



# Care Ecosystem

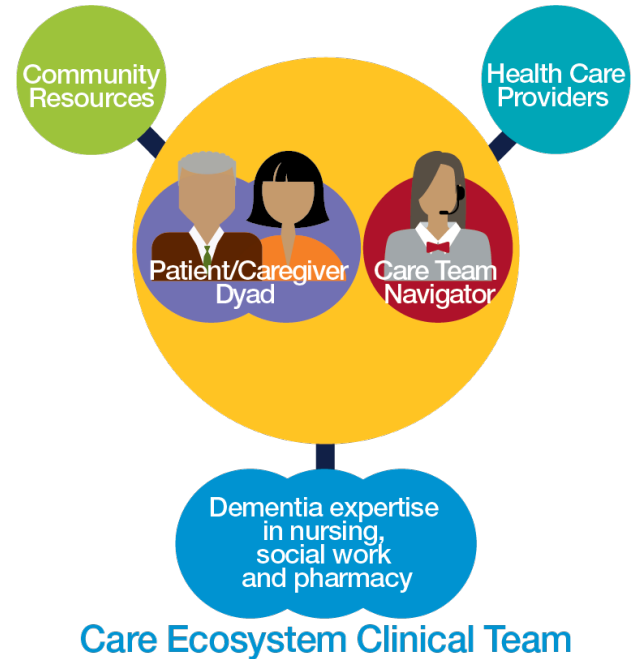
Navigating Patients and Families Through Stages of Care

## Care Ecosystem Tools for Improving Dementia Care

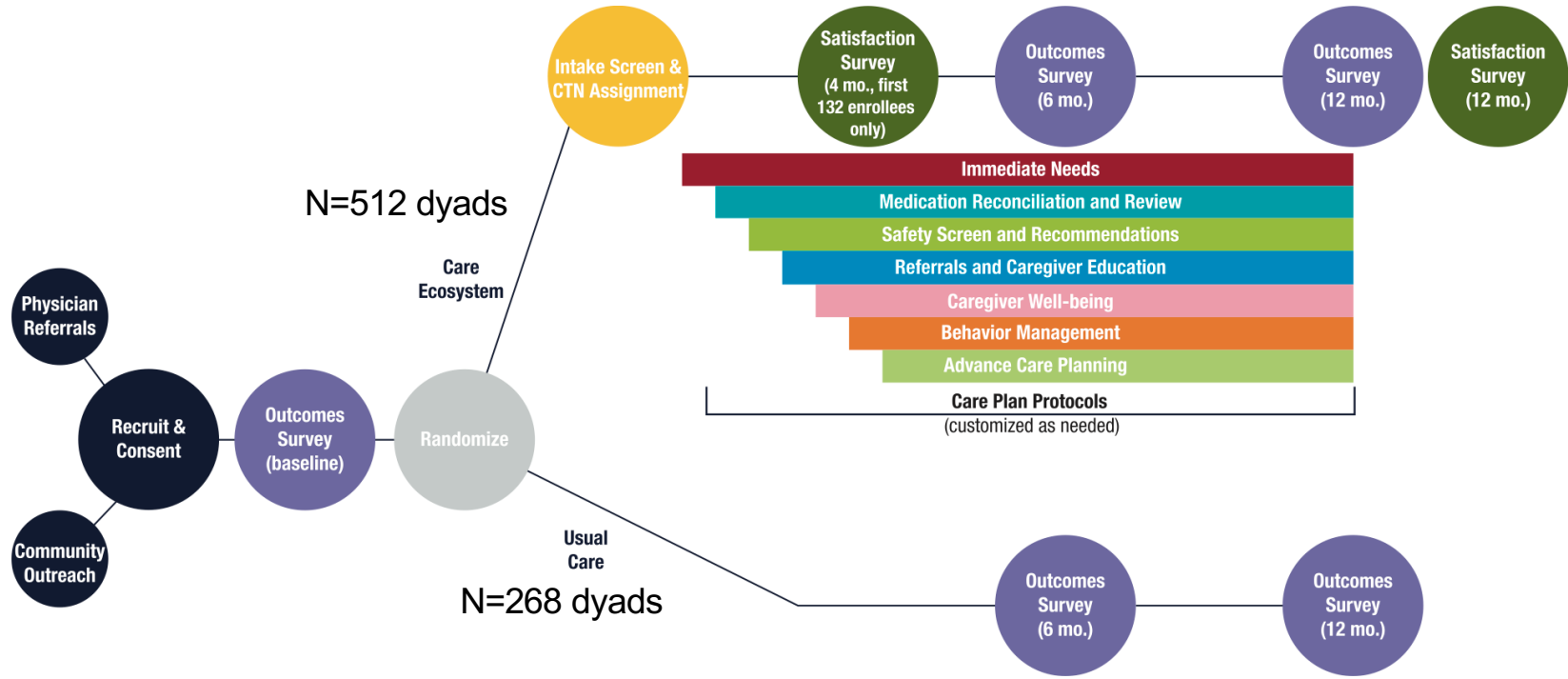
Sarah Dulaney, CNS – Director of Care Ecosystem Clinical Services  
University of California San Francisco

# UCSF's Care Ecosystem Model

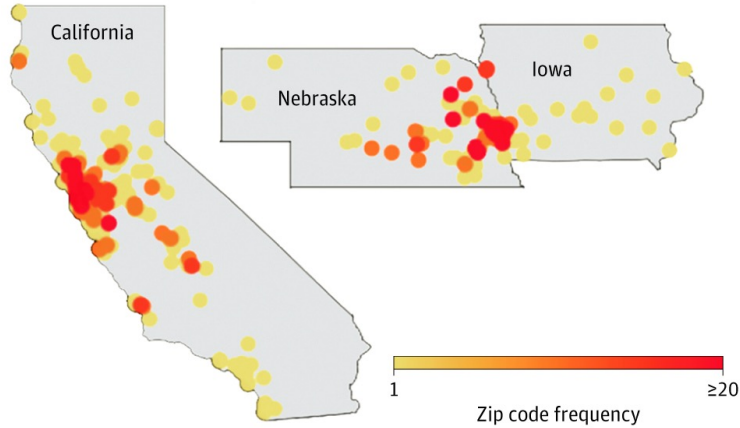
- Telephone-based
- Unlicensed navigator is primary point of contact with caregivers
- All care protocols, educational materials and navigator training program are open-source and accessible on our website



# The Care Ecosystem Randomized Clinical Trial



# 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

# Care Ecosystem is Financially Favorable in Value-Based Care

IN DEPTH

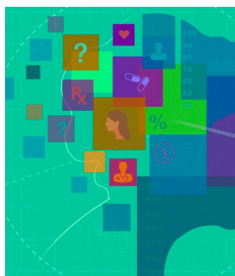
## Making the Business Case for Value-Based Dementia Care

Robert John Sawyer, PhD, ABPP-CN, Ashley LaRoche, CCRC, Sakshi Sharma, MS, Carolina Pereira-Osorio, MS

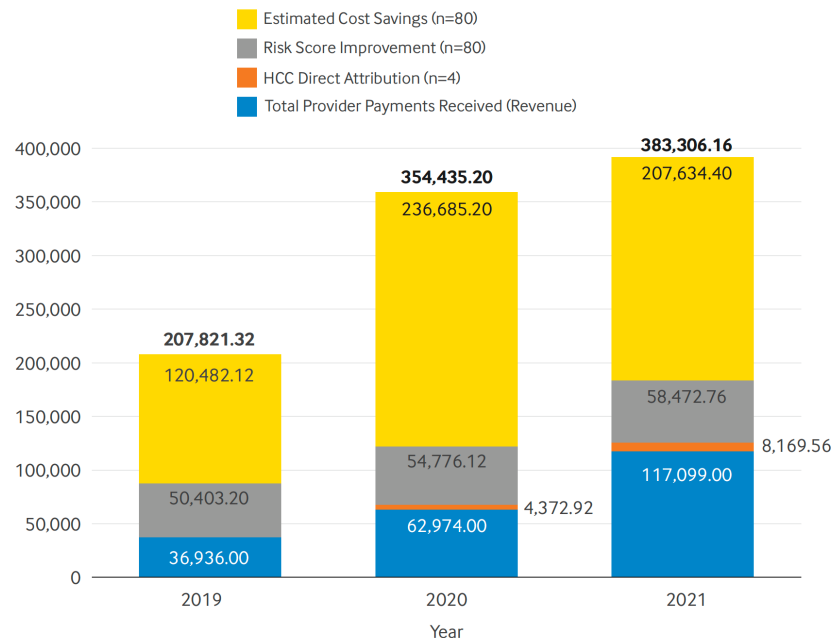
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Alzheimer disease and related dementias (ADRDs) are growing exponentially, making critical to expand dementia/memory assessment and care. Insufficient funding, poor access to care, and low ROIs are some of the barriers that limit the ability of health 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, <https://catalyst.nejm.org/doi/full/10.1056/CAT.22.0304>

# Find the Care Ecosystem Toolkit, Navigator Training Program, and Care Protocols at: [memory.ucsf.edu/care-ecosystem](https://memory.ucsf.edu/care-ecosystem)

## Care Ecosystem

The Care Ecosystem model was designed to help address the unmet needs of persons with dementia and their caregivers.



### Research & Clinical Trials

[Research FAQ](#)

[Clinical Trials](#)

## What is the Care Ecosystem?

The Care Ecosystem is a model of dementia care designed to provide personalized, cost-efficient care for persons with [dementia](#) (PWD) and their caregivers. This telephone and web-based intervention was developed and studied across California, Nebraska and Iowa via an award from the Center for Medicare and Medicaid Innovation (CMMI grant number 1C1CMS331346) from 2014–2018 and continues to be studied with funding from the National Institute for Health (NIH grant number RO1 AG056715) from 2018–2022.

# Free Online Navigator Training Program

## Quiz Communication Strategies

Due No due date   Points 4   Questions 4   Time Limit None

### Attempt History

	Attempt	Time
LATEST	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 'in his brain' and she tries to keep him busy with household chores and errands. He says that he can't do more productively. What concepts may help this couple find a compromise? (Select the best answer.)


**Correct!**

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

## Care Eco Training > Pages > Communication Strategies

- Home
- Modules
- Quizzes
- People
- Grades

# Communication Strategies



Communication Strategies  
Use positive feedback and affirmations

- Give compliments and positive feedback
  - "Good job", "Thank you for helping"
  - "You look great in that color"
- Affirm relationships
  - "Thank you for working so hard"
  - "Thank you for being there for me"
  - "Thank you for all the adventures we have had together"

Watch on YouTube

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>
- <https://www.memory.ucsf.edu/communication>

# Care Protocols



## Caregiver Well-being Protocol



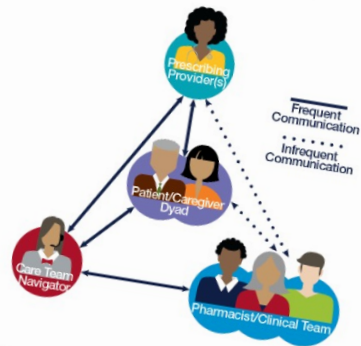
**Purpose:**

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.

When to use this protocol:



## 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 (Applicable if care is continued beyond 12-14 months)



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



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

# Translations in Spanish and Chinese are Available



## 失禁

尿失禁被定義為部分或完全失去控制自己膀胱或排便功能而導致弄髒或弄濕自己。有很多原因會導致大小便失禁，包括藥物，食品或飲料，感染和其他疾病。告訴醫生有關任何失禁的情況是一個好主意，看看有沒有治療方法。失智症也能引起尿失禁。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	喪失興趣去洗手間 無法知道或關心如果衣服被弄濕或弄髒	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拉內褲
健忘	忘了去洗手間 忘記如何去洗手間	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拉內褲
視覺問題	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)	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 在浴室門上放上標誌或圖片 使用有色馬桶
注意力不集中	在上廁所時分心	請患者不要在同一時間 做多件事
移動性的問題	有困難趕得及去洗手間 上下馬桶有難度	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，抬高的馬桶座或尿管 使用容易去除的褲子 (如彈性褲頭或魔術貼)

## ¿Quién me puede ayudar?



### Mi guía de cuidado o la línea de ayuda 24/7 de la Asociación de Alzheimer 1-800-272-3900

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

- Se sienta estresado/a y necesite hablar con alguien.
- Se sienta triste, desesperanzado/a o pierda el interés por hacer actividades diarias.
- Necesite ayuda manejando comportamientos difíciles (la persona con demencia se quiere ir de casa, hace preguntas repetidamente, no duerme, se encuentra molesto/a o agitado/a, o rechaza la ayuda de otros).
- Se sienta preocupado/a sobre cómo cuidar de su ser querido, mantenerlo seguro, encontrar actividades que él/ella disfrute, manejar retos con la alimentación o la higiene.
- Necesite 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).

Mi guía de cuidado se llama:

Su número de teléfono es:

### Un miembro de familia, vecino o amigo cercano

Llame a un miembro de familia, vecino o amigo cuando:

- Necesite a alguien con quien hablar.
- Necesite ayuda con un recado o arreglando cosas del hogar.
- Necesite ayuda supervisando a su ser querido.
- Necesite ayuda calmando o distrayendo a su ser querido.

Puedo 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 (confusión, pérdida de movilidad, agitación, somnolencia).
- Caídas o cambios en el equilibrio o la marcha.
- Irritación estomacal o cambios en el apetito.
- Nuevos síntomas de tos, resfriado, o alergias en la piel.
- Nuevos episodios de incontinencia urinaria o fecal, cambios en la frecuencia urinaria o ardor.
- Dolor de cabeza, espalda, 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 equivocado o exceso de medicamentos.

## The Care Ecosystem Consortium: Locations of Active Programs\*



\*Some locations represent more than one program

# To learn more about the Care Ecosystem:



1. Review the Toolkit, Care Protocols, Online Navigator Training  
[memory.ucsf.edu/care-ecosystem](https://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](mailto:Michelle.Barclay@ucsf.edu)



3. Sign up to participate in monthly “Clinical Skills Workshops” and “Care Ecosystem Implementation Meetings” with dementia care innovators from across the country

**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

**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.