



AFTD Education Conference– May 5, 2023

# You're not alone: Managing a System That Isn't Set up for FTD

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Associate Professor  
Next Generation Scholar (Precision Medicine)  
Health Policy & Behavioral Sciences



# Hidden Agenda: You aren't Alone



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# What is Long-Term Care (LTSS)?



**“Non-medical” services provided to individuals (generally) aimed to assist with activities of daily living.**

- Home health care
- Long-term care residential settings



## **Nursing Home**

provides 24-hour skilled nursing care and medical services to residents.



## **Residential Care Home**

provides room, board, and personal care, but not full-time nursing care.



## **Assisted Living Facility**

provides independent living up through nursing home level care.

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# LTSS & FTLD Syndromes



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## LETTERS TO THE EDITOR

### Treatment of Hypersexuality in an Elderly Patient With Frontotemporal Dementia in a Long-Term Care Setting

Ali Najafian Jazi, MD, MS; Shady S. Shebak, MD

Published: May 25, 2017

To the Editor: Dementia is a common cause often seen in frontotemporal dementia (FTD) behaviors such as compulsive masturbation patients with obsessive-compulsive disorder frontal lobes, particularly the orbitofrontal cingulum, and thalamus, in OCD has been w Presumably, neural disruption of frontotemp underlying mechanism of hypersexuality in p patients with dementia is very challenging. T intervention for hypersexuality in FTD.<sup>4</sup> Altho

## REVIEW ARTICLE

### The meaning of long-term caregiving for patients with frontal lobe dementia

HEGE RASMUSSEN, RN<sup>1</sup> & OVE HELLZEN, Professor<sup>2</sup>

<sup>1</sup>Department of Psychiatry, Namsos Hospital, Nord-Trøndelag Health Trust, Namsos, Norway and <sup>2</sup>Department of health and Science, Nord-Trøndelag University College, Namsos, Norway

#### Abstract

Nursing staff that work with patients with frontal lobe dementia (FLD) experience challenges that may lead to physical and psychiatric distress. The aim of this study was to capture the feelings, experiences, and reflections of the health staff regarding interactions with and caring for patients with FLD and to highlight what it means for health staff to care for patients with FLD through their daily work. This is a qualitative study with a phenomenological hermeneutic approach. Ten health staff members who work with patients with FLD were interviewed using semistructured interviews. The focus during the interview was the experiences of the staff through their everyday work. The interviews were recorded and then transcribed verbatim. The material was analyzed using a phenomenological hermeneutic approach. The result of the study identifies three themes that highlight the meaning of caregiving for patients with FLD, that is, being aware of the relationship with the patients, being insecure, and being safe. The patients' unpredictable behaviour puts the relationship between the staff and the patients on trial. It is essential in caregiving to see the human behind the disease and the behaviour. The interest of finding new solutions in the caregiving is awakened through the relation with the patients, through reflections with colleagues, external guidance and by support from the staff leader.

**Key words:** Frontal lobe dementia (FLD), hermeneutics, insecurity, narrative interviews, nursing care, phenomenological, relation, safety

(Accepted: 24 January 2013; Published: 20 February 2013)

J Mol Neurosci (2011) 45:737–741  
DOI 10.1007/s12031-011-9612-5

### Accessing Community-Based and Long-Term Care Services: Challenges Facing Persons with Frontotemporal Dementia and Their Families

Darby Morhardt

2 July 2011 / Published online: 9 August 2011  
© Springer Science+Business Media, LLC 2011

barriers to accessing services al dementia (FTD), and few needs and satisfaction with f persons with FTD. Persons s have reported consistent o access care and support. ing a diagnosis; (2) financial yment, job-related income; security disability insurance; munity-based and long-term ecessful care practices such am and helpful care models nd the antecedent-behavior- ribered. Further investigation derstand best care strategies

exhaustion leading to caregivers' mental and physical health problems (Shaji et al. 2009; de Vugt et al. 2005; Donaldson et al. 1998) and subsequent increased need for respite care (Sussman and Regehr 2009; Etters et al. 2008). Counseling and support have been shown to significantly delay nursing home placement for persons with dementia, improving mood and caregiver quality of life (Mittelman et al. 2006). It is reported that detailed information about dementia given by qualified health personnel to family caregivers is of singular importance in improving caregiver support and the ability to cope with the illness (Cotter 2006).

There are few studies that have examined the service needs, service delivery, and satisfaction with services for family caregivers of persons with FTD. This is important because it has been shown that this group of caregivers experience a heavier burden of care compared to caregivers of persons with other dementias (Mendez and Perryman 2002; Gregory and Hodges 1996; Passant et al. 2005; Mendez et al. 2007) due to fundamental personality changes and the exhibition of severe behavioral disturbances as the disease progresses (Rosness et al. 2008; Riedijk et al.

ementia · Caregiving ·  
ng-term care

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# General Research on LTSS or even ADRD Use of LTSS May not address key needs for those with FTLD Syndromes

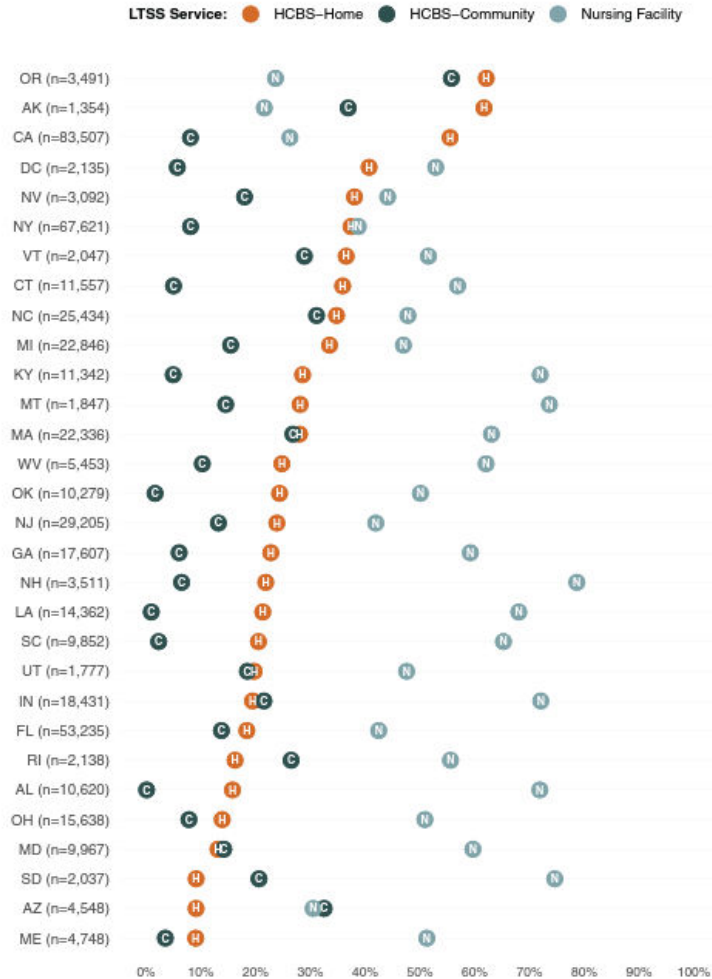


FIGURE 2. Percentage of dual-eligible beneficiaries at least 65 years of age with Alzheimer's disease and related dementias (ADRD) who used any home-based services (H), community-based services (C), and/or long-term nursing facility services (N) in 2016. Source: Authors' analysis of national Medicare/Medicaid data, 2016. Note: Service use is not mutually exclusive, beneficiaries who used more than one type of service were included in each applicable category. Percentages are adjusted for age, sex, number of chronic health conditions, and years since first documented ADRD.

For example, this exceptional review of the use of LTSS in 30 states by “dual beneficiaries” with AD/ADRD. Only applies to those who are over 65. Missing those with young-onset dementias under the age of 65.

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What can we learn from the broader LTSS literature?

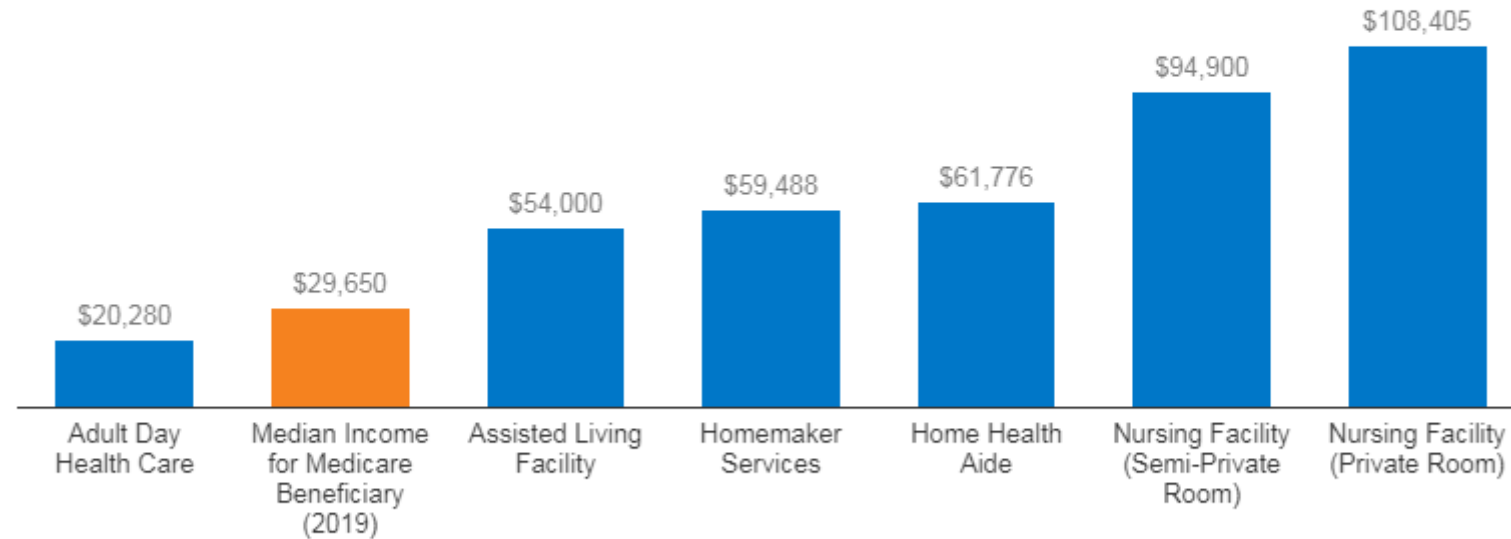
*Lesson: We need better financial models to pay for LTSS*



Figure 2

## LTSS Are Extremely Expensive and Generally Not Covered By Medicare.

Nursing facility costs are higher than those of other services but many people living outside of nursing facilities use multiple services simultaneously. Medicare only covers home health and skilled nursing facility care on a time-limited basis.



NOTE: Dollar amounts are annual costs for each type of care in 2021.

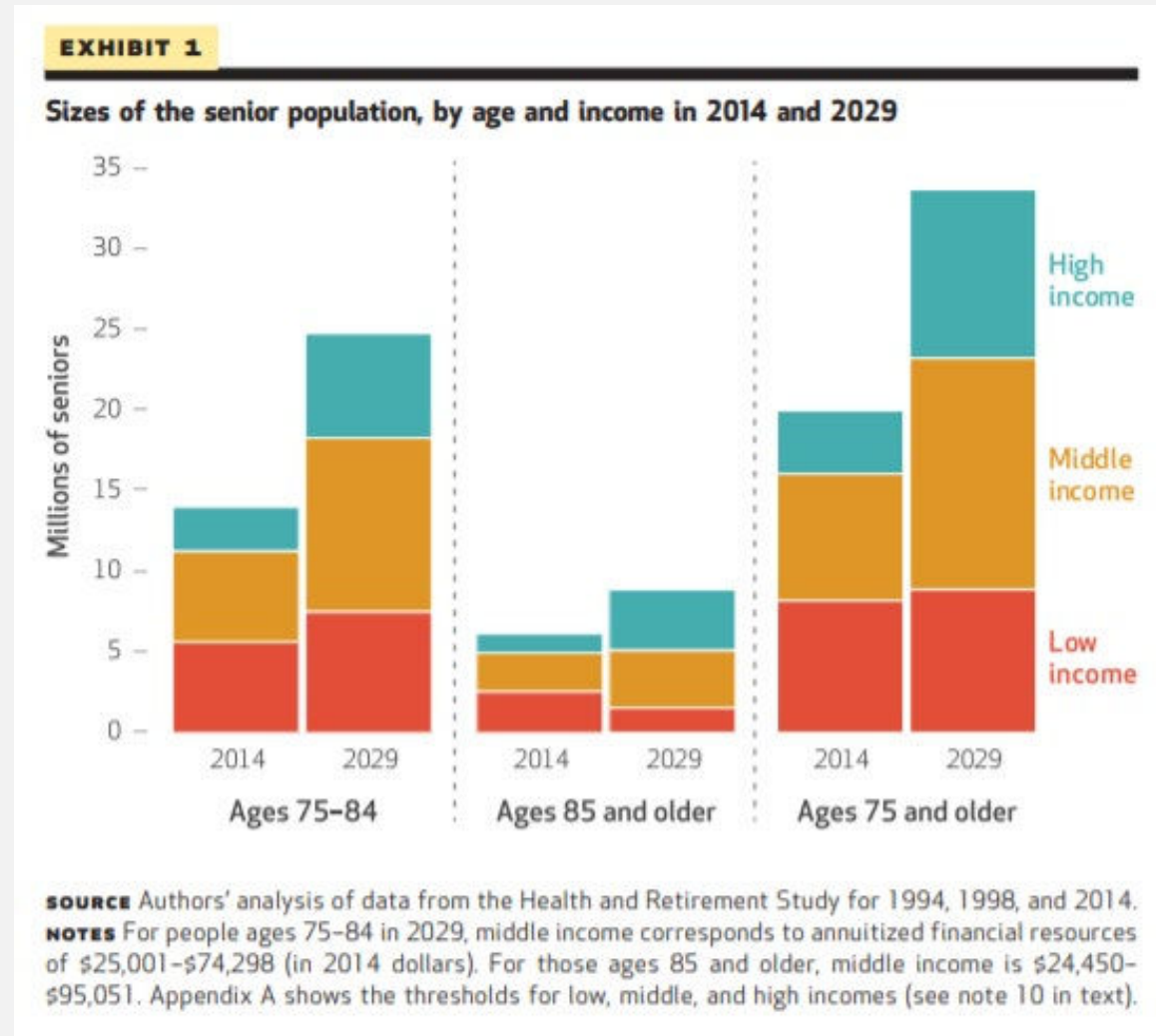
SOURCE: KFF analysis of Genworth 2021 Cost of Care Survey; KFF, Medicare Beneficiaries' Financial Security Before the Coronavirus Pandemic, Urban Institute / KFF analysis of DYNASIM data, 2019. • PNG

**KFF**

<https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/>

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# An Aging Population: The Baby Boomers & The Trouble of the Middle Class



Pearson, et al., *The Forgotten Middle*, Health Affairs (May 2019)

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# Long-term care is expensive: How do people pay for it?

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(Under Review) Title: Jing Li, PhD<sup>a\*</sup>, Hannah Bancroft, MS<sup>b</sup>, Krista L. Harrison, PhD<sup>cde</sup>, Ana M. Tyler, JD<sup>f</sup>, Jalayne J. Arias, JD<sup>g</sup>. *Out-of-pocket Expenses for Long-term care by Dementia Status and Residential Setting among U.S. Older Adults*

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# If a significant % of people will need LTSS, Why Not Private Insurance?

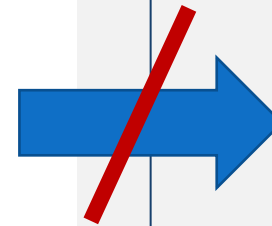


Revised February 2016



## LONG-TERM SERVICES AND SUPPORTS FOR OLDER AMERICANS: RISKS AND FINANCING

*Most Americans underestimate the risk of developing a disability and needing long-term services and supports (LTSS). Using microsimulation modeling, we estimate that about half (52%) of Americans turning 65 today will develop a disability serious enough to require LTSS, although most will need assistance for less than two years. About one in seven adults, however, will have a disability for more than five years. On average, an American turning 65 today will incur \$138,000 in future LTSS costs, which could be financed by setting aside \$70,000 today. Families will pay about half of the costs themselves out-of-pocket, with the rest covered by public programs and private insurance. While most people with LTSS needs will spend relatively little on their care, about one in six (17%) will spend at least \$100,000 out-of-pocket for future LTSS.*



## Private LTCI

High Premiums  
Low Purchase Rates  
Poor benefit structures  
Minimal external benefits  
High rates of medical denials

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# Limitation on Benefits

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## ***Elimination Periods . . .***

Period of time an individual must wait to access coverage after meeting benefit triggers

## ***Benefit Triggers . . .***

Qualification criteria that must be met before an individual is eligible for benefits (usually based on needs for assistance with ADL's)

## ***& Benefit Caps . . .***

Daily, lifetime, or aggregate caps on coverage amounts (daily: \$159)

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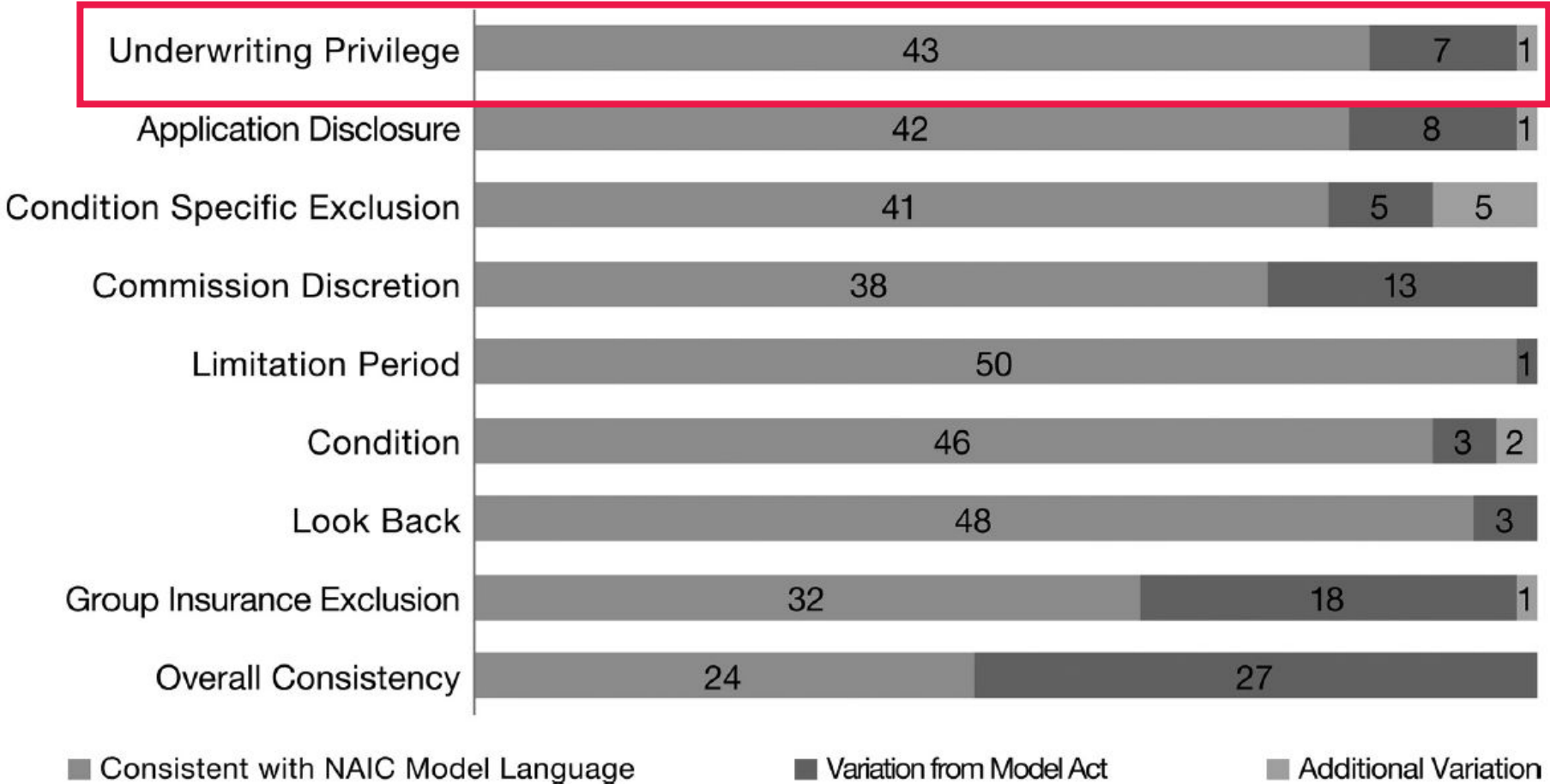
# Underwriting: Consistent with Legal Standards



Discretion & Encouragement

Figure 1

## State Law Consistencies with the NAIC Model Act



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Arias, J., Tyler, A., Oster, B., & Karlawish, J. (2018). The Proactive Patient: Long-Term Care Insurance Discrimination Risks of Alzheimer's Disease Biomarkers. *Journal of Law, Medicine & Ethics*, 46(2), 485-498.  
doi:10.1177/1073110518782955

# Underwriting Practice Limits Access to LTCI



Redacted

Caregiver of Patient

Arias et al, analysis in progress

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# So, if not Private Insurance, Then what?



	Proposed:	Limitations:
The CLASS Act	A voluntary public insurance option.	Not sustainable as a voluntary model due to adverse selection.
Commission On Long-term Care	Provided two potential solutions	Lack of consensus and reliance on public options did not sufficiently support addressing issues plaguing the private LTC insurance market.
Partnership Programs	<ul style="list-style-type: none"><li>• Incentivizing private insurance purchases</li><li>• Individuals who purchase private LTC insurance have different qualifying criteria for Medicaid</li></ul>	Did not impact purchase rates in the middle class.
Hybrid Products	Long-term care benefits that are included with life insurance policies (or similar).	High initial premiums limit access to products for the middle class.

Arias, Jalayne J. "The last hope: how starting over could save private long-term care insurance." Health Matrix 29 (2019): 127.

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# The Role for Private Insurance in the Context of State Program Initiatives



## HOW IT WORKS

### Contributions

Washington workers will pay up to **\$0.58 per \$100 of earnings**. Every employee contributes – employers do not.

EARNING YOUR BENEFITS

### Benefits

Starting in July 2026, each person who is eligible to receive the benefit can access care costing up to **\$36,500** (adjusted annually for inflation) over their lifetime.

COVERED SERVICES AND SUPPORTS

### Eligibility

To be eligible to receive the benefit, you must meet contribution requirements and need help with activities of daily living.

APPLYING FOR BENEFITS

### Self-Employed

If you're self-employed, you can choose to opt in and protect yourself with affordable WA Cares Fund benefits.

SELF-EMPLOYED OPT-IN



<https://wacaresfund.wa.gov/about-the-wa-cares-fund/>

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APRIL 18, 2023

## FACT SHEET: Biden-Harris Administration Announces Most Sweeping Set of Executive Actions to Improve Care in History

 BRIEFING ROOM  STATEMENTS AND RELEASES

Today, President Biden will announce the most comprehensive set of executive actions any President has ever taken to improve care for hard-working families while supporting care workers and family caregivers. Joined by people with disabilities, family caregivers, long-term care workers, early educators, veterans, and aging advocates, the President will sign an Executive Order that includes more than 50 directives to nearly every cabinet-level agency to expand access to affordable, high-quality care, and provide support for care workers and family caregivers.

Too many families and individuals struggle to access the affordable, high-quality care they need. The cost of child care is up 26% in the last decade and more than 200 percent over the past 30 years. For the elderly or people with disabilities long-term care costs are up 40% in the past decade. The result is many Americans – particularly women – stay out of the workforce to care for their families, making it hard for businesses to attract and retain a skilled workforce and for the economy to grow. A [BCG brief](#) forecasts losses of \$290 billion each year in gross domestic product in 2030 and beyond if the U.S. fails to address the lack of affordable child care.

### EXHIBIT 5

## Examples of Long-Term Care Financing Approaches in U.S. States

<b>Social insurance</b>	Washington Cares Fund[a], set to begin covering services in 2026, will cover home and institutional care for those age 65 and older, or those age 18 and older needing assistance with activities of daily living. There is a lifetime coverage limit. Recipients contribute through payroll taxes, similar to Social Security and Medicare.
<b>Universal comprehensive coverage</b>	Maine Universal Home Care Trust Fund[b], a failed ballot initiative in 2018, would have provided comprehensive in-home care for all adults age 65 and older and to younger people with disabilities, without income, health-need, or resident eligibility requirements. Residents earning more than \$128,400 would be subject to an earned income tax of 1.9% (employers also would pay 1.9%), and unearned income would be subject to a 3.8% tax, which would be paid into the fund. Benefits would be available for all, not just those who contribute, unlike the Washington State program. The ballot initiative was one of the most comprehensive, state-specific long-term care financing proposals to come forward in recent years.
<b>Residual (means-tested) systems</b>	Some states offer non-Medicaid coverage to people who otherwise would not qualify for Medicaid based on their income; these programs use Medicaid eligibility guidelines to determine who qualifies. Some include cost sharing but otherwise are funded through general revenues. Examples include: West Virginia's Lighthouse[c], Minnesota's Alternative Care and Essential Community Supports[d], Hawaii's Kupuna Care[e], New Jersey's Jersey Assistance for Community Caregiving[f], and New York's Expanded In-home Services for the Elderly[g].
<b>Privatized long-term care insurance</b>	The California Partnership for Long-Term Care[h] works with long-term care insurance companies offering high-quality policies and consumer protections to ensure state residents have access to reliable coverage.
<b>Cash assistance, grants, or reimbursement of a specific dollar amount to cover specific services</b>	Florida's Home Care for the Elderly Program[i] offers small monthly subsidies for eligible adults age 60 and older to cover medical and nonmedical services. Hawaii's Kupuna Caregivers Program[j] offers subsidies to caregivers who provide assistance to relatives with long-term care needs.

 Download data

[a] State of Washington, Department of Social and Health Services, Washington Cares Fund, "Ensuring Washingtonians Have Access to Long-Term Care When They Need It," n.d.

[b] State of Maine, Sec. 1.5 MRSA §12004-G, sub-§14-1, Sec. 2.5 MRSA §12004-1, sub-§30-B, Sec. 3.22 MRSA sub-T. 4, Pt. 4, 2018.

[c] State of West Virginia, Bureau of Senior Services, "Lighthouse," 2023.

[d] State of Minnesota, Department of Human Services, "Alternative Care," updated Jan. 24, 2020; and State of Minnesota, Department of Human Services, "Essential Community Supports," updated Nov. 21, 2021.

[e] State of Hawaii, "Kupuna Care," July 1, 2005–June 30, 2007.

[f] State of New Jersey, Department of Human Services, Division on Aging Services, "Jersey Assistance for Community Caregiving," last updated 2013.

[g] State of New York, Department of Health, "Expanded In-home Services for the Elderly (EISEP)," last updated Mar. 2010.

[h] State of California, Department of Health Care Services, "The California Partnership for Long-Term Care," last updated July 30, 2021.

[i] State of Florida, Department of Elder Affairs, "Home Care for the Elderly (HCE) Program," last updated May 4, 2021.

[j] State of Hawaii, Executive Office on Aging, "State Launches Landmark Kupuna Caregivers Program to Help Working Caregivers Pay for Support Services for Older Adults," news release, Dec. 13, 2017.

Source: Celli Horstman, Evan D. Gumas, and Gretchen Jacobson, U.S. and Global Approaches to Financing Long-Term Care: Understanding the Patchwork (Commonwealth Fund, Feb. 2023). <https://doi.org/10.26099/2m36-vt53>

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# State and Federal Policies are Emerging



## FACT Adminis Sweeping Imp



Today, President  
executive actions  
working families  
by people with di  
educators, vetera  
Order that includ  
agency to expand  
for care workers a

Too many families and individuals struggle to access the affordable, high-quality care they need. The cost of child care is up 26% in the last decade and more than 200 percent over the past 30 years. For the elderly or people with disabilities long-term care costs are up 40% in the past decade. The result is many Americans – particularly women – stay out of the workforce to care for their families, making it hard for businesses to attract and retain a skilled workforce and for the economy to grow. A [BCG brief](#) forecasts losses of \$290 billion each year in gross domestic product in 2030 and beyond if the U.S. fails to address the lack of affordable child care.

Future work is needed to understand whether and how these policy changes would affect individuals and families needing services due to FTLD related syndromes

## EXHIBIT 5

### U.S. States

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[1] State of Hawaii, Executive Office on Aging, "State Launches Landmark Kupuna Caregivers Program to Help Working Caregivers Pay for Support Services for Older Adults," news release, Dec. 13, 2017.

Source: Celli Horstman, Evan D. Gumas, and Gretchen Jacobson, U.S. and Global Approaches to Financing Long-Term Care: Understanding the Patchwork (Commonwealth Fund, Feb. 2023). <https://doi.org/10.26099/2m36-vt53>

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# A Starting Point: Qualitative Study on Social and Legal Consequences of FTLD Syndromes

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- Semi-structured interviews with caregivers of patients with FTD
- Interviews conducted within 30 days of a research-confirmed diagnosis of FTD
  - A second interview conducted 6-9 months after the confirmed diagnosis
- Interview domains include:
  - Diagnostic path/disclosure process
  - Financial decision-making
  - Employment
  - Social and family relationships
  - Criminal behaviors
  - Planning for long-term care needs
- Adjusted grounded theory to identify themes and trends

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# Results: Demographics



Caregiver Demographics	n=13
Age	65.1
Sex (M/F)	4/9
Education	15.8
Race	
White	13
Ethnicity	
Not Hispanic or Latino	13
Study Partner Relationship	
Spouse/Partner	9/1
Sibling	1
Nephew	1
Parent	1
Employed at time of interview (Y/N)	6/7
Reason for unemployment	
Left early due to family member's diagnosis	2
Retired	4
Never employed	1

Patient Demographics	n=13
Age	66.5
Sex (M/F)	9/4
Education	15.5
Race	
White	12
Asian	1
Ethnicity	
Not Hispanic or Latino	13
Employed at time of interview (Y/N)	0/13
Reason for unemployment	
Disability due to FTD	3
Disability unrelated to FTD	2
Terminated	2
Retired	5
Other	1

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# Results: Themes

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- Diagnostic Experience
- Employment
  - End of employment
  - Interference with job performance
- Caregiver Burden
- Safety/Vulnerability
- “Abusive” behaviors
- Financial Decision-making
  - Mistakes/Poor judgment
- Long-term Care Planning

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# Results: Themes



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  - Mistakes/Poor judgment
- Long-term Care Planning

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# Safety/Vulnerability

Redacted

# Financial Decision Making

Redacted

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*redacted*

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# But we also heard . . .

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# “Abusive” behaviors

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# Lack of Insight & Barriers

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# Impact of Caregiver Burden



Redacted

 ORIGINAL CONTRIBUTION

## Caregiving as a Risk Factor for Mortality The Caregiver Health Effects Study

Richard Schulz, PhD

Scott R. Beach, PhD

**Context** There is strong consensus that caring for an elderly individual with disability is burdensome and stressful to many family members and contributes to psychiatric morbidity. Researchers have also suggested that the combination of loss, pro-

Schulz, Richard, and Scott R. Beach. "Caregiving as a risk factor for mortality: the Caregiver Health Effects Study." *Jama* 282.23 (1999): 2215-2219.



Redacted

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Redacted

## Perception of criminality

- 8/13 interviewees described potentially criminal behavior (4 of the 8 described that behavior as criminal when asked directly)
- Caregivers were mostly concerned about actions that inconvenience/bother people outside of their social group like yelling at strangers, shoplifting, or driving violations.
- No one who reported violence, stalking, or aggression against caregivers or romantic partners characterized that behavior as criminal

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Author manuscript

JAMA Neurol. Author manuscript; available in PMC 2016 March 01.

Published in final edited form as:

JAMA Neurol. 2015 March ; 72(3): 295–300. doi:10.1001/jamaneurol.2014.3781.

## Criminal Behavior in Frontotemporal Dementia and Alzheimer Disease

Madeleine Liljegren, MD<sup>1</sup>, Georges Naasan, MD<sup>2</sup>, Julia Temlett, MD<sup>2</sup>, Katherine P. Rankin, PhD<sup>2</sup>, Jennifer Merrilees, PhD<sup>2</sup>, Lea T. Williams, MD<sup>2</sup>, William W. Seeley, MD<sup>2</sup>, Elisabet Englund, MD<sup>1</sup>, and Bruce L. Miller, MD<sup>2</sup>


<sup>1</sup>Division of Oncology and Pathology, Department of Clinical Science, Karolinska Institutet, Stockholm, Sweden

<sup>2</sup>Memory and Aging Center, Department of Neurology, University of California, San Francisco, California, USA

DOI: 10.1111/jgs.13174


### BRIEF REPORT

## Prevalence of dementia and mild cognitive impairment before incarceration

Randall L. Kuffel BS<sup>1,2</sup>  | Amy L. Byers PhD, MPH<sup>1,2</sup> | Brie Williams MD, MS<sup>4</sup> | Richard Fortinsky PhD, MA<sup>1</sup> | Yixia Li MPH<sup>1,2</sup> | Michael A. Ruderman DO, MPH<sup>1,3</sup> | Lisa C. Barry PhD, MPH<sup>5,6</sup>

### COMMENTARY

## The growing geriatric prison population: A dire public health consequence of mass incarceration

Brie Williams MD, MS<sup>1</sup>  | Michele DiTomas MD, MS<sup>2</sup> | Alison Pachynski MD, MPH<sup>2</sup>

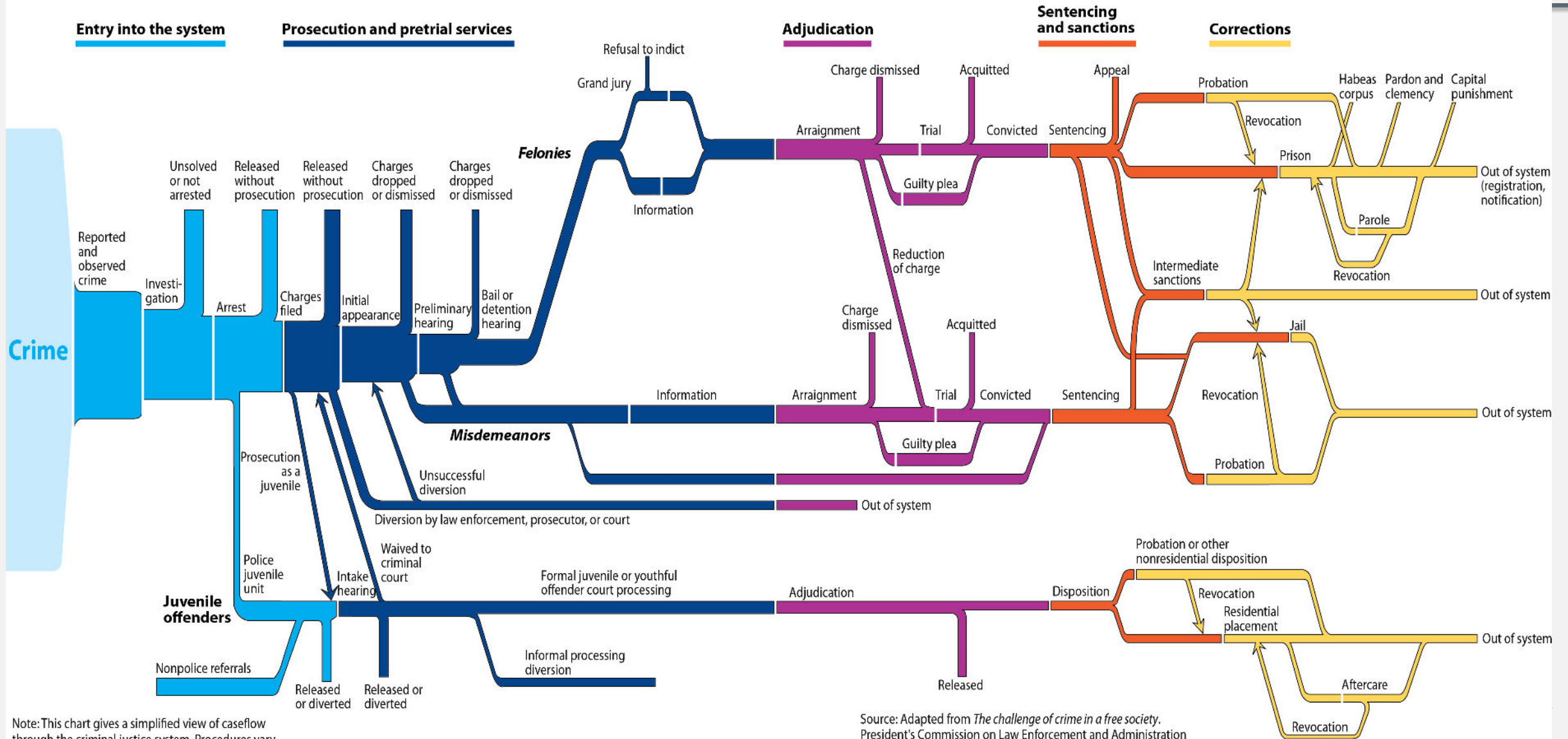
Journal of the  
American Geriatrics Society

San Francisco, San Francisco, California, USA

San Francisco, 2789 25th Street, Suite 350, San Francisco, California, USA

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# What is the sequence of events in the criminal justice system?



Note: This chart gives a simplified view of caseflow through the criminal justice system. Procedures vary among jurisdictions. The weights of the lines are not intended to show actual size of caseloads.

Source: Adapted from *The challenge of crime in a free society*. President's Commission on Law Enforcement and Administration of Justice, 1967. This revision, a result of the Symposium on the 30th Anniversary of the President's Commission, was prepared by the Bureau of Justice Statistics in 1997.

# Legal Standards



Standard for Guilty  
By Reason of  
Insanity

Proof of Disease

Admissible  
Evidence

Dr. Pollock also determined that appellant suffered from a neurological disease of the brain and central nervous system and that he suffered from dementia as well. Dr. Pollock testified that appellant's disorders were aggravated by stress and that exposure to severe stress could cause him to develop psychotic behavior. Dr. Pollock acknowledged that his opinion that appellant suffered from a vascular neurocognitive disorder [...]. *McAfee*

Olivia Li, et al, *in process* **We're doing it #thestateway**



# Identifying Gaps within the System



Screening

Pre-trial release

Competency

Placement (housing)

Criminal liability

Sentencing

Post-Conviction

*Redacted*

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# Threshold Issues



## Dementia Detection

Pre-trial release

*Redacted*

Competency

Criminal liability

Sentencing

## Placement (housing)

Post-Conviction

Experience and Training

Recommendations

*Forthcoming, Arias et al, American Journal of Law and Medicine (Summer 2023)*

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# Long-term Care Planning

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# One Recommendation: Advance Directive?



## Living Will

- States wishes about the medical treatment you want to receive
- Generally, applies only if you are unable to make decisions for yourself

## Power of Attorney

- Power of attorney documents identify who will serve as your decision-maker if you can not make your own decisions
- Power of attorneys come in two types: (1) health care; and (2) durable

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# How are decisions made:



## Identify the Decision-maker

- Patient
- Court Appointed Guardian
- Health Care Power of Attorney
- Next of Kin: California does not have a default surrogate statute.



## Make the decision

Surrogates use one of two standards to make decisions:

- (1) Substituted decision-maker.** This is making the decision based on the patient's values, interests, and wishes.
- (2) Best interest standard.** This standard is used when the patient's values are unknown. This standard asks the surrogate to make the decision in the patient's "best interest" objectively.

*Surrogates should not make decisions based on their own values.*

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WHERE DO WE GO FROM HERE?



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# Acknowledgments



## **Research Team for This Study:**

Ana Tyler, JD, MA  
Jennifer Yokoyama, PhD

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**NIH NIA K01 (K01AG057796)**

**Global Brain Health Institute/ Alzheimer's Association**

**Alzheimer' Association  
(MNIRGD-14-319284)**

**Hellman Fellowship Foundation**

## **Aging Research for Criminal Health Network**

(National Institute on Aging, National Institutes of Health (grant R24 AG065175-01))

## **Research Team:**

Lillian Morgado  
Tatyana Valteau  
Catherine Scipion

## *Former:*

Krystal Karunungan  
Rosa Gonzalez  
Ben Oster, JD, LL.M, MS  
Lauren Sankary, JD, MA  
Ana Tyler, JD, MA

**Contact: [jarias@gsu.edu](mailto:jarias@gsu.edu)**

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