In those first weeks and months after a diagnosis of Alzheimer’s disease, caregivers have many questions, fears, and concerns about confronting upcoming changes in their lives. I know this from personal experience because I am a caregiver for my wife, Clare, who was diagnosed with early-onset Alzheimer’s disease at age 63.

Immediately after Clare’s diagnosis, I had many unanswered questions. Is it still safe for Clare to continue driving? Is it still safe for me to leave Clare alone at home? Are there any special medications that Clare should start taking? Should I contact our attorney to see if we need to update any of our end-of-life documents: will, living will, healthcare proxy, durable power of attorney?

I knew that these types of questions and many others are routinely discussed in caregiver support groups, but it is not always easy to find a local caregiver support group. The Alzheimer’s Association provided more than 30 different caregiver groups on Long Island, but none were specifically for spouse caregivers. Eventually, I was fortunate to find a support group solely for spouse caregivers at the Long Island Alzheimer’s Foundation (LIAF) in Port Washington, New York. This group, led by a gifted social worker, met every Tuesday afternoon and would soon grow to 15 participants ranging in age from late 50s to the mid-80s.

Regardless of age or sex, we all “got it” in my spouse caregiver group. We were addressing many, if not all, of the same behaviors, and although each of our individual situations was somewhat different, it was helpful to learn how others were handling similar situations. Those like me, whose spouses were then in the earliest stages of Alzheimer’s, received much wisdom from those who had already addressed such issues. We also learned about strategies that others used with spouses at more-advanced stages, knowing that one day we might also have to deal with similar situations. All spouse caregivers are swimming in the same lake; we may be paddling in different boats at different speeds, but we are all trying to stay afloat in Lake Alzheimer’s.

I absorbed many practical bits of advice each week as we shared and discussed everything on our minds in a totally nonjudgmental environment, receiving emotional support and helpful suggestions for addressing whatever confronted us.

After 3 years, I had to stop attending my support group so I could take Clare to a day care program in a different location on that day, but I haven’t completely severed my group ties. Each week, I now join a dozen current and former support group members for lunch. All of our spouses are now in moderate or severe stages or have already passed on, but just as we once did in our formal support group, we continue to support each other. As one member of this informal group recently said to me, “This new group just seems to scratch every itch I have!”

As the numbers of people diagnosed with Alzheimer’s disease increases dramatically, more weekly caregiver support groups will be needed. Doctors must become more familiar with the support groups available to their patients and caregivers. Clare and I saw an internist, a neurologist, and two geriatric psychiatrists, yet none of them mentioned anything about joining support groups. In my LIAF support group of 15, only one had been referred there by a doctor. That is a shame.

Doctors working with someone who is caring for a spouse, parent, grandparent, friend, or other family member with Alzheimer’s disease should urge them to join a support group. Let them know that they can learn many practical suggestions from those who have “been there” and how important it is to have a place where they can talk openly about their feelings, fears, and concerns while receiving emotional support from others “who get it.”

Caregivers should not have to “go it alone” when a loved one is declining from an incurable disease, but unless doctors inform them of the existence and value of support groups, many who would find emotional and practical help there will lose out on this wonderful source of information and comfort.

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