RISE TOGETHER

A QUARTERLY NEWSLETTER

RISE DEMENTIA CARE

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Five Years of RISE Dementia Care

Built on Relationships

This October marks five years since RISE Dementia Care began.

RISE wasn't something I had planned. At the time, I was working in senior living in a position I loved when dementia touched my own family.
I made the decision to step away from my role and focus on my family.

But the phone kept ringing.

People who knew my work in senior living continued reaching out. Sometimes there had been a new diagnosis and they didn't know where to begin. Sometimes a family was in crisis. Sometimes someone simply needed help understanding what was happening and figuring out the next step.

RISE Dementia Care grew from those conversations.

Five years later, much of the growth has happened in much the same way. One family told another. One organization led to another. A conversation opened the door to a new opportunity. What began as a way to provide **Resources, Information, Support and Education** to people who were reaching out for help has grown organically into work with families, professionals, organizations and communities.

And along the way, I have continued to learn.

People living with dementia, their families and the professionals who support them have shaped how I think about dementia care today. They have reinforced something that has become central to the work of RISE: dementia may change how a person experiences and interacts with the world, but there is still so much we can do to support connection, purpose, dignity and well-being.

As RISE approaches this five-year milestone, it feels like the right time not only to look back, but to share some of what these five years have taught me.

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What Five Years Have Taught Me

Five years of working alongside people living with dementia, their families, care partners and professionals have reinforced for me that dementia care is about much more than understanding a diagnosis. It is about understanding people, building relationships and creating the support that allows everyone involved to live as well as possible.

See the person, not the diagnosis.

There has been meaningful progress in reducing the stigma surrounding dementia, but there is still work to do. A diagnosis does not erase the person. Their history, personality, preferences, relationships and need to feel valued and loved remain. People living with brain change deserve care that recognizes who they are and meets them where they are.

Listen to people living with dementia.

Some of my greatest teachers over these five years have been people living with dementia. When we take the time to truly listen to what they tell us about their experiences, what helps, what doesn't, what frightens or frustrates them, and what helps them feel supported and understood, there is so much we can learn. Their voices have shaped how I think about dementia care and how I support and educate others. Listening is important, but so is applying what we hear. If we want care to truly be person-centered, the voices of people living with dementia need to be part of how we learn, how we teach, and how we care.

Look for what remains possible.

Dementia brings real changes and losses, and we shouldn't minimize them. But when we focus only on what someone can no longer do, we can miss what they can still do. Abilities, interests, choices, humor, connection, purpose and moments of joy remain possible throughout the journey. Sometimes we simply need to change how an opportunity is offered or redefine what success looks like.

Understanding brain change changes our response.

When we understand more about how dementia can affect processing, communication, vision, movement, sensory experiences and emotional responses, behaviors that once seemed confusing can begin to make more sense. Instead of asking, “Why are they doing that?” we can become curious: “What might they be experiencing?” That shift can help us change our approach rather than expecting the person living with dementia to change theirs.

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Care partners need support, too.

Over the years, I have met so many care partners who are doing everything they can while feeling overwhelmed and under-supported. They are navigating changing relationships, difficult decisions, unfamiliar systems and an uncertain future. They don't always need someone to hand them a long list of things to do. Sometimes they need someone to listen, help them understand what is happening and figure out the next step.

Caring well takes skill, and caring for yourself.

Being an effective care partner isn't simply about loving someone enough. Dementia changes communication and relationships, and learning new skills can help care partners adapt as those changes occur. But skills are difficult to use when someone is completely depleted. Self-care is not separate from dementia care. Having support, taking breaks and tending to your own well-being can help preserve the patience, flexibility and connection that sustain the relationship.

Community matters.

No one should have to navigate dementia alone. Building a support team around both the person living with dementia and their care partner can make an enormous difference. That team may include family and friends, neighbors, healthcare professionals, home care providers, community programs, support groups, faith communities and others who can offer practical help, guidance, companionship or simply a listening ear. Support also doesn't have to come from one person or one place. Different people can meet different needs, and those needs will change throughout the journey. Helping care partners identify who can be part of their team, and allowing themselves to accept that support, is an important part of caring for themselves and sustaining the relationship. Beyond that individual circle of support, we need communities where people living with dementia continue to feel connected, included and valued, and where care partners can find others who understand. When we build those connections, dementia becomes a journey that people navigate with others beside them rather than one they are expected to manage alone. Perhaps that is one of the most important things these five years have taught me: when we create understanding, develop skills and build community around people, we create more opportunities for connection, purpose, dignity and well-being, even as dementia changes the journey.

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RISE Above the Dementia Journey

In a disease that can take so much away, I feel called to come alongside those navigating this journey, to offer love and support, and to encourage them to continue looking for moments of joy.

There is still much work to do to reduce the stigma surrounding dementia, better support care partners, and create communities where people living with brain change are understood, valued and included. We need continued research, better treatments and, ultimately, a cure. But while we wait and work toward that future, people are living this journey today.

I want to help shift the narrative away from one defined only by fear, desperation, loss and overwhelm. Dementia is hard. There is no minimizing that. But resources and information can reduce the unknown, support reminds people they aren't alone, and education builds skill. Together, they can help make the journey feel less frightening and less isolating.

Even within the changes and losses, there can still be connection. There can still be purpose. There can still be love. And there can still be joy.

Five years ago, I chose the name RISE Dementia Care with the hope of helping people RISE above the dementia journey. Today, those words mean even more to me. Rising above does not mean denying the difficult parts of dementia. It means refusing to let them become the whole story.

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LOOKING FOR SUPPORT? REACH OUT. LET’S NAVIGATE THIS TOGETHER.

WITH GRATITUDE

I am incredibly grateful to everyone who has been part of these first five years. Thank you for your trust, your partnership, the lessons you have shared and, most of all, for allowing RISE to be part of your journey.

There is more to learn, more connection to build and more possibility ahead.

THE KALEIDOSCOPE CORNER

The Kaleidoscope Dementia Resource Center continues to create opportunities for people living with dementia, care partners, families, professionals and community members to come together for education, connection and support.

Our Speaker Series, Connection Café and Living Well as Life's Patterns Change reflect something this work has reinforced again and again: no one should have to navigate dementia alone.

Upcoming programs and registration:
www.kaleidoscopedrc.org

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RISE DEMENTIA CARE | 2021 - 2026

Five Years of Resources, Information, Support & Education

Helping people RISE Above the Dementia Journey

UPCOMING EVENTS

National Caregivers Conference
Keeping the Connection: When Dementia Changes the Relationship
November 2, 2026 | 10:45 AM – 12:00 PM
Hyatt Regency Princeton | Princeton, NJ

Power of the Mind: Living a Brain Healthy Life
November 4, 2026 | 9:00 AM – 3:00 PM
Towson University | Towson, MD

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