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

We’re doing it #thestateway
“Non-medical” services provided to individuals (generally) aimed to assist with activities of daily living.

- Home health care
- Long-term care residential settings

What is Long-Term Care (LTSS)?

- **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.
LTSS & FTLD Syndromes

Letters to the Editor

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

All Nagation Josi, MD, MS; Shady S. Sheltbak, MD

Published: May 29, 2017

To the Editor: Dementia is a common cause of hypersexuality, often seen in transcortical dementia (FTD) behaviors such as compulsive masturbation and sexual acts with patients with obsessions-compulsive disorders. In frontal lobe, particularly the orbitofrontal cortex, cingulum, and thalamus, in OCD has been identified. Presumably, neural disruption of frontal-temporal networks and underlying mechanism of hypersexuality in patients with dementia is very challenging. If patients with dementia present with hypersexuality, interventions for hypersexuality in FTD, although

Review Article

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

HEGE RASMUSSEN, RN1 & OVE HELLZEN, Professor2

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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 care 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 behavior 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 behavior. 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 interview, nursing care, phenomenological, relation, safety

(accepted: 24 January 2013; published: 20 February 2013)
General Research on LTSS or even ADRD Use of LTSS May not address key needs for those with FTLD Syndromes

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
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.

**Figure 2**

**NOTE:** Dollar amounts are annual costs for each type of care as of 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


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

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

(Under Review) Title: Jing Li, PhD,*, Hannah Bancroft, MS, Krista L. Harrison, PhD,*, Ana M. Tyler, JD, Jalayne J. Arias, JD. * 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?

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

**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)

We’re doing it #thestateway
## Underwriting: Consistent with Legal Standards


### Figure 1

<table>
<thead>
<tr>
<th></th>
<th>Consistent with NAIC Model Language</th>
<th>Variation from Model Act</th>
<th>Additional Variation</th>
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<tbody>
<tr>
<td>Underwriting Privilege</td>
<td>43</td>
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<td>Application Disclosure</td>
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<td>Condition Specific Exclusion</td>
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<td>5</td>
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<td>Commission Discretion</td>
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<td>Limitation Period</td>
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<td>Look Back</td>
<td>48</td>
<td>3</td>
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<tr>
<td>Group Insurance Exclusion</td>
<td>32</td>
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<tr>
<td>Overall Consistency</td>
<td>24</td>
<td>27</td>
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</tbody>
</table>

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Underwriting Practice Limits Access to LTCI

Redacted

Caregiver of Patient

Arias et al, analysis in progress

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### Proposed: Limitations:

<table>
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<tr>
<th>The CLASS Act</th>
<th>Provided two potential solutions</th>
</tr>
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<tbody>
<tr>
<td>A voluntary public insurance option.</td>
<td>Not sustainable as a voluntary model due to adverse selection.</td>
</tr>
<tr>
<td>Commission On Long-term Care</td>
<td>Lack of consensus and reliance on public options did not sufficiently support addressing issues plaguing the private LTC insurance market.</td>
</tr>
<tr>
<td>Partnership Programs</td>
<td>Did not impact purchase rates in the middle class.</td>
</tr>
<tr>
<td>• Incentivizing private insurance purchases</td>
<td>High initial premiums limit access to products for the middle class.</td>
</tr>
<tr>
<td>• Individuals who purchase private LTC insurance have different qualifying criteria for Medicaid</td>
<td></td>
</tr>
<tr>
<td>Hybrid Products</td>
<td></td>
</tr>
<tr>
<td>Long-term care benefits that are included with life insurance policies (or similar).</td>
<td></td>
</tr>
</tbody>
</table>

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.

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.

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

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

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

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

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 49% 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.

State and Federal Policies are Emerging

EXHIBIT 5
Examples of Long-Term Care Financing Approaches in U.S. States

| Social insurance | Washington Cares Fund(b), set to begin covering services in 2026, will cover home and institutional care for those age 65 and older, or those age 19 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. |
| Universal comprehensive coverage | 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 to younger people with disabilities, without income, health-need, or resident eligibility requirements. Residents earning more than $28,400 would be subject to an earned income tax of 10% (employers would also pay 10%), 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. |
| Residual (means-tested) systems | 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 Support(d), Hawaii’s Kupuna CAND(a), New Jersey’s Jersey Assistance for Community Caregiving(e), and New York’s Expanded In-Home Services for the Elderly(f). |
| Privatized long-term care insurance | The California Partnership for Long-Term Care(g) works with long-term care insurance companies offering high-quality policies and consumer protections to ensure state residents have access to reliable coverage. |

Cash assistance, grants, or reimbursement of a specific dollar amount to cover specific services | Florida’s Home Care for the Elderly Program(h) offers small monthly subsidies for eligible adults age 60 and older to cover medical and nonmedical services. Hawaii’s Kupuna Caregiver Program(i) offers subsidies to caregivers who provide assistance to relatives with long-term care needs. |

[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, 1 MRSA §5054-5, sub-§5-A, Sec. 2, 5 MRSA §5054-4, sub-§30-B, Sec. 3, 32 MRSA sub-B, §1, 4-1, 2018.

State and Federal Policies are Emerging

Future work is needed to understand whether and how these policy changes would affect individuals and families needing services due to FTLD related syndromes.
A Starting Point: Qualitative Study on Social and Legal Consequences of FTLD Syndromes

- 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

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<th>Caregiver Demographics</th>
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<td>Sex (M/F)</td>
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<tr>
<td>Education</td>
<td>15.8</td>
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<tr>
<td>Race</td>
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<tr>
<td>White</td>
<td>13</td>
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<td>Ethnicity</td>
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<tr>
<td>Not Hispanic or Latino</td>
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<tr>
<td>Study Partner Relationship</td>
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<tr>
<td>Spouse/Partner</td>
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<td>Sibling</td>
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<td>Nephew</td>
<td>1</td>
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<td>Parent</td>
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<tr>
<td>Employed at time of interview (Y/N)</td>
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<tr>
<td>Reason for unemployment</td>
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<tr>
<td>Left early due to family member's diagnosis</td>
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<tr>
<td>Retired</td>
<td>4</td>
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<tr>
<td>Never employed</td>
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<table>
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<th>Patient Demographics</th>
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<tr>
<td>Sex (M/F)</td>
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<tr>
<td>Education</td>
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<tr>
<td>Race</td>
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<td>White</td>
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<tr>
<td>Asian</td>
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<td>Ethnicity</td>
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<tr>
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<td>13</td>
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<tr>
<td>Employed at time of interview (Y/N)</td>
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<tr>
<td>Reason for unemployment</td>
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<tr>
<td>Disability due to FTD</td>
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<tr>
<td>Disability unrelated to FTD</td>
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</tr>
<tr>
<td>Terminated</td>
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<tr>
<td>Retired</td>
<td>5</td>
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<tr>
<td>Other</td>
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Results: Themes

• 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

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

We’re doing it #thestateway
Safety/Vulnerability
Redacted

Financial Decision Making
Redacted

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But we also heard . . .

Redacted

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“Abusive” behaviors

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Lack of Insight & Barriers

Redacted

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Impact of Caregiver Burden

Liability/Increased Legal Risk

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Criminal Behavior

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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Criminal Behavior in Frontotemporal Dementia and Alzheimer Disease

Madeleine Liljegren, MD, Georges Naasen, MD, Julia Temlett, MD, Katherine P. Rankin, PhD, Jennifer Merrells, PhD, Lea T. L. Will, William W. Seeley, MD, Elisabet Englund, MD, and Bruce L. Miller, MD

1Division of Oncology and Pathology, Department of Clinical Sciences, Sweden
2Memory and Aging Center, Department of Neurology, University of California, San Francisco, California, USA

BRIEF REPORT

Prevalence of dementia and mild cognitive impairment before incarceration

Randall L. Kuffel BS, Amy L. Byers PhD, MPH, Brie Williams MD, MS, Richard Fortinsky PhD, MA, Yixia Li MPH, Michael A. Ruderman DO, MPH, Lisa C. Barry PhD, MPH

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

Brie Williams MD, MS, Michele DiTomasso MD, MS, Alison Pachynski MD, MPH

Journal of the American Geriatrics Society

#thestateway
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

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Olivia Li, et al, in process
Identifying Gaps within the System

Screening
Pre-trial release
Competency
Placement (housing)
Criminal liability
Sentencing
Post-Conviction

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## Threshold Issues

<table>
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<th>Dementia Detection</th>
<th>Competency</th>
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<td>Pre-trial release</td>
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<tr>
<td>Competency</td>
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<td>Criminal liability</td>
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<td>Sentencing</td>
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<tr>
<td>Placement (housing)</td>
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<td>Post-Conviction</td>
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<tr>
<td>Experience and Training</td>
<td>Forthcoming, Arias et al, American Journal of Law and Medicine (Summer 2023)</td>
</tr>
<tr>
<td>Recommendations</td>
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*We’re doing it thestateaway*
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?
Acknowledgments

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Jennifer Yokoyama, PhD

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