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## Family Caregiver's Third job: Navigating the Maze of Systems

In addition to the care they provide, family caregivers are constantly faced with figuring out complex administrative tasks and systems. The systems caregivers depend on often become a barrier to care when paperwork is hard, confusing, time consuming, and when many phone calls and follow up e-mails are needed. This week's video exposes the struggle caregivers face with the systems that are supposed to help them.

**Watch this four-minute video on**

### **Caregiver's Third Job: Navigating the Maze of Systems**

"Family caregivers have many roles. Negotiating with medical, insurance, and care programs is one of them," said Janet Zander, public policy coordinator for the Wisconsin Aging Advocacy Network. "For many caregivers, interacting with systems is extremely time-consuming and frustrating. It adds a layer of unnecessary stress that contributes to caregiver burnout."

"Caregivers are constantly figuring out complex administrative tasks and systems," said Beth Swedeen, Co-Chair of the Survival Coalition of Wisconsin Disability Organizations. "Too often, systems push the job of how to get the supports people need back on the caregiver. If the caregiver can't find the solution, they go without help."

"Caregivers lose hours and mental energy just to get the care family members need," said Lisa Schneider, Wisconsin Family and Caregiver Support Alliance Co-Chair. "When systems aren't oriented around addressing real caregiver problems in real time, it makes it harder on the people already working their hardest."

States that value the contributions of caregivers provide targeted caregiver supports and are seeing savings of \$20 million annually in taxpayer dollars, mostly due to delayed nursing home placement.<sup>1</sup>

Wisconsin advocates for people with disabilities, older adults and their families are highlighting how the increasing burden on the state's family caregivers is creating an unsustainable crisis that threatens not only the health of caregivers themselves, but of the family members who rely on them for care.

Three organizations, including the Survival Coalition of Wisconsin Disability Organizations, Wisconsin Aging Advocacy Network, and the Wisconsin Family Caregiver Alliance are releasing the 6th and final video focused on the daily challenges faced by Wisconsin's family caregivers as part of Family Caregiver Month.

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<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3202705/>  
[http://www.advancingstates.org/sites/default/files/Washington\\_%20State%20Plan%20on%20Aging.pdf](http://www.advancingstates.org/sites/default/files/Washington_%20State%20Plan%20on%20Aging.pdf)

## Meet Wisconsin's Family Caregivers

- **Watch:** Caregiver's Third Job: Navigating the Maze of Systems (<https://youtu.be/yF7Hy6wrKQ8>)
- **Watch:** All On Our Own: Part Time Help for Full Time Care (<https://youtu.be/KptgGUP-06U>)
- **Watch:** Hidden Costs, Real Expenses: What it Costs to Care (<https://youtu.be/Ulz3pLQMw0Y>)
- **Watch:** No time to be sick, no time to stay well: the physical and mental toll on family caregivers ([https://youtu.be/n5\\_46XwkXI4](https://youtu.be/n5_46XwkXI4))
- **Watch:** Two Jobs, No Breaks: Employed and Caregiving (<https://youtu.be/l5g2RiOBgxs>)
- **Watch:** Family Caregiver Press Event (<https://youtu.be/YrC1mRLjj3Mb>)
- **Watch:** See Us: Wisconsin's Invisible Family Caregivers ([https://youtu.be/\\_3-pILaEqaU](https://youtu.be/_3-pILaEqaU))
- Policy solutions to support family caregivers (<https://arcwi.org/2021/09/23/support-for-family-caregivers-is-critical/>)

## Quick facts: Caregiver's Third Job, Navigating the Systems

- On average caregivers spend:
  - 13 days each month on shopping, food preparation, housekeeping, laundry, transportation, and giving medication.
  - 6 days per month on feeding, dressing, grooming, walking, bathing, and assistance toileting.
- Nearly two-thirds communicate with healthcare professionals on behalf of the care recipient.
- 50% act as an advocate for the care recipient with care providers, community services, or government agencies.
- On average, caregivers spend 13 hours per month researching care services or information on diseases, coordinating physician visits, or managing financial matters.