

By Richard H. Fortinsky and Murna Downs

DOI: 10.1377/hlthaff.2013.1304  
HEALTH AFFAIRS 33,  
NO. 4 (2014): 566-573  
©2014 Project HOPE—  
The People-to-People Health  
Foundation, Inc.

# Optimizing Person-Centered Transitions In The Dementia Journey: A Comparison Of National Dementia Strategies

**Richard H. Fortinsky** (fortinsky@uchc.edu) is a professor of medicine and Health Net, Inc. Chair in Geriatrics and Gerontology at the UConn Center on Aging, University of Connecticut School of Medicine, in Farmington.

**Murna Downs** is a professor of dementia studies and head of the Bradford Dementia Group, School of Health Studies, University of Bradford, in England.

**ABSTRACT** The journey for people with Alzheimer's disease or another dementia involves the need for increasing levels of support, with transitions across care settings. Although transitional care has received increasing attention in the health care arena, no widely accepted transitions typology exists for the dementia journey. At the same time, national dementia strategies are proliferating. We developed a typology containing six transitions that cover the dementia journey from symptom recognition to end-of-life care. We then critically evaluated whether and how the national dementia strategies of Australia, England, France, the Netherlands, Norway, Scotland, and the United States addressed each transition. Adopting a person-centered perspective, we found that most or all of the national strategies adequately address earlier transitions in the journey, but fewer strategies address the later transitions. We recommend that next-generation national dementia strategies focus on later transitions, specify how care coordination and workforce training should make transitions more person centered, and use person-centered outcomes in evaluating the success of the strategies' implementation and dissemination.

**T**he journey for people with dementia is characterized by an increasing need for support as their disease progresses.<sup>1</sup> The journey also involves numerous transitions across care settings, yet the literature on transitional care has largely overlooked people with dementia.<sup>2</sup> These transitions are recognized as inevitable,<sup>1</sup> but there is no widely accepted classification of standard transitions in the dementia journey. However, international concern with improving the quality of dementia care has led to a proliferation of national strategies, formulated by diverse stakeholder groups including government officials, clinical and policy experts, providers, family caregivers, and people with dementia.<sup>3</sup>

This article presents the dementia transitions typology that we developed. It contains six tran-

sitions covering the dementia journey, from recognition of symptoms to end-of-life care. We evaluated seven countries' national dementia strategies, searching for evidence that these strategies clearly addressed each transition. This evaluation used a person-centered care perspective to reflect our primary goal: to determine the extent to which national strategies focused on improving transition experiences from the perspective of people affected by dementia.<sup>4</sup>

We organized our results according to the six dementia transitions shown in Exhibit 1. The relevance of each transition for research, policy, and practice is briefly discussed below, followed by synopses of whether and how each country's national strategy addresses that transition. Person-centered commentary is provided throughout the article, where applicable.

## Transitions In The Dementia Journey Addressed In National Dementia Strategies Of Seven Countries

Transition	Country (time frame of strategy)						
	Australia <sup>a</sup> (2013-17)	England <sup>b</sup> (2009-14)	France <sup>c</sup> (2008-12)	Netherlands <sup>d</sup> (2008-13)	Norway <sup>e</sup> (2007-15)	Scotland <sup>f,g</sup> (2010-16)	US <sup>h,i</sup> (2012, updated 2013)
Symptom recognition to diagnosis	•	•	•	•	•	•	•
Diagnosis to links with community services	•	•	•	•		•	•
Home to hospital and back	•	•	•		•	•	•
Home to residential care						•	
Residential care to hospital			•			•	
Home or residential care to palliative or end-of-life care	•	•					

**SOURCE** Authors' analysis of items cited below; and Alzheimer's Disease International. Government Alzheimer plans [Internet]. London: Alzheimer's Disease International; [cited 2013 Nov 9]. Available from: <http://www.alz.co.uk/alzheimer-plans>. **NOTE** If a country's national dementia strategy specifically addresses the transition, includes an action plan to improve the transition, or both, a bullet point appears in the appropriate cell in the table. <sup>a</sup>Australia Dementia Working Group. Draft consultation paper: national framework for action on dementia 2013-2017 [Internet]. Unpublished manuscript [cited 2014 Feb 27]. Available from: [http://www.health.gov.au/internet/main/publishing.nsf/content/CDA8D72FD1DC88F4CA257BF0001A8D23/\\$File/NFAD2013-2017.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/CDA8D72FD1DC88F4CA257BF0001A8D23/$File/NFAD2013-2017.pdf). <sup>b</sup>Department of Health. Living well with dementia: a national dementia strategy [Internet]. Leeds (UK): Department of Health; 2009 Feb 3 [cited 2014 Feb 27]. Available from: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/168220/dh\\_094051.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf). <sup>c</sup>Republic of France. National plan for "Alzheimer and related diseases" 2008-2012 (Note 18 in text). <sup>d</sup>Ministry of Health, Welfare, and Sport. Caring for people with dementia. The Hague: The Ministry; 2008 Jun 17. <sup>e</sup>Norwegian Ministry of Health and Care Services. Dementia plan 2015 [Internet]. Oslo: Ministry; [cited 2014 Feb 27]. Available from: <http://www.regjeringen.no/upload/HOD/Dokumenter%20KTA/DementiaPlan2015.pdf>. <sup>f</sup>Scottish Government. Scotland's national dementia strategy: 2013-16 [Internet]. Edinburgh: Scottish Government; [cited 2014 Feb 27]. Available for download from: <http://www.scotland.gov.uk/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316>. <sup>g</sup>Scottish Government. Scotland's national dementia strategy: 2013-16 [Internet]. Edinburgh: Scottish Government; 2010 Jun. <sup>h</sup>Department of Health and Human Services. National plan to address Alzheimer's disease [Internet]. Washington (DC): HHS; [cited 2014 Feb 27]. Available from: <http://aspe.hhs.gov/daltcp/napa/NatlPlan.pdf>. <sup>i</sup>Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. National plan to address Alzheimer's disease: 2013 update [Internet]. Washington (DC): HHS; [last updated 2013 Jun 14; cited 2014 Feb 27]. Available from: <http://aspe.hhs.gov/daltcp/napa/NatlPlan2013.shtml>.

## Study Data And Methods

We developed the transitions typology by integrating literature on points along the dementia journey where increased levels of professional guidance and support are required and literature on points where transfers across care settings place people with dementia at risk for poor outcomes.

The seven countries whose national dementia strategies we analyzed were selected as exemplars that met the following two criteria: the strategies or synopses of them were available in English on the Alzheimer's Disease International website in October 2013, and the strategies included clearly specified objectives and action plans. The seven countries were Australia, England, France, the Netherlands, Norway, Scotland, and the United States. We acknowledge the potential suitability and availability of several other countries' national strategies, and we encourage policy makers and researchers to critically review these plans in the context of the transitions framework we present here.

We divided the responsibility for reviewing the seven countries' strategies and determining whether each transition was addressed. Each of us then reviewed the strategies the other author had already reviewed. In the few instances where we disagreed, we discussed our reasoning

and reached mutually acceptable conclusions.

The dementia transitions typology is limited in that it excludes presymptomatic stages of dementia. In addition, it does not distinguish among various postacute care settings following hospitalization.

In the presentation of results that follows, countries are not mentioned when their dementia strategies do not include the transition component being addressed in the section.

## Study Results

**SYMPTOM RECOGNITION TO DIAGNOSIS** The transition between symptom recognition and diagnosis of Alzheimer's disease or another dementia by a health professional is often protracted and includes unacceptable and unhelpful delays. In a European survey of family caregivers, respondents reported that this transition lasted twenty months, on average.<sup>5</sup> International concerns about delays resulting from suboptimal diagnostic practices among primary care physicians have persisted since the 1990s.<sup>6</sup>

Another reason for diagnostic delay is the reluctance of people with symptoms of dementia and their families to seek help because they fear Alzheimer's disease, assuming that it means inevitable suffering, disrupted relationships, no

viable community supports, and diminished quality of life.<sup>7</sup> However, research with people with dementia suggests that these fears are not warranted.<sup>8</sup>

The process of undergoing diagnostic assessment can be unsettling and fraught with confusion, likened to “negotiating a labyrinth.”<sup>9</sup> However, evidence suggests that most people and their families wish to know the diagnosis.<sup>10,11</sup> Best practice suggests that diagnostic disclosure be an ongoing process that includes individually tailored information and support.<sup>10</sup>

► **AUSTRALIA:** The national dementia strategy of Australia specifies that symptomatic individuals should be appropriately assessed and diagnosed in a timely manner by skilled and knowledgeable professionals. To help primary care physicians, the strategy recommends increasing access to standardized screening tools and the services of dementia specialists.

► **ENGLAND:** According to England’s national dementia strategy, timely diagnosis and intervention are among the key service areas in need of improvement. The strategy seeks to ensure early diagnosis so that people with dementia can have a good quality of life.

Objectives that are relevant to this transition include improving public and professional awareness and understanding of dementia and making good-quality early diagnosis and intervention accessible to everyone. The roles of primary and specialist care in the diagnostic process are clearly discussed in the strategy.

► **FRANCE:** Objective 4 of France’s national dementia strategy recommends measures to improve access to diagnosis and care pathways. Within this objective, measure 8 specifies preparing and implementing a system for communicating the diagnosis, including training for physicians working in specialist memory consultation clinics, hospitals, and primary care offices. In addition, measure 11 calls for adding capacity across the country for memory units—that is, outpatient dementia diagnostic centers—so that each region is adequately staffed with specialized, multidisciplinary diagnostic and follow-up units. Attention to individuals’ needs and psychosocial contexts reflects a person-centered approach.

► **THE NETHERLANDS:** The national dementia strategy of the Netherlands seeks to improve this transition by emphasizing the principle that people presenting to a primary care provider with cognitive symptoms should expect that provider to be a physician with sufficient knowledge to diagnose symptoms or to refer them elsewhere for diagnosis. This strategy has many examples of person-centered approaches, including the role of targeted information and case manage-

ment in supporting the individual and his or her family when symptoms have been recognized but no diagnosis has been made, and an emphasis on providing support to help people adjust to the diagnosis.

► **NORWAY:** Norway’s national dementia strategy views diagnosis as a responsibility that is shared by municipal and specialist health services. The strategy supports a person-centered approach to this transition in recognizing that early diagnosis allows for the use of individualized plans of support, which helps meet people’s needs for a sense of predictability and security after receiving a diagnosis of dementia.

► **SCOTLAND:** The national dementia strategy of Scotland views diagnosis as the gateway to effective care and support. Person-centered characteristics include the recognition of both barriers to assistance seeking and actions that help people come to terms with a diagnosis and develop personal plans for living with dementia. These actions include the provision of educational materials and counseling on how to live well with dementia.

► **THE UNITED STATES:** The US national dementia plan’s strategy 2B addresses ensuring timely and accurate diagnosis. Action steps include linking the public to diagnostic and clinical management services, educating people about the benefits of early diagnosis, and providing assessment tools. Like the Scottish strategy, the US plan adopts person-centered action steps that include ensuring the availability of education and support for people with dementia and their families at the time of diagnosis. The US plan also recommends increasing public awareness of dementia to address popular misperceptions and thus make it more likely that people will seek a diagnosis.

**DIAGNOSIS TO LINKS WITH COMMUNITY SERVICES** Primary care physicians vary in their awareness of the community supports and resources that are available for people with dementia.<sup>6,12</sup> Educational interventions have demonstrated modest success in improving physicians’ referral patterns after diagnosis.<sup>6,13</sup>

Promising findings from dementia support interventions that have been initiated in US primary care settings suggest that successful links to community support resources help promote self-management for people with dementia and teach family caregivers about delivering proactive and compassionate care, which in turn helps them maintain their own mental and physical health.<sup>14,15</sup>

However, most innovative community-based dementia care models have not included primary care physicians, which represents a gap in linking people to community resources after di-

agnosis.<sup>16,17</sup>

►**AUSTRALIA:** In Australia's national dementia strategy, support after diagnosis is mentioned as a critical action step to engage people affected by dementia in making informed decisions about their future care. This action step specifies that the support should be person centered and individually tailored to meet changing needs, while supporting family caregivers via training, counseling, and access to support groups.

►**ENGLAND:** Objective 4 of England's national dementia strategy is to make it easier for people to access care, support, and advice following a diagnosis of dementia. The strategy helped establish forty demonstration sites where people with dementia and their caregivers could access support from dementia advisers and peers.

►**FRANCE:** Objective 2 of France's national dementia strategy is to strengthen the coordination between all stakeholders involved after diagnosis. This objective explicitly states that support after diagnosis must be "seen from the viewpoint of the patient and his or her family in order to organise the system around their needs."<sup>18</sup>

The strategy proposes that the individual and his or her family will have a single point of contact to access treatment and services as soon as the diagnosis is made. However, the strategy does not specify who this single point of contact will be, what training this person should have, or what his or her specialties should be.

►**THE NETHERLANDS:** Two aims of the Dutch national dementia strategy emphasize supporting patients and families in the community following diagnosis. The first aim is to create a coordinated range of person-centered options that meet patients' needs and wishes. The second aim is to deliver guidance and support through the provision of timely information and case management.

►**SCOTLAND:** One part of Scotland's national dementia strategy specifically identifies post-diagnostic information and support as a key service delivery area. The self-management of dementia and its symptoms is explicitly included among the objectives of an improved infrastructure for information and support after diagnosis.

►**THE UNITED STATES:** Strategy 2C of the US national dementia plan focuses on educating and supporting individuals and families after diagnosis. Action steps include educating physicians, other health care providers, and providers of long-term services and supports on how to provide assistance to patients and families following diagnosis.

**HOME TO HOSPITAL AND BACK** Having dementia increases people's risk for unplanned hospitalizations resulting from falls, fractures, sei-

zures, and infections.<sup>19,20</sup> Family caregiver factors such as exhaustion and inability to cope with their relative's emotional distress or behavior also lead to unplanned hospitalizations for people with dementia.<sup>19</sup> This transition could be prevented if such causal factors were better anticipated and alleviated in the home setting, particularly by training home care staff and families to recognize risk factors for hospitalization.<sup>19,20</sup>

The transition from hospital to postacute care or home has received extensive scientific attention in the United States.<sup>21,22</sup> Successful randomized trials of transitional care that have led to reduced readmissions in older adults without dementia are being disseminated in US hospitals.<sup>23</sup> However, these models have not yet been fully tested on hospitalized patients with dementia.

►**AUSTRALIA:** The Australian national dementia strategy addresses the transition from hospital to home but does not directly address the transition from home to hospital. To improve the former transition, the strategy calls for the early identification of hospitalized people with dementia, dementia training for hospital staff, and the inclusion of effective discharge planning in clinical pathways.

This strategy addresses the need for people with dementia to have access to transitional care arrangements to improve the continuity of care between hospital and home. The strategy is person centered in recognizing that hospitalized people with dementia often experience multiple comorbidities and excess disability—that is, disability that is in excess of what would be expected from the impairment or health condition alone.

►**ENGLAND:** Actions in England's national dementia strategy to prevent hospitalization include providing high-quality home care services and teaching families how to respond appropriately to their relatives' dementia-related symptoms, such as agitation and wandering. The strategy recognizes that for hospitals to provide person-centered care, they need to gather sufficient information from the family about a patient when he or she is admitted.

The strategy addresses inequities experienced by people with dementia in accessing postacute rehabilitation services. It calls for the development of in-hospital care pathways for people with dementia and for improved hospital discharge planning so that people with dementia will move to the postacute care settings that are most appropriate, given their strengths and needs. The role of families in discharge planning is strongly emphasized.

►**FRANCE:** Objective 3 of France's national dementia strategy is to prevent hospitalizations



by creating home care teams of dementia specialists and using technology to make the home safe. Objective 4 recommends development of a uniform personal treatment and information card—with sections to be completed by health professionals, families, and people with dementia—to be presented by families when emergency care is provided to people with dementia.

The strategy is less person centered in its conceptualization of the behavioral aspects of dementia than the strategies of some other countries. For example, measure 17 states that “recourse to hospitalisation may be necessary and often constitutes the only possible response” to dementia-related behaviors,<sup>18</sup> which suggests little appreciation of more person-centered conceptualizations of behavior.<sup>24</sup>

► **NORWAY:** Challenge 3.2 of Norway’s national dementia strategy focuses on “missing links in the care chain.”<sup>25</sup> Particular goals are improving the level of expertise among municipal health workers to refer people with dementia appropriately to specialist health services and thus help avoid unnecessary hospitalizations from home; and providing adequate geriatric, psychiatric, and general medical care after a patient is released from the hospital.

► **SCOTLAND:** The national dementia strategy of Scotland seeks to ensure that people with dementia are hospitalized only when their local health and local authority services are unable to provide the necessary treatment. The strategy is person centered in recognizing the excess disability associated with hospitalization. It calls for assessment for dementia as soon as possible after hospital admission, hospital environments that minimize room changes for patients with dementia, and training for all levels of hospital staff to meet the needs of patients with dementia. The strategy also stresses the importance of incorporating individuals’ needs and preferences into the hospital discharge planning process.

Unlike the other national strategies that we analyzed, Scotland’s emphasizes the importance of multi-agency planning prior to hospital admission, to guarantee that hospital staff have accurate information to assist with discharge planning. Efforts to ensure smooth transitions between home and hospital include pre-admission team meetings to better prepare people with dementia for hospital stays and immediate post-acute rehabilitation therapy, before they return home.

► **THE UNITED STATES:** Strategy 2F3 of the US national dementia plan seeks to improve understanding of avoidable hospitalizations of people with dementia. Strategy 2F4 seeks to identify and disseminate information about interventions

that can reduce preventable hospitalizations.

The plan also mentions several ongoing demonstration programs funded by the Centers for Medicare and Medicaid Services that are designed to improve care during the transition between home and hospital. Some of these demonstration programs include people with dementia.

► **HOME TO RESIDENTIAL CARE** Most people with dementia around the world live in their own homes with their families.<sup>3</sup> However, research suggests that up to 75 percent of people with dementia in higher-income countries will move permanently into a nursing home or other residential care setting at some point in their journey.<sup>1</sup> Factors associated with this transition include whether family caregivers find their relative’s functional impairment or behavior too challenging to manage and whether family caregivers are themselves too frail or distressed to continue providing care at home.<sup>1,26</sup>

The transition to residential care can be one of the most distressing experiences on the journey of dementia for family caregivers.<sup>27,28</sup> These caregivers frequently experience feelings of guilt, sadness, loss, and bereavement together with a sense of relief. Surprisingly little is known about the experiences of people with dementia who undergo this transition, but relocation is known to lead to short-term disorientation and to have negative effects on well-being.<sup>1</sup>

Most research on this transition focuses on interventions for families that are designed to prevent or delay the admission of people with dementia to residential care. One such study demonstrated delays in residential care admission that averaged eighteen months.<sup>29</sup> Despite a growing evidence base, uptake of these interventions in practice or as public policy has been minimal.<sup>1,17</sup>

It is beyond the scope of this article to review the culture-change movement in residential care settings.<sup>30,31</sup> However, the transition from home could be easier if such innovations in quality of care were more widespread.

► **SCOTLAND:** Many position statements in Scotland’s national dementia strategy recognize the need for improved formal care in the home setting to prevent or delay nursing home admission. Pilot programs that had started before the national strategy was released were still being evaluated for their success in keeping people with dementia living at home longer.

The strategy also recognizes that hospitalization is often a route to residential care admission for people with dementia who had been living at home. As a result, a goal of hospital care should be to permit patients to return to their homes instead of being admitted to nursing homes.

**RESIDENTIAL CARE TO HOSPITAL** A growing body of research tests interventions that are designed to reduce rates of avoidable hospital admissions from nursing homes.<sup>32</sup> Single- and multicomponent interventions that focus on care pathways, making nurses and care assistants better able to assess acute changes in health conditions, and coordinating support from primary or emergency care providers have been found to be effective.<sup>33-35</sup>

There is growing recognition of the fact that embedding these promising interventions developed by researchers into everyday practice requires ongoing attention, including adoption by nursing home staff and involvement of family members.<sup>36,37</sup>

►**FRANCE:** Objective 5 of France's national dementia strategy recognizes that increasing the dementia care expertise of nursing home staff, particularly by improving understanding of patients' behavior patterns, is a key way to avoid repeated hospitalization of residents with dementia.

►**SCOTLAND:** Item 50 in the national dementia strategy of Scotland recognizes that giving better training in dementia care to nursing home staff members could help prevent hospitalizations of nursing home residents with dementia.

**HOME OR RESIDENTIAL CARE TO PALLIATIVE OR END-OF-LIFE CARE** Transitions to palliative care for people with dementia living at home or in residential care settings are receiving increasing attention, with the need to increase advance care planning a particular focus of interest.<sup>38</sup> Critics of this approach to improving end-of-life care point to the difficulty in ensuring advance planning, given the low diagnosis rates of dementia and difficulties with prognostication.<sup>39</sup> However, a recent consensus paper on the use of palliative care in dementia from the European Association of Palliative Care identified advance planning, improved prognostication, and the timely recognition of dying as essential elements of improved palliative and end-of-life care.<sup>38</sup>

►**AUSTRALIA:** The national dementia strategy of Australia recognizes dementia as a terminal illness and states that people should receive appropriate palliative care that is tailored to their needs. The strategy also recognizes that many people need support to engage in advance planning for end-of-life care and discusses the need to make palliative and bereavement care more available.

►**ENGLAND:** Objective 12 of England's national dementia strategy is to improve end-of-life care. The strategy argues that people should be involved in planning where they will receive that care. Like the Australian plan, the English strategy recommends advance care planning.

## Discussion And Conclusion

Several conclusions flow from these results. First, most national dementia strategies directly address improving transitions earlier in the dementia journey, but fewer of them directly address later transitions. Most strategies focus on needed actions primarily within care settings such as hospitals, instead of on transition points.

Second, national strategies vary in the degree to which they specify action plans to address transitions, even when these transitions are addressed by noting gaps in support or training. Third, most strategies emphasize preventing or delaying transitions and devote less attention to easing or facilitating transitions for people with dementia and their families.

Fourth, few strategies refer specifically to using evidence-based approaches to improve transitions. In addition, most offer little guidance about how people with dementia and their families can access services at transition points.

Finally, several national strategies refer to dementia care coordinators and advisers, but it is unclear whether these people are charged with ensuring successful transitions throughout the full journey of living with dementia. The strategies' focus seems to be on the earlier transitions in particular.

Living with progressive dementia inevitably requires transitions to sites that can provide more complex care, such as hospitals and residential care settings. To ensure that the needs of people with dementia and their families are met, national strategies need to focus explicitly on these transitions—and, ideally, to provide person-centered ways to improve them.

**POLICY RECOMMENDATIONS** Our findings and conclusions lead to several policy recommendations. First, next-generation national dementia strategies should devote equal attention to improving care within settings and to improving transitions across them. The transitions typology introduced here can help focus stakeholders' attention on how to improve each transition along the dementia journey.

For example, each country's national strategy should establish minimum clinical criteria and associated reliable and valid measures to use in establishing a diagnosis of dementia. To be consistent with a person-centered focus, we also recommend that a diagnostic procedure commence when someone expresses concern about symptoms or the person's family requests that a diagnosis be made.

Second, all countries' strategies should explicitly embrace person-centered approaches at transitions, given that this is internationally considered best practice.<sup>3</sup> Many strategies have person-centered components that focus on

achieving quality of life by meeting individuals' needs, involving people with dementia and their families in care planning, and tackling un-supportive care practices as well as stigma and discrimination. Most strategies recognize and emphasize the need for person-centered dementia training and education for practitioners and the general public. These broad components should be refined to produce a greater focus on transitions.

More creative solutions are also required, such as the use of information technology to digitally record key events in the lives of people with dementia. These records would follow people throughout the dementia journey and accompany their health and social service records as they go through different transitions.

Third, national strategies should pay greater attention to conducting research and evaluation projects and disseminating their results. For example, countries that train care coordinators to link people with dementia and their families with community services after diagnosis should conduct robust evaluations of these initiatives and report their findings. All evaluations should identify and monitor measurable outcomes that are relevant to people with dementia and their families. Strategies must also devote attention to the more effective dissemination of evidence-based innovations.

Fourth, primary care physicians and other health care practitioners, such as nurses and occupational therapists, should help craft additional action steps designed to improve the earlier transitions in the dementia journey. In addition, hospital workers, nursing home workers, and palliative care specialists should collaborate to improve the later transitions. To be consistent with a person-centered focus, we also recommend the continued active involvement of people with dementia and their families in

determining what action steps related to transitions should be included in the next-generation national strategies.

Finally, social and financial issues cannot be overlooked in any consideration of the development and implementation of national dementia strategies addressing transitions. In Australia, France, and England the public sector is primarily responsible for financing the implementation of national strategies. However, the US strategy envisions a larger role for the private sector, in partnership with federal, state, and local governments.

**CONCLUSION** In many countries, health and social care providers for older adults with dementia are in the private sector, particularly in care homes and other supervised living settings. Therefore, the private sector will have to be willing to devote time to training direct care workers—that is, personal care assistants and nursing assistants who provide hands-on care—so that the care they provide is more person centered.

The development and adoption of evidence-based measurement tools and care strategies, which are called for in many national strategies, will also require an investment of time and money—on the part of both the public and the private sector. Shared social and financial stakes will help build coordinated care pathways across the care settings where many transitions occur in the dementia journey.

In closing, we note that there have been important recent studies that compared countries in terms of their dementia strategies and service systems.<sup>40,41</sup> This article complements these studies with its focus on transitions throughout the dementia journey and its person-centered perspective on improving these transitions for everyone who is affected by dementia. ■

## NOTES

- Prince M, Prina M, Guerchet M. World Alzheimer report 2013: journey of caring: an analysis of long-term care for dementia [Internet]. London: Alzheimer's Disease International; 2013 Sep [cited 2014 Feb 27]. Available from: <http://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf>
- Gilmore-Bykovskiy A, Kind A. Transitions in dementia care. In: Downs M, Bowers B, editors. Excellence in dementia care: research into practice. 2nd ed. Maidenhead (UK): Open University Press; forthcoming.
- World Health Organization, Alzheimer's Disease International. Dementia: a public health priority [Internet]. Geneva: WHO; 2012 [cited 2014 Feb 27]. Available from: [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1)
- Downs M. Putting people—and compassion—first: the UK's approach to person-centered care for individuals with dementia. *Generations*. 2013;37(3):53–9.
- Bond J, Stave C, Sganga A, O'Connell B, Stanley RL. Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey. *Int J Clin Pract Suppl*. 2005;(146):8–14.
- Koch T, Iliffe S. Dementia diagnosis and management: a narrative review of changing practice. *Br J Gen Pract*. 2011;61(589):e513–25.
- Moniz-Cook E, Manthorpe J, Carr I, Gibson G, Vernooij-Dassen M. Facing the future: a qualitative study of older people referred to a memory clinic prior to assessment and diagnosis. *Dementia*. 2006;5(3):375–95.
- De Boer ME, Hertogh CM, Dröes RM, Riphagen II, Jonker C, Eefsting JA. Suffering from dementia—the patient's perspective: a review of the literature. *Int Psychogeriatr*. 2007; 19(6):1021–39.
- Samsi K, Abley C, Campbell S, Keady J, Manthorpe J, Robinson L, et al. Negotiating a labyrinth: experiences of assessment and diagnostic journey in cognitive impairment and dementia. *Int J Geriatr Psychiatry*. 2014;29(1):58–67.

- 10 Robinson L, Gemski A, Abley C, Bond J, Keady J, Campbell S, et al. The transition to dementia—individual and family experiences of receiving a diagnosis: a review. *Int Psychogeriatr*. 2011;23(7):1026–43.
- 11 Connell CM, Roberts JS, McLaughlin SJ, Carpenter BD. Black and white adult family members' attitudes toward a dementia diagnosis. *J Am Geriatr Soc*. 2009;57(9):1562–8.
- 12 Fortinsky RH, Zlateva I, Delaney C, Kleppinger A. Primary care physicians' dementia care practices: evidence of geographic variation. *Gerontologist*. 2010;50(2):179–91.
- 13 Downs M, Turner S, Bryans M, Wilcock J, Keady J, Levin E, et al. Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study. *BMJ*. 2006;332(7543):692–6.
- 14 Callahan CM, Boustani MA, Unverzagt FW, Austrom MG, Damush TM, Perkins AJ, et al. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *JAMA*. 2006;295(18):2148–57.
- 15 Vickrey BG, Mittman BS, Connor KI, Pearson ML, Della Penna RD, Ganiats TG, et al. The effect of a disease management intervention on quality and outcomes of dementia care. *Ann Intern Med*. 2006;145(10):713–26.
- 16 Gallagher-Thompson D, Tzuang YM, Au A, Brodaty H, Charlesworth G, Gupta R, et al. International perspectives on nonpharmacological best practices for dementia family caregivers: a review. *Clin Gerontol*. 2012;35(4):316–55.
- 17 Maslow K. Translating innovation to impact: evidence-based interventions to support people with Alzheimer's disease and their caregivers at home and in the community [Internet]. Washington (DC): Alliance for Aging Research; 2012 Sep [cited 2014 Feb 27]. (White Paper). Available from: [http://www.aoa.gov/AoA\\_Programs/HPW/Alz\\_Grants/docs/TranslatingInnovationtoImpactAlzheimersDisease.pdf](http://www.aoa.gov/AoA_Programs/HPW/Alz_Grants/docs/TranslatingInnovationtoImpactAlzheimersDisease.pdf)
- 18 Republic of France. National plan for “Alzheimer and related diseases” 2008–2012 [Internet]. Paris: Republic of France; 2008 Feb 1 [cited 2014 Feb 27]. Available from: [http://www.plan-alzheimer.gouv.fr/IMG/pdf/Plan\\_Alzheimer\\_2008-2012\\_uk.pdf](http://www.plan-alzheimer.gouv.fr/IMG/pdf/Plan_Alzheimer_2008-2012_uk.pdf)
- 19 Toot S, Devine M, Akporobaro A, Orrell M. Causes of hospital admission for people with dementia: a systematic review and meta-analysis. *J Am Med Dir Assoc*. 2013;14(7):463–70.
- 20 Covinsky KE, Pierluissi E, Johnston B. Hospitalization-associated disability: “she was probably able to ambulate, but I'm not sure.” *JAMA*. 2011;306(16):1782–93.
- 21 Coleman EA, Parry C, Chalmers S, Min SJ. The care transitions intervention: results of a randomized controlled trial. *Arch Intern Med*. 2006;166(17):1822–8.
- 22 Naylor MD, Brooten DA, Campbell RL, Maislin G, McCauley KM, Schwartz JS. Transitional care of older adults hospitalized with heart failure: a randomized, controlled trial. *J Am Geriatr Soc*. 2004;52(5):675–84.
- 23 Burton R. Health Policy Brief: improving care transitions. *Health Affairs* [serial on the Internet]. 2012 Sep 13 [cited 2014 Feb 27]. Available from: [http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief\\_id=76](http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=76)
- 24 Whall AL, Kolanowski AM. The need-driven dementia-compromised behavior model—a framework for understanding the behavioral symptoms of dementia. *Aging Ment Health*. 2004;8(2):106–8.
- 25 Norwegian Ministry of Health and Care Services. Dementia plan 2015 [Internet]. Oslo: Ministry of Health and Care Services; [cited 2014 Feb 27]. Available from: <http://www.regjeringen.no/upload/HOD/Dokumenter%20KTA/DementiaPlan2015.pdf>
- 26 Gaugler JE, Yu F, Krichbaum K, Wyman JF. Predictors of nursing home admission for persons with dementia. *Med Care*. 2009;47(2):191–8.
- 27 Davies S, Nolan M. “Making the best of things”: relatives' experiences of decision about care-home entry. *Ageing Soc*. 2003;23(4):429–50.
- 28 Davies S, Nolan M. “Making it better”: self-perceived roles of family caregivers of older people living in care homes: a qualitative study. *Int J Nurs Stud*. 2006;43(3):281–91.
- 29 Mittelman MS, Haley WE, Clay OJ, Roth DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*. 2006;67(9):1592–9.
- 30 Kane RA, Lum TY, Cutler LJ, Degenholtz HB, Yu TC. Resident outcomes in small-house nursing homes: a longitudinal evaluation of the initial Green House program. *J Am Geriatr Soc*. 2007;55(6):832–9.
- 31 Koren MJ. Person-centered care for nursing home residents: the culture-change movement. *Health Aff (Millwood)*. 2010;29(2):312–7.
- 32 Ouslander JG, Lamb G, Tappen R, Herndon L, Diaz S, Roos BA, et al. Interventions to reduce hospitalizations from nursing homes: evaluation of the INTERACT II collaborative quality improvement project. *J Am Geriatr Soc*. 2011;59(4):745–53.
- 33 Loeb M, Carusone SC, Goeree R, Walter SD, Brazil K, Krueger P, et al. Effect of a clinical pathway to reduce hospitalizations in nursing home residents with pneumonia: a randomized controlled trial. *JAMA*. 2006;295(21):2503–10.
- 34 Lisk R, Yeong K, Nasim A, Baxter M, Mandal B, Nari R, et al. Geriatrician input into nursing homes reduces emergency hospital admissions. *Arch Gerontol Geriatr*. 2012;55(2):331–7.
- 35 Olsan TH, Sweet R, Tourje N, Bioso J. Reducing avoidable rehospitalizations by improving residents' transitions to the nursing home. *J Am Med Dir Assoc*. 2011;12(3):B22.
- 36 Tena-Nelson R, Santos K, Weingast E, Amrhein S, Ouslander J, Bookvar K. Reducing potentially preventable hospital transfers: results from a thirty nursing home collaborative. *J Am Med Dir Assoc*. 2012;13(7):651–6.
- 37 Young Y, Inamdar S, Dichter BS, Kilburn H, Hannan EL. Clinical and nonclinical factors associated with potentially preventable hospitalizations among nursing home residents in New York State. *J Am Med Dir Assoc*. 2011;12(5):364–71.
- 38 Van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med*. 2014;28(3):197–209.
- 39 Froggatt K, Goodman C. Palliative care. In: Downs M, Bowers B, editors. *Excellence in dementia care: research into practice*. 2nd ed. Maidenhead (UK): Open University Press; forthcoming.
- 40 Nakanishi M, Nakashima T. Features of the Japanese national dementia strategy in comparison with international dementia policies: how should a national dementia policy interact with the public health- and social-care systems? *Alzheimers Dement*. [Epub ahead of print].
- 41 Rosow K, Holzapfel A, Karlawish JH, Baumgart M, Bain LJ, Khachaturian AS. Countrywide strategic plans on Alzheimer's disease: developing the framework for the international battle against Alzheimer's disease. *Alzheimer Dement*. 2011;7(6):615–21.



Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.