

# Making Sure Today's Caregivers/Care Partners Don't Become Tomorrow's Patients



Beth Fields, PhD, OTR/L, BCG  
Department of Kinesiology  
University of Wisconsin-Madison  
[befields2@wisc.edu](mailto:befields2@wisc.edu)

1

## Disclosure

- No relevant financial relationships with ineligible companies to disclose.
- I do not intend to discuss any unlabeled/unapproved uses of drugs/devices in the presentation.



2

# 105 Million

American adults provide unpaid care to an adult family member/friend

(RAND, 2024)

3

## Key Numbers

**11 Million  
Caring for  
PLWD**



**18 Billion  
Hours**



**Valued at  
\$350 Billion**



PLWD=person living with dementia

(Alzheimer's Association, 2023)

4

“

There are only four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.

”

—Rosalynn Carter, Former First Lady of the US

## Words Matter

### **Emergency Contact**

Conveys to healthcare providers/emergency services who should be contacted in medical or mental health crisis

### **Caregiver**

Conveys someone is giving care and PLWD is more dependent

### **Support Person or Care Partner**

Conveys people are working together to enhance care

(Stall et al., 2019)

# Term to Avoid

## Informal Caregiver

Can be insulting and invalidating, demonstrating that care is not complex

(Stall et al., 2019)

7

# A Public Health Crisis

## The Invisible Toll

Rep. Lauren Underwood (D-IL), Barbara Ebel and Tim Shriver on the need for a more robust caregiving labor force, the extent of unpaid work involved and the burden on family members shouldering a majority of the work

By Washington Post Live  
November 15, 2022 at 9:00 a.m. EST

FAMILY CAREGIVING

## Many Caregivers Neglect Their Own Health

Medical costs and lack of insurance are major factors, study finds

Home / News / Health News / The Plight of Unpaid Caregivers

COMMENTARY

## Drained: The Plight of Unpaid Caregivers

Being a caregiver isn't easy, but help can make it more manageable.

By Jamie Sharp, MD | April 12, 2023, at 11:24 a.m.

SCIENCE

## The Quiet Cost of Family Caregiving

Many employees reduce their hours or stop working to help ailing family members. But it may be years before they fully return to the work force, studies indicate.

By Paula Span

PRINT EDITION  
September 6, 2022, Page D3

Health / For Better / Caregivers Need Support Too

## Caregivers Need Support Too

Caregivers play a vital role in patient care, but they're often left behind in the health care system.

By Anthony Cirillo, FACHE | April 6, 2022, at 12:00 p.m.



8

## Caregiving Themes

- Caregivers often **fulfill multiple caregiving roles** across their lives
- The caregiving **experience wears on people over time**, leading to adverse psychosocial and physical health outcomes
- Caregivers and care recipients **each have goals** that affect the approach to care, and these **can be aligned or not**; they can also change over time
- **Transition periods** increase the strain on caregivers and affect the experience
- The health care system and related services are **highly fragmented**, difficult to navigate, and result in significant disparities

(Rosalyn Carter Institute for Caregivers, Inc. & Duke University, 2024)

9

## Factors That Affect Experiences

(Rosalyn Carter Institute for Caregivers, Inc. & Duke University, 2024)

### Community & Policy

e.g. environments for aging and disability services

### Family Factors

e.g. care recipient illness characteristics, other family roles

### Individual Caregiver Factors

e.g. demographics, race, role, complexity, resources

10

(National Academies of Sciences, Engineering, and Medicine, 2016)

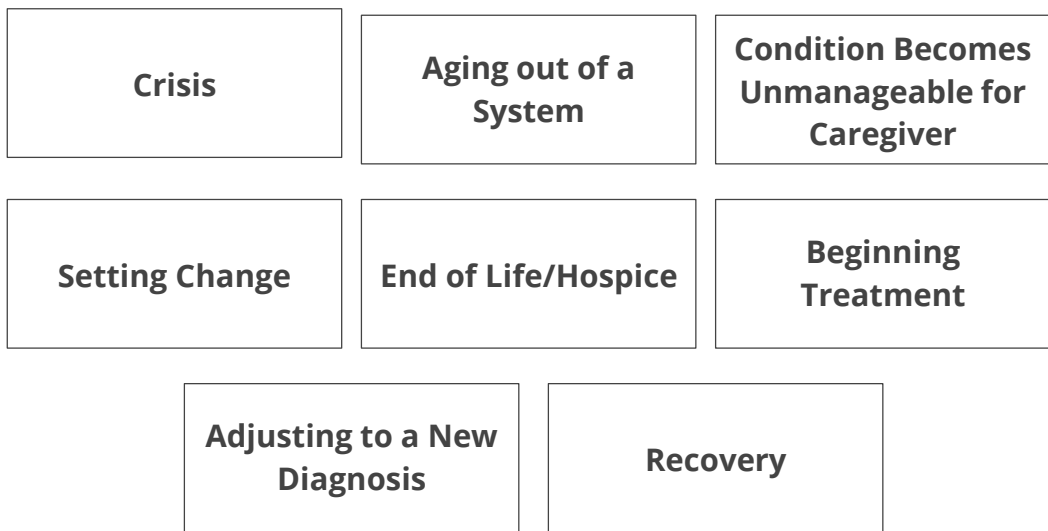
## Stressors of Caregiving



11

(National Academies of Sciences, Engineering, and Medicine, 2016; Gitlin & Wolff, 2012)

## Phases of Caregiving



12

## Goals of Caregiving

<b>Adjust to a New Normal</b>	<b>Prevent a Crisis</b>	<b>Prepare for Independence</b>
<b>Stable Illness Management</b>	<b>Maintain Independence</b>	<b>Good Death</b>

13

## Case Study: Dale and Dawn

- Dale discharged home from hospital following a knee replacement
  - Experiencing changes in memory and difficulty completing daily activities
- Dawn feels overwhelmed with increasing caregiving tasks
- Dale falls at home 29 days after discharge while walking to the bathroom
  - Readmitted to hospital

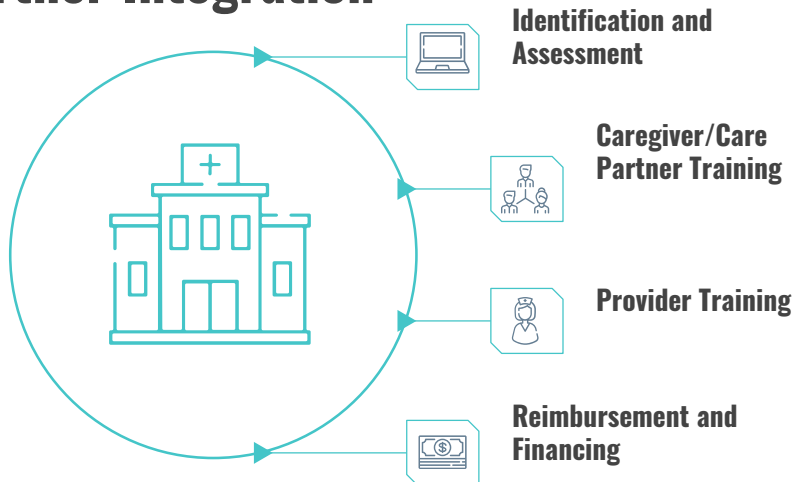
14

**Could Dawn's identification and assessment have led to tailored training and the implementation of resources to optimize Dale's home care?**

**Would Dawn's training have altered Dale's short- and long-term care trajectory?**

15

## **Targets to Improve Caregiver/Care Partner Integration**



(Riffin et al., 2022)

16



Outreach



Inclusion



Services



Finances



Data



## 2022 National Strategy to Support Family Caregivers

17

### Policy Examples



#### Goal 1: Outreach

'Caregiver-friendly policies'

- Shopping discounts
- Inclusive advertising



#### Goal 5: Data

'Standardized caregiving questions'

- Caregiving resource hub
  - Evidence-based interventions
  - [www.wisconsincaregiver.org](http://www.wisconsincaregiver.org)

18

## Target 1: Identification



- ✔ State: Caregiver Advise Record Enable (CARE) Act (law in 45 states and territories)
  - Ask the patient on admission about caregiver
  - Notify the caregiver of discharge
  - Provide caregiver training

(Leighton et al., 2020; Lee et al., 2023; Griffin et al., 2024; AARP, 2014)

19

## Target 2: Assessment



- ✔ Tools
  - Care Partner Hospital Assessment Tool (CHAT) (Fields et al., 2023)
  - Dementia Care Partner Hospital Assessment Tool (DCHAT) (Fields et al., 2024)

20

# Supporting Work

ARTICLES

## Including and Training Family Caregivers of Older Adults in Hospital Care Facilitators and Barriers

Fields, Beth PhD, OTR/L; Rodakowski, Juleen OTD, MS, OTR/L; Leighton, Cassandra PhD, MPH; Feller, Connie MSN; Minnier, Tami MSN; James, A. Everette JD, MBA

Author information

Journal of Nursing Care Quality 35(1):p 88-94, January/March 2020. | DOI: 10.1097/NCQ.0000000000000400



Brief Report

## The Development and Content Validation of the Care Partner Hospital Assessment Tool

Beth Fields<sup>1,\*</sup>, Richard Schulz<sup>2</sup>, Lauren Terhorst<sup>3</sup>, Madeline Carbery<sup>1</sup> and Juleen Rodakowski<sup>3</sup>



Article

## Evaluating the Appropriateness and Feasibility of the Care Partner Hospital Assessment Tool (CHAT)

Madeline Carbery<sup>1</sup>, Richard Schulz<sup>2</sup>, Juleen Rodakowski<sup>3</sup>, Lauren Terhorst<sup>3</sup> and Beth Fields<sup>1,\*</sup>

Available access | Review article | First published online December 10, 2018

## Assessments for Caregivers of Hospitalized Older Adults

Beth Fields, PhD, OTR/L, Rose L. Turner, MLIS, et al., and Juleen Rodakowski, OTD, MS, OTR/L (authors and affiliations)

Volume 29, Issue 6 | https://doi.org/10.1177/1054773818816207

JOURNAL ARTICLE ACCEPTED MANUSCRIPT

## Evaluation of Face Validity and Acceptability of the Care Partner Hospital Assessment Tool (CHAT)

Beth Fields, PhD, OTR/L, BCG, Maddie Carbery, MS, OTR/L, Richard Schulz, PhD, Juleen Rodakowski, OTD, MS, OTR/L, FAOTA, Lauren Terhorst, PhD, Catherine Still, BS

Innovation in Aging, igad011, https://doi.org/10.1093/geroni/igad011

Published: 06 February 2023 Article history

Published on 22.6.2023 in Vol 12 (2023)

Preprints (earlier versions) of this paper are available at https://preprints.jmir.org/preprint/46808, first published February 26, 2023.

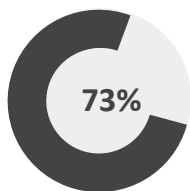


## Adapting and Testing the Care Partner Hospital Assessment Tool for Use in Dementia Care: Protocol for a 2 Sequential Phase Study

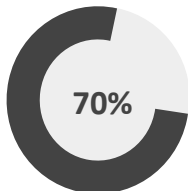
Beth Fields<sup>1</sup>, Nicole Werner<sup>2</sup>, Manish N Shah<sup>3</sup>, Scott Hetzel<sup>4</sup>, Blair P Golden<sup>5</sup>, Andreea Gilmore-Bykovskiy<sup>6</sup>, Dorothy Farrar Edwards<sup>7</sup>

21

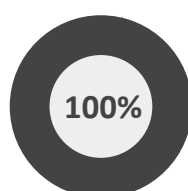
# Participant Satisfaction



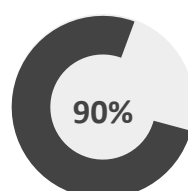
Right length



Helpful



Feasible



Overall

22



23

### Dementia Care Partner Hospital A

**Overview:** The purpose of the D-CHAT is to help you (and after your family member or friend's hospital stay).

**Who is a part of the patient's support network?**  
The questions below are about your personal information. Care partners, for each statement, please fill in or select the response that best fits your situation.

Care partner

1. What is your first and last name?

2. What is your phone number?

3. Are you the primary contact for the patient during hospitalization?  
 Yes  No

4. What is your relationship to the patient?  
 Spouse/partner  
 Son/daughter  
 Parent  
 Sibling  
 Friend  
 Other: \_\_\_\_\_

5. Did the patient live with you prior to this hospitalization?  
 Yes  No  
↳ Select where:  
 Own home/apartment  
 Assisted living  
 Nursing home  
 Long-term care/memory care

**How would you like to be involved in the patient's hospital care?**

14. What is your general availability during the patient's hospital stay?  
 Morning  Afternoon  Evening

15. How do you like to learn new information? Select all that apply:  
 Visually (pictures, diagrams, charts)  
 Auditory (listen)  
 Reading (written notes)  
 Hands-on (practice doing something)  
 Other: \_\_\_\_\_

16. Do you currently have access to the patient's electronic health record? (e.g., MyChart)  
 Yes  No/unsure

If you answer no/unsure to the previous statement, education from a medical receptionist is suggested.

### D-CHAT Survey Response

**This section is intended exclusively for the healthcare team:** Once the care partner have finished the survey, a clinician will analyze the responses to questions 16-27 and use the consultation key to make appropriate referrals for necessary caregiving education.


If "yes/unsure" to	Discipline	Education
If "no/unsure" Question 16	Medical receptionist	<input type="checkbox"/>
Question 17	Physician	<input type="checkbox"/>
Question 18	Pharmacy	<input type="checkbox"/>
Question 19	Catheter/pumps/wound care/giving injections - nursing oxygen - respiratory g-tube - nutrition	<input type="checkbox"/>
Question 20	Dressing/bathing/toileting - occupational therapy - feeding - speech	<input type="checkbox"/>
Question 21	Occupational therapy	<input type="checkbox"/>
Question 22	Physical therapy	<input type="checkbox"/>
Question 23	Physical therapy	<input type="checkbox"/>
If "no/unsure" Question 24	Social work	<input type="checkbox"/>
Question 25	Social work	<input type="checkbox"/>
Question 26	Social work & coordinated care	<input type="checkbox"/>
Question 27	Social work & nursing	<input type="checkbox"/>

24



25

---



---

***Selected Caregiver Assessment Measures:  
A Resource Inventory for Practitioners  
2nd Edition***

[https://www.caregiver.org/uploads/legacy/pdfs/SelCGAssmtMeas\\_ResInv\\_FINAL\\_12.10.12.pdf](https://www.caregiver.org/uploads/legacy/pdfs/SelCGAssmtMeas_ResInv_FINAL_12.10.12.pdf)

(Feinberg, 2014; National Alliance for Caregiving, 2021; Straus et al., 2011)

26

## Target 3: Caregiver/Care Partner Training



- ✔ Mayo and VA Caregiver Support Programs (Griffin et al., 2024; Van Houtven et al., 2019)
- ✔ Interprofessional
- ✔ Occur throughout the patient's hospital stay (if possible)
- ✔ Multi-modal learning
  - ▾ Written, teach back, audio
- ✔ Tailored to include diverse content areas that address unmet needs
- ✔ **Document!**

(Carbery et al., 2021)

27

## Evidence-based Trainings/Programs

- ✔ Skills<sub>2</sub>Care<sup>®</sup> (Gitlin et al., 2005)
- ✔ Best Practice Caregiving Database

**Dementia Care Programs  
for Family Caregivers**

**Best Programs for Caregiving** is a free online national database of proven effective dementia care programs for family caregivers and the organizations that provide them.

In Best Programs for Caregiving you will find:

- Descriptions of dementia care programs that are available in your area
- Languages programs are given in
- How to know if you're eligible
- Whether a program is offered online, in person, or hybrid
- How to enroll
- Information on the program providers

[I Care for Someone with Dementia](#)

**Dementia Care Program Info  
for Program Providers**

**Best Programs for Caregiving** is a free online national database of proven dementia programs for family caregivers. It offers a searchable, interactive, national database of vetted, effective programs that offer much-needed information and support. The database is an invaluable tool for healthcare and community-based organizations, as well as funders and policy makers to discover and share high quality programs for caregivers.

[I'm a Program Provider](#)

28

# Target 4: Provider Training



## Level 1 - Foundational

Take the Foundational course to learn about Caregiver-Centered Care.

[LEARN MORE](#)



## Level 2 - Advanced

Designed for healthcare providers who have a role and responsibility for partnering with and supporting family caregivers.

[LEARN MORE](#)



## Level 3 - Champions

Designed for Champions who will lead Caregiver-Centered Care initiatives in their organizations.

[LEARN MORE](#)



## COVID-19 Education

This course outlines how to best partner with and support family caregivers during times of changing care restrictions.

[LEARN MORE](#)

29

# Target 5: Reimbursement and Financing

Code	Definition	Service	Participants	Time
96202	Multiple-family group behavior management/ modification training for parent(s)/guardian(s)/ caregiver(s) of patients with a mental or physical health diagnosis, administered by physician or other qualified health care professional (without the patient present), face-to-face with multiple sets of parent(s)/guardian(s)/ caregiver(s); initial 60 minutes	Behavior management/ modification training	Multiple sets of caregivers (regarding different patients)	Entire 60 minutes
96203	each additional 15 minutes	Behavior management/ modification training	Multiple sets of caregivers (regarding different patients)	Entire 15 minutes
97550	(Caregiver training in strategies and techniques to facilitate the patient's functional performance in the home or community (e.g., activities of daily living [ADLs], instrumental ADLs [IADLs], transfers, mobility, communication, swallowing, feeding, problem solving, safety practices) (without the patient present), face-to-face; initial 30 minutes)	Functional performance of ADLs	One or more caregiver (s) for a single patient	Entire 30 minutes
97551	each additional 15 minutes	Functional performance of ADLs	One or more caregiver (s) for a single patient	Entire 15 minutes
97552	(Group caregiver training in strategies and techniques to facilitate the patient's functional performance in the home or community (eg, activities of daily living [ADLs], instrumental ADLs [IADLs], transfers, mobility, communication, swallowing, feeding, problem solving, safety practices) (without the patient present), face-to-face with multiple sets of caregivers).	Functional performance of ADLs	Multiple sets of caregivers (regarding different patients)	Not timed

(1)

30

# Moving Towards Caregiver-Centered Care

(Parmar, 2019; Fields et al. 2024)

31

## Positive Implications for Caregiver-Centered Care



Recognize  
Caregivers



Provide Tools to  
Support System  
and Clinical  
Decision Making



Champion  
Caregiving  
Policy



Improve Health and  
Service Utilization  
Outcomes

32



## Dale, Dawn, and Chichi



33

1. Point your camera at the code.
2. When your camera scans the QR code, you'll see an icon or web address on your screen near the code.
3. You'll go to the associated website via your phone's web browser, which should launch automatically.



34

# Thanks!



(608) 263-7975



[ghsrl@education.wisc.edu](mailto:ghsrl@education.wisc.edu)



Follow us @ Geriatric Health Services  
Research Lab



Follow us @Fields\_Lab

Check out our [website](#)  
for more information!



**GERIATRIC HEALTH SERVICES**  
**RESEARCH LAB**

Slide template from Slidesgo.com