

RISE TOGETHER

A QUARTERLY
NEWSLETTER



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Still Me: Staying Part of the Conversation as Things Change

Still Me, even as things change


There is a moment that often comes quietly. It does not arrive with an announcement or a clear turning point. It shows up in small ways, a hesitation before answering a question, a pause when trying to make a decision that once felt simple, a shift in confidence that may not be obvious to others but is felt deeply. And alongside that shift, something else is often present. A need to still be included. To still be heard. To still be known. Still me.

When we think about conversations around goals, wishes, and what matters most, it is easy to assume they need to be formal or carefully timed, something we plan for and get just right. But more often, they begin in everyday moments. A quiet comment like, "I don't like going there anymore." A passing remark, "That feels like too much for me." Or even a silence, when something that once felt familiar no longer does. These are not small things. They are communication. And when we slow down enough to notice them, they offer us something important, a way to understand what still matters.

Like so much of the dementia journey, these conversations are not experienced in the same way by both people. For the person living with cognitive change, there may be a growing awareness that something feels different, a desire to hold onto independence, and moments of frustration when words do not come as easily. There is often a deep need to feel respected rather than managed. For the care partner, the experience can look different. There may be a sense of responsibility to plan ahead, concern about safety, and uncertainty about when or how to begin these conversations, along with a quiet pressure to get it right. Neither perspective is wrong. But without realizing it, conversations can begin to shift from trying to understand to trying to decide, and that is where something meaningful can get lost.



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Even as abilities change, the person does not disappear. Preferences may shift, expression may look different, and timing may matter more, but the need to have a voice, to be included in decisions that affect daily life and future care, remains. Sometimes that voice is clear and direct. Other times, it shows up more subtly, in pulling away from something that once felt comfortable, in becoming quiet during a conversation, or in showing distress when routines change. These are not obstacles to work around. They are part of the conversation.

There is no perfect script for how to begin. What matters most is not saying the right thing, but creating the conditions for the conversation to feel safe enough to unfold. It may be less about sitting down for a single conversation and more about opening a door, a moment of curiosity, a willingness to wonder together. This is not about forcing decisions. It is about creating space.

Out of love and concern, care partners often begin to carry more of the decision making. At times, this becomes necessary, especially as needs change or safety becomes a greater concern. These shifts are best made in partnership, with input from the person whenever possible and with support from the broader care team, so that decisions reflect both clinical guidance and what matters most to the individual. Even then, there is a difference between supporting someone through a decision and removing them from it. Even when thinking is slower, when words take longer, or when answers do not come right away, there is still value in waiting, in offering choices, and in returning to the conversation another day. Involvement builds trust, and trust is what allows these conversations to continue.

I remember a conversation with a family navigating early changes. The daughter wanted to begin talking about future plans. She was thoughtful, prepared, and clearly acting out of love. Her mother listened quietly for a while and then said, “I know you’re trying to help... I just don’t want everything to change all at once.” There was nothing resistant in that moment. It was honest. And the conversation did not stop, it shifted. From planning everything to pacing it. From urgency to partnership. That shift made all the difference.



These conversations do not need to happen all at once. Sometimes they begin with something simple, a question that invites rather than directs, followed by a willingness to truly listen. Not to correct or redirect, but to understand. Because underneath the changes, the hesitations, and the adjustments, there is still a person who wants to be known.

As this journey unfolds, there will be decisions to make, some small, some more complex. But when those decisions are grounded in what matters most to the person, in their voice, their preferences, and their experience, we are doing more than planning. We are protecting something essential.

“WHEN WE KEEP SOMEONE PART OF THE CONVERSATION, WE ARE PROTECTING MORE THAN THEIR VOICE. WE ARE PROTECTING THE RELATIONSHIP.”

-MAUREEN BRAEN

Even as things change, even as conversations take more time, even as roles begin to shift, the person is still there. And when we take the time to ask, to listen, and to include, we remind them, and ourselves, that they are still part of the story.

Looking for support? Reach out. Let's navigate this together.



A NOTE FROM MAUREEN

As we move into a new year, connection remains at the center of everything we do at The Kaleidoscope Dementia Resource Center, a space I am honored to support through my work with Rise Dementia Care.

Our monthly Speaker Series continues on the first Wednesday of each month, offering education, insight, and shared understanding for those navigating the dementia journey. On the second Saturday of each month, the Resource Center opens its doors for a unique and supportive experience. Individuals living with dementia are engaged by a dedicated team of volunteers, creating space for care partners to step into a support group centered on reflection, connection, and shared experience.

Beginning April 18, we will also introduce a new 6-week Conversation and Connection Group **exclusively** for individuals living with MCI or early-stage dementia. This small group experience offers a space for meaningful conversation, shared understanding, and connection with others walking a similar path.

For additional details, upcoming dates, and registration information, please visit the Events page on the website.

WHAT'S NEW AT RISE DEMENTIA CARE

Recent Blog Reflections

These recent reflections have connected with many families and care partners:

The Things We Carry Together

A reflection on the shared emotional weight of the dementia journey and how connection can help carry what feels heavy.

When Caring Feels Complicated

An honest look at the mixed emotions that can arise in caregiving, and how understanding those feelings can open the door to greater compassion for both partners.

Read more at: www.risedementiacare.com/blog

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UPCOMING EVENT

Power of the Mind: Alzheimer's & Dementia Conference

Hosted by Arden Courts
Northern New Jersey

I will be presenting at this upcoming conference focused on education, awareness, and practical strategies to support those living with dementia and their care partners.

This event brings together professionals, families, and community members for a day of learning and connection.

Event details and registration can be found on the Events page of my website.