



NAPA 2024

Kate Possin, PhD
John Douglas French Foundation Endowed
Professor
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Global Brain Health Institute



Nothing to disclose

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Talk Outline

- What is the Care Ecosystem
- Results from our randomized clinical trial
- How we are supporting implementing sites

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The Team that Designed the Care Ecosystem in 2013



Jennifer Merrilees
Nurse, caregivers



Bruce Miller
Neurologist



Kirby Lee
Pharmacy



Caroline Prioleau
Content Developer



Sarah Hooper
Elder Law



Winston Chiong
Neuroethicist



Joe Hesse
Strategist



Michael Schaffer
Technology



Steve Bonasera
Geriatrician, rural



Rosalie Gearhart
Nurse Visionary



Sarah Dulaney
Nurse Leader



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Care Ecosystem Model

The Care Team Navigator (CTN) is the primary point of contact



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Care Modules



Medications
Review and monitor patient medicines to make sure they are safe and effective



Caregiver Support
Offer suggestions and advice about caring for the patient and provide customized caregiver education, support, and community resources



Behavior
Coach and advise caregivers on strategies to manage behaviors while promoting safety and quality of life



Decision-Making
Provide support and resource links for medical, legal, and financial care planning



CTN



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Alissa
Sideman, PhD

Caregiver Needs by Dementia Stage

Based on qualitative analysis triangulating data from clinical notes and interviews with clinical team members and caregivers.

Mild: processing and accepting the diagnosis, navigating changes in the relationship with the PLWD, advance care planning, learning about resources available

Moderate: managing challenging behaviors, addressing safety concerns, managing new symptoms (incontinence, disinhibition, hygiene, sleep disruptions), identifying community resources, decision-making about care transitions

Advanced: assessing and treating pain, need for caregiver respite and in-home support, managing grief and questions about prognosis, connecting with hospice



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UCSF's Care Ecosystem Model + 3 additional requirements = Medicare's GUIDE payment model

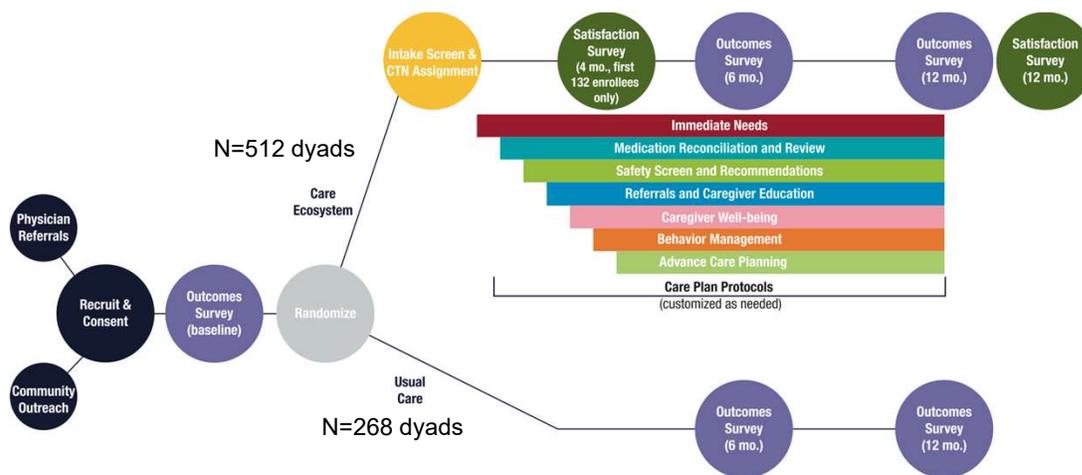


GUIDE additional requirements
 (not included in Care Eco research)
 + 24/7 access
 + home visit for patients in moderate to advanced stages
 + CMS will pay for caregiver respite services, \$2,500 per year.



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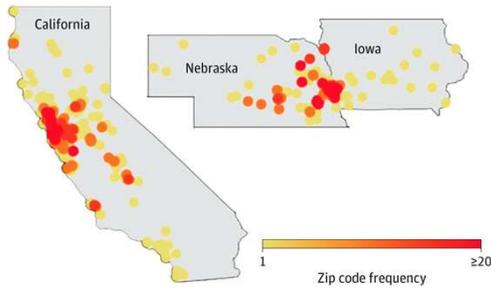
The Care Ecosystem Randomized Clinical Trial



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Randomized Clinical Trial: N=780 PLWD-caregiver dyads



- ✓ Improved caregiver well-being
- ✓ Improved patient quality of life
- ✓ Reduced emergency room visits
- ✓ Reduced polypharmacy and potentially inappropriate medication use
- ✓ Reduced total cost of care based on Medicare claims

Possin et al., JAMA IM, 2019; Liu et al., 2022, Alz & Dementia; Guterman et al., 2023, JAMA IM

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Effects of the Care Ecosystem on Medication Use



Kirby Lee



Amy Liu

Table 2. Treatment effects for primary and secondary medication outcome measures^a

	Mean (SD)				Difference between means (95% CI) ^b	P
	Care Ecosystem N = 304		Usual Care N = 186			
	Baseline	Follow-up	Baseline	Follow-up		
Primary Medication Outcome						
Number of PIMs ^c	1.49 (1.59)	1.43 (1.51)	1.42 (1.48)	1.72 (1.69)	-0.35 (-0.49 to -0.20)	<.0001
Secondary Medication Outcomes						
Number of medications	10.43 (5.23)	10.68 (5.38)	10.28 (5.01)	11.03 (5.42)	-0.53 (-0.92 to -0.14)	.008
PIMs for dementia or cognitive impairment ^c	0.44 (0.76)	0.45 (0.78)	0.39 (0.74)	0.56 (1.04)	-0.14 (-0.23 to -0.05)	.002
CNS-active PIMs ^c	1.40 (1.42)	1.41 (1.36)	1.33 (1.28)	1.63 (1.61)	-0.28 (-0.42 to -0.14)	<.0001
ACB Scale score ^d	1.62 (1.98)	1.64 (1.99)	1.40 (1.56)	1.69 (1.97)	-0.20 (-0.39 to -0.01)	.035
Antipsychotics	0.15 (0.37)	0.17 (0.40)	0.15 (0.40)	0.21 (0.47)	-0.03 (-0.08 to 0.00)	.126
Benzodiazepines	0.13 (0.33)	0.12 (0.34)	0.11 (0.34)	0.16 (0.43)	-0.05 (-0.09 to -0.01)	.008
Opioids	0.20 (0.50)	0.18 (0.49)	0.16 (0.44)	0.23 (0.52)	-0.09 (-0.14 to -0.03)	.002

Number Needed to Treat to reduce 1 potentially inappropriate medication = 3

Liu et al., Alzheimer's & Dementia, 2022



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The Care Ecosystem's Cost Savings Appear to be Greatest Among Dyads with Higher Needs

Subgroup	N	Treatment effect (95% CI)	P
Overall	428	-3026.71 (-5899.07, -154.34)	0.04
Patient Dementia Severity			
None to mild	257	-1708.02 (-5484.33, 2068.30)	0.30
Moderate to Severe	171	-4773.7 (-9218.08, -329.33)	
Patient Baseline ED Visits			
0	244	-527.86 (-4246.86, 3191.14)	0.07
1 or more	184	-5944.31 (-10335.99, -1552.63)	
Caregiver Burden			
Not High	193	-2763.95 (-7045.95, 1518.05)	0.87
High	235	-3246.11 (-7130.52, 638.30)	
Caregiver Depression			
None	258	-658.32 (-4386.23, 3069.58)	0.05
Mild to Severe	170	-6555.72 (-11059.46, -2051.98)	



Elan Guterman, MD

Monthly cost reduction of ≈ \$500 overall sample
 \$800 for moderate to severe dementia
 \$1000 for PLWD with baseline ED visit use
 \$1000 for caregivers who were depressed at baseline

JAMA Internal Medicine, 2023



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Care Ecosystem is Financially Favorable in Value-Based Care

NEJM Catalyst | Innovations in Care Delivery

IN DEPTH

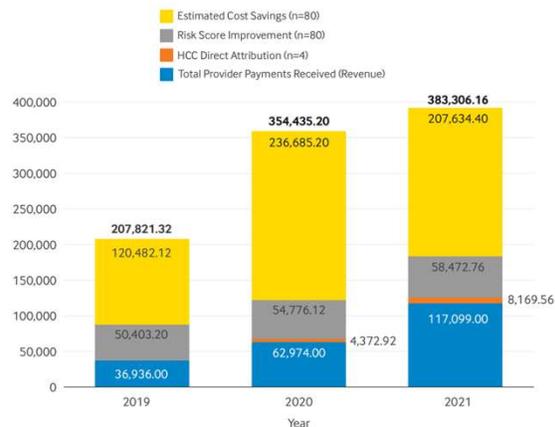
Making the Business Case for Value-Based Dementia Care

Robert John Sawyer, PhD, ABPP-CN, Ashley LaRoche, CCRC, Sakshi Sharma, MS, Carolina Pereira-Osorio, MS
 Vol. 4 No. 3 | March 2023
 DOI: 10.1056/CAT.22.0304



Alzheimer disease and related dementias (ADRDs) are growing exponentially, making critical to expand dementia/memory assessment and care. Insufficient funding, poor access to care, and low ROIs are some of the barriers that limit the ability of health care organizations to build comprehensive dementia care programs. This article aims to make a business case for developing and maintaining programs for patients with dementia at

Value Diversification and Improvement (\$)



Source: Care Ecosystem Team at Ochsner Health, based in New Orleans, LA



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Costs of the Care Ecosystem Program

- Costs vary by caseload and are highest during start-up when caseloads are low.
- At a caseload of 79 patients, costs were \$86 in Omaha and \$105 in San Francisco per-patient-month.
- In contrast, the savings to Medicare was about \$500 per-patient-month.
- These costs do not include the home visits, respite support, and 24/7 access that are required for GUIDE.



Talita Rosa, MS, MD

Rosa et al., Journal of the American Geriatrics Society, 2019



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Find the Care Ecosystem Toolkit, care protocols, and CTN training program at:
memory.ucsf.edu/care-ecosystem

The screenshot shows the UCSF Memory and Aging Center website. The header includes the UCSF logo and navigation links: Clinic, Dementia & the Brain, Caregiving & Support, Research & Clinical Trials, and Our Center. The main content area features a dark blue box with the text "Care Ecosystem" and "The Care Ecosystem model was designed to help address the unmet needs of persons with dementia and their caregivers." Below this is a photo of four people in a meeting. To the right, there is a section titled "What is the Care Ecosystem?" with a detailed description of the model and its funding. On the left, there are three buttons: "Research & Clinical Trials", "Research FAQ", and "Clinical Trials".



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Free Online Navigator Training Program



Sarah Dulaney
Nurse Leader

Quiz Communication Strategies

Due: No due date Points: 4 Questions: 4 Time Limit: None

Attempt History

LATEST	Attempt	Time
	Attempt 1	2 minutes

Score for this quiz: 4 out of 4
Submitted Aug 19 at 11:11am
This attempt took 2 minutes.

Question 1

A spouse caregiver is concerned that her husband, who has dementia, watches soccer on TV brain' and she tries to keep him busy with household chores and errands. He says that he is more productive. What concepts may help this couple find a compromise? (Select the best)

- Correct!**
- Trying to understand where the other person is coming from and focusing on what matters.
 - Distraction and redirection
 - Simple directions and alternative options
 - Verbal, visual, and tactile communication strategies

Care Eco Training > Pages > Communication Strategies

- Home
- Modules
- Quizzes
- People
- Grades

Communication Strategies



Please view this video and click "next" to complete a brief quiz on this content.

Additional Resources:

- <https://memory.ucsf.edu/caregiving-support/tips#Communication>

Source: <https://canvas.instructure.com/courses/1665716>



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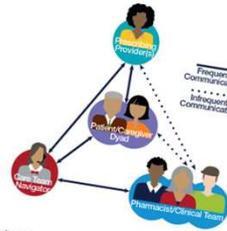
Care Protocols



Purpose:
To promote the physical health, emotional well-being, and self-efficacy of the caregiver by building rapport, listening to and reflecting on their experience, supporting their work, recognizing their strengths, and appreciating and encouraging their efforts.



Medication Review and Monitoring Protocol



Purpose:
To provide proactive medication management support that optimizes medication use and reduces potentially inappropriate medications for the patient with the aid of the caregiver.

When to Use to this Protocol:

- During comprehensive care planning that is completed at the following time points:
 - Baseline (months 0-3)
 - After major transitions (e.g., hospital discharge or long-term care placement)
 - Annually (annually if care is continued beyond 12-14 months)

Source: <https://ucsf.box.com/v/CareProtocols2022>



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Curated Education Library



Responding to Threatening Behavior

Sometimes things can get out of control and feel very scary. These are tips and strategies for dealing with especially challenging behaviors. If you think that you or others may be in immediate danger, call 911.

IF	THEN
The person with dementia is threatening you or acting physically violent, such as hitting, pushing, or kicking you	<ul style="list-style-type: none"> Give the person space and time to calm down Stay out of arm's reach and position yourself near the exit Avoid small spaces like kitchens, bathrooms, and cars Remove or secure objects that could be used as weapons Reduce background noise (loud conversations, TV, radio) Keep a phone with you in case you need to call for help Go outside, to a neighbor's house, or public place if needed to stay safe Take a deep breath and try to stay calm Listen Empathize/apologize: "I am sorry this is so frustrating" Offer reassurance: "I know this is difficult. It is going to be okay" or "I am here to help" Give yourself a break; take time to care for your own needs Get help (medical, emotional, social support, respite) Call the Alzheimer's 24/7 Helpline 1-800-272-3900 Call 911 if you think you or others are in imminent danger <ul style="list-style-type: none"> Tell the dispatcher your name and location and that your family member has dementia. Tell the dispatcher if a weapon is involved



Incontinence

Incontinence is defined as a partial or total loss of control over bladder or bowel function that results in wetting or soiling oneself. Many things can cause incontinence, including medications, food or drink, infections, or other medical problems. It is a good idea to tell a doctor about any new incontinence to see if treatment is available. Dementia can also cause incontinence. The table below shows how symptoms of dementia can lead to incontinence and strategies to help caregivers manage each symptom. At the end of this handout, you will find pictures of a variety of products that can help with continence care needs.

Symptom	Result	Strategy
Apathy	<ul style="list-style-type: none"> Loss of interest in going to the bathroom Inability to notice or care if clothes get wet or soiled 	<ul style="list-style-type: none"> Set a routine toileting schedule Provide respectful reminders and cues as needed Use pads or pull-up briefs for occasional accidents
Forgetfulness	<ul style="list-style-type: none"> Forgetting to go to the bathroom Forgetting how to go to the bathroom 	<ul style="list-style-type: none"> Set a routine toileting schedule Provide respectful reminders and cues as needed Use pads or pull-up briefs for occasional accidents
Visual problems	<ul style="list-style-type: none"> Difficulty finding the bathroom Going to the bathroom in the wrong place (e.g., bathtub, houseplant, sink) 	<ul style="list-style-type: none"> Make sure the pathway to bathroom is clear of clutter Keep a light on in the bathroom or use motion sensor nightlights Place a picture or sign on the door to the bathroom Use a colored toilet seat
Inattention	<ul style="list-style-type: none"> Getting distracted on their way to the bathroom 	<ul style="list-style-type: none"> Ask the person to do one thing at a time
Mobility problems	<ul style="list-style-type: none"> Difficulty getting to the bathroom in time Difficulty getting on and off the toilet Trouble with zippers and belts 	<ul style="list-style-type: none"> Set a routine toileting schedule Give the person enough time to get to the toilet Ask a doctor for a referral to an occupational therapist Try using a commode, grab bars, raised toilet seat, or anal Use pants that are easy to remove (e.g., those with an elastic waist or Velcro fly)

Source: <https://ucsf.app.box.com/folder/7649063766?v=CurriculumFINAL>



Translations in Spanish and Chinese are Available



失禁

失禁被定義為部分或完全失去控制自己膀胱或腸道的功能導致尿液或糞便自己。有很多原因會導致大小便失禁，包括藥物、感染或疾病、感傷和其他疾病。你醫生有關於你失禁的情況是一個好主意。當沒有治療方法。失禁也能引起尿失禁。以下顯示了失智症如何導致失禁。它包括可以幫助照顧者管理各種症狀的策略。

症狀	結果	對策
冷漠	<ul style="list-style-type: none"> 失去興趣去洗手間 無法知道或關心如果衣服被弄濕或弄髒 	<ul style="list-style-type: none"> 設置例行如廁時間表 有需要時提供提醒和提示 當失禁情況發生時使用護墊或外褲內褲
健忘	<ul style="list-style-type: none"> 忘了去洗手間 忘記如何去洗手間 	<ul style="list-style-type: none"> 設置例行如廁時間表 有需要時提供提醒和提示 當失禁情況發生時使用護墊或外褲內褲
視覺問題	<ul style="list-style-type: none"> 很難找到廁所 在錯誤的地方去洗手間 (例如，垃圾桶，室內植物) 	<ul style="list-style-type: none"> 確保通往浴室的路沒有障礙 保持一盞燈在浴室或使用動作感應夜燈 在高窗戶上裝上膠紙或圖片 使用有色馬桶
注意力不集中	<ul style="list-style-type: none"> 在上廁所時分心 	<ul style="list-style-type: none"> 請患者不要在同一時間做多件事
移動性的問題	<ul style="list-style-type: none"> 有關難纏得及去洗手間 上下廁所困難 	<ul style="list-style-type: none"> 設置例行如廁時間表 給患者足夠的時間去廁所 請醫生給你推薦一個職業治療師 (occupational therapist) 嘗試使用坐便器，扶手，抬高的馬桶座或尿圈 使用容易脫穿的褲子 (如彈性褲頭或魔術貼)

¿Quién me puede ayudar?



Un miembro de familia, vecino o amigo cercano
24/7 de la Asociación de Alzheimer
1-800-272-3900

Llame a la guía de cuidado o a la línea de ayuda cuando:

- Se siente estresado y necesita hablar con alguien.
- Se siente triste, desesperado/a o pierde el interés por hacer actividades diarias.
- Necesita ayuda manejando comportamientos difíciles (si persona con demencia se queda en casa, hace preguntas repetidamente, no duerme, se encuentra molesto/a o agitado/a, o rechaza la ayuda de otros).
- Se siente preocupado/a sobre cómo cuidar de su ser querido, mantenerlo seguro, encontrar actividades que él/ella disfruta, manejar retos con la alimentación o la higiene.
- Necesita encontrar recursos en la comunidad (grupos de apoyo, programas de día, servicios de cuidado en casa, transporte, instituciones de cuidado, apoyo legal para el adulto mayor).

La guía de cuidado se llama:

Su número de teléfono es:

911

Llame al 911 en caso de una emergencia médica o de seguridad (a excepción de casos en los que haya accidentes o días designados con su médico, como por ejemplo llamar al hospicio). Algunos ejemplos de emergencias son:

- Dolor en el pecho o dificultad para respirar.
- Accidentes que resultan en alguien herido (en la cabeza, captura de un hueso, quemadura, o sangrado).
- Sensación imprevista de debilidad, entumecimiento, cambios en la visión, o dificultad para hablar.
- Dolor agudo e intolerable.
- Tímor por su seguridad e integridad física o la de otra persona.
- Ideas de hacerse daño a sí mismo/a o a otros.

Un miembro de familia, vecino o amigo cercano

- Llame a un miembro de familia, vecino o amigo cercano:
- Necesite a alguien con quien hablar, arreglando cosas del hogar.
 - Necesite ayuda supervisando a su ser querido.
 - Necesite ayuda calmando o distrayendo a su ser querido.

Puede llamar a:

Su número de teléfono es:

Médico General (PCP) o la línea de enfermería 24/7

Llame a estas personas para consultas médicas que NO son urgentes o emergencias. Por ejemplo:

- Cambios súbitos (caídas, pérdida de movilidad, agitación, somnolencia).
- Cadidas o cambios en el equilibrio o la marcha.
- Infección urinaria o cambios en el sueño.
- Dolor de cabeza, espasmo, o de las articulaciones.
- Nuevos síntomas de tos, resaca, o alergias en la piel.
- Nuevos episodios de incontinencia urinaria o fecal, cambios en la frecuencia urinaria o fecal.
- Dolor de cabeza, espasmo, o de las articulaciones.
- Preguntas sobre medicamentos.

El Médico General (PCP) se llama:

Su número de teléfono es:

Control de Envenenamiento
1-800-222-1222

Llame si su ser querido ingiere veneno o alguna sustancia tóxica, toma el medicamento de la Asociación o accede de impropiedades.





The Care Ecosystem Consortium: Locations of Active Programs*



*Some locations represent more than one program

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How can you get support from the Care Ecosystem as you implement collaborative dementia care?



1. Review the Toolkit, Care Protocols, Online Navigator Training
memory.ucsf.edu/care-ecosystem



2. Contact Michelle Barclay, Program Manager, to set up a
consultation with one of our program leaders
Michelle.Barclay@ucsf.edu



3. Join our Care Ecosystem Consortium for ongoing collaborative
learning.

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Thank you to the families who have participated in Care Ecosystem research

Thank you to our funders:

Centers for Medicare and Medicaid Innovation
National Institute on Aging
Administration for Community Living
Global Brain Health Institute
Alzheimer's Association
Merck Foundation
John Douglas French Foundation

Thank you to the amazing health care innovators who are implementing effective dementia care navigation models into diverse health systems and community-based organizations! Together, we can improve dementia care.

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