WSA BY THE NUMBERS

Founded 1988

20+ support group meetings each month

425+ Supporting Members

- 3,100+ Facebook support group members
- 30+ National Conferences since inception

6-10 events per year

6 Mainstay Newsletters per year

<u>2020 - 2021</u>

BOARD OF DIRECTORS

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The Well Spouse Association, a nonprofit 501(c)(3) membership organization, advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse or partner. We offer peer-to-peer support and educate health care professionals and the general public about the special challenges and unique issues "well" spouses face every day. To achieve this mission the Well Spouse Association:

- coordinates a national network of peer support groups • publishes the *Mainstay* newsletter 6 times per year.
- •organizes regional respite weekends several times each year
 - organizes an annual national conference for caregivers
 - produces symposiums and webinars for caregivers
- •maintains an active online presence for members and for outreach to the public, including our website, online support groups and resources, a marketplace, and a private online forum
- facilitates a mentor program
 provides continuing support for members whose spouses have died

•advocates on behalf of spousal caregivers
•seeks out new initiatives to help caregiver spouses and their families cope with the emotional and financial stresses associated with chronic illness and/or disability.

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Spousal Caregiving in the U.S.

- Of the 47.9 million caregivers in the U.S., it is estimated that there are 5.7 million spousal or partner caregivers
- Among all caregivers, 29% have been caregivers for 5+ years
- Spousal caregiving tends to be higher-intensity than other types of caregiving (more medical and nursing tasks, less sense of control over caregiving decisions, more solo caregiving). 66% of spousal caregivers provide care without any unpaid or paid help (versus 29% for other types of caregivers).
- The strain of caring for a chronically ill or disabled spouse or partner is undeniable in 2020, the proportion of spousal caregivers reporting their health was "excellent" or "very good" was only 32%, and that reflected a decline from NAC/AARP's 2015 report from 45%. As people with chronic illness or disability live longer with more complex medical situations, caregivers often pay a steep price by providing the care their loved one desires or needs.
- The nature of the relationship changes and losses due to caregiving are different for spouses and partners than for other caregivers the caregiver/patient role often includes the loss of a singular intimate relationship and companionship. The financial losses can be different too often the patient AND the caregiver must give up paid employment (at the same time that expenses increase due to costly medical needs). It impacts the decision to have children, the way children are raised, and when and how one lives and retires. There are few areas of life that are left untouched by the caregiver/patient role in these relationships.

Source: NAC/AARP 2020 Caregiving in the U.S. Report

WSA's Members

WSA has approximately 425 members (both Supporting and Digital) who are or were caregivers or partners to an ill or disabled partner or spouse as of Spring 2021. WSA's active Facebook support group includes 3,100 members.



What People Say About Well Spouse Association

From Sharon from CA

"... I began to feel better soon after my first [WSA support group] meeting. I had been angry about my situation at home and felt I had to talk with someone. Then I read a blurb about Well Spouse Association in our weekly local paper. In the first meeting I learned it's OK to be angry, frustrated, sad, etc. It was a relief to know that others have similar programs and they deal with them. I learned to do more things for ME, and that has freed me greatly."

From "Langley27" from AZ "... when I see the effect we're having on people's lives who discover the WSA for the first time I see how important it is to keep this work going."

From Lisa from MA "I joined WSA 2 years ago and have found your newsletter every month helpful in knowing I am not alone."

From Susan from NY

"My husband died after a courageous struggle with Parkinson's Disease for 28 years. . . I must tell you how very grateful I am to the Well Spouse Association for helping me manage and get through the difficult times and for the friends I have made there."

The New York Times

"How to Be a Caregiver" – 12/9/20

"Some of the best advice for caregivers will come from other caregivers...<u>The Well Spouse</u> <u>Association</u> coordinates a national network of support groups, and offers "respite" weekends and an online chat resource."

Brain&Life

"How to Balance Being A Caregiver and a Spouse" - August/September 2016

"Connecting with caregivers in the same situation offered much-needed emotional support for [Ted] Vahan, who attended the [WSA]'s annual conference, where he was surprised to meet so many people."



The Moneyist: "My wife has a degenerative neurological disease. My father-in-law wants to put her in a facility — and take over our finances" – 1/23/21

"... I recommend seeking out counseling and/or support to help you through this difficult time. The Well Spouse Association is a nonprofit organization that has support groups in communities all over the country."