

IOWA Department of HUMAN SERVICES

IDA IOWA DEPARTMENT ON AGING

IOWA STATE UNIVERSITY

## Caregiving to Care Partnership

Dr. Megan Gilligan, Iowa State University

There are no financial relationships to disclose.

1

---

---

---

---

---

---

---

---

## The Language of Care

- **Caregivers** provide care to people who need some degree of ongoing assistance with everyday tasks on a regular or daily basis.
- The **recipients** of care can live independently or in residential or institutional settings, and range from children to older adults, and may have episodic or chronic illnesses or disabling conditions.

<https://www.cdc.gov/aging/caregiving/index.htm>

2

---

---

---

---

---

---

---

---

## Caretaker

‘**Caretaker**’ in Iowa means a related or non-related person who has the responsibility for the protection, care, or custody of a **dependent adult** as a result of assuming the responsibility voluntarily, by contract, through employment, or by order of the court.

<https://dhs.iowa.gov/DependentAdultProtectiveServices/Families/WhoQualifies>

3

---

---

---

---


---


---


---

---

## Support Exchanges

 Emotional Support

 Tangible Support

 Financial Support

---

---

---

---

---

---

---

---

4

### Formal vs Informal Caregivers

- **"Formal"** caregivers are paid for their services and have had training and education in providing care. This may include services from home health agencies and other trained professionals.
- **"Informal"** caregivers, which includes family caregivers, are people who give care or support to family or friends usually without payment.

<https://www.hopkinsmedicine.org/health/caregiving/being-a-caregiver>

---

---

---

---

---

---

---

---

5

### Who are informal caregivers?

The majority of **informal** caregivers are:

**Family Members: Spouses and Adult Children**

- Friends, neighbors, adult grandchildren, community members, and other family members may also serve as caregivers

**Women**

Over 30% of caregivers are 65 or older

<https://www.caregiver.org/resource/caregiver-statistics-demographics/>

---

---

---

---

---

---

---

---

6

Care Partnerships

- “A caregiver gives care
- A care partner partners in care”

<https://heapsnow.com/blog/caregiver-vs-care-partner-why-you-need-to-know-the-difference/>

7

---

---

---

---

---

---

---

---

Older Adults As Active Members of Care Partnerships

**RECIPROCITY** is important for the health and well-being of all care partners.

8

---

---

---

---

---

---

---

---

Older Adults As Active Members of Care Partnerships

What are older adults preferences and expectations for care?

9

---

---

---

---

---

---

---

---

Older Adults' Care Preferences

- Within-Family Differences Study: Study of over 500 later-life families focused on understanding the relationships between older parents and their adult children.
- Asked the mothers and fathers their preferences regarding which of their adult children they would prefer help from if they needed help on a daily basis.

<https://web.ics.purdue.edu/~jsuitor/within-family-differences-study/>

10

---

---

---

---

---

---

---

---

Older Adults' Care Preferences

The majority of older parents reported preferences for which of their adult children they would like to receive care from.

The majority of adult children were unaware of their parents' care preferences.

- Only 44.6% of adult children accurately reported their mothers' preferences for particular offspring as caregivers.

<https://web.ics.purdue.edu/~jsuitor/within-family-differences-study/>

11

---

---

---

---

---

---

---

---

Consequences of Violated Care Preferences

Within-Family Differences Study: Followed the families over a 7-year period.

Older mothers who received assistance from children whom the mothers did not identify as their preferred future caregivers reported higher depressive symptoms.

<https://web.ics.purdue.edu/~jsuitor/within-family-differences-study/>

12

---

---

---

---

---

---

---

---

**Older Adults' End-of-Life Preferences**

Wisconsin Longitudinal Study: 2,750 married couples in their 60s

Asked respondents questions about their own end-of-life preferences in the context of **cognitive impairment** and **severe pain**.

Asked spouses their perceptions of their spouses' preferences.

Moorman, S. M., Hauser, R. M., & Carr, D. (2009). Do older adults know their spouses' end-of-life treatment preferences?. *Research on Aging*, 32(4), 463-491.

13

---

---

---

---

---

---

---

---

**Older Adults' End-of-Life Preferences**

- Spouses incorrectly reported their spouses' end-of-life preferences **13%** of the time in the context of **cognitive impairment**
- Spouses incorrectly reported their spouses' end-of-life preferences **26%** of the time in the context of **severe physical pain**
- Across a 2-year period, **25%** of the participants altered their end-of-life preferences.

Moorman, S. M., Hauser, R. M., & Carr, D. (2009). Do older adults know their spouses' end-of-life treatment preferences?. *Research on Aging*, 32(4), 463-491.

14

---

---

---

---

---

---

---

---

Have conversations regarding preferences and expectations **EARLY** and **OFTEN**.

<https://theconversation.com/end-of-life-conversations-can-be-hard-but-your-loved-ones-will-thank-you-173614>

15

---

---

---

---

---

---

---

---



<https://miamioh.edu/cas/academics/centers/scripps/research/ofow/>

**Contact**  
 For more information about the Our Family, Our Way materials or process, please contact Dr. Jennifer Heaton-Mullins at (513) 529-1958 or [heatonj@miamioh.edu](mailto:heatonj@miamioh.edu)

16

---

---

---

---

---

---

---

---

### Our Family Our Way – Miami University

#### Should we include the person with care needs in our family meeting?

Is the person with care needs aware of their health conditions or diagnoses?

Does the person with care needs have insight into how their condition affects or limits them?

Will attending the meeting upset the person with care needs?

If it's determined that including the person with care needs in the family meeting isn't a good idea, **they should still have a voice in the process**

[https://miamioh.edu/cas/\\_files/documents/scripps/ofow/Tip-Sheet\\_Should-we-include-the-person-with-care-needs-in-our-family-meeting\\_2021.pdf?](https://miamioh.edu/cas/_files/documents/scripps/ofow/Tip-Sheet_Should-we-include-the-person-with-care-needs-in-our-family-meeting_2021.pdf?)

17

---

---

---

---

---

---

---

---

### Supporting Care Partners

Care partners experience physical and psychological consequences

Greatest consequences for care partners of individuals living with Alzheimer's disease and related dementias.

Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and aging, 18*(2), 250.

18

---

---

---

---

---

---

---

---

### Consequences of Caregiver Stress

Caregiver burnout was associated with increased depression, decreased reports of subjective health, and increased perpetration of violent behaviors.

Caregiver stress was associated with increased rates of nursing home placement.

Géreau, P., & Zech, E. (2022). A harmful care: the association of informal caregiver burnout with depression, subjective health, and violence. *Journal of Interpersonal Violence, 37*(11-12), NP9738-NP9762.

Spillman, B. C., & Long, S. K. (2009). Does high caregiver stress predict nursing home entry? *INQUIRY: The Journal of Health Care Organization, Provision, and Financing, 46*(2), 140-161.

19

---

---

---

---

---

---

---

---

### Unique challenges to care provision during the pandemic

### Care Partnerships During the COVID-19 Pandemic

- Difficulty getting needed medical care for care recipient
- Confusion on recommended public health guidelines
- Providing less care to reduce risk/spread of COVID-19
- Decrease in support from family and friends

Leggett, A. N., Carmichael, A., Leonard, N., Jackson, J., Kirch, M., Solway, E., ... & Gonzalez, R. (2021). Care challenges due to COVID-19 and mental health among caregivers of US adults with a chronic or disabling condition. *Innovation in Aging, 5*(3), igab031.

20

---

---

---

---

---

---

---

---

### Care Partnerships During the COVID-19 Pandemic

60% of caregivers in this sample reported at least one of these challenges.

All of these challenges were associated with increased stress, depression, and interpersonal conflict.

Leggett, A. N., Carmichael, A., Leonard, N., Jackson, J., Kirch, M., Solway, E., ... & Gonzalez, R. (2021). Care challenges due to COVID-19 and mental health among caregivers of US adults with a chronic or disabling condition. *Innovation in Aging, 5*(3), igab031.

21

---

---

---

---

---

---

---

---

Care Partnerships During the COVID-19  
Pandemic

50% of the caregivers  
in this national  
sample reported  
feeling isolated.

Leggett, A. N., Carmichael, A., Leonard, N., Jackson, J., Kirch, M., Solway, E., ... & Gonzalez, R. (2022). Care challenges due to COVID-19 and mental health among caregivers of US adults with a chronic or disabling condition. *Innovation in Aging*, 5(3), igab031.

---

---

---

---

---

---

---

---