

Couples and young-onset dementia: Study of coping offers hope for new interventions

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Researchers from Massachusetts General Hospital (MGH) have used a couples-based framework to describe the experiences of individuals diagnosed with young-onset dementia (YOD) and their partners. In a study published in *JAMA Network Open*, the team conducted in-depth interviews to understand how couples navigate challenges related to YOD. This framework has been used to successfully develop patient-caregiver treatments for other severe medical conditions, including stroke, breast cancer and neurological injury. Using this approach to understand couples' coping patterns within YOD can help increase much-needed resources for affected couples.

Young-onset dementias are defined by their symptom onset before age 65. The most prevalent form of the illness is Alzheimer's disease, followed by [frontotemporal dementia](#), a progressive form of brain damage that affects behavior and personality. YOD significantly disrupts [couples'](#) daily lives and challenges them to navigate complex medical decisions and plan for an [uncertain future](#) with no available cure or meaningful treatment to delay symptom

progression.

"Young-onset dementia strikes people while they're still working, parenting or serving as caregivers for other [family members](#)," says lead author Sarah Bannon, Ph.D., [clinical psychologist](#) and postdoctoral fellow within the Integrated Brain Health Clinical and Research Program in the MGH Department of Psychiatry. "Despite the major life disruptions that accompany YOD, there are very few age-appropriate resources available for couples to participate in together. Our work shows the potential to develop resources that actively involve both partners and teach them skills to increase positive communication and mutual problem-solving. Our long-term goal is to develop a program delivered early after diagnosis that helps couples collaboratively plan for the future and preserve their relationship strengths and quality of life."

The research team interviewed 23 couples recruited from MGH Department of Neurology clinics and social media support groups for YOD. This study is the first to identify coping patterns of couples living with a YOD diagnosis, which will help inform couples-based treatments for YOD. "We looked at both positive and negative ways that couples coped with the challenges they faced after symptom onset. We noticed that many couples mutually avoided discussing their individual thoughts and feelings with each other in the weeks and months early after diagnosis," explains Bannon, a couples and family psychologist. "That avoidance was understandable, but frequently led to an accumulation of frustration and negative communication between partners over time. Our research found that couples who were better adjusted were able to use positive coping strategies such including viewing YOD as a 'we-illness,' involving a teamwork approach. The model we conceptualized can directly inform resources for both partners and can be tailored to meet the unique needs and challenges of each couple."

Findings emphasize the importance of teaching partners skills to manage their emotions in order to have more open, frequent and explicit communication about difficult topics. "Our study suggested that when partners openly communicate about their challenging or painful emotions, they could work to understand each other's perspectives," says senior author Ana Maria Vranceanu, Ph.D., director of the MGH Integrated Brain Health Clinical and Research Program. "That mutual understanding was critical for couples maintaining their close relationship and adjusting to the 'new normal' as a team."

"Teaching skills to both partners early, while the person living with YOD can still participate, may help both partners manage their own difficult emotions produced by the many stressors and life changes that accompany YOD," Vranceanu adds. "It can also enable partners to better plan for their future time together and focus on meaningful activities and creative ways of staying connected."

Bannon is a clinical psychology fellow in the Department of Psychiatry at MGH and at Harvard Medical School (HMS). Vranceanu is founder of the Integrated Brain Health Clinical and Research Program at MGH and associate professor of Psychology at HMS. Co-author Bradford Dickerson, MD, is director of the MGH Frontotemporal Disorders Unit, chair of Progressive Aphasia Research and professor of Neurology at HMS.

Provided by Massachusetts General Hospital

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