this disease with faith and grace. I love the fact that we are like-minded people in this fight."



**Arnold**  
living with mixed dementia

"After my diagnosis of mild cognitive impairment and early onset dementia I was devastated. I had to leave my profession. I fell into a deep hole and felt alone. Through National Council of Dementia Minds, I learned there were others like me. It took me out of my feeling of isolation and helped give me back an identity."

# PROGRAM AREAS

## Dementia Minds Groups

NCDM develops and sustains peer support groups that empower individuals living with dementia to connect, share experiences, and support one another. These groups foster a sense of community and belonging, reducing isolation and building meaningful relationships. We also provide opportunities for people with dementia or mild cognitive impairment to come together in large group settings for our “Meetings of the Minds.”



## Educational Opportunities

We offer virtual and in-person educational programs tailored to individuals living with dementia, families, care partners, healthcare professionals, researchers, and other stakeholders. These sessions provide direct access to the lived experience of persons with dementia, creating transformative learning moments that challenge misconceptions and inspire meaningful action.



## Resources for Living Well with Dementia

We develop and share practical resources designed to support individuals living with dementia and their care partners. Our materials focus on strategies to enhance daily life, promote well-being, and strengthen the care partnership, addressing real-world challenges faced by individuals and families impacted by dementia.



## Lived Experience Expertise

We provide consulting and co-researcher opportunities that convey the lived experience expertise of people living with dementia. We collaborate with organizations, academic researchers, and care providers to inform policy and practices, and spark innovations in dementia care.



# 2024 ACCOMPLISHMENTS

Your support this year made all these things possible:



**10**  
ongoing  
Dementia Minds  
groups



**44**  
interactive educational  
programs delivered by  
persons with dementia



**4,000**  
participants across all  
categories in our  
educational programs



**188**  
media outlets published  
stories about NCDM,  
including the Wall Street  
Journal & CNN



**1,700**  
social media  
followers on  
Facebook & LinkedIn



**823 million**  
total media  
audience reach  
in 2024



# TRANSFORMING LIFE WITH DEMENTIA

In April 2024, we published ***Transforming Life with Dementia: A Groundbreaking Needs Analysis Report on Support and Services by Persons Living with Dementia***—a project made possible thanks to funding and support from the Michigan Health Endowment Fund.

This report was the culmination of a two-year research project in which members of NCDM—individuals living with dementia—served as co-researchers alongside medical professionals and academic partners. Together, we examined the current support landscape and identified critical gaps in the dementia care continuum, focusing on the crucial period from the time of a dementia or mild cognitive impairment diagnosis to one year afterward.

Our analysis resulted in **131 recommendations** across six key areas: stigma, social, emotional, medical, financial, and legal.

Following the report's release, we launched an awareness and dissemination campaign that included **26 virtual and in-person presentations** and resulted in **19 media stories** that shared our findings widely.

By the end of 2024, NCDM had developed **10 new resources** inspired by the report, including **5 videos** and **2 written tools**.

Our work to implement the report's recommendations continues in 2025.



NAME: _____		DATE: _____	
Section Six - Social Functioning: The ability to recognize, interpret and respond to information about others, which helps us explain and predict how people behave. This includes awareness of our feelings and whether they are appropriate for the circumstances. Beyond social situations, this category may include poor emotional control in general.			
Example of impaired social functioning may include:	Check if applicable	Duration	Example(s):
Inability to distinguish sarcasm from sincerity	<input type="checkbox"/>		
Difficulty correctly identifying facial expressions	<input type="checkbox"/>		
Decreased ability to infer the thoughts and feelings of others	<input type="checkbox"/>		
Socially withdrawn or inappropriate (poor "fit")	<input type="checkbox"/>		
Loss of motivation or caring about things that were previously important (apathy)	<input type="checkbox"/>		
Decreased ability to understand or share the feelings of others (empathy)	<input type="checkbox"/>		
More argumentative or obstinate in situations than previously	<input type="checkbox"/>		
Excessively anxious or alternatively, lacking concern when appropriate	<input type="checkbox"/>		
Holding onto a false belief despite all evidence to the contrary (delusion)	<input type="checkbox"/>		
Other:	<input type="checkbox"/>		

*Transforming Life with Dementia*  
RECOMMENDATIONS ON PEER SUPPORT

NATIONAL COUNCIL OF DEMENTIA MINDS  
Image of People Living with Dementia Doing Activities

The following recommendations come from the National Council of Dementia Minds' comprehensive 2024 needs assessment in which we—people living with dementia—identified key information and services we want to live with during our first year after being diagnosed.

**What People Living with Dementia Should Know**

- Peer support groups have been life-changing for us. They help us find answers we can't get anywhere else, provide a sense of belonging and create lasting friendships.
- Peer support enriches our lives by empowering us to help others in meaningful ways.
- The impact of peer support groups reaches beyond us. It makes life better for our families, too.
- Different kinds of peer support opportunities are needed. It's not one size fits all.

**What Healthcare Systems, Care Providers and Policymakers Should Know**

**What types of peer support do we need?**

- We need peer support groups for every stage of our dementia journey, from individuals who are newly diagnosed to individuals who have lived with dementia for many years.
- We need peer support groups that reflect who we are—our communities, our cultures, and our experiences, such as we're African-American/Black, Hispanic/Latino, LGBTQ+, or from another underrepresented group.
- Where possible, identify opportunities to create groups that share demographic connections such as life stage, gender, professional backgrounds and interests.
- One-on-one peer support is especially important for newly diagnosed individuals, with flexible scheduling for people who are still in the workplace.

**When do we need it? The sooner, the better!**

- Doctors should provide contact information for dementia-specific peer support groups when they provide a diagnosis of dementia.
- Healthcare providers should tell patients, during cognitive change, how peer support groups can help us adjust to our diagnosis, reduce isolation, and improve our quality of life. They should encourage us—and our care partners—to connect with these groups as soon as possible.

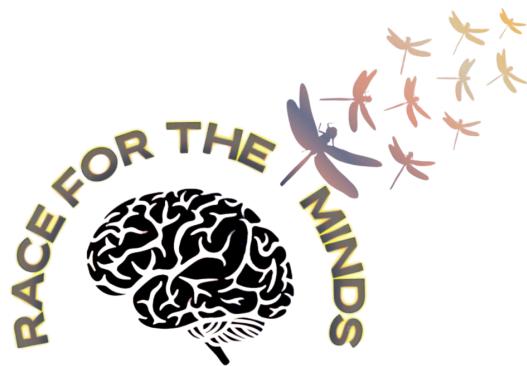
## SOURCES OF SUPPORT

The work of NCDM is made possible through the generosity of grant funders and individual donors like you, who believe in our mission.

In 2024, our **largest sources** of funding came from grants provided by the Michigan Health Endowment Fund, the Arthur N. Rupe Foundation, and the Michigan Department of Health & Human Services. We are deeply grateful for their trust in our work and their continued support.

Our third annual Race for the Minds fundraiser, held on August 11, was our most successful race yet—selling out with **250 participants** and **9 sponsors**. We are especially grateful to Lacey Abell, our dedicated volunteer Race Coordinator, for her leadership in making this event a success once again.

We are also deeply grateful to our volunteer support team members, who generously dedicated approximately **2,800 hours** of their time in 2024 as Dementia Minds group facilitators.



# LEADERSHIP

## 2024 BOARD OF DIRECTORS

Bonnie Erickson, President

Steven Barbieri, Vice President

Mark Roberts, Secretary

Monica Downer, Treasurer

Dr. Arnold Beresh, Board Member at Large



## STAFF

Brenda Roberts, Executive Director

Lisa Dedden Cooper, Director of Operations

Lauren Strich, Director of Support & Communications

*We are additionally grateful for the professional guidance of RSKM Consulting, LLC.*



### Why the Dragonfly Logo?

For centuries, the dragonfly has been a symbol of change and self-realization. It represents hope, happiness, adaptability, and new beginnings.

# CONTACT US

## National Council of Dementia Minds

P.O. Box 74  
Owosso, MI 48867

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## Website

[dementiaminds.org](http://dementiaminds.org)

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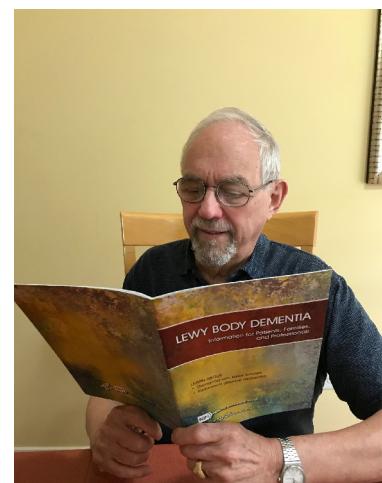


## Email

[dementiaminds@dementiaminds.org](mailto:dementiaminds@dementiaminds.org)

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## Donate



## Social Media

