Imagine a difficult situation that many of us experience: an aging parent is beginning to forget things, to have difficulty speaking, to struggle physically, and is diagnosed with dementia. As they lose the capacity to function independently, their family begins to make decisions for them, to respond to emergencies, and to support them financially. While helping aging parents is often seen as a filial duty, dementia brings other, more tangled aspects to the relationship. For family members, the stressful role of caregiving can often lead to depression, guilt, and anxiety, diminishing the quality of life and the care that is being provided to the beloved parent.

“If you come away feeling like a horrible caregiver, and you feel like you’re falling short all the time, your lens for seeing what is going well becomes distorted,” says Laura Rice-Oeschger, lead teacher and program director of the Presence Care Project, a nonprofit that brings the Buddhist-
derived principles of mindfulness, loving-kindness, and meditation to dementia and end-of-life care. She observes that many people caring for loved ones with Alzheimer’s or dementia put off their own health and well-being: “There’s this hyper-vigilance and stress reactivity in caregiving. . . . We’re setting conditions on ourselves all the time about when it is we will experience relaxation or peace.”

The Presence Care Project was founded in San Francisco by Marguerite Manteau-Rao, a social worker and meditation practitioner, to bring mindfulness into dementia care. Buddhist-inspired practices help family members, whom they refer to as “care partners,” to remain resilient throughout the stressful routines of the day. The six-week curriculum teaches care partners to incorporate mindfulness into their daily role—from feeding someone to calming them down, to just sitting and enjoying their company. Based on Jon Kabat-Zinn’s Mindfulness Based Stress Reduction (MBSR), a secular derivative of Buddhist mindfulness, the program encourages awareness of everyday life and uses familiar Buddhist ideas of walking and sitting meditation and counting the breath. Created, run, and taught entirely by women, who combine their own meditation practices with social work and medical science, the Presence Care Project also forms an informal sangha of sorts; a group of mutually supportive caregivers who can help each other. This is applied Buddhism—using techniques and tools learned on the cushion to deal with one of life’s most stressful events: the slow loss of a loved one.

Caring for someone else is inextricably linked to self-awareness. “How is it that we tune in to hear what someone else needs? We have to be able to be aware of our own body and presence to see it in someone else,” says Rice-Oeschger, who co-founded the Ann Arbor Center for Mindfulness and is a certified MBSR teacher. “We’re adding [additional stress] to caregiving when we’re not aware, when we’re on autopilot.” The approach Manteau-Rao developed, called Mindfulness-Based Dementia Care (MBDC), makes caregiving itself the practice: taking a deep breath before walking into a care facility. Seeing chores such as cooking meals as an opportunity for connection and creativity, rather than a burden. Sitting with someone whose sense of time no longer flows linearly and simply being in the present moment with them.
Dementia patients often experience a deep sense of loss. A person with Alzheimer’s may feel like the world is constantly shifting under their feet and many do not understand why names, memories, and abilities are disappearing from their lives. As a clinical social worker, Rice-Oeschger meets weekly with diagnosed patients and talks with them about the loss of the knowledge and ability they once valued in themselves. Buddhist ideas of attachment often surface. “What they tend to explore is, what is the attachment with my sense of self, with knowledge, and with memory?” she says. With mindfulness as part of the process, “an opportunity for a new kind of identity emerges. Rather than the focus being on the loss, it’s on what is emerging.”

Often, what emerges are simple, wordless moments of relationship: simply being in the now with a loved one, sometimes without speaking. A dementia diagnosis is not the end, points out Rice-Oeschger: “There are many years of enjoyment, of slowing down . . . of friendship.” Learning to
be present with the current reality is part of maintaining a shifting relationship with family members and caregivers. Tibetan Buddhist teacher Pema Chödrön has written about being “groundless” and watching what happens when life sucks the stability out from under us. In a sense, caring for someone with dementia is an exercise in groundlessness, requiring constant reassessment of where you stand. “We don’t have the answers,” Rice-Oeschger observes. “We don’t have a cure for Alzheimer’s, we can’t stop it . . . but that doesn’t mean there’s not room for healing.”

That’s where MBDC comes through—encouraging moments of compassion, both for the person being cared for and the caregiver. “Care partners typically are carrying a lot of guilt and shame, so to suggest right from the beginning that there’s self-compassion doesn’t feel right for a lot of care partners. It feels self-indulgent,” explains Rice-Oeschger. Instead, the approach allows compassion to arise naturally through mindfulness practice—and later, once practitioners are more comfortable, confronts it directly through teachings on metta (Pali; often translated as loving-kindness).

With MBDC, a cure or a solution is not the goal, rather it is being in a relationship with the changing, shifting reality of another person, without feeling over-taxed. “Most care partners want to connect with their family member, whether that family member is also really engaged and conversing and really insightful, or whether the journey is much longer and they are no longer in verbal communication,” says Rice-Oeschger. MBDC strives to help maintain that healthy relationship for both parties, the caregiver and care receiver, by rewriting the narrative of decline. Moments of awareness and healing are interspersed throughout the times of frustration and loss, and in MBDC, stepping back to observe and acknowledge those small moments matters. The driving question, says Rice-Oeschger, is “how can we support autonomy, a sense of self, of worth and dignity, all of these human values, without denying suffering? Without denying that there is also joy?”
The leaders of the Presence Care Project do not necessarily consider themselves Buddhist teachers—they are students of Buddhism and teachers of the mindfulness practices of MBSR. Still, they often see that caregivers and people with dementia begin to embody Buddhist principles of living in the present moment, expressing compassion, and letting go of attachment. “I’ve spent the majority of the last 20 years working toward that stillness, and trying to let go more and be less attached, and here they are: perfectly open,” says Rice-Oeschger, laughing. “From a Buddhist perspective, I think that’s just amazing. The irony is that someone is experiencing what we would define as “decline” in the medical sense and in a social and cognitive sense, but they are embodying this practice which we’re looking so hard to do on the cushion every day.”

See more
The Presence Care Project
Ann Arbor Center for Mindfulness