

2020 FORESIGHT:

# San Francisco's Strategy For Excellence In Dementia Care

Research, recommendations, and an action plan to address the growing crisis in dementia care, and an economic analysis of that care.



## Part Two of Two

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*By Alzheimer's/Dementia Expert Panel*

*For Department of Aging and Adult Services*

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## Appendix I: Evidence Based Practice & Emerging Research

### 1. OVERVIEW

The Best Practice summary that follows was developed by the Evidence-Based Practice and Emerging Research Subcommittee and the Research Team. This summary was based on an evaluation of over 160 documents, many of which were identified by the Alzheimer's/Dementia Care Expert Panel. A priority was given to documents published in 2003 or later. Research was reviewed from England, Scotland, Sweden, Australia, New Zealand, Korea, Canada, and the United States. The scope of the review included an examination of evidence-based approaches to:

- Each component of care for those with cognitive impairment, e.g. diagnosis, pharmacological treatment, caregiver support, including education and prevention; and
- How other public health and social welfare challenges have been addressed through the implementation of a 'system of care' approach that integrates and coordinates services and supports; and
- Dementia-focused capitated systems such as those in Canada, Australia, England and Scotland, as well as locally developed closed systems like On Lok's PACE model.

Among one of the more interesting discoveries in conducting the research was meeting Esther. "Esther" was invented by a team of physicians, nurses, and other providers who joined together to improve patient flow and coordination of care for elderly patients within a six-municipality region in Sweden. "Esther" is not a real patient, but her persona as a gray-haired, ailing, but competent elderly Swedish woman with a chronic condition and occasional acute needs has inspired impressive improvements in how patients flow through a complex network of providers and care settings. The Esther Project is essentially predicated upon the premise that system changes are best designed by adopting the perspective of the patient, Esther. While not focused upon patients with cognitive impairment, Esther is organized around creating a system of care that is responsive to the needs of frail, chronically ill older adults.

The Esther Project team has become one of two international teams participating in the Pursuing Perfection initiative. This program, launched by The Robert Wood Johnson Foundation (RWJF), is designed to help physician organizations and hospitals dramatically improve patient outcomes by pursuing perfection in all their major care processes. The Institute for Healthcare Improvement serves as the National Program Office for this RWJF initiative. During the three-year project, the Esther Team was able to achieve the following improvements:

- Hospital admissions fell from approximately 9,300 in 1998 to 7,300 in 2003.
- Hospital days for heart failure patients decreased from approximately 3,500 in 1998 to 2,500 in 2000.
- Waiting times for referral appointments with neurologists decreased from 85 days in 2000 to 14 days in 2003.
- Waiting times for referral appointments with gastroenterologists fell from 48 days in 2000 to 14 days in 2003.

Beyond these gains, through an exhaustive number of interviews with patients, nurses, doctors and caregivers, it achieved a sensitive understanding of life as Esther lives it. The Esther Project grew

from a need that many US health systems share: to improve the way patients flow through the system of care by strengthening coordination and communication among providers. The url below provides a link to the Esther home page and the cover article provides compelling evidence of the benefits of planning from a patient-centered perspective.

<http://www.ihl.org/IHI/Topics/Flow/PatientFlow/ImprovementStories/ImprovingPatientFlowTheEstherProjectinSweden.htm>

## 2. SYSTEMS: HOW DO THE BEST SYSTEMS OF CARE FUNCTION?

Currently, San Francisco does not offer a seamless system of services for the care of individuals with dementia and faces organizational, fiscal and regulatory barriers to operating in such a manner. Instead, San Francisco has an open network of public and private non-profit as well as for-profit service providers that together offer a range of dementia care services. These are provided within San Francisco's larger long term care service delivery network.

Nonetheless, the intent of the Expert Panel was that the planning process should identify ways in which dementia care services could be delivered in a more comprehensive, coordinated and integrated manner so that the client experience is seamless with well-coordinated transitions in care and well-coordinated linkages to all services and supports. Panelists suggested that what should be considered is the integration of care for cognitive impairment into the larger framework of health, social services, and housing. This is because the broader health, social services, and housing context is so intertwined with effectively addressing the quality of life of individuals with cognitive impairment. To fully address the needs of individuals with cognitive impairment requires delivering as comprehensive an array of services, as seamlessly as possible. To achieve this purpose, there is much to learn from how:

- Other countries have operated systems to serve individuals with cognitive impairment;
- Closed systems of care for cognitive impairment have been developed in the United States;
- Systems have been developed in the United States to address other populations.

### *Systems of Care including Health and Social Services*

Regardless of cross-national differences in the delivery of long-term care, countries confront similar challenges, including fragmented services, disjointed care, less-than-optimal quality, system inefficiencies and difficult-to-control costs. Integrated or whole-system strategies are becoming increasingly important to address these shortcomings through the seamless provision of health and social care.<sup>1</sup> The effective treatment of cognitive impairment requires a broad array of services delivered by professionals, paraprofessionals, and informal caregivers, in the home, community and in health care and assisted living environs. This care involves medical, mental health, housing and financial systems support.<sup>2</sup> The effort to improve the effectiveness of this multi-faceted challenge has led to "investigation of whole system approaches to improve the manner in which sectors, institutions, providers and services work in tandem as a long-term care enterprise."<sup>3</sup>

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<sup>1</sup> Kodner, D.L., *Whole system approaches to health and social care partnerships for the frail elderly: an exploration of North American models and lessons*, Health and Social Care in the Community, 14(5), 384-400, 2006.

<sup>2</sup> Feder, J., Komisar H. & Niefeld M. *Long-Term Care in the United States: An Overview*. Health Policy 19, 40-56. 2000.

<sup>3</sup> Kodner, D.L., *The quest for integrated systems of care for frail older people*, Aging Clinical and Experimental Research, 14(4), 307-313.

At the core of a systems approach, is an integrated approach to care that Kodner defines as “a discrete set of techniques and organizational models designed to create connectivity, alignment, and collaboration within and between the cure and care sectors at the funding, administrative and provider levels.”<sup>4</sup> According to Leutz, integrated care comes in three varieties: 1) *Linkages*. Where health and social service providers still operate in silos while attempting to collaborate and coordinate across systems; 2) *Coordination*, which involves the ‘rebalancing’ of systems with the design of purposeful bridges to integrate silos, share information and improve coordination; and 3) *full integration*, which results in fully shared fiscal and service responsibility, global management and unified service delivery. San Francisco operates somewhere in between delivery of linked and coordinated services.

There is a growing body of research that describes whole system models, particularly those that are prototypes that are nested under one roof in an integrated health and social care system. These studies indicate that a ‘whole systems’ approach to support to individuals with cognitive impairment improves consumer outcomes, reduces stress on caregivers, and reduces public expenditures.<sup>5</sup> The thirty nations that comprise the Organization of Economic Co-Operation and Development (OECD) have recently promoted policies of deinstitutionalization and community-based care for the elderly. These policies respond to common cost pressures associated with population aging, and the challenge of providing improved care for the elderly. They aim to substitute less costly services for institutional care, to improve patient satisfaction and decrease public expenses.

Johri, Beland and Bergman took a comparative cross-national approach to identify common features of an effective system of integrated care, and to examine the potential of such models to positively affect both the care of the elderly, and the cost to public finances. They conducted a systematic review of recent demonstration projects testing innovative models of care for the elderly in OECD countries. Projects included aimed to create comprehensive integration of acute and long-term care services, and were evaluated using a comparison group. For each project, Johri, Beland and Bergman reported on available results on rates of hospitalization, long term care institutionalization, utilization and costs, impact on process of care, and health outcomes. In addition, the following common features of an effective integrated system of care were identified:

- A single entry point;
- Case management, geriatric assessment and a multidisciplinary team; and
- Use of financial incentives to promote utilization of lower levels of care.

Johri, Beland and Bergman concluded community-based care can impact favorably on rates of institutionalization and cost of care. They also concluded that comprehensive approaches to program restructuring are necessary, as cost-effectiveness depends on characteristics of the system of care.<sup>6</sup>

Senin, Cherubini, Mecocci studied the management of frail elderly subjects, using a "comprehensive geriatric assessment", as well as a model of long-term care developed in Italy. This approach was shown to reduce the risk of hospitalization and nursing home admission, with a parallel decrease in expenses and an improvement in the patient's quality of life. The effectiveness of the long-term care system depended on: 1) the availability of all the services that are necessary for the frail elderly, both in the hospital and in the community; 2) the presence of a coordinating team, the comprehensive geriatric assessment team, which develops and implements the individualized treatment plans,

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<sup>4</sup> Ibid.

<sup>5</sup> Ibid

<sup>6</sup> Johri M., Beland F., and Bergman H., *International experiments in integrated care for the elderly: a synthesis of evidence*. International Journal of Geriatric Psychiatry, 18(3): 222-35. March 2003.

identifies the most appropriate setting for each patient and verifies the outcomes of the interventions; 3) the use of common comprehensive geriatric assessment instruments in all the settings; and 4) the gerontological and geriatric education and training of all the health care and social professionals.<sup>7</sup> The study suggests that the ‘whole system’ approach extends beyond service delivery and includes the use of a common language, instruments and tools, systematic reflection on patient outcomes to verify the most effective interventions, and a professional education system that supports whole system approaches and the use of effective, research-based practices.

Three models will be examined of whole systems approaches to care for individuals with cognitive impairment: 1) PACE; 2) SIPA; and 3) PRISMA.

### ***Program of All-inclusive Care for the Elderly (PACE)***

Established in 1971 and expanded with federal demonstration funding from 1987-1997, PACE has operated as a fully integrated system that provides acute and long-term care services coordinated by and organized around an adult day health center. Adapted by On Lok, and based upon the British day hospital approach to care, PACE offers adult day health center services integrated with geriatric primary care health, social and respite services, woven together by a case management system. The goal of the program is to maintain frail older individuals in the community for as long as possible. The program targets individuals who are eligible for Medicare and Medicaid. PACE emphasizes the role of informal caregivers and incorporates linkages with limited supportive housing resources.

PACE is a provider under Medicare and a state option under Medicaid. As of January 2005, there were 36 PACE programs in 18 states serving over 10,500 people with the average age of participants of 80 years, with 49% having been diagnosed with dementia. Elements of integration include:

- ***Financing.*** Pooled Medicare and Medicaid revenues along with total control over all program expenditures in a fully capitated system;
- ***Service delivery.*** Services are delivered staff of an adult health care center or through contracts for specialty medical services, acute hospitalization, and nursing home care;
- ***Multidisciplinary case management.*** Responsible for comprehensive assessment, service provision, care coordination, and clinical monitoring;
- ***Focus on prevention.*** Emphasis upon consolidated service delivery, system efficiencies; and risk-based capitation.

The US Health Care Financing Administration financed a qualitative evaluation conducted by Kane et al and a quantitative evaluation conducted ABt Associates. Kane et al and Zimmerman et al found the PACE model to be an effective integration mechanism<sup>8</sup>. Researchers emphasized the highly personalized service delivery and high client satisfaction.<sup>9</sup> Participation in PACE was associated with a decrease in hospital use, reduced institutionalization, balanced with substantial increases in utilization of outpatient medical care as well as home-based support.<sup>10</sup> Chatterji et al also found favorable measures in terms of client health status and overall satisfaction. Overall,

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<sup>7</sup> Senin U., Cherubini A., and Mecocci P. *Impact of population aging on the social and the health care system: need for a new model of long-term care. Annals of Italian Medicine International.* 18(1):6-15. Jan-Mar 2003.

<sup>8</sup> Kane, R., Illsont L., & Miller N., *Qualitative analysis of the program of all inclusive care for the elderly (PACE).* The Gerontologist 32, 771-780. 1992.

<sup>9</sup> Zimmerman Y., Pemberton D. & Thomas L. *Evaluation of the Program of All-Inclusive Care for the Elderly (PACE): Factors Contributing to Care Management and Decision-making in the PACE Model.* US Health Care Financing Administration, 1998.

<sup>10</sup> Chatterji P., Burstein N., Kidder D. & White A. *Evaluation of the Program of All-inclusive Care for the Elderly (PACE) The Impact of PACE on Participant Outcomes.* US Health Care Financing Administration, Baltimore. 1998.

evaluations found that PACE is a successful, cost-effective model for managing and maintaining elderly individuals in the community.

Kodner et al also found that key features to the PACE model limit the scalability (scalability is the terminology used in the research) of the model. Specifically, without the assistance and cooperation of the federal and state governments, substantial capital and start-up costs in the millions of dollars are difficult to generate privately and to obtain necessary state waivers, a sponsoring organization must also secure letters of credit, reinsurance, and other required financial documents. Secondly, many elderly do not elect to participate if they are not comfortable with the adult day care setting. Finally, the small size of each program site, serving around 300 clients, makes replication contingent upon multiple adult day care center sites to serve as the hub of the system.

The John A. Hartford Foundation has been a sponsor of the PACE model, providing over \$3.5 million in start-up funding to support the National PACE Association, for technical assistance to local communities interested in creating PACE model programs and assisting in accessing requisite start-up funding. It identified a range of options for financing start-up including tax-exempt bonds, foundation investments, and equity transfer from sponsoring health systems.

### ***System of Services Integrated for Person who are Aging (SIPA)***

Developed at McGill University/Universite de Montreal Research Group is a community-based, primary-care led, case managed health care system for the frail elderly. Operating at two Canadian *centers of local community services (CLCS)*, from June 1999-March 2001 *SIPA* served 160 clients at each site. As with PACE, the majority of services were delivered at the CLCS with specialty medical services, hospitalization and nursing home services provided under contract. Key features included:

- ***Multidisciplinary team*** comprised of therapists, home care workers, pharmacists, nutritionists, a personal physician, with a nurse or social worker serving as the care coordinator;
- ***Commitment to Evidence-based Geriatric techniques*** including multidisciplinary clinical protocols, intensive home care, 24-hour on-call responsibility are all organized around reducing inappropriate institutionalization and maintain community living;
- ***Simulated prepaid capitation system*** that was never fully implemented, but nonetheless retained a flexible use of funds and close scrutiny of costs of care.

SIPA is the only North American integrated whole system model to be evaluated through a randomized control trial. Beland reported the program was highly effective in increasing access to community-based health and social services and reduced hospitalizations by 50%<sup>11</sup>. While SIPA reduced length and cost of emergency room stays, increased the likelihood of returning home after an emergency room stay, and reduced the cost and length of institutionalization, these savings were offset by the increase in the cost of community-based care. Moreover, there were no differences in health outcomes or total costs between experimental and control groups. As a result of the mixed results, the Quebec government discontinued the program while considering how to incorporate elements of the model.<sup>12</sup>

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<sup>11</sup> Beland F., et al, *A system of integrated care for older persons with disabilities in Canada: results from a randomized control trial. Journal of Gerontology: Medical Sciences 367-373. (2006).*

<sup>12</sup> Hollander M., Miller J., Ritter R., MacAdam M., & Straka. *The Cost-Effectiveness and Cost-Benefit of Home and Community Care within the Broader Continuum of the Health System. Report Prepared for Home and Continuing Care Unit, Health Services Division, Health Canada. Hollander Analytical Services Ltd, Victoria.*

## ***PRISMA (Canada)***

The PRISMA model is composed of six main integrating elements:

- ***Inter- and intra-organizational coordination*** provided by a joint governing board on the governance level and a service coordination committee on the managerial level;
- ***Single-point-of-entry mechanism*** allowing access to all covered healthcare and social services;
- ***Clinical care management*** through a team of case managers who with both physicians, providers and family members;
- ***Common assessment instruments, clinical charts, and care plan***
- ***Capitated financial structure***
- ***Integrated information system*** including computerized tools, automated clinical records and patient utilization data.

A three-year quasi-experimental study was undertaken with measurements taken at 12 month intervals<sup>13</sup> that found a declining trend in institutional care, improved functional autonomy with more frail patients for two years and had a positive effect on caregiver burden. However, the intervention failed to alter use of services or impact mortality.

### **General Findings about Whole System Care**

Leutz found that integration must be customized to local conditions and Hudson et al found that success depends to a significant degree upon local leadership forging local partnerships rather than through top-down structural reforms. These two factors make generalizing about replication of models very difficult. Kodner identified four key factors that contributed to successful implementation of whole system models:

- ***Umbrella organizational structures*** that facilitate integration of services at the administrative, managerial and service provision levels;
- ***Multidisciplinary case management*** with a single point of contact that facilitates care planning and evaluation;
- ***Organized provider networks*** bound by standardized assessment, referral and service agreements that provide a seamless and uniform service experience;
- ***Financial incentives or structures*** that promote the utilization of prevention strategies and interventions that foster efficiency and lower levels of care.

### ***San Mateo County, San Mateo, CA***

This project is a Program Enhancement of a project funded by a FY2004 AoA Integrated Care Management grant. Utilizing two years of federal demonstration funding, San Mateo County Aging and Adult Services established the Integrated Information Project, a component of the effort to achieve a fully capitated Medicare/Medicaid long-term care system. The Integrated Information Project involves implementation of a uniform assessment tool using a single automated case management system for all members of the target population entering home and community-based long-term care services in the county. No evaluation data on this demonstration has been identified.

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<sup>13</sup> Tourigny et al, *Evidence in action, acting on evidence, PRISMA: Developing integrated services delivery for functional autonomy*, Canadian Institutes of Health Research 2004.



## Conclusion

Taken together, the components and qualities of an effective whole system approach include:

- Oversight body that incorporates administration, management, line staff and caregivers that carefully review utilization data, satisfaction surveys, financial data, and current research;
- Integrated financial system or shared financial risks and incentives;
- Automated data system with electronic patient records and shared information across service sites;
- Emphasis upon the use of evidence based practice to inform use of effective strategies that maintain individuals at ever lower levels of care and within the community;
- System wide adherence to ‘guidelines’ that outline recommended interventions and protocols;
- Use of common assessment tools and referral criteria;
- Strong education and support for caregivers;
- Seamless referral strategies for treatment for co-morbid conditions and during transitions between home care, institutional care, hospitalization, and nursing care with adult day health care programs at the hub of the system of services; and
- Case management or care coordination creating a single point of contact and consistent assistance in navigating the varied services and supports required.

Achieving a fully coordinated, integrated and whole system approach for the delivery of health and social services in San Francisco would require significant start-up investments, the support and encouragement of the state and federal government, and a significant investment in system-wide planning. As even a mid-term goal, this may be asking more than a financially strapped public and private sector can bear. However, given the new administration’s interest in bold investments to stimulate the economy, at least conceptualizing how to incorporate features of effective systems into San Francisco’s open network of care may be a worthwhile activity. At worst, it provides a map of the most effective and efficient means of coordinating care, reducing stress on caregivers, and improving the quality of life of individuals with cognitive impairments.

## 3. EDUCATION & PREVENTION: WHAT WORKS?

This section describes the ways in which education and prevention strategies can reduce the impact of dementia upon people with dementia, on their caregivers, and on the public. Since there is no viable intervention that can actually *prevent* dementia, risk-reduction strategies are presented here that can delay progression and suppress the negative impact of some symptoms. But dementia is inexorable and there is no pharmacological or non-pharmacological treatments that can fully prevent progression, only moderate it somewhat. In this context, prevention involves implementation of key interventions proven to delay progression and help individuals remain in lower cost, less restrictive environments for as long as possible. Where education and prevention come together is that for ‘prevention’ or risk reduction strategies to achieve their maximum benefit, they must be implemented on a timely basis. For that to occur, primary care doctors, nurses, attendants, and caregivers must be aware of indicators of specific symptoms and they must know the correct intervention.

Effective ‘prevention’ strategies are identified in most every section of this report. However, accompanying the description of each one is invariably research showing that these research-based strategies are under-utilized. *What is needed is an effective means of educating providers and caregivers so that the right knowledge is both available and utilized at precisely the right moment.* As described below, current education and training approaches are not achieving the intended results: primary care, emergency room doctors and other healthcare staff do not have consistent, current knowledge of resources and treatment alternatives and consistently miss opportunities for early identification, diagnosis and referral. While there are excellent inventories and guidelines outlining what works, this information simply is not considered consistently at the moments when the information is most needed. This section concludes with reference to Section IV.C. as in the research on care coordination may lie solutions that could facilitate access to the most important information at the most timely moments.

### ***The Importance of Prevention or Risk Reduction Strategies***

The World Health Organization (WHO) identifies three successive stages of prevention:

- ***Primary prevention.*** This stage of prevention covers all activities designed to ‘reduce’ the instances of an illness in a population and thus to reduce, as far as possible, the risk of new cases appearing. In relation to dementia, currently there is no treatment or intervention that has been proven to prevent onset of dementia.
- ***Secondary prevention.*** This covers activities aimed at reducing the prevalence of an illness in a population and thus to reduce its duration. Except in relation to a small number of reversible forms of dementia generally caused by other treatable co-morbid conditions, there is no treatment or intervention that can reverse or reduce the duration of dementia.
- ***Tertiary prevention.*** This aims to reduce the incidence of chronic incapacity or recurrences in a population, and thus to reduce the functional consequences of an illness, i.e. therapy, various rehabilitation techniques and intervention designed to assist the patient to return to educational, family, professional, social and cultural life. Here, too, there is no treatment that can restore functioning and assist a person with dementia to a prior level of functioning.

There are currently no proven measures or treatments that prevent dementia and the causative factors are considered too complex to make general population screening possible.<sup>14</sup> Further, while there is a substantial body of research that suggest the onset and progression of dementia and other forms of cognitive impairment can be delayed, there is no cure.

Therefore, in this report, prevention is more accurately described as *risk reduction strategies* that slow progression of the disease, effectively treat or prevent co-morbid conditions, improve patient quality of life, ease caregiver burden and reduce reliance on high-end assisted living, hospitals and skilled nursing facilities. In this regard, subsequent sections of this report identify numerous treatments and interventions that have been demonstrated to delay progression and alleviate symptoms that left unchecked result in institutionalization.

While they do not meet the classic definition of a prevention strategy, nonetheless, the effective, broad and consistent implementation of these practices can reduce patient suffering, caregiver stress, and public costs.

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<sup>14</sup> National Institute of Health and Clinical Excellence and Social Care Institute for Excellence, *Dementia: Supporting People with Dementia and their Caregivers*, 2006.

In respect of Alzheimer's disease alone (given that Alzheimer's accounts for 59% of all cases of dementia), Access Economics estimates<sup>15</sup> that, if from 2005 the average onset of Alzheimer's could be delayed by:

- 5 months, there would be a 5% reduction in new cases each year. This would result in 3.5% fewer cases by 2020 (4,583) and 4.8% fewer cases by 2040 (18,970).
- 5 years, there would be a 50% reduction in new cases each year. This would result in 35.2% fewer cases by 2020 (46,568) and 48.5% fewer cases by 2040 (96,690)
- In 2004, assuming that Alzheimer's disease costs some 59% of the cost of all dementias, and allowing for increased prevalence due to demographic aging and cost increases of 2.5% per annum between 2002 and 2004, the cost of Alzheimer's disease in Australia is estimated by Access Economics to be \$3.6 billion.

On the basis of their modeling, Access Economics has presented cumulative savings scenarios. If the average onset of Alzheimer's disease was reduced by 5 months from 2005, then by 2020 cumulative savings of \$1.3 billion would be realized and by 2040, \$6.6 billion. If the average onset of Alzheimer's disease was reduced by 5 years from 2005, then by 2020 cumulative savings of \$13.5 billion would be realized and by 2040, \$67.5 billion. The savings in terms of human suffering are immeasurable.

To achieve these savings, it is imperative to identify dementia early. Changes in memory can be detected up to 10 years before dementia is diagnosed<sup>16</sup>. Research has revealed some of the factors that increase the risk of dementia. Modifying these factors may prevent or delay the onset of dementia. Greater understanding of the neurodegenerative processes involved in dementia has opened avenues for the development of new treatments. An important discovery is that vascular disease plays a large role not only in vascular dementia, but also in Alzheimer's disease<sup>17</sup>. There are a multitude of ways that cardiovascular risk factors interact with Alzheimer's disease. Diabetes increase the risk threefold for Alzheimer's disease possibly by diminishing the ability to clear Alzheimer's disease related proteins and ischemic injury to the brain lowers the threshold for the expression of a dementia associated with Alzheimer's disease pathology.

Risk factors for vascular disease include high blood pressure, cholesterol and homocysteine, diabetes, smoking and obesity. These risk factors in midlife and beyond have been linked to decline in cognition and risk of dementia. Diet influences risk of dementia. Foods or supplements containing antioxidants or omega-3 fatty acids have been found to be protective but consumption of foods high in total and saturated fat and cholesterol increase risk. Activity levels also moderate dementia risk. Higher levels of leisure, physical and mentally stimulating activity in elderly people are associated with lower rates of dementia. This is consistent with the protective effect of formal education over and above socioeconomic status. Public health intervention for modifiable risk factors can prevent or delay dementia onset at the population level. For example, a randomized controlled study of hypertension treatment reduced the risk of dementia by 55% after 4 years.

Among the conditions that are associated with reduced risk of dementia or delayed onset:

- Hypertension treatment for subjects with high blood pressure;
- Normal midlife blood pressure;
- Normal midlife cholesterol;
- Weekly fish or seafood consumption;

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<sup>15</sup> Dementia Estimates and Projections: Victoria and its Regions, A Report by Access Economics PTY Limited, (Feb 2005)

<sup>16</sup> Ibid

<sup>17</sup> Ibid

- Moderate wine consumption (8 to 14 drinks per week)
- Use of Vitamin E and C supplements;
- Highest quintile of dietary Vitamin E intake;
- High leisure activity;
- High physical activity
- Frequent cognitive exercise (top 10%); and
- More than two years of non-steroidal anti-inflammatory drug users.

Many of the above have small correlations with reduced incidences of dementia and it should not be understood to suggest that keeping fit and eating well can prevent dementia, only that such behaviors can lead to a reduced prevalence in some forms of mostly vascular-related dementias across a large population.

In addition to there being opportunities for delaying the onset of dementia, there has been substantial improvement in clinical diagnosis of the different dementias. Earlier diagnosis provides benefits for both the person with dementia and the person's family through treatment, support and planning. This will become more important as disease-modifying treatments become available. As the following section suggests, beginning with diagnosis and extending through all stages of treatment, the gap between what we know and what we do has significant impact upon the quality of care, patient quality of life, caregiver burden and public and private costs for care.

***Missed Opportunities: When Knowledge is not Translated into Practice***

To understand the critical importance of ensuring that education and training efforts translate into common practice, brief references are made to sections of this report. Each one provides evidence of the availability of knowledge, best practice, community resources, treatments and interventions each of which have improved the quality of care, reduced patient suffering, delayed functional decline, eased caregiver burden and most often reduced public expenditures. Yet, research shows the knowledge of these options has not consistently translated into common practice. In short, the knowledge available is not at the fingertips of those responsible for making critical decisions about patient care and caregiver support. ***It is important not to interpret the following summary of Section 4. SERVICES & SUPPORTS, starting on page 19, as an indictment of medical practice as relates to dementia. It is simply the case that much more is known about caring for people with dementia than health professionals can possibly have at their fingertips and, with rare exceptions, no systems are in place to address this systemic weakness.***

- Sections 4. A and B describe the billions of dollars in cost savings that could result from earlier identification and referral of dementia and the failure to diagnose and treat co-morbid conditions effectively. People with dementia in early stages manifest symptoms that while subtle and similar to normal memory loss, nonetheless are detectable and then diagnosable if the correct diagnostic tools are utilized. Yet, half of all cognitive impairments are never formally diagnosed. Failure to identify and diagnose dementia in early stages represents a missed opportunity for care planning, early pharmacological and non-pharmacological interventions, and education of caregivers, which collectively can significantly slow progression and reduce the burden of caregiving. Expert panelists noted the impact of missed diagnoses where individuals with mild to moderate cognitive impairment present at emergency rooms or primary care clinics and despite being seriously disoriented, obtain only treatment for physical ailments without addressing disorientation. But too often primary care doctors, emergency technicians or doctors, nurses, or caregivers overlook the symptoms and fail to seek or prescribe tests to obtain a diagnosis.

- Section 4. C describes the benefit of non-pharmacological interventions available in the community, while noting that out of absence of information about these resources, most often primary care doctors prescribe drugs, but do not make referrals to community resources. Partners in Dementia Care, a New York state partnerships with the Veterans Administration demonstrated that pairing primary care doctors with care coordinators who were current on all the available interventions and community resources and could assist the caregiver in getting trained and educated, resulted in significant reductions in stress on the caregiver, reduced instances of depression, and improved quality of care.
- Section 4. D describes the devastating effect of incorrect prescriptions for medications to control behaviors or depression, the negative impact of primary doctors selecting the wrong cholinesterase inhibitors for the specific stage of cognitive impairment. In Expert Panel meetings, expert panelists described this as being commonplace and gave examples of the crippling effects of drug interactions or prescription of drugs for depression that significantly accelerated functional decline.
- Section 4. E describes the availability of numerous interventions that reduce costs, improve or slow the loss of memory, manage behaviors, and maintain physical functioning. Yet one study of 240 dementia patients revealed that a chart review found absolutely no evidence of referral for anything other than pharmacological treatment. Caregivers were not sent to education programs, exercise, nutrition, and adult day care programs were not suggested, and patients were not referred to memory exercise programs and other community-based resources that can slow the progression of functional decline. The potential benefit of sensitivity to environmental factors is also described that can reduce patient stress and alleviate other behavioral symptoms, e.g. adjustments in lighting to treat sleep disorders. Yet, too often environmental modifications are not evident in residential programs or recommended for patients still living at home.
- Section 4. F describes the tremendous benefit to the patient and the significant reduction in public expenditures that result from individuals remaining in the home as long as possible. One study<sup>18</sup> projected that simply delaying by one month entry into skilled nursing facilities would result in savings of \$1.2 billion annually. Here caregiver education is of tremendous importance and the failure of health professionals to refer caregivers to resources like the Family Caregiver Alliance or the Alzheimer's Association results in caregivers lacking an understanding of how to modify their home environment, provide effective home support, modify behaviors and being familiar with alternative treatment options and community resources, or just understanding the condition and its progression so that care planning can be made in advance. Yet, far too often referral to these sources does not occur, first because the diagnosis does not occur as early as possible and second because primary care doctors do not systematically make these referrals.
- Section 4. G describes co-morbid conditions and how they can be identified and treated. Here again, it is too often a story of missed opportunities. Expert Panelists commented about how common it is for co-morbid conditions to be misdiagnosed or mistreated, particularly in relation to behavioral conditions. Here the consequences of prescribing the wrong medication can lead to significant and unnecessary complications. Many behavioral problems can be addressed with environmental modifications. Since behavioral problems are one of the most common reasons that caregivers ultimately place their loved ones in assisted living programs, being adept at balancing pharmacological and environmental modifications can significantly reduce reliance on more restrictive levels of care.

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<sup>18</sup> Leon, Cheng, and Neumann, 1998.

- Sections 4. H and I describe how adult day health care, social day care centers and Alzheimer's Day Care Resource Centers can significantly slow the progression of cognitive decline while also easing the burden placed upon caregivers, particularly in early and mid stages of cognitive impairment. Unfortunately, primary care physicians do not routinely refer patients and caregivers to these resources.
- Section 4. J describes a summary of strategies for supporting caregivers with one large study indicating that caregiver education and referral to community resources can lead to improved outcomes for both the caregiver and patient.<sup>19</sup> Indeed in no less than 19 studies psycho-educational programs have been shown to be one of the most effective interventions with the broadest impact upon caregivers and patients.<sup>20</sup> As noted above, however, too often caregivers are not referred to resources that will provide the beneficial education, training and community resources: another missed opportunity.
- Section 4. K describes various kinds of assisted living or Residential Care Facilities for the Elderly (RCFE) and the extent to which regulations proscribe wholly insufficient levels of training for staff in these programs. The failure to adequately train staff in RCFEs often results in patients being referred to skilled nursing facilities before this would be necessary if staff had been better trained to address patient needs, particularly in relation to behavioral problems.
- Section 4. L describes skilled nursing facilities and their care for individuals in mid to late stages of dementia. San Francisco is blessed with two extraordinary such facilities (Laguna Honda Hospital and the Jewish Home). However, as in other jurisdictions, the failure of the network of services and supports to identify and implement effective risk reduction strategies leads to increasing numbers of individuals being discharged from assisted living facilities sooner than would have otherwise been the case. The result is the demand for skilled nursing facilities far outstrips the supply, a situation that will only worsen significantly as San Francisco's baby boomer generation ages.
- Finally, Section 4. M describes a discussion of end-of-life and hospice care. Here unlike elsewhere, the real problem is applying too much of what is known to intervene and extend life with medical interventions (feeding tubes, etc.). Extending the life of individuals with advanced dementia may only extend suffering and create more stress on loved ones who struggle with the moral implications of making the difficult decision to cease efforts to extend life.

In all instances cited above, it is not the lack of information in the literature about the benefits of specific interventions and strategies. It is the failure of that information to be translated into common practice that results in preventable human suffering, caregiver burden and public costs.

Each of the above examples represent missed opportunities to implement effective strategies that either reduce symptoms, slow the advance of the condition, and/or improve the capacity of caregivers to support the individual with a cognitive impairment. ***The problem is not with individual doctors, other health professionals, or individual hospitals that are indifferent to the need to what is best for patients. The problem is systemic: with too much information that changes frequently, there is no system for ensuring that those responsible for patient care and caregiver support, have the information they need, when they need it. In the absence of such a system, the story of the crisis in dementia care will be a litany of missed opportunities, unnecessary human suffering, and avoidable public expenditures.***

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<sup>19</sup> Feil, D. G., MacLean, C., & Sultzer, D. (2007). Quality indicators for the care of dementia in vulnerable elders. *Journal of the American Geriatrics Society*, 55, S293-S301.

<sup>20</sup> Feil, D. G., MacLean, C., & Sultzer, D. (2007). Quality indicators for the care of dementia in vulnerable elders. *Journal of the American Geriatrics Society*, 55, S293-S301.

## ***Education Strategies***

Education strategies have the potential for significantly improving the quality of care for individuals with cognitive impairment, improving their quality of life, reducing the amount of time spent in more expensive, more restrictive settings, and lowering the burden on caregivers. In part, this is due to current knowledge of best or most effective practices as identified in the literature and in a variety of ‘guidelines’ developed in the United States and internationally. Current research and guidelines point to specific practices, treatments, and interventions that if employed could significantly improve the quality of care for those with cognitive impairment. However, research shows that to a very significant degree, practitioners in a variety of settings do not implement recommended practices with any degree of consistency. Put simply, the gap between what is known and what is done is quite large, and the impact of that gap can be very significant in terms of human suffering and public costs.

In the subsection on Prevention above, references are made to the missed opportunities resulting from this gap between what is known and what is done. The key individuals who are able to bridge this gap are doctors and other health care staff who treat individuals with cognitive impairment, and their caregivers, and an array of individuals who have routine contact with individuals with impairments such as social services staff and residential services staff. As noted above, the solution lies in each of these individuals having the right information at the right moment.

### ***Primary care and emergency room physicians***

Physicians have the functional role of identifying, diagnosing and treating individuals with a cognitive impairment. With primary care and emergency room doctors, missed opportunities result from a combination of factors:

- Less than ideal level of training in medical school in the identification and treatment of dementia;
- The vast number of conditions, symptoms and ailments about which a doctor should be current;
- Lack of time to keep current with a variety of emerging promising practices; and
- Lack of time to carefully observe and question elderly patients to identify signs of memory loss.

Most primary care physicians do not access websites for disease-specific information unless they are specifically looking for something related to a current case. Primary care physicians have too many possible areas about which they should know to routinely look for emerging trends in every condition that is prevalent among elder patients. As a result, they tend to use free or fee-based subscription services that email journal articles or updates. For example, with Amedeo.com doctors can identify the areas where they would like information and a daily list of articles would be provided. However this free service requires the doctor to then scan a long list of journals and seek out the information amidst a dizzying number of options.

UCSF offers its doctors a similar but, more user-friendly service. “Up to Date” provides periodic summaries of current research with links to articles. This is a more accessible and time-efficient means of getting information as it doesn’t just present doctors with a list of relevant journals, but rather introduces each resource with narrative identifying its relevance. A doctor could scan the

email and identify issues and research relevant to his or her current practice/patients. But “Up to Date” still requires a busy doctor to pour over a lengthy email and as s/he finds something of interest, then to print out an article. When you consider the number of medical issues for which it would be advisable for a primary care doctor to be current, it is no wonder that it doesn’t happen with consistency. It is also not surprising that these same doctors rely more heavily on pharmacological interventions as they receive a regular stream of reader-friendly, easily digestible information from pharmaceutical corporations with ‘research’ demonstrating the efficacy of their products. Unfortunately, this leads to an over-reliance upon pharmacological interventions and a corresponding under-utilization of effective non-pharmacological interventions.

There are other resources that could be used to inform and improve the practice of the entire network of services and supports for individuals with dementia. Guidelines have been developed in Europe and the United States with some being narrowly focused upon one aspect of care and others covering the full spectrum of the cognitive impairments. Among the excellent resources containing the most current and effective practice recommendations:

**Guidelines and Protocols for Cognitive Impairment in the Elderly – Recognition, Diagnosis and Management** (January 2008). This guideline focuses on protocols for identification, diagnosis and management of early stages of cognitive impairment. It is but one of dozens of examples that could have been cited. It contains very specific recommendations for identifying individuals with cognitive impairment and then confirming the specific condition with diagnostic tools.

***Guideline for Alzheimer’s Disease Management, Final Report.*** California Department of Public Health and Alzheimer’s Association. Providing perhaps the most current analysis of evidence-based practice in assessment, diagnosis, treatment, and community-based care, these guidelines provide detailed recommendations based upon research for virtually every aspect of treatment and care for individuals with dementia. It is an excellent resource. As with other resources, however, it is incumbent upon the health professional to seek it out or to have it accessible at the moment that a diagnosis, prescription, or referral must be made.

***Tools for the Early Identification, Assessment, and Treatment for People with Alzheimer’s Disease and Dementia.*** Another publication by the Alzheimer’s Association that provides specific tools for identifying and assessing dementia.

***Dementia Care Practice: Recommendations for Assisted Living Residences and Nursing Homes, Alzheimer’s Association Campaign for Quality Residential Care.*** As with the Final Report above, this guideline provides comprehensive and specific guidelines related to all aspects of operations in assisted living and skilled nursing facilities.

***Dementia Care Practice: Recommendations for Assisted Living Residences and Nursing Homes, End of Life Care.*** This guideline extends the recommendations in the guideline above with recommendations for end-of-life care.

The point of the above references is to underscore the degree to which information is accessible related to virtually every aspect of the identification, treatment and support for people with cognitive impairment and their caregivers. An effective information delivery system can ensure that the best information is available to health professionals at the moment when that information is needed.



## *Training for other Health Professions*

**Certified Nursing Assistant Training:** The “WHAT HAS HAPPENED TO ME” dementia specific training program has been developed in order to expand training of the Certified Nursing Assistant (CNA), the front line care giver, in how to understand and care successfully for the resident with dementia.

The Dementia Training Standards Act of 2001, AB 1347, Chapter 389, Statutes of 2001, focuses on the CNA staff caring for residents in California Skilled Nursing and Intermediate Care facilities. The Act requires a 2 (two) hour initial Dementia specific training component to be incorporated into each facility’s orientation program and to provide an additional mandatory 5 hours in-service training per year for CNAs.

The “WHAT HAS HAPPENED TO ME” dementia program discusses the complex scope of dementia, different disorders that can cause dementia and allows the CNA to identify different forms of Dementia, behavioral problems associated with Dementia and how to provide daily care in a compassionate and dignified manner. The Alzheimer Association also has a range of caregiver resources and training options. For example, it provides a multimedia, online training program appropriate to all staff in assisted living programs. The CARES Program is divided into six modules, each one approximately one hour in length. The training includes segments on:

- Introduction to an Effective Care Team
- Introduction to Dementia
- Understanding Resident Behavior as Communication
- Making a Connection with the Resident
- Eating Well
- Recognizing Pain

In this context, the challenge is to find ways to ensure that physicians responsible for caring for the elderly are able to easily access the most recent guidelines related to diagnostic and treatment protocols. Again, these resources are easily accessible. The challenge is developing a framework in which primary care doctors, other health care personnel, emergency medical technicians, emergency room doctors and caregivers are able to access this information at the right moment.

## *Caregivers*

Research shows that caregivers who have been educated or trained experience far less stress and those for whom they care tend to remain at home and out of expensive residential programs. An informed caregiver is able to advocate for the correct pharmacological prescription, environmental modification, exercise regimen, or other community resource. An informed caregiver can be a critical factor in ensuring that a patient receives the most appropriate treatments at the most appropriate time. In short, an informed caregiver can serve to avoid many missed opportunities and prevent many mistakes simply by questioning physicians, presenting alternatives, and insisting upon adherence to guidelines and best practice. Fortunately, there are good and reasonably accessible resources for providing caregivers with the information needed to advocate effectively. Unfortunately, this requires that caregivers devote a significant amount of time, not just for caring for their loved one, but researching how best to do so.

Among the best resources for caregivers are guidelines, educational materials and training most significantly from the Family Caregiver Alliance and the Alzheimer’s Association. All of these resources are accessible via the websites of each organization.

**Family Caregiver Alliance.** The Family Caregiver Alliance website has a wide variety of tools, assessments, articles, guidelines on how to handle a wide range of legal, treatment, housing, and support issues. These support materials are well organized by topic, easily sortable, and were developed explicitly to support caregivers. It is an excellent resource.

[http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=368](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=368)

At this site is an online database, *Family Caregiving: Emerging Practices & Tools for Professionals*, that houses an inventory of well-indexed practices and tools relevant to issues faced by family caregivers and organized into:

- Education and Training;
- Selected Evidence-Based Interventions
- Focusing on the Caregiver
- Daily Care

This database is designed to bridge the research-to-practice gap and ensure professionals working with families have access to meaningful and quality programs and services. It will assist researchers, program administrators, and practitioners identify successful and innovative programs, and provide an understanding of what makes these programs successful. The aim of this repository is to:

- highlight fresh ideas from emerging practices
- promote adoption of practices informed by research
- foster innovation

*Family Caregiving: Emerging Practices & Tools for Professionals* is the first step towards the creation of an Innovations Clearinghouse on Family Caregiving of cutting edge programs and policies in caregiving and aging. This online Clearinghouse will evolve to include evidence-based practices, advocacy efforts and public policies that offer meaningful solutions, strengthen the caregiving voice and support families in their caregiving role. It will also provide dynamic educational opportunities and online communities of a national scope for professionals. For now, it provides a model framework for maintaining an inventory of current practice that is easy to use and provides valuable information to caregivers.

**Alzheimer's Association Savvy Caregiver Training.** The six-week Savvy Caregiver Training Program, which the chapter last year began to offer, is that opportunity.” Based on research by experts, the Alzheimer's Association Savvy Caregiving series tackles caregiving as a set of learnable skills, centered around the twin goals of taking care of oneself while helping the care-receiver maintain a state of contented involvement in activities. Caregivers learn to step back, to become a skilled observer, to understand their family member through the Alzheimer's lens, and to strategize and take control of the evolving situation. Participants report an increased sense of mastery over their caregiving role.

**The Memory and Aging Center at UCSF:** The Memory and Aging Center hosts an award winning website with state of the art information for caregivers and professionals on the major neurodegenerative conditions. It offers special emphasis on non-Alzheimer's disease dementias including frontotemporal dementia and prion disorders. The website offers videos linked to YouTube that describe the clinical features of neurodegenerative conditions, and has extensive caregiver advice.

**Powerful Tools for Caregivers Online Mather LifeWays Institute on Aging.** Another resource for caregivers is based on the Chronic Disease Self-Management Program at Stanford University. Powerful Tools for Caregivers Online is a six-week, online educational course that will help the caregiver:

- manage the common stresses associated with caring for a relative or friend with a chronic medical condition
- design effective action-planning tools and time management as a caregiver
- communicate more effectively with friends, family, health care providers, and coworkers
- find resources
- cope with emotions such as guilt and depression

The recurrent theme of this section is that a gap exists between what is known and what is done and the seeming inability to bridge this gap. The research points to a number of possible strategies to help narrow this gap.

### **Final Considerations**

***Team-Based, Coordinated Care.*** A variety of team-based, care coordination programs and demonstrations integrated care coordinators, case managers and care advocates whose function it was to be the team expert as to the most appropriate treatments and supports. A primary care physician has dozens of conditions, diseases, and symptoms to consider in caring for the elderly. By taking a coordinated team approach, it allows multiple perspectives and multiple resources to be focused upon the needs of the patient. Section IV.C. describes a number of these models, most all of which demonstrated significantly improved patient and caregiver outcomes.

***Quality Assurance Systems.*** One feature that distinguishes a network from a system is the reliance upon system-wide quality assurance practices. One of the goals of the Alzheimer’s Association’s Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes is to “incorporate the practice recommendations into quality assurance systems.”

Extremely limited fiscal resources may be available to address our health and human needs. This is a disease that is projected to increase exponentially in prevalence potentially financially compromising the health system, leaving hundreds of patients in late stages with literally nowhere to go. At the same time, research from throughout the world points to a large number of strategies and

interventions – beginning with identifying cognitive impairment at the earliest possible moment – that can slow the progression of cognitive impairment thereby significantly delaying entry into the most restrictive care settings that are in greatest demand. Given that we face a potentially catastrophic landscape by 2020, much depends upon developing a framework that incorporates the best of what we know from the research.

## **4. SERVICES & SUPPORTS**

The summary of research in relation to services and supports is organized into 14 subsections with each subsection focused upon a particular component of care for individuals with cognitive impairments. Each subsection begins with a review of the literature, followed by identification of specific models or exemplary practices, as available.

While over 140 documents were reviewed, several sources were utilized extensively and warrant acknowledgment, including:

***Guideline for Alzheimer's Disease Management, Final Report.*** California Department of Public Health. Provided perhaps the most current analysis of evidence-based practice in assessment, diagnosis, and community-based care.

***Practice parameter: management of dementia (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology.*** According to the guideline developer, this guideline has been reviewed and is still considered to be current as of October 2003. This review involved new literature searches of electronic databases followed by expert committee review of new evidence that has emerged since the original publication date. This review identified over 2500 studies, 380 of which met the criteria for inclusion in the meta-analysis. Practices then were rated: Standard (highest evidence of benefit), Guideline (moderate level of documented benefit) and Practice Option (where there was significant uncertainty of benefit).

[http://www.guideline.gov/summary/summary.aspx?ss=15&doc\\_id=2818&nbr=2044](http://www.guideline.gov/summary/summary.aspx?ss=15&doc_id=2818&nbr=2044)

***Guideline 86: Management of Patients with Dementia: A National Clinical Guideline,*** Scottish Intercollegiate Guidelines Network, National Health Service, Feb. 2006.

Guideline 86 is a national clinical guideline from Scotland with evidence-based recommendations for diagnosis, pharmacological and non-pharmacological treatments, and services for patients and caregivers.

<http://www.sign.ac.uk/guidelines/published/support/guideline86/index.html>

***Improving Services and Support for People with Dementia,*** National Audit Office, July 2007

This document is a very current and exhaustive summary of the literature relating to services and supports for caregivers of individuals with cognitive impairments.

[http://www.nao.org.uk/publications/0607/support\\_for\\_people\\_with\\_dement.aspx](http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx)

***The National Evaluation of the Aged Care Innovative Pool Dementia Pilot: Final Report.,*** Australian Institute of Health and Welfare, 2006.

This document is a nearly 500-page review of the Australian system's national demonstration project. The document includes both literature citations, reviews of randomized clinical trials, and evaluations of outcomes on four short-term case management-caregiver education demonstrations and four long-term case management models.

<http://www.aihw.gov.au/publications/index.cfm/title/10288/>

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**4 A. IDENTIFICATION AND REFERRAL:** *Multiple points in emergency services, primary care, and community-based services where individuals with early stage cognitive impairments can be identified and referred to the right place in a sensitive way.*

There is a significant amount of research available in relation to most of the components of care for individuals with cognitive impairments, particularly as relates to treatment of mid to late stages of the disease, however, while there is also abundant research supporting the benefit to early

identification of individuals with cognitive impairments, research on systems and strategies for early identification were difficult to find. As a result there is a significant diagnosis gap with only between one-third to one-half of people with cognitive impairments ever receiving a formal diagnosis<sup>21</sup>. Often cognitive impairments are not diagnosed until a person is admitted for an acute physical illness, but often even here a cognitive impairment diagnosis and referral may be missed.<sup>22</sup>

Early identification of cognitive impairment allows for care management to be initiated with the potential for reducing costs associated with pneumonia, chronic skin ulcers, infection, depression, behavioral disturbances, hip fracture, malnutrition, dehydration, intestinal obstruction, lacerations, sprains, hypothermia and burns.<sup>23</sup> What's more, early identification reduces costs for hospitalization, delays nursing home placement, and permits advance planning.<sup>24</sup> Finally, fiscal projections related to early identification and the early introduction of treatments that can delay onset of cognitive impairments suggest that an average delay of onset of one year would reduce the number of patients with cognitive impairments by 210,000, creating an annual projected savings of \$10 billion<sup>25</sup>.

As noted in Section 4.E., there are numerous interventions that can lead to improvements in memory and physical care, can delay the onset of cognitive impairments and reduce the cost of formal and informal care. For these interventions to have effect and to maximize potential cost savings, individuals with cognitive impairments must be identified early and referred effectively to those programs that deliver these interventions.

People with symptoms associated with the possible onset of cognitive impairments often do not present to their primary care physician because of fear and the stigma associated with a diagnosis of cognitive impairment. The attitudes of the physician to the disease can also hamper diagnosis, with many holding the view that little can be done<sup>26</sup>. The British National Audit Office report on improving services and support for people with cognitive impairments suggests that memory assessment services can help to break down barriers and reduce stigma by:

- being called 'memory' services rather than 'mental health' or 'old age psychiatry' services
- improving communication
- moving away from intimidating psychiatric or other hospital settings to a primary care environment.

Developed in England and recommended by the National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence, *memory services* are a multidisciplinary team focusing on early detection, assessment and treatment of cognitive impairment. This is a single point of referral for all cases suspected of cognitive impairment. Memory services like the Croydon Memory Services can provide a cost-effective way of significantly increasing the number of people seen for early diagnosis and treatment.<sup>27</sup>

Clues to cognitive impairments may be subtle and nonspecific, however, symptoms often are stimulated by physical or emotional crisis. As such, emergency rooms, emergency medical

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<sup>21</sup> Philip I, *A Recipe for Care—Not a Single Ingredient*, Department of Health, 2007.

<sup>22</sup> Holmes, J., *Research School of Medicine*, University of Leeds (1999)

<sup>23</sup> Alzheimer's Association website: [www.alz.org](http://www.alz.org). February 12, 2002.

<sup>24</sup> Shelton, P. Schraeder C, Dworak, D, Fraser C, Sager MA. Caregiver's utilization of health services: results from the Medicare Alzheimer's Disease Demonstration, Illinois site. *American Journal of Geriatric Society*. 2001; 49: 1600-1605.

<sup>25</sup> Brookmeyer, R., S. Gray, and C. Kawas. (1998). "Projections of Alzheimer's Disease in the United States and the Public Health Impact of Delaying Disease Onset." *American Journal of Public Health*, 88(9): 1337-1342.

<sup>26</sup> Audit Commission (2002) *Forget me not 2002: developing mental health services for older people in England*. London: Audit Commission.

<sup>27</sup> Banerjee S, Willis R, Matthews D, Contell F, Chan J, Murray J. *Improving the Quality of Care for Mild to Moderate Dementia: An Evaluation of the Croydon Memory Service Model*. (2006)

technicians, fire and police services are often in position to recognize cognitive impairments and refer individuals appropriately. Postal workers, clergy members, bankers, family members and friends are others who are likely to observe behaviors that could lead to a referral for an evaluation. The Alzheimer's Association publication entitled *Ten Warning Signs of Alzheimer's Disease* is an excellent tool to sensitize individuals to identify cognitive impairment. However, we could not find models offering widespread training of those outside of the primary care system.

In addition to the *Ten Warning Signs*, the Alzheimer's Association has also developed a family questionnaire for the purposes of obtaining information from family members about behaviors that could indicate cognitive impairment.

As noted in Section 4.B. below, the challenge is not the absence of screening and diagnostic assessment tools that are effective once a person has been identified exhibiting behaviors suggestive of cognitive impairment, but the absence of models for training individuals to be more sensitive to these behaviors and to understand the importance of early detection and referral for services. The solution to this dilemma may lie in the review of education and prevention literature and the identification of a training program targeting individuals who come into contact with individuals during the very early stages of cognitive impairments.

The Michigan Dementia Plan outlines a plan for training community "gatekeepers" to be better able to identify and refer individuals with cognitive impairments, identifying postal workers, clergy, and emergency services providers as being in a position to identify persons with cognitive impairments, however, researchers were unable to identify an evaluation of the implementation of this strategy.

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**4 B. ASSESSMENT & DIAGNOSIS - EARLY SCREENING:** *Assessment of daily functioning, cognitive status, co-morbid medical conditions, behavioral symptoms, medications, living arrangements, transportation, caregiver resources, recreation/ activities and future planning issues, and a need for palliative and/ or end-of-life planning.*

The literature contains a wide range of standardized assessment tools designed to assess daily functioning, cognitive status, and co-morbid medical conditions, as well as to assess living environment and caregiver capacity. Early, accurate functional assessment facilitates implementation of strategies that maximize patient independence and can delay cognitive impairment's advance. Barthel Indices assess a patient's capacity for self-care and independent living,<sup>28</sup> and can be administered either directly to the patient or to caregivers.<sup>29</sup> These early functional assessments provide primary care physicians and caregivers with a baseline of functionality that can be used to measure patient decline.

Cognitive status should be assessed and reassessed periodically (most recommend every 6 months) to identify sudden changes and to monitor the possible harmful effects of environment and medication. The Mini-Mental State Exam (MMSE)<sup>30</sup> is the most commonly used tool for cognitive assessment even with the assertion that it is too much influenced by education and language on performance<sup>31</sup>. The MMSE is not sensitive to the early stages of cognitive impairment and is particularly weak at capturing cognitive symptoms associated with non-Alzheimer's disease dementias. Further, the MMSE is a proprietary tool with added administrative costs that may cause providers to utilize other tools that have been demonstrated to be valid and reliable. Distinguishing

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<sup>28</sup> Katz, S., Down, T.D., Cash, H.R., & Grotz, R.C. (1970), *The Gerontologist*, 10, 20-30.

<sup>29</sup> Byrni, L., Wilson, P., Bucks, R., Hughes, A., & Wilcock, G. (2000), *International Journal of Geriatric Psychiatry*, 15, 656-661.

<sup>30</sup> Folstein, M.F., Folstein, S.E., & McHugh, P.R., *Journal of Psychiatry Research*, 12, 189-198, 1975.

<sup>31</sup> Escobar, J.I., Burnam, A., Karno, M., Forsythe, A., Landsverk, J., & Gloding, J.M. (1986), *Journal of Nervous and Mental Disease*, 174, 607-614.

the different forms of cognitive impairment can be achieved through the use of neuropsychological testing, particularly in the early stages of cognitive impairment.<sup>32</sup>

Since upwards of 25% of patients with cognitive impairments suffer from co-morbid physical conditions,<sup>33</sup> it is important that functional assessments also include physical, psychological, and socio-economic domains. Structured interviews with a caregiver and patient can be used to obtain a medical history and to assess current physical condition. The assessment should include a review of all medications both prescribed and non-prescribed and reassessments every six months should be conducted to identify rapid cognitive decline, as this can be a result of wide variety of reversible co-morbid conditions.

Eighty percent of patients with cognitive impairments experience behavioral symptoms and 50% experience depression. Since symptoms associated with behavioral conditions can be among the most challenging for caregivers, they often precipitate institutionalization.<sup>34</sup> As a result, behavioral assessments should be conducted, as appropriate. The sudden onset of behavioral symptoms should also trigger other assessments as sudden onset can result from pain, medication, infection or cardiopulmonary disease. Effective communication between the caregiver and physician about decline in cognition and functioning is essential in managing depression as a decline in functioning without a commensurate decline in cognition often precedes the first episode of depression.<sup>35</sup>

In addition to monitoring changes in the patients cognitive, behavioral, and physical conditions, it is also important to assess the patient's living environment as this form of assessment could identify functioning capacity in a familiar setting, as well as the need for environmental supports to maximize safety. Safety concerns relate to three main areas: 1) falls, which is the leading cause of injury and death among elder adults; 2) wandering; and 3) driving. The use of a home safety checklist, such as the one developed by the Alzheimer's Association, can assist the primary care physician and caregiver in assessing these safety concerns.

Individuals with cognitive impairments are at particularly high risk of personal neglect, caregiver neglect and abuse. Whenever three of the following seven risk factors are present, an assessment or investigation should also be conducted to identify abuse or neglect. Indeed, the presence of only one or two risk factors, may suggest the need for intervention or investigation. Risk factors include:

- Problems with short-term memory
- Psychiatric diagnosis
- Alcohol abuse
- Difficulty interacting with others
- Self-reported conflict with family members or friends
- Feelings of loneliness
- Inadequate or unreliable support system<sup>36</sup>

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**4. C. CARE COORDINATION:** *Treatment planning and service coordination to ensure integration of medical, medication, environmental assessment and modifications, social, financial, caregiver, and support needs and ongoing monitoring of need for reassessment every six months.*

Care for people with cognitive impairment is a test of how well health and social services and other partners work together. There is significant level of international research indicating that care

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<sup>32</sup> Jacova, C., Kertesz, A., Blair, M., Fisk, J.D., & Feldman, H.H. *Alzheimer's and Dementia*, 3, 299-317 (2007).

<sup>33</sup> Maslow, Selstad, & Denman, 2002

<sup>34</sup> Mittelman, M.S., Haley, W.E., Clay, O.J., & Ruth, D.L., *Neurology*, 67, 1592-1599 (2006).

<sup>35</sup> Holtzer, et al, *Journal of American Geriatrics Society*, 53, 2083-2089 (2005).

<sup>36</sup> Shugarman et al, *Journal of American Geriatrics Society*, 51, 24-31 (2003).

coordination or care management is a cost-effective intervention that can delay institutionalization and improve the quality of life for both the patient and the caregiver. Primary care physicians often do not make referrals for community-based care due to lack of sufficient information about resources.<sup>37</sup> There is also research that indicates that embedding case managers into primary care settings can ease the burden on the physician and ensure better use of community resources<sup>38</sup>. But with most US research focusing upon pharmacological intervention or a basic search for a cure, far less has focused on how this coordination of service delivery is best implemented.<sup>39</sup> While there has been some research done on isolated, non-pharmacological treatments and supports, there is little US research on the benefit of care coordination, case management or the integration of services specifically in relation to individuals with cognitive impairments. Far more research on coordination of care has been done in England, Scotland, Canada, and Australia, however these coordinated care practices operate in health systems that are vastly different from San Francisco, limiting the relevance or applicability of this research. US studies on care coordination summarized below provide some evidence of the effectiveness of care coordination on both patient and caregiver outcomes.

***Improving care for individuals with cognitive impairments through community linkages: A multi-site demonstration project.***<sup>40</sup> The purpose of the multi-site project was to develop and implement a model for care for individuals with cognitive impairments that improved linkages of caregivers to community services. Key components of the model included a single point of informational contact, provider education, case-finding, caregiver education and support, internal linkages, and linkages with community services. The model was implemented at six medical centers. Outcome measures included caregiver, provider, and community agency satisfaction. Caregivers reported high satisfaction with information provided to them about community resources. Primary care providers reported that services for individuals with cognitive impairments had improved from one year earlier. Community agencies reported high satisfaction with the dementia program. Caregivers identified the “single point of contact” as the single greatest factor contributing to their support. Unfortunately, the absence of a control group limits the scope of these findings.

***Partners in Dementia Care (PDC)*** was an innovative partnership of the U.S. Department of Veterans Affairs (VA) health care network in upstate New York (VISN 2) and four Alzheimer’s Association chapters in the same area. From 1997-2003, these organizations worked together to improve care and outcomes for veterans with Alzheimer’s disease and other cognitive impairments and their family caregivers. The model of care used in the PDC project was intended to address four problems that are common in VA and non-VA health care settings: 1) under-identification of possible cognitive impairment, 2) lack of adequate diagnostic assessments, 3) lack of coordination between medical care and community services, and 4) lack of information and support for family caregivers. The model includes procedures and tools for early identification, assessment, care management, and family caregiver information and support.

PDC placed strong emphasis on training and conducted a wide array of formal and informal training activities throughout the project. A new VA position, Dementia Care Coordinator (DCC), was

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<sup>37</sup> Hinton, L., Franz, C. E., Reddy, G., Flores, Y., Kravitz, R. L., & Barker, J. C. (2007). Practice constraints, behavioral problems, and dementia care Primary care physicians’ perspectives. *Journal of General Internal Medicine*, 22, 1487-1492.

<sup>38</sup> Callahan, C. M., Boustani, M. A., Unverzagt, F. W., Austrom, M. G., Damush, T. M., Perkins, A. J., et al. (2006). Effectiveness of collaborative care for older adults with Alzheimer Disease in primary care: A randomized controlled trial. *JAMA*, 295, 2148-2157.

<sup>39</sup> Bullock, R., Iliffe, S. and Passmore, P., *Can We Afford Not to have Integrated Dementia Services?*, *Age and Ageing*, June 11, 2007.

<sup>40</sup> Venohr, Fine, et al. *Improving dementia care through community linkages: A multi-site demonstration project*. *Home Health Quarterly*, 2000 19(4).



created for PDC, and one DCC was placed in each of VISN 2's five medical centers. The DCCs performed many functions related to planning, training, enrollment and assessment of veterans and their families, and ongoing care coordination within VA and between VA and chapters. The DCCs also functioned as a resource and team leader for the many VA physicians, nurses, and other staff who participated in PDC at each medical center.

PDC identified, enrolled, and served more than 550 veterans and 500 family caregivers. An extensive evaluation conducted by an independent research team focused primarily on the feasibility of the intervention and its impact on veterans and their families. Evaluation findings show many positive outcomes. VA and chapter staff members were enthusiastic about the model, the training, and the VA/Chapter partnership. They agreed on average that PDC improved quality of care and outcomes for veterans and families, increased their own ability to provide care, and gave them confidence that services needed by veterans diagnosed with cognitive impairment were available. Almost all veterans who enrolled in PDC received the recommended diagnostic assessment, and more than half of the families chose to use chapter services. Veterans and caregivers who participated in the telephone interviews reported on average that they had received enough information or help with important areas of care, including treatment options, family concerns, daily living tasks, and legal and financial issues. Veterans and caregivers who used chapter services were more likely to say they had enough information or help with these areas of care. Those who said they had enough information or help with particular areas of care were more likely to be satisfied and less likely to have symptoms of depression and other negative psychosocial outcomes.

Use of VA health care services changed very little between the 6 months before enrollment in PDC and 6 months after enrollment. Use of chapter services was associated with a higher likelihood that the veteran would have a VA primary care visit and, for veterans with mild memory impairment, a larger number of primary care visits. For veterans with moderate to severe memory impairment, use of chapter services was associated with a lower likelihood of having a specialty physician visit. In addition to these findings, PDC data indicate many findings and associations that did not reach statistical significance but suggest important areas for future research.

The findings from PDC are encouraging. With funding from the Robert Wood Johnson Foundation, the PDC project team used these findings and learning from implementation in VISN 2 to refine the project model. The resulting best practice model is now ready for implementation in other VA health care systems and rigorous testing with a treatment/control group research design.

Conclusions about the impact of PDC on the use and cost of VA health care services for veterans with dementia must await the results of this research. Some PDC procedures were clearly feasible and well accepted. These procedures could be incorporated in quality improvement projects in VA health care settings. They include: the early identification procedures and tools; involvement of non-physician providers, including all clinic staff, in identifying people with possible dementia who need a diagnostic assessment; and the VA/Chapter partnership, including the consent process that allows chapters to initiate contact with families rather than waiting for families to call the chapter.

Anecdotal reports and previous research findings suggest some physicians are reluctant to identify and diagnose dementia because they believe the condition is hopeless and there is "nothing to do" for the person or family. Although not provable with the existing data, it is likely the VA/Chapter partnership in PDC and the availability of information and support for veterans who received a diagnosis of dementia and their families increased physician willingness to make these diagnoses.

***The Integrated Care Management Grant Program.*** The Administration on Aging (AoA) Integrated Care Management grant program is designed to identify and support innovations in aging services that involve the use of partnerships with managed care organizations or Medicare Modernization Act Demonstrations and/or the creation and use of capitated financing arrangements that improve older people's access to social and preventive services. This program is part of a strategic effort AoA has undertaken to strengthen the role of community aging services programs in promoting a more balanced and integrated system of health and long-term care for older people.

Projects include either program enhancements that build on existing approaches or new models that support the design and/or implementation of new approaches in managed care. Grantees include Area Agencies on Aging (AAAs) and Community Aging Services Providers (CASPs). A broad mix of partnerships between area agencies on aging, community organizations, managed care organizations, universities, and health care providers are represented in the programs. Ten grants were awarded to the following organizations in FY2005, one of which is operating in San Mateo County. Researchers were unable to identify any evaluation of these projects, but would expect that evaluations of these programs will be available soon.

***Effectiveness of Collaborative Care for Older Adults With Alzheimer's Disease in Primary Care***<sup>41</sup>. Researchers assert that this study was the first randomized clinical trial testing the effectiveness of treatment guidelines for Alzheimer's disease as delivered through a collaborative care model. Further, researchers assert that this is the first trial in this area that integrates these recommendations within primary care. This setting is important because it represents the care site where most older adults receive their medical care, including those with cognitive impairment, and primary care physicians frequently prescribe psychoactive medications to these older adults. This setting is also important because it represents the logical target for any initiatives to improve the early identification and treatment of dementia or precursor conditions. The primary care practices targeted in the current study serve a medically-indigent, mixed-race population with multiple comorbid conditions. These patient groups have been understudied in previous treatment trials<sup>42</sup> of Alzheimer's disease and these patients have fewer personal resources, including family caregivers.

A randomized controlled trial was conducted in Indianapolis primary care settings that compared outcomes for two groups, one afforded "augmented usual care" and the other to receive "care management services." The experiment was conducted over a 12-month period with improved outcomes for the care management group both at 12 months and at 18 months, six months after care management services was discontinued.

There were 2 care managers, each of whom was an advanced practice nurse, with 1 based at each of the 2 large primary care practices. The care manager saw caregivers and patients in the primary care clinic bimonthly initially and then contacts were lengthened to monthly for a period of 1 year. At each contact with the care manager, caregivers completed the Memory and Behavior Problems Checklist<sup>43</sup> to assess current symptoms and stressors. Based on the caregiver's responses, individualized recommendations were made regarding how to manage a patient's behavioral symptoms.

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<sup>41</sup> Callahan, C.M, MD et al, JAMA. May 2006; 295:2148-2157.

<sup>42</sup> Sink KM, Holden KF, Yaffe K. Pharmacological treatment of neuropsychiatric symptoms of dementia: a review of the evidence. JAMA. 2005;293:596-608.

<sup>43</sup> Teri L, Truax P, Logsdon R, Uomoto J, Zarit S, Vitaliano PP. Assessment of behavioral problems in dementia: the revised Memory and Behavior Problems Checklist. Psychol Aging. 1992;7:622-631.

The primary care physician and the care manager were supported through two additional mechanisms. First, the care manager had weekly meetings with a support team comprised of a geriatrician, geriatric psychiatrist, and a psychologist who reviewed the care of new and active patients and monitored adherence to the standard protocols. Second, the care manager was supported by a Web-based longitudinal tracking system that managed the schedule for patient contacts, tracked the patient's progress and current treatments, and provided an instrument for communicating the patient's and caregiver's current clinical status to the entire care team. All intervention patients and their caregivers also were invited to participate in voluntary group sessions. During these sessions, caregivers were taken to a support session led by a social psychologist that focused on caregiver stress. Patients were taken to a nearby room for a group chair-based exercise class led by a health psychologist and the care manager.<sup>44</sup>

To assess outcomes, a telephone interview was repeated at 6, 12, and 18 months. The interview included 3 standardized instruments developed by the Alzheimer's Disease Cooperative Study investigators<sup>45</sup>: the Neuropsychiatric Inventory (NPI),<sup>46</sup> activities of daily living,<sup>47</sup> and health care resource use.<sup>48</sup> Intervention patients experienced significant improvements in total NPI scores compared with patients who received augmented usual care. Lower NPI scores reflect fewer behavioral symptoms. Although the intervention was discontinued at 12 months, significant improvements in NPI scores continued at the 18-month assessment. Caregivers experienced significant improvements in caregiver stress at 12 months but not at 18 months as measured by the caregiver NPI. Lower scores on the caregiver NPI reflect fewer symptoms of stress related to the patient's behavioral and psychological symptoms of dementia.

***Medicare Alzheimer's Disease Demonstration.*** The Medicare Alzheimer's Disease Demonstration was conducted to determine the effects of increased access to community-based care on client and caregiver outcomes. While there is significant evidence of increased client and caregiver satisfaction with home/community-based care, it is unclear whether these programs will result in lower public expenditures and in at least one study, there was limited evidence of reduction of depression and burden on caregivers.<sup>49</sup> These findings point to the lack of certainty in terms of the value of case management and increased access to care, as in this demonstration, patients with case management accessed more services and patients and caregivers had higher levels of satisfaction with services, yet only modest benefit to caregivers was found. The study did not examine impact upon patient outcomes.

Several international studies were reviewed in relation to projects studying the effects of coordination of care. Two are summarized below.

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<sup>44</sup> Rimmer J. Alzheimer disease. In: Durstine JL, ed. Exercise Management for Persons With Chronic Diseases and Disabilities. Champaign, Ill: Human Kinetics; 1997

<sup>45</sup> Ferris SH, Mackell JA, Mohs R, et al. A multicenter evaluation of new treatment efficacy instruments for Alzheimer's disease clinical trials: overview and general results: the Alzheimer's Disease Cooperative Study. *Alzheimer Dis Assoc Disord.* 1997;11(suppl 2):S1-S12.

<sup>46</sup> Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology.* 1994;44:2308-2314.

<sup>47</sup> Galasko D, Bennett D, Sano M, et al. An inventory to assess activities of daily living for clinical trials in Alzheimer's disease: the Alzheimer's Disease Cooperative Study. *Alzheimer Dis Assoc Disord.* 1997;11(suppl 2):S33-S39.

<sup>48</sup> Ferris SH, Mackell JA, Mohs R, et al. A multicenter evaluation of new treatment efficacy instruments for Alzheimer's disease clinical trials: overview and general results: the Alzheimer's Disease Cooperative Study. *Alzheimer Dis Assoc Disord.* 1997;11(suppl 2):S1-S12.

<sup>49</sup> R Newcomer, M Spitalny, P Fox, and C Yordi, Effects of the Medicare Alzheimer's Disease Demonstration on the use of community-based services. *Health Serv Res.* 1999 Aug;34(3):669-89.

***Manchester Intensive Case Management for Dementia.*** This quasi experimental study was designed to evaluate a model of intensive case management for people with dementia based in a community-based mental health service for older people. Individuals in one community team setting received case management and were compared with those in a similar team without such a service. Forty-three matched pairs were identified. Eligible older people and their caregivers were interviewed at intake and again at 6 and 12 months. The impact of the scheme upon placement occurred in the second year at the end of which 51% of the experimental group remained at home compared with 33% of the comparison group. For the experimental group significant improvements in the social contacts of older people were noted; a decrease in the stress of their caregivers was observed, together with a reduction in their input to the care of the client; and there were significant improvements on ratings of overall need reduction, aspects of daily living and level of risk.

***The National Evaluation of the Aged Care Innovative Pool Dementia Pilot: Final Report., Australian Institute of Health and Welfare, 2006.*** This study examined the impact of four short-term case management and caregiver training pilots and four long-term case management models. The study provides convincing evidence of the efficacy of both models with significant improvement in daily functioning, lower levels of stress among caregivers, and delayed entry into institutional care.

The studies cited provide convincing evidence of the efficacy of coordinated service delivery. There are far too many models of care coordination to summarize and the health system context in which care coordination is delivered further complicates adoption of models from other countries.

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#### **4. D. PHARMACOLOGICAL INTERVENTION & MEDICATION MANAGEMENT:**

*As a person's disease progresses, close monitoring of medications for cognitive impairment (cholinesterase inhibitors, NMDA antagonist and other medications for cognitive impairment) and medications related to co-morbid conditions.*

##### ***Pharmacological Interventions***

While there is no cure for dementia, there is some evidence that there are some treatments that can help with the symptoms. Drug treatments are one element. There are scores of drugs that have been used in treatment of cognitive impairment and co-morbid conditions associated with cognitive impairment. It is outside the scope of this summary to provide a description of all of them. Below is a brief summary of those drug treatments for which there is evidence of their positive impact as demonstrated in randomized controlled studies. Even here, there is much debate about the possible debilitating side effects of these drugs.

This review does not go into depth regarding the relative effectiveness of each drug at different stages of cognitive impairment and for different forms of dementia. It is important to note that pharmacological research advances very quickly as it is one area where there is significant investment in research. As such, the understanding of the delicate interaction of pharmacological treatments changes quickly. So, while it is important to capture current best practices, it is more important to realize it is vital that, as this information changes, the most current and recommended treatment protocols for each form of dementia and for each stage of the disease be made available to primary care physicians. A challenge to providing the most effective care to individuals with cognitive impairment is the need to increase the capacity of primary care physicians to utilize the most current pharmacological treatments and to effectively refer patients for non-pharmacological services and supports that can slow cognitive decline. Indeed, it has been noted (below), that very often the use of the wrong pharmacological treatments can exacerbate symptoms and accelerate decline, particularly in relation to the use of pharmacology to control or manage behavioral symptoms.

Currently there are four commonly used FDA-approved medications for Alzheimer's disease (AD). Each has been shown to be effective at different stages of Alzheimer's Dementia. Evidence exists that the acetylcholinesterase inhibitors, donepezil, rivastigmine and galantamine may have beneficial effects at all stages of dementia (mild, moderate and severe), whereas the NMDA receptor antagonist, memantine is most effective in moderate-severe AD. Furthermore, combinations of an acetylcholinesterase inhibitor and memantine may offer benefits over use of either drug alone. Finally, some evidence exists that cholinesterase inhibitors may offer modest benefits to individuals at the earliest stages of AD, what is sometimes referred to as mild cognitive impairment, particularly those with genetic risk factors for progression to dementia such as the ApoE4 allele.

It should also be recognized that a variety of new diagnostic tools and treatments that have the potential to alter or modify the progression of the underlying AD are progressing through human clinical trials and may soon be available for routine clinical use. Diagnostic tools such as measurement of AD-related protein levels in the spinal fluid and blood, as well as new types of brain scans that can detect accumulation of AD-related amyloid protein may eventually help to improve specificity of an AD diagnosis and possibly even identify individuals at earlier, pre-dementia stages of disease when treatments and other interventions are most likely to be effective.

***Cholinesterase inhibitors.*** Drugs known as cholinesterase inhibitors help some people with cognitive impairment become less forgetful and confused, though they cannot stop the disease from eventually worsening. In 2006, the National Institute of Health in England advised that cholinesterase inhibitors are cost-effective in moderate Alzheimer's disease and in the United States the use of cholinesterase inhibitors is recommended at all stages of dementia.

Several second-generation cholinesterase inhibitors including donepezil, rivastigmine and galantamine have been introduced. At the case control study level, there is support for long term use of cholinesterase inhibitors to delay institutionalization.<sup>50</sup> The cost of additional community services is not taken into account in this study, but savings in the cost of caring for patients in institutions may be substantial.

- **Donepezil.** A systematic review of the use of donepezil in people with vascular dementia demonstrated some benefit to patients with mild to moderate dementia examined over a six month period.<sup>100</sup> There is a large body of consistent evidence indicating the effectiveness of donepezil in reducing psychiatric symptoms and a limited number of behavioral problems in patients with mild to severe dementia.<sup>51 52</sup>
- **Galantamine** is effective for the maintenance of cognition in people with mild to moderate Alzheimer's disease.<sup>53</sup> There is evidence of some cognitive benefit to patients with mixed Alzheimer's disease and cerebrovascular disease.<sup>54</sup> Higher doses of galantamine are more

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<sup>50</sup> Lopez OL, Becker JT, Wisniewski S, Saxton J, Kaufer DI, DeKosky ST. Cholinesterase inhibitor treatment alters the natural history of Alzheimer's disease. *J Neurology Neurosurgery Psychiatry* 2002;72(3):310-4.

<sup>51</sup> Feldman H, Gauthier S, Hecker J, Vellas B, Emir B, Mastey V, et al. Efficacy of donepezil on maintenance of activities of daily living in patients with moderate to severe Alzheimer's disease and the effect on caregiver burden. *Journal of American Geriatrics Soc* 2003;51(6):737-44.

<sup>52</sup> Tariot PN, Cummings JL, Katz IR, Mintzer J, Perdomo CA, Schwam EM, et al. A randomized, double-blind, placebo-controlled study of the efficacy and safety of donepezil in patients with Alzheimer's disease in the nursing home setting. *J Am Geriatr Soc* 2001;49(12):1590-9.

<sup>53</sup> Clegg A, Bryant J, Nicholson T, McIntyre L, De Broe S, Gerard K, et al. Clinical and cost-effectiveness of donepezil, rivastigmine, and galantamine for Alzheimer's disease: A systematic review. *Int J Technol Assess Health Care* 2002;18(3):497-507.

<sup>54</sup> Erkinjuntti T, Kurz A, Gauthier S, Bullock R, Lilienfeld S, Damaraju CV. Efficacy of galantamine in probable vascular dementia and Alzheimer's disease combined with cerebrovascular disease: a randomised trial [comment]. *Lancet* 2002;359(9314):1283-90.

effective than lower doses, although there is no added benefit of doses in excess of 24 mg per day.<sup>55</sup> Slow dose escalation appears to improve tolerability to the drug.<sup>56</sup> One study suggests that the greatest benefit is achieved in patients with moderate dementia with an MMSE score of less than 18.<sup>57</sup>

- **Rivastigmine.** In people with mild to moderately severe Alzheimer's disease, rivastigmine treatment showed significant benefits in cognitive and global function.<sup>58</sup> 114-116. Like Galantamine, rivastigmine is approved by the FDA for mild to moderate dementia. None of the cholinesterase inhibitors are approved for mild cognitive impairment.
- **N-methyl-D-aspartate (NMDA) antagonist memantine.** People in mid or late stage dementia should be prescribed NMDA. In two randomized trials<sup>59</sup> NMDA was tested against a placebo with 900 mild to moderate level dementia patients. In a pooled analysis of the data, subgroups were examined. In a first analysis, patients were stratified by severity of dementia (measured by the MMSE total scores at baseline). In this analysis, memantine was superior to placebo in all subgroups, but the magnitude of effect was more pronounced in the more severely demented patients.

In these trials, Memantine at a dose of 10 mg b.i.d. was safe and well tolerated with a frequency of dropouts due to adverse events that was close to placebo. Memantine is approved for the treatment of moderate to severe, but not mild dementia.

### ***Pharmacological Interventions for Behavior Management***

When non-pharmacological treatments are not effective in reducing agitation or other behavioral symptoms, psychotropic medications may be used with caution and require close monitoring due to potential interaction with other medications and side effects.<sup>60</sup> While medication may reduce symptoms, rarely will they eliminate them. Indeed, with the exception of atypical anti-psychotics, there is little evidence of the efficacy of medication in relieving behavioral symptoms and significant evidence of possible deleterious side effects.<sup>61</sup>

### ***Medication Management***

Inappropriate management of medications is a significant cause of co-morbidity and mortality in adults, particularly for adults with dementia.<sup>62</sup> As a result, patients and caregivers should bring all medications, prescribed and not, as well as all herbal and other nutritional supplements for every medical appointment. To identify the need for altering medication treatments, it is recommended that the primary care physician ask questions about each medication, such as:

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<sup>55</sup> Rockwood K, Mintzer J, Truyen L, Wessel T, Wilkinson D. Effects of a flexible galantamine dose in Alzheimer's disease: a randomised, controlled trial. *J Neurol Neurosurg Psychiatry* 2001;71(5):589-95.

<sup>56</sup> Tariot PN, Solomon PR, Morris JC, Kershaw P, Lilienfeld S, Ding C. A 5-month, randomized, placebo-controlled trial of galantamine in AD: The Galantamine USA-10 Study Group. *Neurology* 2000;54(12):2269-76.

<sup>57</sup> Wilcock GK, Lilienfeld S, Gaens E. Efficacy and safety of galantamine in patients with mild to moderate Alzheimer's disease: Multicentre randomised controlled trial. *BMJ* 2000;321(7274):1445-9.

<sup>58</sup> Corey-Bloom J, Anand R, Veach J. A randomized trial evaluating the efficacy and safety of ENA 713 (rivastigmine tartrate), a new acetylcholinesterase inhibitor, in patients with mild to moderately severe Alzheimer's disease. *International Journal of Geriatric Psychopharmacology* 1998;1(2):55-65.

<sup>59</sup> *International Psychogeriatrics* (2003), 15:207-213 Cambridge University Press

<sup>60</sup> Lyketsos, C. G., Colenda, C. C., Beck, C., Blank, K., Doraiswamy, M. P., Kalunian, D. A., et al. (2006). Position statement of the American Association for Geriatric Psychiatry regarding principles of care for patients with dementia resulting from Alzheimer disease. *American Journal of Geriatric Psychiatry*, 14, 561-572.

<sup>61</sup> Schneider, L. S., Dagerman, K., & Insel, P. S. (2005). Risk of death with atypical antipsychotic drug treatment for dementia: Meta-analysis of randomized placebo-controlled trials. *JAMA*, 294, 1934-1943.

<sup>62</sup> Budnitz, D.S., Shehab, N., Kegler, S.R., & Richards, C.L. *Annals of Internal Medicine*, 147, 755-765 (2007).

- Is this medication achieving its purpose?
- Is this medication causing an adverse effect that is annoying or severe enough to warrant discontinuation?
- Is this medication interacting with other medications in a dangerous way?
- Is this medication necessary?
- Can the dose of the medication be decreased?
- Can use of this medication be safely discontinued?

Some types of medications should be avoided among Alzheimer's patients, especially those that cause increased confusion, e.g. sedative-hypnotics and barbiturates, particularly in those patients who are using acetylcholinesterase inhibitor agent.<sup>63</sup>

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**4. E. NON-PHARMACOLOGICAL APPROACHES AND SUPPORTS.** *Especially in early stages, introduction and support for different home-based environmental modifications, task simplification, and appropriate activities that may delay advances in the disease. While many of these approaches have not undergone rigorous evaluation, they represent a promising, but not yet proven range of interventions.*

There are numerous studies demonstrating the efficacy of non-pharmacological approaches. Data implies that cost savings in the care of people with Alzheimer's are potentially large. Data show that interventions that lead to improvements in memory and physical functioning or that delay the rate of decline could lead to cost savings for both formal and informal care.<sup>64</sup>

Unfortunately, knowledge of these treatments and how to make referral to them is not common. Even primary care doctors working with identified patients with cognitive impairments over 75 years of age rarely refer their patients for anything other than pharmacological interventions. Indeed in one chart review of 240 managed care patients, researchers found so few references for non-pharmacological care that they chose not even to report on this data.<sup>65</sup>

Given the potential benefits in costs and patient/caregiver outcomes derived from these non-pharmacological treatments and indications that primary care physicians do not routinely refer patients for these interventions, the need for training for physicians about these benefits is clear. There is also research that the availability of knowledgeable case managers in the primary care setting can ease the burden on the physician and ensure follow-through on the part of the family.<sup>66</sup>

A summary of a variety of non-pharmacological approaches follows.

**Cognitive Stimulation.** Cognitive stimulation may occur informally through recreational activities or formally through:

- A program of memory provoking, problem-solving, and conversational fluency activities;
- The space retrieval method; and
- Face name training.

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<sup>63</sup> Fick, D.M., et al, *Archives of Internal Medicine*, 163, 2716-2724, (2003).

<sup>64</sup> Leon J, Cheng C, Neumann P. Alzheimer's disease care: Costs and potential savings. *Health Affairs*. 1998, 17:206-16.

<sup>65</sup> Boise, L., Neal, M. B., & Kaye, J. (2004). Dementia assessment in primary care: Results from a study in three managed care systems. *Journals of Gerontology*, 59A, 621-626.

<sup>66</sup> Callahan, C. M., Boustani, M. A., Unverzagt, F. W., Austrom, M. G., Damush, T. M., Perkins, A. J., et al. (2006). Effectiveness of collaborative care for older adults with Alzheimer Disease in primary care: A randomized controlled trial. *JAMA*, 295, 2148-2157.

Formal cognitive stimulation produced a positive clinical impact on cognitive function in people with cognitive impairment. Although memory of specific pieces of information improved, it did not produce general benefits to memory function.<sup>67</sup>

**Behavior Management.** Before recommending any pharmacological treatments or non-pharmacological interventions for behavior management, it is important to assess for co-morbid physical conditions that could be the root cause of the behavior.

The term “behavior management”, is used to reflect structured, systematically applied and normally time-limited interventions usually carried out by caregivers or care home staff under the supervision of a professional with expertise in this area. Four randomized clinical trials reported behavior management as an intervention for patients living in a variety of residential settings, although how these relate to level of severity of dementia in individuals is not clear.<sup>68 69 70 71</sup> Each of the studies reported behavioral interventions with different levels of complexity. Evidence suggests that reduction of repetitive verbalizations, management of aggression and management of eating behaviors in people with dementia have a positive effect on behavior and well-being.<sup>72</sup>

There is evidence to support the use of behavioral management to reduce depression in people with dementia living in the community with a caregiver. Evidence also suggests that provided the intervention is tailored to the individual that behavioral management is also effective in reducing inappropriate behaviors across a number of settings.<sup>73</sup>

**Psychological Support.** Although it may be difficult for those with moderate to later stage dementia to benefit from therapy, due to memory and language impairments, there is clear evidence suggesting that those experiencing mild cognitive impairment or early stage dementia benefit from individual or group psychotherapy. For example, depression in people with dementia receiving behavioral therapy either involving pleasant events or problem solving was compared to that in control groups. Depression was improved for up to six months after both interventions. In addition, supportive therapy appears to be an important part of the coping process for those individuals in the early stages of dementia. Therapy with those with memory impairments may require some adaptations (such as providing more written information, slower presentation of information) but can be beneficial.<sup>74</sup>

**Changes in Environment.** Residential unit design, such as corridor configuration, can influence restlessness, anxiety and disorientation in institutionalized people with dementia.<sup>75</sup> Given that people with dementia experience increasing memory impairment and cognitive decline it is important to

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<sup>68</sup> Gormley N, Lyons D, Howard R. Behavioural Management of Aggression in Dementia: A randomized controlled trial. *Age Ageing* 2001;30(2):141-5.

<sup>69</sup> Beck CK, Vogelpohl TS, Rasin JH, Urry JT, O'Sullivan P, Walls R, et al. Effects of behavioral interventions on disruptive behavior and affect in demented nursing home residents. *Nurs Res* 2002;51(4):219-28.

<sup>70</sup> Teri L, Logsdon RG, Uomoto J, McCurry SM. Behavioral treatment of depression in dementia patients: a controlled clinical trial. *J Gerontol B Psychol Sci Soc Sci* 1997;52(4):159-66.

<sup>71</sup> Bourgeois MS, Burgio LD, Schulz R, Beach S, Palmer B. Modifying repetitive verbalizations of community-dwelling patients with AD. *Gerontologist* 1997;37(1):30-9.

<sup>72</sup> *ibid*

<sup>73</sup> Livingston, G., Johnston, K., Katona, C., Paton, J., Lyketsos, C., Old Age Task Force of the World Federation of Biological Psychiatry. *Systematic Review of Psychological Approaches to the Management of Neuropsychiatric Symptoms of Dementia*, *American Journal of Psychiatry*. 162: 11, November 2005

<sup>74</sup> Junaid, O., and Hegde, S., *Supportive psychotherapy in dementia*, *Advances in Psychiatric Treatment*, vol. 13, 17-23, (2007).

<sup>75</sup> Elmstahl S, Annerstedt L, Ahlund O. How should a group living unit for demented elderly be designed to decrease psychiatric symptoms? *Alzheimer Dis Assoc Disord* 1997;11(1):47-52.



have an environment that aids orientation. A descriptive systematic review of the design of environments for people with dementia including cohort, quasi-experimental and longitudinal studies, cross-sectional surveys and one-off case studies showed that changes in environment can have a positive impact on associated symptoms of dementia.<sup>76</sup> Findings from the studies are impaired by the absence of comparison groups, comparison between non-equivalent groups and small sample size. The studies examined:

- Environmental comparisons
- Design features
- Environmental services and policies
- Problem behaviors in people with dementia in different physical environments.

The most common outcome measures were impact on problem behaviors, on ADLs and on cognitive and social function. Physical environment interventions including simple modifications such as signage and homelike environments resulted in positive outcomes in patients' ADLs, behavior, and orientation. Small-scale group living also had a positive therapeutic impact. Measures which should be considered when planning an environment for people with dementia include:

- Incorporating small size units
- Separating non-cognitively impaired residents from people with cognitive impairment
- Offering respite care as a complement to home care
- Relocating residents, when necessary, in intact units rather than individually incorporating non-institutional design throughout the facility and in dining rooms
- In particular, moderating levels of stimulation, incorporating higher light levels, using covers over fire exit bars and door knobs to reduce unwanted exiting
- Incorporating outdoor areas with therapeutic design features
- Considering making toilets more visible to potentially reduce incontinence
- Eliminating factors that increase stress when bathing.

***Physical Exercise.*** A well-conducted meta-analysis showed that in people aged over 65 with cognitive impairment and dementia, exercise was associated with statistically significant positive outcomes.<sup>77</sup> The quality of the study was limited by small sample size and the absence of blinding.

Evidence from patients in residential care suggests that a combination of conversation and exercise on a structured basis may reduce deterioration in mobility in people with cognitive impairment but there is no evidence to support the use of either intervention in isolation. Overall the clinical impact of Memantine is approved for the treatment of moderate to severe, but not mild dementia. The impact of physical activities on core or associated symptoms of cognitive impairment is minimal.<sup>78</sup>

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**4. F. VARIOUS INDEPENDENT LIVING, IN-HOME SUPPORT AND SUPPLEMENTAL SERVICES.** *Includes money management, food / meal delivery, transportation assistance and other services to address needs as identified by the person with cognitive impairment and their family caregiver.*

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<sup>76</sup> Day K, Carreon D, Stump C. The therapeutic design of environments for people with dementia: a review of the empirical research [see comment]. *Gerontologist* 2000;40(4):397-416.

<sup>77</sup> Heyn P, Abreu BC, Ottenbacher KJ. The effects of exercise training on elderly persons with cognitive impairment and dementia: a meta-analysis. *Arch Phys Med Rehabil* 2004;85(10):1694-704.

<sup>78</sup> Cott CA, Dawson P, Sidani S, Wells D. The effects of a walking/talking program on communication, ambulation, and functional status in residents with Alzheimer disease. *Alzheimer Dis Assoc Disord* 2002;16(2):81-7.

The importance of effective independent living, in-home support and supplemental services can't be overstated, as even a one-month average delay in institutionalization is projected to result in savings of \$1.2 billion annually.<sup>79</sup> For an individual living with cognitive impairment to remain at home, a wide variety of independent living, supplemental services and in-home supports are essential. Historically, caregivers most often provide these supports. San Francisco has a disproportionate number of adults approaching ages at risk of cognitive impairment who do not have family members in the City or nearby. In this context, it is essential that San Francisco identify models to provide these forms of supports without relying upon family caregivers. Unfortunately, very little research could be found on evidence-based practices in relation to most of these forms of support.

***Meal Delivery.*** Inadequate food and fluid intake can result in malnutrition, dehydration, skin breakdown, delirium, and increased morbidity and mortality.<sup>80</sup> As a result, the provision of routine delivery of nutritious meals is a key component of in-home support. This is particularly the case as cognitive impairment advances and people lose their ability to maintain their diet and even more important for patients being discharged from a hospital. In the hospital, patients with dementia are more likely than other older patients to lose self-care abilities, including self-feeding, and are much less likely to regain these abilities after discharge<sup>81</sup>. Consequently providing interventions that are tailored to the patients' cognitive and related communication abilities can dramatically impact both immediate as well as long-term health and function.

Simple delivery of nutritious meals may not guarantee increased nutritional intake as patients' cognitive functioning declines. In an interesting presentation given at the Alzheimer's Australia NSW Dementia Symposium 2006, Les MacDonald from Meals on Wheels outlined some of the challenges of ensuring that its service responds to home-bound individuals with cognitive impairment. He described the dual need for drivers to spend more time with individuals with cognitive impairment even providing supervised environments for clients while eating. However the need to spend more time with clients is balanced by the demand to maintain a delivery schedule to ensure the maintenance of food temperature. He pointed to Meals on Wheels reforms that resulted in training for those who deliver meals in identifying individuals with cognitive impairment and in recognizing signs of malnutrition. Meals on Wheels also has developed 'snack packs' of nutritious snacks that can be consumed when the client desires. Even with the most responsive food delivery system, as individuals experience progressive decline in their cognitive functioning, additional support will be required to ensure that meals are consumed and consumed according to a routine.

***Transportation.*** When an individual is diagnosed with dementia, one of the first concerns of families and caregivers relates to transportation. A diagnosis may not mean a person can no longer drive safely. In the early stages of cognitive impairment, some but not all people may still possess skills for safe driving. Most cognitive impairment, however, is progressive; symptoms such as memory loss, visual-spatial disorientation, and decreased cognitive function will worsen over time. A person's driving skills will decrease and, eventually, they will have to stop driving. Many people associate driving with self-reliance and freedom; the loss of driving privileges is likely to be upsetting. Some people, recognizing the risks, will limit or stop driving on their own. Others may be unable to assess their own skills and may insist on driving even when it is no longer safe. Families and caregivers may have to intervene when an individual's symptoms pose too great a traffic risk.

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<sup>79</sup> Leon, Cheng, and Neumann, 1998.

<sup>80</sup> Amella, E.J. (2004). Feeding and hydration issues for older adults with dementia. In M. Mezey, E. Capezuti, & T. Fulmer (Eds.).

Care of Older Adults: Nursing Clinics of North America, 39(3), 607-623.

<sup>81</sup> McCusker, J., Kakuma R., & Abrahamowicz, M. (2002). Predictors of functional decline in hospitalized elderly patients: A systematic review. *Journal of Gerontology: Medical Sciences*, 57A(9), M569-577.

Because the progression of cognitive impairment varies from person to person, it is difficult to know at what point an individual can no longer drive safely, but primary care physicians are required to report a dementia diagnosis to the Department of Motor Vehicles (DMV). Upon notification, the DMV will conduct an assessment of client medical records, personal interviews and other information to determine if a person should continue to drive.

The inability to drive may limit access to community-based resources, participating in recreation, and completing simple chores like shopping. The availability of public transportation and assisted transportation systems becomes critical for people with limited caregiver support. Eldercare Locator at (800) 677-1116, a nationwide directory assistance service, is designed to help older persons and caregivers locate local support resources, including transportation, for aging Americans.

**Money Management.** A team of doctors from the University of Alabama, Birmingham, developed a 25-minute test that physicians can use to determine the competence of patients with cognitive impairments to handle financial affairs. The test, described as the first designed specifically to evaluate financial capabilities, was introduced by Dr. Daniel C. Marson at the 2006 International Conference on Alzheimer's Disease and Related Disorders in Madrid, Spain. "Impairment and eventual loss of financial abilities are an important and often devastating consequence of Alzheimer's disease and related cognitive impairment," Marson said. "As the disease progresses, patients lose arithmetic and other basic money management skills, and the ability to make both complex and simple financial decisions. The test examines eight areas of financial activity: basic monetary skills, conceptual knowledge, cash transactions, checkbook management, bank statement management, judgment, bill payment and knowledge of personal assets and/or estate arrangements. In an aging population, physicians increasingly are asked to evaluate the financial competence of patients, Marson said, and the test will give families and courts guidance in doing this. The doctors administered the test to 248 people - 69 healthy older adults with no memory problems; 54 patients with mild cognitive impairment, known as MCI; 98 patients with mild Alzheimer's; and 27 patients with moderate Alzheimer's. They were judged by physicians as capable, marginally capable or incapable in each of the test's eight areas, then graded on overall financial capacity. The study found that 94 percent of normal older adults were capable based on their judgments, as compared to 84 percent for patients with mild cognitive impairment, 26 percent for mild Alzheimer's patients and 1.5 percent for moderate Alzheimer's patients.

"The findings suggest financial capacity first becomes mildly impaired in MCI, and then rapidly deteriorates in the mild and moderate stages of Alzheimer's," Marson said. "He said the team recommends people diagnosed with MCI, along with their families, become engaged in financial and estate planning in anticipation of developing Alzheimer's and rapid loss of financial competence.

**Legal Counsel.** There are many legal considerations that are increasingly relevant at mid and late stages as cognitive decline robs the person of the ability to make sound decisions. Via the California Due Process in Competence Act, a set of standards has been codified to guide the courts in determining competence in different contexts. A diagnosis of cognitive impairment is not sufficient to prove incompetence and doctors are often called upon to perform competency assessments to respond to court requirements, for example prior to establishing a conservatorship. Planning for the inevitable loss of competency is a sensitive issue and the primary care doctor may need to raise it more than once before the person and/or caregiver take action. During early stage Alzheimer's it is critical to obtain input and direction from the person diagnosed as to how end-of-life treatment should be handled and this should be codified in an advance directive. The *Guideline for Alzheimer's Disease Management, 2008*, has detailed, step-by-step guidance for addressing the issue of competency.

***In Home Supports.*** In order to maintain a person with dementia at home, a range of independent living, in-home supports and supplemental services are necessary, particularly for those with limited or no caregiver support. In-home support is vital to delaying institutionalization. One qualitative study reported caregivers needing to coordinate home supports from over a dozen providers with different schedules, points of contacts, and services.

In California, the primary source of in-home support assistance is through the Department of Aging, In Home Support Services (IHSS) program. The IHSS program provides personal care and domestic services to aged, blind or disabled individuals in their own homes. The purpose of the program is to allow people to live safely at home rather than in costly and less desirable out-of-home facilities. IHSS is an entitlement program; federal and state laws mandate the program's existence. While IHSS regulations determine the range of services, it is the consumer who drives the program. In San Francisco, two modes exist: (1) the independent provider mode, provided through the IHSS Public Authority, in which the consumer hires a family member or relative who is trained to provide IHSS services; and (2) the contract mode, provided through the IHSS Consortium, in which IHSS services are provided by trained homecare workers.

IHSS is unique among programs in California's long-term care service delivery system in the types of services it provides. This is because IHSS employs a social model rather than a medical model. Services are determined by a social worker assessment rather than medical criteria. The social model focuses on activities of daily living and the IHSS consumer's ability to function in his or her own home. The medical model assesses clients on medical deficits.

The challenges facing IHSS are best viewed in the context of California's changing demographics. As the population ages and individuals become less able to care for themselves, there will be an increasing demand for personal assistance services. Against California's demographic backdrop are the multiple challenges that are expected to result from the Olmstead decision of the Supreme Court and the passage of Assembly Bill (AB) 1682, both of which occurred in 1999. These two events have the potential to increase the number of IHSS consumers statewide, with an associated increase in program operating costs. In addition, further caseload growth is expected with the aging population.

***Medicaid Home & Community-Based Services (HCBS) 1915 – C Waiver.*** HCBS waivers allow people eligible for nursing home care to receive care and support in the community and remain at home. This is a potential benefit for people with dementia. In a study conducted in Indiana from 2001 to 2005, researchers studied the relative use of emergency room and other primary care services of nursing home residents with dementia and a cohort of nursing home eligible people who used a HCBS waiver to receive long-term support in the home. Results from the study showed, that while people living at home used a significantly higher level of inpatient services, their overall cost of care was significantly lower than among those living in nursing homes.<sup>82</sup>

AB 2968 requires the California Department of Health Care Services (DHCS) to write a HCBS waiver application specifically for San Francisco, to fund wraparound services to support the elderly and people with disabilities in residential settings. As of December 2009, a draft of the HCBS waiver application had been completed for San Francisco by DCHS and shared with CMS informally.

Once the informal review is completed, a formal submission of the application will be made. The eligibility criteria is Medi-Cal eligible adults age 22 and higher who:

- 1) are at Nursing Facility B level of care;
- 2) either a) reside in a nursing facility or b) are being diverted from a nursing facility;

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<sup>82</sup> Sands, L., et al. Comparison of Resource Utilization for Medicaid Dementia Patients Using Nursing Homes Versus Home and Community Based Waivers for Long-Term Care. Regenstrief Center for Healthcare Engineering, Purdue University, 2008.

- 3) have a recent history (past 30 days) of behavioral problems and/or substance abuse use;
- 4) are capable of residing in a licensed board and care community-based setting or in supportive housing with waiver services; and
- 5) require daily oversight and assistance, including intermittent RN or LVN services.

People with dementia are also included in this waiver. This target population was raised at the Stakeholders' Meeting in July 2009, and DPH and the State responded this would be the case.

***The Living at Home/Block Nurse Program Model***<sup>83</sup> is the product of over 20 years of work with elders, their caregivers, home nursing and senior-serving organizations, and supporters in the community. It is a citizen-action model, based on the conviction that local volunteer governed entities can and do serve the needs of local people best, as opposed to top-down corporate or agency models. Community ownership and operations limited to a small geographic area guarantee highly focused efficiencies and flexible, non-bureaucratic effectiveness in helping elders. By receiving in-home social support and health care, elders are enabled to stay in their homes for extended periods of time, preserving their quality of life and retaining their community networks, while at the same time avoiding expensive nursing home costs.

The principle of neighbors helping neighbors is central; where consent, caring and mutual respect form the trust basis for all relationships. Use of expensive acute services, like an emergency room visit, is reduced while older people remain healthy longer, continue to live at home, participate in their communities, and receive assistance as needed from family members and neighbors. Ultimately, this support system helps avoid caregiver burnout and premature institutionalization.

This model is very cost-effective. Given current costs of acute medical care and nursing home stays, a typical rural community Program's annual budget can be more than recovered by helping just two elders avoid or delay using the expensive institutional services for a year. Higher costs in many urban settings may mean a doubling of the above numbers, but current Programs in all locations are saving taxpayers several times the cost of their operations.

This model's unique attributes stem from the fact that the leadership, planning and implementation are done by people living in the community. While unable to identify independent evaluation of this program model, in the context of San Francisco's dire need to identify models that promise to provide patient support akin to that provided typically by family, *Living at Home* is worth considering.

Whether delivered by IHSS, other in-home support providers, or by caregivers, in addition to those described above, the types of support needed depends on what the individual requires, but the range of services most often needed includes:

- Light cleaning duties
- Preparing a light meal
- Assisting with laundry
- Providing caregivers with a short break
- Providing a day, evening and night sitting service
- Assistance on hospital discharge
- Shopping
- Collecting pensions/prescriptions
- Assistance to attend appointments

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<sup>83</sup> <http://www.elderberry.org/model.asp>

Research cited elsewhere points to the importance of coordination of services and simplification of routines. As the disease progresses, the importance of simple access to in-home supports becomes more important. ***Given the high proportion of ‘un-befriended’ aged adults without a family caregiver in the vicinity, it is vitally important that San Francisco explore alternatives to family care support in order to prevent these un-befriended adults overtaxing the scarce supply of affordable beds in assisted living and skilled nursing facilities.***

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#### **4. G. IDENTIFICATION AND TREATMENT OF CO-MORBID CONDITIONS:**

*Integration of primary care and services for individuals with cognitive impairments to ensure effective, prompt identification and treatment of co-morbid conditions.*

Medical and behavioral co-morbid conditions are very common among individuals with cognitive impairment and benefit from early identification, treatment and close monitoring. As cognitive impairment advances, self-monitoring of medications and maintenance of healthy routines becomes more difficult, increasing the need for caregiver support and primary care physician monitoring.

Considering the disease's prevalence and the absence of effective treatments, it is not surprising that much research focuses on this condition. While the importance of disease research is recognized, there is much debate about whether people with Alzheimer's and related dementias should be permitted to participate in clinical trials and under what conditions. Discussions have focused on the appropriate risk-benefit ratio of Alzheimer's disease trials and the types of consent (subject, proxy, or advance directive) that are acceptable. The debates over the ethical conduct of research centers on determining the appropriate balance between protecting a vulnerable population from the potential risks of research while allowing subjects to participate in trials that could lead to personal medical benefit, as well as medical benefit for the population as a whole.

Research on people with Alzheimer's and related dementias have been almost exclusively concerned with studies of treatments for the disease. Although this is an important starting point, more attention should be given to the inclusion of people with Alzheimer's disease in research on co-morbid medical conditions. As a result, we do not know as much as might be expected about treatment for co-morbid conditions among individuals with dementia. It has been shown that the treatment of co-morbid medical conditions such as cardiovascular disease, infection, pulmonary disease, renal insufficiency, arthritis, and diminution of vision and hearing can improve functionality and cognition in persons with Alzheimer's disease.<sup>84</sup>

#### ***Co-Morbid Medical Conditions***

Regardless of the condition, routine reassessment requires that the primary care physician<sup>85</sup>:

- Review treatment of existing co-morbid conditions, including dosages of medications;
- Evaluate acute changes; and
- Expect unreported problems.

A discussion of the diagnosis of co-morbid behavioral conditions is in Section 4.B. Many of the non-pharmacological treatments identified in Section 4.E. are helpful in managing behavioral symptoms.

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<sup>84</sup> Wall, A. *Including Persons with Alzheimer Disease in Research on Comorbid Conditions*, from IRB: Ethics & Human Research, February, 2009.

<sup>85</sup> Larson, E. (1998). Management of Alzheimer's disease in a primary care setting. *American Journal of Geriatric Psychiatry*, 6, S34-S40.

**Auditory and visual impairments** are common among people with dementia and can affect patient performance on other assessments of cognitive functioning. Further, there is evidence that unaddressed sensory impairments can accelerate cognitive decline.<sup>86</sup> As a result, ensuring that prescriptions for glasses and hearing aids are current and that they are being used appropriately is very important.

**Pain** is a co-morbid condition and is positively associated with increased use of health services. Indeed, in a Veteran's Center study conducted by Kunik et al, self-reported pain was associated with having an inpatient medical admission. People who reported their overall level of pain in the previous week as "very bad" were almost seven times as likely to have an inpatient medical stay in the next year as those who reported no pain. On the basis of the findings of this study, it seems possible that targeting pain for clinical intervention would reduce use of health care services by patients with dementia. Previous research has shown that pain is highly prevalent among people with dementia, yet pain is not often systematically addressed and is frequently under-diagnosed and under-treated by health care teams. Although research has validated the assessment of pain among people with mild to moderate impairment, limited support exists for accurately assessing pain among people with severe cognitive impairment. With deficits in language leading to limited capacity for self-report, people with dementia have been noted to manifest symptoms of pain through behaviors that overlap widely with those indicative of other conditions, such as aggression. These behaviors can affect well-being of the person, the caregiver and health service use.

Although pain among nonverbal people with dementia is poorly understood, research in this area may shed significant light on issues of behavioral and psychiatric disturbances in this population. Subsequently, the cause or causes of these difficulties could be appropriately addressed by health care professionals, which would probably have an impact on these patients' quality of life and future use of health care services.<sup>87</sup>

**Infection.** Patients with dementia respond to subtle insults with delirium, a highly morbid condition characterized by confusion, agitation apathy and motor symptoms including falls, muscle jerks and sometimes seizure. Infections, particularly urinary or pulmonary can precipitate delirium in the elderly and lack of recognition often leads to hospitalization or even death. Recognizing that infection can lead to worsening of symptoms is important. Recognizing infections can be difficult in patients who cannot communicate.<sup>88</sup>

**Dental Care.** Even before diagnosis, people with cognitive impairments have especially high risk of tooth decay which increases severity of cognitive decline.<sup>89</sup> Poor oral hygiene can also have a negative effect on overall health, nutritional intake, behavioral symptoms, social interactions and quality of life.<sup>90</sup>

**Malnutrition.** Inadequate food and fluid intake can result in malnutrition, dehydration, skin breakdown, delirium, and increased morbidity and mortality.<sup>91</sup> A number of environmental

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<sup>86</sup> Kane, R., Ouslander, J., & Abrass, R. (1994). *Essentials of Clinical Geriatrics*. (3rd ed.) NY: McGraw-Hill, Inc.

<sup>87</sup> Mark E. Kunik, M.D., M.P.H., Jeffrey A. Cully, Ph.D., A. Lynn Snow, Ph.D., Julie Soucek, Ph.D., Greer Sullivan, M.D., M.S.P.H. and Carol M. Ashton, M.D., M.P.H. *Treatable Comorbid Conditions and Use of VA Health Care Services Among Patients With Dementia*, *Psychiatric Services*, 56:70-75, January 2005

<sup>88</sup> Bird T, Miller BL. Memory Loss and Dementia. In: *Harrison's Textbook of Medicine*, Kasper DL, Braunwald E, Fauci A, Hauser S, Longo D, Jameson JL. 2005, McGraw Hill, New York, 2394-2406.

<sup>89</sup> Ellefsen, B., Holm-Pedersen, P., Morse, D. E., Schroll, M., Andersen, B. B., & Waldemar, G. (2008). Caries prevalence in older persons with and without dementia. *Journal of the American Geriatrics Society*, 56, 59-67.

<sup>90</sup> Chalmers, J., & Pearson, A. (2005). Oral hygiene care for residents with dementia: a literature review. *Journal of Advanced Nursing*, 52, 410-419.

<sup>91</sup> Amella, E.J. (2004). Feeding and hydration issues for older adults with dementia. In M. Mezey, E. Capezuti, & T. Fulmer

modifications can increase food intake, including provision of favorite foods, playing music while eating, and providing verbal reinforcement and prompts. The use of feed tubes is not recommended, as discussed in Section 4.N.

**Falls.** Injuries from falls are very common among individuals with cognitive impairments. The provision of environmental modifications can reduce injuries of this type. Hallways with guardrails, low-back chairs, non-slip carpet or bath mats and creation of safe, contained areas for wandering all contribute to patient safety. A significant amount of research has been conducted in relation to the prevention of falls, most of it pointing to the need for very customized solutions that respond to individual situations. Common interventions that have not proven to reduce hip fractures or falls that cause them include: exercise, tai chi, hip pads, and many forms of staff training. As cognitive impairment advances the onus of responsibility shifts to the staff and staff compliance with guidelines is a critical factor.<sup>92</sup>

**Sleep Disorders.** Sleep disorders are common for people with cognitive impairment. Pharmacological interventions should be tried when other non-pharmacological treatments have failed. A combination of “sleep hygiene” education for caregivers and daily walking for people with dementia reduced sleep disturbances for those with mid-stage dementia.<sup>93</sup> Sleep hygiene include:

- Sleeping area free of distractions;
- Naps should be limited and short;
- Increased exercise and activity in morning and early afternoon;
- Patients should be dressed during the daytime; and
- Caffeine and nicotine should be avoided and nighttime fluids and diuretics should be restricted.

There is recent evidence that the mere participation in adult day care by itself can improve nighttime sleep.<sup>94</sup> Even warm milk and tryptophan, a tepid bath, or light snack high in carbohydrate can be helpful.<sup>95</sup>

Pharmacological treatments for sleep disorders should be tried only after non-pharmacological treatments have been tried and failed, and even then medications should be used only with great caution as their efficacy has not been demonstrated and the risks and side effects inherent in their use is considerable, particularly if the underlying cause of the sleep disorder is related to depression.<sup>96</sup>

### ***Co-Morbid Behavioral Conditions***

It is important to note that many individuals with dementia may have pre-existing behavioral health conditions that may or may not have been identified before a diagnosis of cognitive impairment. Regardless of whether behavioral symptoms preceded a diagnosis of cognitive impairment, behavioral symptoms may pose a greater challenge than cognitive decline for patients with dementia

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(Eds.).

Care of Older Adults: Nursing Clinics of North America, 39(3), 607-623.

<sup>92</sup> Tilly, J., & Reed, P.I Falls, Wandering, and Physical Restraints: Interventions for Residents with Dementia in Assisted Living and Nursing Homes, Alzheimer's Association 2006.

<sup>93</sup> McCurry, S. M., Gibbons, L. E., Logsdon, R. G., Vitiello, M. V., & Teri, L. (2005). Nighttime insomnia treatment and education for Alzheimer's Disease: A randomized, controlled trial. *Journal of the American Geriatrics Society*, 53, 793-802.

<sup>94</sup> Femia, E. E., Zarit, S. H., Stephens, M. A. P., & Greene, R. (2007). Impact of adult day services on behavioral and psychological symptoms of dementia. *The Gerontologist*, 47, 775-788.

<sup>95</sup> Warshaw, G., Gwyther, L., Phillips, L., & Koff, T. (1995). *Alzheimer's Disease: An overview of primary care*. Tucson, AZ: University of Arizona Health Sciences Center Press.

<sup>96</sup> Ibid.



and their caregivers. The nature and frequency of psychotic symptoms varies over the course of illness, but in most patients, these symptoms occur more often in the later stages of disease. Management of psychosis requires a comprehensive non-pharmacologic and pharmacologic approach, including an accurate assessment of symptoms, awareness of the environment in which they occur, and identification of precipitants and how they affect patients and their caregivers. Non-pharmacologic interventions include counseling the caregiver about the non-intentional nature of the psychotic features and offering coping strategies. Approaches for the patient involve behavior modification; appropriate use of sensory intervention; environmental safety; and maintenance of routines such as providing meals, exercise, and sleep on a consistent basis. Pharmacologic treatments should be governed by a "start low, go slow" philosophy; a mono-sequential approach is recommended, in which a single agent is titrated until the targeted behavior is reduced, side effects become intolerable, or the maximal dosage is achieved. Atypical anti-psychotics have the greatest effectiveness and are best tolerated. Second-line medications include typical anti-psychotics for short-term therapy; and, less often, anticonvulsants, acetylcholinesterase inhibitors, antidepressants, and anxiolytics. Goals of treatment should include symptom reduction and preservation of quality of life.

**Depression.** Depression affects 50% of people with dementia with the nature of the depression changing with the severity of the disease. Symptoms of dysphoria are associated with early stage of cognitive impairment and agitation, apathy and motor slowing more typical of later stages. With a third of individuals with cognitive impairments suffering from depression experiencing fear, suspicion and delusions, the primary care physician must recognize symptoms that underline depression.<sup>97</sup> Many of the non-pharmacological treatments identified in IV.E. have proven effective in treating depression among those with cognitive impairment including increasing participation in pleasant experiences, especially when done with the caregiver. Recreation and adult day care participation are also shown to reduce depression. In one recent study, persons with early stage cognitive impairment who participated in recreational activities designed to stimulate cognitive, physical and psychosocial well-being were significantly less depressed at both 6- and 12-month follow-ups than peers who did not participate.<sup>98</sup> More on identification of depression is in Section IV.B and on the prevention and treatment of depression in Section 4.E. and 4.D.

**Substance Abuse.** Conditions that cause cognitive and functional impairment are not mutually exclusive; hence the question of whether the dementia is comorbid with another condition, such as delirium, depression, or substance abuse, or a medical condition, such as tumor or infection, must be addressed. Often, treatment of the coexisting condition can reduce the degree of impairment and improve the quality of life. Dementia may also have multiple etiologies. For example, substance abuse can contribute to dementia of other etiologies as well as cause dementia in their own right, eg, dementia due to substance-induced persisting dementia. Because an older individual may present with a complex history and multiple medical comorbidities, it is important to diagnose the patient, not the disease.

**Agitation.** A frequent symptom experienced by individuals with cognitive impairments, anxiety is complex both in diagnosis and treatment. Treatments include modification of the environment, interpersonal strategies, and the use of physical or chemical restraint, however research has demonstrated that the use of restraints is not recommended as it has been found to increase

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<sup>97</sup> Zubenko, G. S., Zubenko, W. N., McPherson, S., Spoor, E., Marin, D. B., Farlow, M. R., et al. (2003). A collaborative study of the emergence and clinical features of the major depressive syndrome of Alzheimer's Disease. *American Journal of Psychiatry*, 160, 857-866.

<sup>98</sup> Buettner, L. L., & Fitzsimmons, S. (2006). Recreation clubs: an outcome-based alternative to daycare for older adults with memory loss. *Activities Directors' Quarterly for Alzheimer's & Other Dementia Patients*, 7, 10-22.

mortality.<sup>99</sup> If reassurance does not allay symptoms, patients may respond favorably to short-acting anxiolytics, such as oxasepam or lorazepam, although each may have significant adverse effects and are rarely effective as a long-term therapy.<sup>100</sup>

**Psychosis.** Psychotic features of dementia include hallucinations (usually visual), delusions, and delusional misidentifications. Hallucinations are false sensory perceptions that are not simply distortions or misinterpretations. They usually are not frightening and therefore may not require treatment. Delusions are unshakable beliefs that are out of context with a person's social and cultural background. Delusional misidentification may result from a combined decline in visual function and cognition.<sup>2</sup> For example, patients may suspect that their family members are impostors (i.e., Capgras' syndrome), believe that strangers are living in their home, or fail to recognize their own reflection in a mirror.

In studies of patients with Alzheimer's disease, three psychotic features were present in 15 to 75 percent of patients. Delusional misidentifications are thought to occur in at least 30 percent of patients with dementia.

The above list of co-morbid conditions is far from complete, but represents the major conditions found in individuals with dementia and other forms of cognitive impairment.

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#### **4. H. ADULT DAY HEALTH CARE (ADHC) & SOCIAL DAY CARE CENTERS**

Particularly valuable for those in early and mid-stage dementia is the availability of daily recreation, socialization and stimulation in day care centers designed to accommodate dementia. It is important to distinguish between ADHCs and social model day care centers. Many individuals with early stage cognitive impairment/dementia do not require participation in an ADHC and can generate significant benefit from a social day care center. Indeed for those in early stages of cognitive impairment, participation in ADHCs can be startling as ADHCs serve only individuals who are eligible for skilled nursing facilities and thus the participants tend to be at mid-stages of dementia. Unfortunately, there is a financial incentive to over-utilize the more expensive adult day health care programs as they are eligible for MediCal reimbursement while social model day care centers are not. Furthermore, MediCal regulations prevent families from 'double-dipping' meaning that if a family utilizes an Adult Day Health Care program, it may not use Medi-Cal to reimburse in-home support. This puts families in the difficult position of either having to choose between the two or to seek placement in an assisted living facility.

**Social Model Day Care & Early Memory Loss Programs.** An emerging trend is the development of social model day care centers that integrate a memory loss program. Brookdale Foundation has been promoting the development of these specialized Early Memory Loss Program, a community-based, social model, day service program that provides dementia-specific group activities for participants and respite from caregiving tasks for family caregivers. Programs are open a minimum of one day a week for at least four hours per session, offering people with Alzheimer/dementia and other memory disorders regularly scheduled opportunities for socialization and group activities in a supportive environment.

At least one paid professional staff member and a core of trained volunteers, students and program assistants, provide staffing for sites. In addition, programs offer access to other services for

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<sup>99</sup> Bredthauer, D., Becker, C., Eichner, B., Koczy, P., & Nikolaus, T. (2005). Factors relating to the use of physical restraints in psychogeriatric care: a paradigm for elder abuse. *Zeitschrift für Gerontologie und Geriatrie*, 38, 10-18.

<sup>100</sup> Sink, K. M., Holden, K. F., & Yaffe, K. (2005). Pharmacologic treatment of neuropsychiatric symptoms of dementia: a review of the evidence. *JAMA*, 293, 596-608.

participants and their families, such as individual counseling for caregivers, information and referral to other health and social services, and support group meetings for family members.

***Adult Day Health Care (ADHC).*** Given the increasing structure, consistency, support, and personal assistance required by a person with cognitive impairment and the increased burden placed upon caregivers to provide the vast majority of this support, adult day health care is one of the best settings for the mid-stage individual living in the community. As compared with non-users of adult day care, caregivers of individuals with cognitive impairments using adult day care experienced:

- Fewer difficult-to-manage care recipient behaviors and less time spent managing these symptoms;<sup>101</sup>
- Fewer hours managing memory difficulties and less burden, strain, and worry;<sup>102</sup>
- Fewer recreational restrictions and conflicts between caregiving and other responsibilities;<sup>103</sup>
- A better relationship with the patient;<sup>104</sup> and
- Lower levels of depression, anger and perceived overload.<sup>105</sup>

To achieve maximum caregiver benefits, it is recommended that individuals with cognitive impairments attend adult day services at least twice a week for an extended period of at least three months. Particularly when initiated early, sustained use of adult day care generates benefits for the patient, as well, delaying nursing home placement<sup>106</sup> and attenuating the cognitive decline associated with institutionalization.<sup>107</sup>

Attendance in adult day care can increase access to many of the non-pharmacological treatments identified in IV.E. (above). The moratorium on adult day health centers ends in 2010. The Expert Panel may want to consider recommending expansion of ADHC and social day care centers in this report.

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***4. I. ALZHEIMER'S DAY CARE RESOURCE CENTERS (ADCRC):*** *ADCRCs provide care specifically for people with Alzheimer's disease or other cognitive impairments, and support and education for caregivers and the community.*

The benefits of participation in adult day care programs for caregivers and people with dementia is described in Section 4.H., above. However, people with dementia advance in the disease it becomes increasingly important that their environment, routine of activities, and treatments be customized to their condition. Adult day care and social day care centers, while increasingly sensitive to the needs of individuals with cognitive impairments, staffing, activities, staff training and the environment are not consistently structured to be responsive to individuals with cognitive impairment. Alzheimer's

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<sup>101</sup> Gaugler, J. E., Jarrott, S. E., Zarit, S. H., Stephens, M-A. P., Townsend, A., & Greene, R. (2003a). Adult day service use and reductions in caregiving hours: Effects on stress and psychological well-being for dementia caregivers. *International Journal of Geriatric Psychiatry*, 18, 55-62.

<sup>102</sup> Gaugler, J. E., Jarrott, S. E., Zarit, S. H., Stephens, M-A. P., Townsend, A., & Greene, R. (2003b). Respite for dementia caregivers: The effects of adult day service use on caregiving hours and care demands. *International Psychogeriatrics*, 15, 37-58.

<sup>103</sup> Schacke, C., & Zank, S. R. (2006). Measuring the effectiveness of adult day care as a facility to support family caregivers of dementia patients. *Journal of Applied Gerontology*, 25, 65-81.

<sup>104</sup> Dziegielewski, S. F., & Ricks, J. L. (2000). Adult day programs for elderly who are mentally impaired and the measurement of caregiversatisfaction. *Activities, Adaptation & Aging*, 24, 51-64.

<sup>105</sup> Zarit, S. H., Stephens, M. A., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: effects of adult day care use. *Journals of Gerontology*, 53B, S267-S277.

<sup>106</sup> *Ibid*

<sup>107</sup> Wilson, R. S., McCann, J. J., Li, Y., Aggarwal, N. T., Gilley, D. W., & Evans, D. A. (2007). Nursing home placement, day care use, and cognitive decline in Alzheimer's Disease. *American Journal of Psychiatry*, 164, 910-915.

Day Care Resource Centers (ADCRC) provide a positive experience and care for persons with Alzheimer's disease and other cognitive impairment with a program explicitly designed to respond to the needs of individuals with cognitive impairments and their caregivers.

The primary purpose of the ADCRCs are to: prevent premature or inappropriate institutional placement of persons with moderate to severe levels of impairment due to cognitive impairment; provide support and respite for caregivers; serve as models of the optimum type and level of day care services that are needed by persons with cognitive impairment; make training opportunities available to professionals and other persons providing care and treatment for this population; and increase public awareness and knowledge about Alzheimer's disease and related disorders.

The centers provide services that support the physical and psychosocial needs of persons with Alzheimer's disease or related cognitive impairment. Individual care plans are developed for each program participant with activities scheduled in accordance with these plans. The overall objective is to keep the participants as healthy and active as possible by helping them maintain their highest level of functioning and to improve the quality of their lives while providing respite to caregivers. Persons who have been diagnosed as having Alzheimer's disease or other cognitive impairment are eligible to participate, without regard to age or financial resources. Targeted are those persons having moderate to severe levels of care needs and behavioral problems which make it difficult for them to participate in other care programs.

Participants are requested to share in the cost of care through fees based on the cost of services and a sliding fee scale that is specific to each site. Approximately one-third of the sites are administered under Adult Day Health Care licensure and certification, permitting them to accept Medi-Cal eligible persons.

While researchers were unable to identify any outcome evaluations or clinical trials of ADCRCs, that they deliver the kinds of evidence-based non-pharmacological treatments and supports as described in Section 4.E. and in a physical environment explicitly tailored to the needs of individuals with cognitive impairments, it is reasonable to assume their achieving at least the level of benefit found in research on involvement in adult day care settings.

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#### **4. J. CAREGIVER EDUCATION, SUPPORT & RESPITE:** *Assessment and support for caregivers, including respite.*

While estimates vary, especially during early and mid-stages of cognitive impairment, caregivers provide the vast majority of support for people with dementia. Over half of all individuals with cognitive impairments live in home settings<sup>108</sup> and 87% of individuals with cognitive impairments are cared for primarily by family members,<sup>109</sup> with the three-quarters of caregivers being women.<sup>110</sup> There is widespread evidence to support the use of comprehensive caregiver support in reducing institutionalization. In one study, 65% of the intervention group was living at home after 30 months compared to 26% in the control group.<sup>111</sup>

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<sup>108</sup> American Geriatrics Society. (2008). The Alzheimer's Disease Caregiver. Retrieved March 30, 2008, from <http://www.americangeriatrics.org/education/forum/alzcare.shtml>

<sup>109</sup> Alzheimer's Association & National Alliance for Caregiving. (2004). Caring for persons with Alzheimer's: 2004 national survey. Chicago, IL: Alzheimer's Association.

<sup>110</sup> Ory, M. G., Hoffman, R. R. III, Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist*, 39, 177-185.

<sup>111</sup> Brodaty H, Gresham M, Luscombe G. The Prince Henry Hospital dementia caregivers' training programme. *Int J Geriatr Psychiatry* 1997;12(2):183-92.

In a Finnish study the median time of residing in the community following a program of systematic comprehensive support by a nurse or dementia family care coordinator was 647 days in the intervention group and 396 days in the control group.<sup>112</sup>

Unfortunately, benefit to the person with cognitive impairment comes at considerable cost to the caregiver. There is considerable research that caregivers are at extreme risk of developing physical and behavior morbidity, including cardiovascular disease, depressions, stress and anxiety.<sup>113</sup> However, other research suggests that caregiver assessment, education and referral for community resources can lead to improved outcomes for both the caregiver and person who has dementia.<sup>114</sup>

The starting point for caregiver education and support is to assess caregivers to determine their capacity to provide the level of support required by the person with cognitive impairment. This should cover:

- Current knowledge base of cognitive impairment, its trajectory, and service options and limits;
- Level of social support;
- Psychiatric symptomology and burden;
- Existing family conflict
- Ethnic and cultural issues.

The American Medical Association website has a caregiver self-assessment tool including these topics.

Many supports and resources have been demonstrated to benefit the caregiver and patient with cognitive impairment. Increased social support has been linked to greater well-being and support from spouses and family members have lower risk for depression.<sup>115</sup> Caregiver education increases the chances of patient treatment compliance.<sup>116</sup> Seamless services and facilitated access to critical services is essential for both people with dementia and their caregivers.<sup>117</sup> Evidence suggests that counseling, support group participation and access to phone support may preserve caregiver health and delay institutionalization.<sup>118</sup>

A recent literature review found 19 studies supporting the value of caregiver interventions, including psycho-educational skill building programs, psychotherapy and counseling and multi-component interventions. Psycho-educational programs have shown to be among the most effective forms of therapy with broad impact with caregivers showing consistent improvement in measures of burden depression, well-being, ability, and relevant knowledge with a corresponding improvement in patient outcomes.<sup>119</sup>

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<sup>112</sup> Eloniemi-Sulkava U, Notkola IL, Hentinen M, Kivela SL, Sivenius J, Sulkava R. Effects of supporting community-living demented patients and their caregivers: a randomized trial [comment]. *J Am Geriatr Soc.* 2001;49(10):1282-7.

<sup>113</sup> Family Caregiver Alliance (2006). *Caregiver Assessment: Principles, Guidelines and Strategies for Change*. Report from a National Consensus Development Conference (Vol.1). San Francisco: Author.

<sup>114</sup> Feil, D. G., MacLean, C., & Sultzer, D. (2007). Quality indicators for the care of dementia in vulnerable elders. *Journal of the American Geriatrics Society*, 55, S293-S301.

<sup>115</sup> Atienza, A. A., Collins, R., & King, A. C. (2001). The mediating effects of situational control on social support and mood following a stressor: A prospective study of dementia caregivers in their natural environments. *Journals of Gerontology*, 56B, S129-S139.

<sup>116</sup> Callahan, C.M, MD et al, *JAMA*. May 2006; 295:2148-2157.

<sup>117</sup> Family Caregiver Alliance (2006). *Caregiver Assessment: Principles, Guidelines and Strategies for Change*. Report from a National Consensus Development Conference (Vol.1). San Francisco: Author.

<sup>118</sup> Mittelman, M. S., Haley, W. E., Clay, O. J., & Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*, 67, 1592-1599.

<sup>119</sup> Sørensen, S., Pinguart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42, 356-372.

Cognitive Behavioral Therapy offered in group or individual settings have reduced caregiver depression and improving quality of life for African Americans, Hispanic and Caucasian caregivers.<sup>120</sup>

**Respite.** Given the challenges of caregiving, it is not surprising respite is cited as the service most needed by caregivers.<sup>121</sup> Respite programs come in many forms and structures with a need for home-based respite, emergency respite and respite extending overnight or for several days. With so many variations, researchers did not find any evaluations of the efficacy of specific models or levels of respite that correspond with reductions in caregiver burden or delays in institutionalization.

**Caregiver Coaching: StillMee.** StillMee coaches can provide a better understanding of the mental and physical health of the person with memory loss and what s/he is experiencing. StillMee is designed to teach caregivers how to better interact with someone with memory loss. StillMee offers:

- In Home Coaching for family caregivers; face to face, by telephone and email
- Staff Training
- Public Presentations
- Assisted Living Residence Support

StillMee coaching services are designed to help caregivers to:

- Understand what cognitive impairment is and how to get a good diagnosis
- Understand and accept the behaviors commonly seen in cognitive impairment
- Learn new ways to respond to changes in behavior
- Give you confidence in making it easier for your family member to participate safely in his own care and to continue to find pleasure in life.

StillMee coaches have completed the Habilitation Therapy training course developed by Paul Raia, Ph.D. and Joanne Koenig-Coste M. Ed, who are pioneers in the field of care for individuals with cognitive impairments. This service was recommended by an Expert Panel member, but no evaluations were available to document its impact.

**Cultural Dimensions of Support.** Culturally diverse caregivers view cognitive impairment in very different ways with some cultures far more likely to view cognitive impairment as a source of shame or retribution for sins (e.g. Chinese Americans).<sup>122</sup> As a result of caregiver cultural differences education and support must be customized to be culturally responsive. A substantial body of research and practices has evolved that incorporates sensitivity to these cultural nuances and primary care providers should be familiar with this research and culturally relevant supports.

**The Best Friends.** Given evidence that in San Francisco up to 40% of individuals with cognitive impairment will not have a family member within one-hour's drive of San Francisco, a system of care predicated upon support from family members will be unresponsive to a significant proportion

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<sup>120</sup> Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., et al. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals of Internal Medicine*, 145, 727-738.

<sup>121</sup> McConnell and Riggs, 1994

<sup>122</sup> Wang, P.-C., Tong, H.-Q., Liu, W., Long, S., Leung, L. Y. L., Yau, E., et al. (2006). Working with Chinese American families. In G. Yeo & D. Gallagher-Thompson (Eds.). *Ethnicity and the dementias* (2nd ed.) (pp. 173- 188). New York, NY: Routledge/Taylor & Francis Group.

of our population. The Best Friends approach to Alzheimer's care was developed in the mid 1990's by Virginia Bell and David Troxel. Best Friends is predicated upon the principle that the role of caregiver need not be limited to family members. While we were unable to identify any evaluation findings as to the efficacy of the model, there are several books available on The Best Friends website outlining the model and presenting the training that the organization can provide. Similar in design to the *Living at Home* model described in Section IV.F., this is a model that San Francisco may want to explore to address the high number of individuals with cognitive impairments who are projected to be without readily accessible family members support.

***Family Caregiver Alliance.*** The Family Caregiver Alliance website has tools, assessments, articles, guidelines on how to handle a wide range of legal, treatment, housing, and support issues. These support materials were developed explicitly to support caregivers. It is an excellent resource.

[http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=368](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=368)

***Alzheimer's Association Savvy Caregiver Training.*** The six-week Savvy Caregiver Training Program, which the chapter last year began to offer, is that opportunity.” Based on research by experts, the Alzheimer's Association Savvy Caregiving series tackles caregiving as a set of learnable skills, centered around the twin goals of taking care of oneself while helping the care-receiver maintain a state of contented involvement in activities. Caregivers learn to step back, to become a skilled observer, to understand their family member through the Alzheimer's lens, and to strategize and take control of the evolving situation. Participants report an increased sense of mastery over their caregiving role.

***Powerful Tools for Caregivers Online.*** Another resource for caregivers is based on the Chronic Disease Self-Management Program at Stanford University. “Powerful Tools for Caregivers Online” is a six-week, online educational course that will help the caregiver:

- manage the common stresses associated with caring for a relative or friend with a chronic medical condition
- design effective action-planning tools and time management as a caregiver
- communicate more effectively with friends, family, health care providers, and coworkers
- find resources
- cope with emotions such as guilt and depression

In early and mid-stages of cognitive impairment, the majority of community and home care is provided by unpaid family members, most often women as partners or children of the person with dementia. This section describes how to support family caregivers, however this presumes a family member or loved one to be that caregiver. San Francisco faces a unique challenge due to estimates that as many as 40% of older adults do not have a relative living within an hour of the City, about double the percentage found in other urban communities. These “un-befriended” individuals will not be able to rely upon routine family support and are likely to require assisted living or nursing home care far earlier than would be the case if they had in-home support of the kind that would typically be provided by a family member. This presents a significant challenge to San Francisco for elderly adults and it is imperative that alternative forms of in-home support be identified.

Our research did not identify the ‘silver bullet’ or model program that could address this gap in services. This may be the single greatest weakness in San Francisco. Accordingly, if not addressed, it would put pressure on the dwindling supply of affordable beds in assisted living and skilled nursing facilities.

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**4. K. ASSISTED LIVING & RESIDENTIAL CARE FACILITIES FOR THE ELDERLY (RCFE):** *Housing for early and mid-stage people with dementia to prevent or delay entry into higher levels of care.*

Assisted living is an amorphous concept—not just a level of care on a continuum between independent living and nursing homes, but increasingly an alternative to nursing homes. “Assisted living” has no legal standing as a program, rather it is a term used to describe a range of regulated facilities designed to care for the elderly. Regulations in some states specifically allow assisted living communities to care for an individual through end of life.

Some nursing homes are working on reinventing themselves to reflect the same priorities as assisted living, with the full support of the federal government's Centers for Medicare and Medicaid Services and the state Quality Improvement Organizations. Assisted living communities are, for the most part, still privately funded. So when their residents need assistance from Medicaid they are forced to relocate to a nursing home. But in states with Medicaid waiver programs that allow Medicaid to help fund assisted living, this is not the case.

An excellent study conducted by Hyde, Perez, and Forester, *Dementia and Assisted Living*<sup>123</sup> highlighted many of the challenges individuals with cognitive impairments face in entering and maintaining residence in assisted living residences. There are some constraints on moving into assisted living if a person has cognitive decline. For example, in a study of state regulations, more than half of the states studied had admission and discharge criteria that limited admission and retention of people with dementia.

Hyde also found that based on his review of six national studies, Golant (2004) concluded that assisted living residences were more likely to accept frail older persons when these people had less serious cognitive impairments and when they did not require ongoing supervision (e.g., did not wander; or did not have memory, judgment, or behavioral problems). He also indicated that less than 50% of the assisted living residences would accept older persons if they had moderate to severe dementia.

Hyde's study cites Hawes and colleagues (2003) who found that fewer than 45% of assisted living providers would retain a resident with severe dementia. Ball and associates (2004), in their study using qualitative methods in five assisted living facilities, found that even in assisted living residences that wish to serve the most frail residents and have it be their last home, there are many issues, including impaired residents being ostracized and moved to dementia units. And when care needs are very high, residents can experience neglect that calls into question their quality of life as they age in place.

Hyde concludes by noting that assisted living was developed specifically to be responsive to residents' own definition of quality. The challenge will be to design assisted living facilities that respects that mission and honors the dignity of those whom assisted living seeks to serve; to find meaningful and appropriate ways to ask questions of people with dementia; and to measure, with reasonable reliability and validity, their responses to care and treatments.

As described above, there really is no one kind of assisted living program, indeed “assisted living” isn't even a program designation relevant to any of the regulatory bodies responsible for overseeing residential care. Among the kinds of residential care programs:

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<sup>123</sup> Hyde, J., Perez, R., and Forester, B., *Dementia and Assisted Living*, *The Gerontologist*, 47:51-67 (2007).



***Residential Care Facilities for the Elderly (RCFE).*** There are gradations of RCFEs as relates to the provision of care for individuals with mid to late stage cognitive impairment or dementia. According to Section 3.2 of the regulations governing residential care for the elderly, every facility is required to be licensed under this chapter. There are essentially three levels of RCFE licensed by the State Department of Social Services (DSS) in California:

- RCFE- The standard RCFE is not required to provide dementia-specific training for staff and does not require dementia-advised environmental accommodations. But unless a RCFE meets the requirements of Section 87705 they are not legally able to care for individuals with a diagnosis of dementia, but may care for individuals with other forms of mild to moderate cognitive impairment. In reality as individuals age in place and their impairment advances, many of these facilities do care for individuals with moderate to advanced forms of dementia despite 87705.
- RCFEs licensed through section 87705 care for individuals diagnosed by a physician with dementia. These RCFEs receive additional funding through an additional monthly charge that is based upon a sliding scale and differs by provider. Each RCFE must also comply with a range of safety, on the job training, staffing and facility requirements developed to ensure that the facility meets the needs of individuals with dementia, as advertised.. In fact, the requirements are woefully inadequate **and** the oversight of adherence to the regulations is inadequate. What compounds access to these RCFE are that according to the RCFE regulations, all residents designated as having dementia, are technically “ non-ambulatory”- a designation for the physical plant of the particular RCFE, set by Fire Marshal standards. There are general RCFE of the board and care variety and assisted living type with not particular focus on dementia care. In these facilities expect to find residents with mild to moderate dementia, or with MCI. Then there are RCFE that still have what is called a dementia waiver, referring to a prior requirement for Community Care Licensing (CCL) to approve a RCFE for admitting and retaining persons who need protective supervision. The standards are less than for those which advertise.
- RCFEs that advertise they specialize in caring for individuals with dementia have another level of regulatory compliance (chapter 87706) that specifies a range of training, facility, program activity, assessment and other requirements. For these RCFE there are requirements for annual physician reports, and re-appraisal of care needs- a requirement not required for the general RCFE facilities, despite the reality of very real longitudinal changes in care needs for the elderly residents. Again, as with the designation to care for individuals with dementia, the requirements are low and the oversight inadequate.

The problems with the above continuum of assisted living options is that high quality RCFEs specializing in care for people with dementia are scarce, especially as a person advances in the level of impairment or starts manifesting challenging behaviors. With demand outstripping an affordable supply, many people with dementia: (1) languish in residential facilities not prepared or required to address their needs; or (2) are diverted to Laguna Honda Hospital, the Jewish Home, or other nursing facilities that are costly and in short supply.

However, in nursing facilities the standards of practice for resident care, including modalities of treatment for dementia care and related behaviors, are better articulated. For instance, in nursing facilities there is clear language requiring special informed consent for psychotropic medications, and prohibiting the use of chemical and physical restraints for the convenience of staff. While RCFEs may be less restrictive, these protections are not as stringent. Aside from this, dementia care in larger institutional settings may not be as particular to the resident in terms of management of behaviors, and may not allow the possibility of establishing residential communities where consumers can flourish in a setting that is away from a medical model of care.

San Francisco is faced with the challenge of identifying or developing other models of assisted living to address the needs of people with mid-stage dementia so as to preserve the resources of Laguna Honda and the Jewish Home for late stage dementia and other rehabilitative needs. Unfortunately there are few alternative models to RCFEs. Models worthy of exploration are described below:

***Continuing Care Retirement Communities*** are licensed as an insurance product. Individuals pre-pay for care that is theoretically insured to continue as they age in place. Primary oversight focuses upon ensuring that these programs are adequately capitalized so they can continue providing appropriate levels of care once care needs increase. But in reality what happens is that programs have to raise the cost of services as care needs increase often individuals are removed, often for 'behavioral' or 'safety' issues. In many cases, these individuals have invested their resources and once discharged are then dependent upon public resources for continued care. In some respects Continuing Care Retirement Communities that 'evict' difficult residents can be viewed as managed care with an unadvertised policy, which is made apparent at the exit door. While this approach may not be typical, the Research Subcommittee members described it as not an infrequent occurrence.

***Residential Care Facilities for the Chronically Ill (RCFCI)***. An RCFCI is an innovative model of assisted living licensed by the State DSS that emerged in the 1980s to serve the unique needs of people with HIV/AIDS. RCFCIs tend to be a more community-based model that integrate medical care services into the residential care. It is a lower cost model than skilled nursing facilities.

Maitri Compassionate Care is a "best practice" RCFCI in San Francisco. Since 1987, Maitri has been providing hospice and 24-hour care to people with AIDS. In this 15-bed facility, skilled professionals and dedicated volunteers offer nursing and personal care as well as emotional and spiritual resources to help meet the needs associated with HIV-related illness. This non-profit program is focused especially on those who might otherwise be without adequate resources or care.

***The Green House Model*** has been promoted by the Robert Wood Johnson Foundation. It may be licensed as: (1) a nursing facility; or (2) either a residential care or an adult foster care facility. Green House homes transform long-term-care practices and outcomes for the most impaired residents within existing regulatory guidelines and reimbursement levels. Each Green House is designed to be a home for eight to ten elders who require a skilled nursing level of care. Each elder has a private living space and bathroom. There is a central hearth or living room with an adjacent open kitchen and dining area. All meals are cooked by the direct service staff or Shahbazim in the Green House and are eaten at a long dining table that acts as a focal point for a 'convivium', or communal meal.

One licensed nurse is available to provide skilled nursing care for two to three houses, depending on the clinical needs of the elders. Clinical staff specializing in speech therapy, recreation, diet, OT, and PT, also visit as required by the care plan. There is no nursing station. Nurses visit frequently each day. The majority of the care is provided by two Shahbazim on the day and evening shifts and one assigned to night duty. Only the Shahbazim and the elders have direct entry access to the house.

The principles at the core of the model are:

- Maximizing of independence.
- Resident-centered care.
- Self-managed direct-care work teams.
- Small homes focused on creating intentional communities, in which all residents of home are seen as part of a community within the house and within the larger area in which the house is located. This differs from a nursing home where the older adult is a patient and the institution does not represent a community.

Near the end of the 3rd grant, the Robert Wood Johnson Foundation Board of Trustees approved a national Green House replication effort. This \$9,584,202 project (ID# 053217), which runs through October 2010, is called the Green House Replication Initiative. Its goal is to stimulate development of 50 or more Green House projects by the end of that year.

An evaluation was conducted of the Green House model in Tupelo, Mississippi by Dr. Rosalie Kane of the University of Minnesota. Findings included that Green House elders reported a better quality of life and greater satisfaction, and their family members were more satisfied with their relatives' care and with how they themselves were treated. There was less of a decline in the ability to do activities of daily living, a lower prevalence of depression, less incontinence without a toileting plan, and less use of anti-psychotic drugs without a diagnosis among residents of the Green House homes.

Green House staff reported that they felt more empowered to assist residents, they knew residents better, and they experienced greater intrinsic and extrinsic job satisfaction. They were also more likely to say they planned to remain in their jobs.

Among lessons learned:

- Green House project designers have had to revise the training curriculum and staffing patterns to better fit the facilities that used the original model and critiqued it.
- In addition, they report that some experienced CNAs find it difficult to switch to the Shahbaz model, since the daily responsibilities of a Shahbaz are, at times, significantly different than those of a traditional CNA.
- Project administrators have found that the general costs associated with running a Green House are similar to the costs incurred by a traditional nursing home facility. For example, in Tupelo, the Green House was able to operate at the Medicaid daily rate of \$117 a day when it opened in 2003. However, in more expensive communities like San Francisco, a Greenhouse model program could not operate with only SSI/Medicaid to sustain it.
- While certain economies of scale are lost when operating a small residence, the Green House model is designed to shift resources away from institutional overhead towards supporting the direct care needs of residents. For example, many of the costs of conducting regular house maintenance and cooking are transferred to the daily operations of the direct-care worker.

**Mission Creek Senior Community.** This mixed-use development combines 140 apartments for older adults with San Francisco's first new branch library in 40 years and an adult day health care center. Developed by Mercy Housing California, the \$43.7 million project received support from the San Francisco Redevelopment Agency (SFRA). The development is in the Mission Bay neighborhood. SFRA brought together Mercy Housing California and the San Francisco Public Library to create a place for housing, care, and community.

In addition to the 7,500-square-foot branch library and a coffee house, there is a third-floor community room. One of the most important components of Mission Creek is the adult day health center (ADHC), which provides key health and social services to seniors. Many of the residents have suffered long episodes of homelessness or institutionalization. Operated by North & South of Market Adult Day Health, Inc., ADHC services include medical care and occupational and physical therapy. Clients also receive lunch. More than 50 seniors use the center daily. About 20 are residents of the building, with the others coming from the neighborhood.

The development's biggest achievement is providing housing for very low income seniors with special needs. Fifty-one apartments are designated for formerly homeless and frail or disabled seniors. The rents for these units are subsidized by the San Francisco Department of Public Health.

Eighty-eight units are for residents earning no more than 50% of the AMI (area median income), and 51 units are for those earning no more than 20% of the AMI. All are one-bedroom units. The average income of the seniors at Mission Creek is below 20% of the AMI. There is also a manager's apartment. Rents are as much as 90% below market-rate rents in the area.

**EliteCare, Tigard, Oregon.** Another innovative model of care opened in August 2008 in Tigard Oregon. EliteCare homes deliver relationship-based care that stresses sustained relationships with families and loved ones. Suggested by a Expert Panel member, there is little but promotional material written about the program, but it appears worth exploring as it employs a person-centered philosophy of care.

Finally, while living in any assisted living program an individual with dementia may require rehabilitative services that extend beyond what is available in even the most skilled RCFE. Currently, these patients wind up in need of transfer to a skilled nursing facility, however, at one time San Francisco.

**Comprehensive Outpatient Rehabilitation Facility (CORF)** A mid-level assisted living program, CORFs must provide coordinated outpatient diagnostic, therapeutic, and restorative services, at a single fixed location, to outpatients for the rehabilitation of injured, disabled or sick individuals. CORFs can be an effective resource for maintaining an individual in an assisted living program if rehabilitation is not available at the RCFE but is needed to remain out of a skilled nursing facility. Physical therapy, occupational therapy and speech-language pathology services may be provided in an off-site location. The following are considered "core" services that a CORF must provide:

- Consultation with and medical supervision of non-physician staff, establishment and review of the plan of treatment and other medical and facility administration activities
- Physical therapy services, social or psychological services
- CORFs are surveyed every six years at a minimum.

While a CORF exists in San Leandro, there is no CORF operating in San Francisco. Access to such a resource might extend the length of time individuals could remain in an assisted living facility.

***The absence of sufficient affordable assisted living programs appropriate for caring for individuals with dementia and related conditions places an extraordinary stress upon the shrinking number of skilled nursing facility beds in San Francisco.***

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**4. L. NURSING HOMES & HOSPITALS:** *Institutional care for people with Alzheimer's and other dementias, from mid to late stage.*

There is considerable evidence that early diagnosis of dementia, community-based treatments, and caregiver support can reduce reliance upon nursing homes and hospitals, especially for those needing early stage care. A case study conducted in Lincolnshire, England found that many people with dementia placed in acute wards no longer needed to be there. In Lincolnshire, they redirected 6.5 million pounds of funding from acute care to alternative bed and home care services and to

improve early diagnosis services.<sup>124</sup> These kinds of redirections of resources are more easily achieved in capitated, managed care structures such as those found in other countries. However, it is reasonable to assume that in the USA we also have large numbers of people with dementia in nursing homes and hospitals at early and even mid-stage of cognitive impairment who, with appropriate levels of support, could reside in lower levels of care.

It is important to note that while a nursing facility is expensive, especially in the later stages of cognitive impairment, often this type of facility (particularly, the exemplary models in San Francisco such as Laguna Honda Hospital and the Jewish Home) is the most appropriate placement for the individual and the family. While every network or system tries to avoid premature placement in its highest levels of care, at times, placement in skilled nursing, especially at late stage, is in the best interest of the person with dementia and their loved ones.

Much is known about evidence-based practices in nursing facilities, some of which is applicable to living in community-based long-term assisted living facilities. The application of these research-based practices would significantly improve outcomes and quality of life of patients. However, the research has shown the difficulty of getting primary care doctors, nurses, and other health personnel to consistently apply research-based guidelines. Significant levels of training and administrative cues may be necessary to increase the use of these evidence-based practices.

***Practices Related to Physiological Needs.*** Routines that can be implemented by assisted living, nursing home, and hospital settings can significantly improve the quality of life and health outcomes for people with dementia. The recommendations that follow were identified through a review of 325 peer-reviewed studies conducted by the Alzheimer's Association.<sup>125</sup> In relation to *nutrition and feeding* research has demonstrated that: allowing residents to exercise more control of the eating process increases caloric intake; when verbal prompts and encouragement are offered, patients are more likely to complete meals; eating while listening to music resulted in people consuming more food and reducing anxiety; eating in small rooms immediately adjacent to the patient's room reduced anxiety resulting from incidents in transit from living to eating area. In relation to incontinence: prompted voiding, behavior modification, and scheduled toileting should be used to reduce urinary incontinence and that even making toilets more visible increases their use.

Similar strategies for bathing, dressing, sleeping, and other daily living functions demonstrate that a pleasant environment, individually tailored interventions and supports that promote independence all contribute to reduced anxiety and improved functioning. Environmental modifications such as use of low chairs, railings, and on-skid bath mats and chairs reduce injuries due to falls. The provision of an enclosed space for wandering reduced the consequences of wandering.

The body of work on agitation and aggression in nursing homes and hospitals encompasses 20 individual intervention studies and 11 reviews of the behavioral health literature. In large part, the studies show reductions in resident agitation or aggression using a variety of interventions including morning bright light; twice daily application of lemon balm oil to residents' hands and faces; aromatherapy using lavender oil; administration of melatonin; admission to special care units with the environment altered to reduce sound, increase visual stimulation, and facilitate safe wandering; listening to "white noise"; use of a therapy dog; one-to-one interaction between residents and research staff and residents viewing a videotape of family members talking to them; music therapy; staff training; increased nurse staffing in a special care unit; a walking program; multi-sensory stimulation program; hand massage; and individually-tailored interventions.

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<sup>124</sup> *Improving Services and Support for People with Dementia*, National Audit Office, p. 11, 2007.

<sup>125</sup> Tilly, D., and Reed, P., *Evidence on Interventions to Improve Quality of Care for Residents with Dementia in Nursing and Assisted Living Facilities*, The Alzheimer's Association. 2004.

Although the methods of reducing agitation and aggression are diverse, the studies have several underlying themes. When residents live in environments that reduce disruptive stimulation such as excessive noise, and provide bright, entertaining areas for residents, agitation and aggression may be reduced. In addition, properly trained and supervised staff, who have training in handling the behaviors associated with dementia, have the potential to reduce residents' agitation and aggression.

In San Francisco, Laguna Honda Hospital (LHH) and the Jewish Home are themselves best practice providers of skilled nursing care. LHH was originally created with a waiver that allowed 33 beds per ward thus making a high quality of care affordable. This open ward style of providing care is no longer the standard and the waiver has been terminated by the federal government. LHH has experienced a reduction of beds devoted to chronic care and a shift to using beds for short-term rehabilitation. LHH is now being rebuilt to become a model skilled nursing facility with 780 beds.

In the absence of a continuum of assisted living programs that maintain individuals in a lower level of care, many individuals with dementia are admitted to LHH or the Jewish Home for lack of any other assisted living options. However, as beds devoted to chronic care disappear, individuals with moderate to advanced stages of dementia have no appropriate public facility for care.

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#### **4. M. END OF LIFE & HOSPICE CARE:** *Terminal care for people with late-stage dementia.*

Growing evidence suggests there is a lack of understanding of end-of-life issues among the general population. End of life decisions need to take into account effective pain management, the goals of the patient, (via advance directive), and patient and caregiver satisfaction.<sup>126</sup> Advance directives and healthcare surrogates should be defined early while a patient can have detailed input into a variety of situations, including do-not-resuscitate orders, artificial nutrition plans, and health care proxies.<sup>127</sup> Such measures ensure patient preferences are followed. A barrier to advance completing informed consent forms and appointment of surrogates is that these documents are written at high literacy levels impeding low-literacy and non-English speaking populations from completing them. Another barrier is that the legal system does not honor non-blood relatives while among some cultures rely upon "fictive kin" who are considered family and who would routinely be involved in medical decisions. In these instances it is particularly important that assistance is sought to respect these culturally honored, informal relationships.<sup>128</sup>

People in late stages of dementia have limited capacity to verbalize ailments. The American College of Physicians recently recommended that primary care physicians regularly assess patients for pain, dyspnea, and depression.<sup>129</sup> Assessments exist to assess pain even with non-verbal patients.<sup>130</sup>

As people move from mild, to mid stage, to late state dementia, weight loss is likely. Research recommends against the use of feed tubes as it is uncertain if there are any clinical benefits,<sup>131</sup> has not been proven to extend life or decrease suffering, and when used with restraints to prevent patients from removing the tubes, may increase anxiety and confusion, reducing quality of life.<sup>132</sup>

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<sup>126</sup> Kettl, P. (2007). Helping families with end-of-life care in Alzheimer's Disease. *Journal of Clinical Psychiatry*, 68, 445-450.

<sup>127</sup> Ibid.

<sup>128</sup> Valle, R. (2001). Ethics, ethnicity and dementia: A "culture fair" approach to bioethical advocacy in dementing illness. *Georgia Law Review*, 35, 465-515.

<sup>129</sup> Qaseem et al, *Annals of Internal Medicine*, 148, 370-78 (2008).

<sup>130</sup> van Herk, van Dijk, Baar, Tibboel, and de Wit, *Nursing Research*, 56, 34-43 (2007).

<sup>131</sup> Finucane, T. E., Christmas, C., & Travis, K. (1999). Tube feeding in patients with advanced dementia: A review of the evidence. *JAMA*, 282, 1365-1370.

<sup>132</sup> Gillick, M. R. (2000). Rethinking the role of tube feeding in patients with advanced dementia. *The New England Journal of*

However, there are perverse financial incentives for the use of feeding tubes, as they reduce the level of care required and provide for higher Medicaid reimbursement. In a New York Times article dated May, 18, 2004, Dr. Christine Cassel, an expert in geriatrics, ethics and end of life care and president and chief executive of the American Board of Internal Medicine, indicated, “We are spending a huge amount of money keeping people with irreversible brain damage alive. If the technology exists, we feel we must use it. Our colleagues in Europe consider what we do bizarre to the point of disbelief.” The decision to remove or to not insert a feeding tube is an enormously difficult decision for the family member, even with advance directive indicating this to be the preference of the person.

Predicting end-of-life of people with dementia is difficult, but necessary to obtaining entry into hospice care, which requires a prognosis of mortality within six months. Instruments have been developed for this purpose (e.g. Mini Suffering State Examination). In addition a number of conditions commonly predict immanent mortality, including:

- |  |   |
|--|---|
| <input type="checkbox"/> Dependence on others for activities of daily living | <input type="checkbox"/> Weight loss                    |
| <input type="checkbox"/> Recurrent infections                                | <input type="checkbox"/> Loss of mobility               |
| <input type="checkbox"/> Multiple pressure ulcers                            | <input type="checkbox"/> Recent hip fracture            |
| <input type="checkbox"/> Cardiovascular disease                              | <input type="checkbox"/> Diabetes mellitus              |
| <input type="checkbox"/> Need for oxygen therapy                             | <input type="checkbox"/> Excessive sleep <sup>133</sup> |

Under any of the above circumstances, referral to end of life and hospice care should be considered.

## Conclusion

One theme pervades the review of the literature above: missed opportunities. Research points the way to numerous practices, interventions, policies, and approaches each of which if implemented can identify dementia earlier, delay its progression, prevent some co-morbid conditions, or improve the quality of life of individuals with dementia and their caregivers. At each step in dementia’s progression are opportunities to improve care for the person with cognitive impairment, to better educate a caregiver, to create a treatment plan with the individual’s input, to access important pharmacological interventions, or to use environmental interventions to better protect the safety of the individual living in the community.

This literature review points to one over-arching need: a network that delivers specific, current best practice guidelines and standards to individuals, caregivers, service providers and policymakers so that they have an impact on care and on critical decisions that must be made related to interventions, placements, referrals, education and policy making. Too often decisions are based on a limited understanding of available options and their relative benefit. This is not the fault of caregivers, service providers or policy makers. Treatment advances occur rapidly and we have not identified the way to harness our advance in understanding into an easily accessible framework that would facilitate swift access to the key information needed to make the best possible decision about a prescription, referral, or placement. As a result, we continue to make decisions based upon imperfect knowledge at great fiscal and human cost.

Put simply, the service providers and other organizations and individuals involved in San Francisco’s network of health care and social services for people with dementia and their caregivers must find a way to translate what we know into what we do.

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<sup>133</sup> Mitchell et al, *Journal of the American Medical Association*, 291, 2734-40, (2004).

**Appendix II: Inventory of Dementia Services & Supports  
(November 2009)**

SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Adult Day Centers	Bayview Hunter's Point Adult Day Health Center	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Adult Day Centers	Catholic Charities CYO – Social Day Care and Alzheimer's Day Care Resource Center	Mild	Moderate	Advanced		Means Tested	Fee for Service
Adult Day Centers	For Profit Adult Day Health Centers	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Adult Day Centers	Institute on Aging – Irene Swindells Center for Social Day Services	Mild	Moderate				Fee for Service
Adult Day Centers	Institute on Aging – Ruth Ann Rosenberg Adult Day Health Center and Alzheimer's Day Care Resource Center	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Adult Day Centers	Jewish Family & Children's Services – L'Chaim Adult Day Health Center	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Adult Day Centers	Kimochi, Inc. – Social Day Care	Mild	Moderate			Means Tested	Fee for Service
Adult Day Centers	North and South of Market Adult Day Health Center – Golden Gate Day Health	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Adult Day Centers	North and South of Market Adult Day Health Center – Mabini Day Health	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Adult Day Centers	North and South of Market Adult Day Health Center – Mission Creek Day Health	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Adult Day Centers	North and South of Market Adult Day Health Center – Presentation Day Health	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Adult Day Centers	On Lok Lifeways – PACE Model (On Lok & Institute on Aging)	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Adult Day Centers	Self Help for the Elderly – Adult Day Health Center and Alzheimer's Day Care Resource Center	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Adult Day Centers	St. Mary's Adult Day Health Center	Mild	Moderate		Entitlement	Means Tested	Fee for Service



SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Adult Day Centers	<i>(Need more Alzheimer's Day Care Resource Centers)</i>		Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Advocacy & Protection	Adult Protective Services	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Advocacy & Protection	California Advocates for Nursing Home Reform – legal referral, nursing home list, violations	Mild	Moderate	Advanced	Entitlement		
Advocacy & Protection	Public Guardian		Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Advocacy & Protection	San Francisco Long Term Care Ombudsman Program	Mild	Moderate	Advanced	Entitlement		
Care Management	30 <sup>th</sup> Street Senior Center (Multi Purpose Senior Center)	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Care Management	Bernal Heights Neighborhood Center (Multi Purpose Senior Center)	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Care Management	Catholic Charities CYO – Senior Center (Multi Purpose Senior Center)	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Care Management	Community Living Fund	Mild	Moderate	Advanced	Public		
Care Management	Curry Senior Center	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Care Management	Eldercare Services	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Care Management	Elder Plan Consultation and Care Management	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Care Management	Family Services Agency	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Care Management	Golden Gate Regional Center	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Care Management	IHSS Consortium	Mild	Moderate		Entitlement	Means Tested	Fee for Service

SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Care Management	Institute on Aging – Multipurpose Senior Services/Linkages Programs	Mild	Moderate		Entitlement		
Care Management	Janet Pomeroy Center – Traumatic Brain Injury – Specialty Care (Multi Purpose Senior Center)	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Care Management	National Association of Geriatric Care Managers	Mild	Moderate				Fee for Service
Care Management	Network for Elders	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Care Management	New Leaf Services for Our Community (LGBT)	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Care Management	Private Professional Geriatric Care Managers	Mild	Moderate	Advanced	Entitlement		Fee for Service
Care Management	Probate Conservatorship		Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Care Management Needed	<i>(Need more probate conservatorship)</i>						
Care Management	Russian Senior Center (Multi Purpose Senior Center)	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Care Management	San Francisco Senior Center	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Care Management	Self Help for the Elderly	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	Paid Caregivers	Mild	Moderate	Advanced			
Caregiver Services & Supports	Informal caregivers – family members, partners, friends, others	Mild	Moderate	Advanced			
Caregiver Services & Supports	Adult day health centers and social day centers	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	Alzheimer’s Association	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service

SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	Assisted Living Facilities	Mild	Moderate				Fee for Service
Caregiver Services & Supports	Catholic Charities CYO	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	Family Caregiver Alliance	Mild	Moderate	Advanced	Entitlement		
Caregiver Services & Supports	Geriatric Case Managers	Mild	Moderate	Advanced			Fee for Service
Caregiver Services & Supports	Hospice Programs			Advanced	Entitlement		Fee for Service
Caregiver Services & Supports	IHSS Consortium	Mild	Moderate	Advanced		Means Tested	
Caregiver Services & Supports	IHSS Public Authority	Mild	Moderate				Fee for Service
Caregiver Services & Supports	Institute on Aging	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	Jewish Family & Children's Services	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	Kimochi, Inc.	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	Masons	Mild	Moderate	Advanced		Means Tested	Fee for Service
Caregiver Services & Supports	Network for Elders	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	New Leaf Services for Our Community (LGBT)	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	On Lok	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	Private Providers – Respite	Mild	Moderate				Fee for Service

SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	Self Help for the Elderly	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	Senior Centers	Mild			Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports	Support Groups		Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Caregiver Services & Supports Needed	<i>(Need early stage groups)</i>						
Caregiver Services & Supports	VA Medical Center	Mild	Moderate	Advanced	Entitlement		
Diagnostic Assessment	California Pacific Medical Center	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Diagnostic Assessment	Institute on Aging – Geriatric Assessment Service	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Diagnostic Assessment	Kaiser Permanente Hospital HMO	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Diagnostic Assessment	Other HMOs	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Diagnostic Assessment	Private Physicians – neurologists, geriatricians, geriatric nurse practitioners	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Diagnostic Assessment	San Francisco Clinical Research Center – Alzheimer's and Dementia Clinic	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Diagnostic Assessment	SF General Hospital	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Diagnostic Assessment	UCSF Memory and Aging Center	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Diagnostic Assessment	VA Medical Center	Mild	Moderate	Advanced	Entitlement		
Education	Alzheimer's Association	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service

SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Education	American Society on Aging	Mild	Moderate	Advanced			Fee for Service
Education	Department of Aging and Adult Services	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Education	<i>(Need early state programs)</i>						
Education Needed	Family Caregiver Alliance	Mild	Moderate	Advanced	Entitlement		
Education	Institute on Aging	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Education	On Lok	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Education	Stanford Geriatric Research, Education & Clinical Center	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Information and Referral	Alzheimer's Association	Mild	Moderate	Advanced			
Information and Referral	211 – Community Services Information Line – operated by United Way	Mild	Moderate	Advanced	Entitlement		
Information and Referral	California Advocates for Nursing Home Reform – legal referral, nursing home list, violations	Mild	Moderate	Advanced	Entitlement		
Information and Referral	Department of Aging and Adult Services – Information, Referral, and Assistance (Long Term Care Intake and Screening Unit)	Mild	Moderate	Advanced	Entitlement		
Information and Referral	Ombudsman	Mild	Moderate	Advanced	Entitlement		
Information and Referral	Resource Centers	Mild	Moderate		Entitlement		
Information and Referral	Alzheimer's Day Care Resource Centers (see Adult Day Centers)	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Information and Referral Needed	<i>(Need 24/7 dementia specific hotline)</i>						

SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
In-Home Support Services (Chore & Personal Care)	Private Funded	Mild	Moderate				Fee for Service
In-Home Support Services (Chore & Personal Care)	Public Funded	Mild	Moderate		Entitlement		
Legal Services	California Advocates for Nursing Home Reform – legal referral, nursing home list, violations	Mild	Moderate	Advanced	Entitlement		
Legal Services	Family Caregiver Alliance	Mild	Moderate	Advanced	Entitlement		
Legal Services	Private Counsel	Mild	Moderate	Advanced			Fee for Service
Mental Health Services	City-Wide Mental Health Services – under DPH Community Behavioral Health Services	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Mental Health Services	Community Mental Health Services – Medical Crisis Treatment Team	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Mental Health Services	Family Services Agency	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Mental Health Services	Institute on Aging – Center for Elderly Suicide Prevention and Grief-Related Services	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Mental Health Services	Jewish Family & Children's Services	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Mental Health Services Needed	<i>(Need gero-psych, acute and chronic care)</i>						
Money Management	Conard House	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Money Management	Institute on Aging – Support Services for Elders	Mild	Moderate	Advanced			Fee for Service
Money Management	Lutheran Social Services	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Money Management	Private Guardianship	Mild	Moderate	Advanced			Fee for Service

SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Money Management	Public Guardian – Probate Conservatorship	Mild	Moderate	Advanced	Entitlement		
Money Management	Social Security Administration – Representative Payee Program	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Money Management Needed	<i>(Need to expand money management programs)</i>						
Multi Purpose Senior Centers	<i>(There are 48 Senior Centers – do you want to list them all?)</i>						
Needed Services	<i>(Assisted Living Technology)</i>				Entitlement	Means Tested	Fee for Service
Needed Services	<i>(Grocery/Meals delivery services (pilot project): more may be needed)</i>				Entitlement	Means Tested	Fee for Service
Needed Services	<i>(Additional Legal and Financial Planning)</i>						
Needed Services	<i>(Dementia services for homeless people)</i>						
Needed Services	<i>(Medication – service exists w/ Friendship Line for reminders: is this sufficient?)</i>				Entitlement	Means Tested	Fee for Service
Needed Services	<i>(Transportation services specifically for dementia)</i>				Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	<i>(Current system taxed; limited number of Medi-Cal &amp; Medicare [Medi-Medi] beds)</i>			Advanced	Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	California Advocates for Nursing Home Reform – legal referral, nursing home list, violations			Advanced	Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	California Convalescent Hospital			Advanced	Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	Central Gardens			Advanced	Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	Convalescent Center Mission Street			Advanced	Entitlement	Means Tested	Fee for Service

SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	Golden Gate Health Care Center			Advanced	Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	Grove Street Extended Care and Living Center			Advanced	Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	Hayes Convalescent Hospital			Advanced	Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	Jewish Home for the Aged			Advanced	Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	Laguna Honda Hospital			Advanced	Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	Laurel Heights Convalescent Hospital			Advanced	Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	Mission Bay Convalescent Hospital			Advanced	Entitlement	Means Tested	Fee for Service
Nursing Care & Hospital	Sheffield Convalescent Hospital			Advanced	Entitlement	Means Tested	Fee for Service
Ongoing Medical Treatment	Health Maintenance Organizations	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Ongoing Medical Treatment	Hospice Programs			Advanced	Entitlement	Means Tested	Fee for Service
Ongoing Medical Treatment	Lakeside Senior Medical	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Ongoing Medical Treatment	Nurse Practitioners				Entitlement	Means Tested	Fee for Service
Ongoing Medical Treatment	On Lok – PACE Sites	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Ongoing Medical Treatment	Private Physicians - All	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service



SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Ongoing Medical Treatment	<u>Public Health Centers:</u> Castro-Mission Health Center Children's Health Center at SFGH Chinatown Health Center Curry Senior Center Family Health Center at SFGH General Medical Clinic at SFGH Maxine Hall Health Center Ocean Park Health Center Potrero Hill Health Center Silver Avenue Family Health Center Southeast Health Center STD Clinic on 7 <sup>th</sup> Street station (PEP)  <u>Affiliated Partners:</u> Glide Health Services Haight Ashbury Free Medical Clinic Lyon-Martin Women's Health Services Mission Neighborhood Health Center Native American Health Center North East Medical Services San Francisco Community Clinic Consortium (SFCCC) San Francisco Free Clinic South of Market Health Center St. Anthony Free Clinic	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Ongoing Medical Treatment	San Francisco Clinical Research Center – Alzheimer's and Dementia Clinic				Entitlement	Means Tested	Fee for Service
Ongoing Medical Treatment	<u>SF Community Clinic Consortium:</u> 1. Curry Senior Center 2. Glide Health Services 3. Haight Ashbury Free Clinics, Inc. 4. Lyon-Martin Health Services 5. Mission Neighborhood Health Center 6. Native American Health Center 7. North East Medical Services 8. St. Anthony Free Medical Clinic 9. San Francisco Free Clinic 10. South of Market Health Center	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service

SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Ongoing Medical Treatment	Tenderloin Health				Entitlement	Means Tested	Fee for Service
Ongoing Medical Treatment	UCSF Memory and Aging Center	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Ongoing Medical Treatment	VA Medical Center	Mild	Moderate	Advanced	Entitlement		
Other Services	AIDS – Related Dementia Services	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Other Services	Resource Centers	Mild			Entitlement		
Public Policy	Alzheimer’s Association	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Public Policy	California Advisory Board of Alzheimer’s Disease, Health & Human Services	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Public Policy	California Advocates for Nursing Home Reform – legal referral, nursing home list, violations	Mild	Moderate	Advanced	Entitlement		
Public Policy	Family Caregiver Alliance	Mild	Moderate	Advanced	Entitlement		
Public Policy	Mental Health Association of San Francisco	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Public Policy	San Francisco Long Term Care Ombudsman Program	Mild	Moderate	Advanced	Entitlement		
Public Policy	UCSF Memory and Aging Center	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Research & Development	Alzheimer’s Association of Northern California and Northern Nevada	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Research & Development	Family Caregiver Alliance	Mild	Moderate	Advanced	Entitlement		
Research & Development	Institute on Aging	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service

SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Research & Development	San Francisco Clinical Research Center – Alzheimer's and Dementia Clinic	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Research & Development	Self Help for the Elderly	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Research & Development	Stanford Geriatric Research, Education & Clinical Center	Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Research & Development	UCSF Memory and Aging Center	Mild	Moderate		Entitlement	Means Tested	Fee for Service
Research & Development	VA Memory and Disorders Clinic	Mild	Moderate	Advanced	Entitlement		
Residential Care	<a href="http://www.cclid.ca.gov/docs/cclid_search/cclid_search.aspx">http://www.cclid.ca.gov/docs/cclid_search/cclid_search.aspx</a> . Community Care Licensing – list of all licensed RCFEs	Mild	Moderate	?			
Residential Care	California Advocates for Nursing Home Reform – legal referral, nursing home list, violations		Moderate	Advanced	Entitlement		
Residential Care	Community Care Licensing		Moderate	Advanced			Fee for Service
Residential Care	Masons		Moderate	Advanced		Means Tested	Fee for Service
Residential Care Needed	<i>(Need access to training and problem solving on site)</i>		Moderate	Advanced	Entitlement		
Residential Care Needed	<i>(Need more intermediate care facilities)</i>		Moderate	Advanced			
Residential Care Needed	<i>(Need to look into RCFCI model)</i>		Moderate	Advanced			
Residential Care Needed	<i>(Need more facilities service people with severe dementia without skilled nursing needs)</i>			Advanced		Means Tested	Fee for Service
Residential Care Needed	<i>(Need more public funded beds)</i>		Moderate	Advanced	Entitlement	Means Tested	
Residential Care Needed	<i>(Need ratio of dementia beds available to # of people with dementia. There are currently approximately 3200 beds available in RCFEs in SF county)</i>		Moderate	Advanced		Means Tested	Fee for Service

SERVICE	PROVIDER	DEMENTIA SEVERITY			FEE STRUCTURE		
		Mild	Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Respite Care	Family Caregiver Alliance		Moderate	Advanced	Entitlement		
Respite Care	Various Assisted Living Facilities		Moderate	Advanced			Fee for Service
Respite Care	Adult Day Centers		Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Respite Care	Care Management Services		Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Respite Care	<i>(Need new policy around easier access to skilled level of care)</i>		Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Respite Care	<i>(Need more respite care services)</i>		Moderate	Advanced	Entitlement	Means Tested	Fee for Service
Respite Care	<i>(Need services for low and medium income)</i>		Moderate	Advanced	Entitlement	Means Tested	

## **Appendix III: Education & Prevention - Recommendation Details**

### **EDUCATION AND PREVENTION SUBCOMMITTEE FINDINGS AND RECOMMENDATIONS**

#### **INTRODUCTION**

This document is the final report of the Education and Prevention Subcommittee, working under the auspices of the Alzheimer's/Dementia Expert Panel investigating the crisis in dementia care. The document contains findings and recommendations and details regarding the content areas that should be included or addressed in education initiatives.

The subcommittee's charge was to consider how best to educate the San Francisco community about Alzheimer's and related dementias to change attitudes, beliefs, behaviors, standards of practice, and outcomes associated with the disease.

Specific topics addressed include:

- Protective factors relating to dementia, including risk factors and brain health
- Early identification of dementia
- Early access to services
- Community education
- Education of professionals and nonprofessionals, including physicians, psychiatrists and psychologists, social workers, nurses, and other caregivers, both paid caregivers and informal caregivers such as family and friends
- Ethical issues
- Policy issues

#### **FINDINGS AND RECOMMENDATIONS**

##### **Introduction**

The dissemination of accurate information about Alzheimer's and related dementias can play an important role in delaying the onset of dementia, slowing disease progression, and improving the quality of life for people with dementia and their caregivers and the other people in their lives.

A great deal of information about dementia is available, but it is often fragmented, hard to find, or not delivered to people when they need it. For example, the subcommittee identified many good examples of educational materials appropriate for people who provide informal caregiving services to people with dementia, but at the same time found that caregivers often receive no support or information about early symptoms and little to no information or referrals at the time their loved ones are diagnosed. The opposite problem is information overload, and the need to ensure that people receive information when they need it and are able to handle it.

In addition to ensuring that information about dementia is organized and available, effective education and prevention efforts will also require countering stigma associated with older adults and with dementia.

It is also important that education and prevention efforts be culturally competent, so as to address effectively the needs of San Francisco’s diverse population. San Francisco is very ethnically diverse with a large Asian Pacific Islander population, a large Hispanic population, and a smaller African American population, with different cultural attitudes toward dementia and the person who has it. Many people from different racial and ethnic communities, especially those who are mono-lingual, require assistance with decision-making, and assistance with paperwork – for example, the paperwork required to establish a Durable Power of Attorney for Health Care.

Education and prevention initiatives must also account for differences in health literacy. This means that some information must be designed for people with low literacy, some must be in languages other than English, and materials must be accessible—this may mean making materials available in Braille or large type, having audio versions, and having materials both online and in easily-accessed neighborhood centers. Finally, materials should account for differences in learning styles and preferences. One subcommittee member suggested that a video of a person with dementia could be a valuable educational tool.

San Francisco also has a large lesbian, gay, bisexual, and transgender (LGBT) population, many of whom are in their late sixties, seventies, and eighties. While persons under age 50 tend to be more open about their sexual identity, many of those in their later years have remained closeted or return to the closet out of fear that their needs will not be met as they become unable to care for themselves. Some have partners but are often alone when the partner dies. Many do not have a younger friend or relative to serve as a caregiver should they develop dementia.

Dementia care is especially challenging for older adults who live alone. While some have forged new familial relationships, many are living by themselves, relying on friends, neighbors, their landlord, the corner grocer, or their IHSS home care worker for essential care and support.

The work of education and prevention will involve a wide range of individuals and public and private entities. As discussed below, partnerships with existing public and private agencies will be needed to better disseminate high-quality information about dementia. Organizations one doesn’t normally think of in connection with health care or social services can play an important role. The Alzheimer’s Association’s Early Detection Alliance with corporate employers is a good example of an innovative program that leverages the private sector in helping to raise awareness of the early signs of dementia and how to obtain a diagnostic evaluation.

Nine content areas were identified to be part of comprehensive education and prevention efforts. Following are these content areas with the corresponding key recommendations. These content areas and recommendations are not listed in priority order.

- Risk Reduction – Key recommendation: Promote cognitive health and create a culture of “brain fitness” through mental stimulation, social engagement, physical exercise, and diet.
- Early Identification of Dementia – Key recommendation: Educate people about the signs of dementia, how they differ from normal aging, and when and where to seek a diagnosis.
- What To Expect as the Disease Progresses – Key recommendation: Offer diagnosed individuals, caregivers, and health care providers information about what to expect throughout the course of Alzheimer’s and related disorders, which will help with future planning.

- Services and Resources – Key recommendation: Ensure that caregivers are aware of and have access to community resources, training and support.
- Caregiver Wellness and Support – Key recommendation: Help caregivers understand the stresses inherent in caring for a person with dementia and provide resources for self-care.
- Disease Management for Mild, Moderate, & Advanced Dementia, Including End-of-Life Issues – Key recommendation: Effective management of early to moderate dementia can slow the advance of cognitive impairment, reduce the impact of co-morbidity, and delay entrance into institutional care. Informed medical management of late stage and end-of-life co-morbidities will decrease unnecessary treatment and ease the burden and suffering of the person with dementia and caregiver at the end of life.
- Advanced Care Planning – Key recommendation: Advance care planning can help foster greater patient and caregiver understanding of the patient’s medical condition, promote more patient-centered care, and ensure that a person’s preferences are honored at the end of life.
- Ethical Issues – Key recommendation: Create an ethics review committee/group to consult on difficult ethical situations involving persons with dementia.
- Emergency Preparedness and Safety – Key recommendation: Promote awareness of steps to take to prepare for an emergency and to address common dangerous behaviors prevalent in persons with dementia so as to avoid catastrophic outcomes.

Education and prevention efforts should target the San Francisco population, though certain interventions will need to focus on specific segments. For example, detailed information about disease management is most appropriate for professional and family caregivers. The general public should understand that dementia is a condition caused by diseases, how to recognize the signs of dementia, and ideally should have some information about available resources.

The subcommittee identified specific information needs for:

- Persons with dementia
- Informal caregivers as well as other family, friends, and neighbors
- Physicians
- Allied health care professionals
- Other professional caregivers, including those working in home care, assisted living, and nursing home settings
- Care managers
- Social workers and other social service providers
- Elder law attorneys
- Adult Protective Services
- Emergency and safety officers, including police, fire, and emergency medical staff
- Gatekeepers such as postal workers and meal delivery services

In a limited funding environment, education and prevention strategies will have to be prioritized. Detailed findings and recommendations for each of these content areas follow.

## 1. RISK REDUCTION

### Introduction

A growing body of scientific research shows that specific lifestyles and actions can improve the health and cognitive functioning of our brains, regardless of age. Neuroplasticity is enhanced when the rate of creation and survival of new neurons in certain parts of the brain is increased, when the rate of creation and survival of synapses (the connections between neurons) speeds up, and when a neuro-chemical environment that supports learning is nurtured.

The Centers for Disease Control (CDC) and a variety of medical groups emphasize the importance of controlling cardiovascular risk factors such as obesity and diabetes to reduce the probability of experiencing cognitive decline.

Lifestyle plays a major influence on brain health, especially aerobic and mental exercise and managing cardiovascular health risk factors. Additional influences are social engagement, stress management, nutrition, and sleep. Our goal must be more than “risk reduction”; rather it should be about promoting a culture of “brain fitness”: inspiring healthy and proactive lifestyles that can contribute to the maintenance of cognitive functions throughout the lifespan.

Recent public awareness campaigns promote a multi-pronged approach to maintaining cognitive health drawing evidence from clinical trials, epidemiological studies, and basic neurobiology. Some examples follow.

Campaign	Sponsors	Pillars of Brain Fitness Promoted by Campaign
“Fit For Life” (2008): an ongoing initiative to promote brain health through public libraries. Pilots are underway in 18 library systems.	Dana Alliance for Brain Initiatives, Libraries for the Future, MetLife Foundation	Diet Physical exercise Intellectual challenge Mental stimulation through new experiences Socialization
Cognitive Fitness At Work (2007): educational activities in workplaces aimed at improving performance (no direct emphasis on Alzheimer’s)	Dana Alliance for Brain Initiatives, The Conference Board	Physical Activity Social Interaction Mental Stimulation Diet Sleep Stress Management
“Maintain Your Brain” (2004)	Alzheimer’s Association	Mental Stimulation Social Engagement Physical Exercise Diet
Healthy Brain Initiative (2005)	Centers for Disease Control and Prevention in partnership with the Alzheimer’s Association.	1. Cardiovascular Risk Factors 2. Physical Exercise and Diet 3. Diabetes Management



Two additional and emerging pillars of brain fitness not explicitly promoted in major public awareness campaigns so far are: (1) managing medications to prevent drug-induced cognitive impairment and other negative cognitive side-effects from medications; and (2) cognitive training, which is targeted cognitive exercises, sometimes using a computer, that aim to improve specific cognitive functions.

NOTE: In March 2009, the consumer advocacy group, Public Citizen, released a list of 136 drugs that can cause cognitive impairment.

## Content Areas

The following topics should be covered in education and prevention efforts related to risk reduction:

- What does brain fitness mean and why do we want to promote a culture of brain fitness?
  - People pay attention to issues based on fear (e.g., of getting Alzheimer’s disease), but they only sustain healthy habits if driven by positive language, support, and outcomes.
  - Brain Fitness is a proactive approach to maintaining a variety of important cognitive functions. It’s about performance, vitality, and quality-of-life and it draws on the intuitive understanding of the need for proactive and multi-pronged physical fitness.
  - The starting points of this approach are first that there is no magic pill; rather there is a need for a multi-pronged approach; and second, everyone needs to learn more about cognition and the brain in order to understand dementia (e.g., executive functions, early identification, etc.) and to be able to make informed decisions.
- Aerobic exercise and the impact on brain health
  - Physical fitness training can increase cognitive performance in healthy adults between the ages of 55 and 80.
  - As little as three hours a week of brisk walking has been shown to halt or even reverse the brain atrophy (shrinkage) that starts in a person’s forties, especially in the regions responsible for memory and higher cognition. Higher-intensity aerobic exercise seems to be even better at building basic capacities—the heart rate must go up for significant benefits to kick in.
- Cognitive stimulation and the cognitive reserve
  - Cognitively stimulating activities help build a neuro-protective cognitive reserve. Multiple epidemiological studies since the 1990s show that individuals more exposed to mentally stimulating activities through education, jobs, or leisure pursuits present have 30-50 percent lower risk of developing Alzheimer’s symptoms, controlling for other factors. No ceiling has been found to this relationship, so the more cognitive activity, the less risk. Building a larger “cognitive reserve” of neurons and abilities seems to offset the losses caused by pathology.
  - To a population that mostly views doing one more crossword puzzle as the best cognitive exercise, emphasis should be on the importance of novelty, variety and challenge to maintain if not enhance cognitive functions.
  - Key messages: ‘It’s never too late to start’; and ‘the more, the better.’
- Managing cardiovascular health risk factors
  - Controlling cardiovascular risk factors such as obesity, diabetes, and smoking reduces the risk of experiencing cognitive decline.

- Stress management
  - Prolonged exposure to high levels of stress can damage the brain, including blocking the formation of new neurons in the hippocampus and even leading to cell death.
  - Learning how to manage stress efficiently is an important life skill to develop.
- Nutrition
  - Experts usually recommend a balanced diet, that is, getting healthy nutrients from the food we eat rather than by ingesting supplements.
  - Most studies have shown that supplements such as ginkgo biloba are not beneficial to brain health, and there may be contra-indications with medications.
- Managing medications
  - A wide array of commonly prescribed medications can cause cognitive impairments, often temporary, while taking the drug.
  - This problem, often overlooked, becomes especially important when people are taking multiple medications.
- Cognitive training
  - Specific perceptual and cognitive abilities that tend to decline with age respond to training. The effects of that training last beyond the training itself. (Reference: See the latest MindAlert by the American Society on Aging/MetLife Foundation, which includes an in-depth review article by Michael Marsiske.)
  - Given growing interest and media attention, consumers and professionals need to understand and navigate claims about cognitive training. The promising evidence, however, does not support proposing/endorsing specific cognitive training interventions in a public awareness campaign.

## Existing Services

There are a number of non-profit, for-profit and online resources. People also should be able to obtain comprehensive and quality information at easily accessible physical locations.

- AARP's Brain Health program offers resources and lifestyle advice.
- Maintain Your Brain includes resources and lifestyle advice provided by the Alzheimer's Association.
- PBS's The Secret Life of the Brain is a fun website which includes a history of the brain, anatomy, illusions, brain scanning, and development from child through adulthood.
- SharpBrains offers a blog, providing free informational resources, and brain teasers.
- The Society for Neuroscience's Neuroscience Core Concepts is a "Brain 101" curriculum for educators.
- The Dana Foundation offers several excellent online resources: Brainy Kids Online, which offers children, teens, parents and teachers links to games, labs, education resources and lesson plans; Brain Resources for Seniors, which provides older adults and their caretakers with links to sites related to brain health, education and general information; and a new Staying Sharp DVD.

## **Approaches to Education and Prevention**

- Partner with places of mental or physical exercise to piggyback on their efforts. Special opportunity: health clubs, libraries, bookstores, and schools.
- Conduct public awareness campaigns through television, radio and print ads; note opportunity to take advantage of unused advertising inventory in current economic climate.
- Distribute written materials (such as a bookmark) in multiple languages through health fairs, city offices, library and hospital systems, and community agencies.
- Offer workshops and classes in schools, libraries, and universities.
- Create websites and blogs.
- Distribute a monthly or quarterly newsletter.
- Approach public television and radio stations about promoting brain health messages and community programs.

## **Recommendations**

- The best prevention is to invest in education, public awareness, and citizen empowerment.
- Promote a culture of brain fitness by partnering with health clubs (promote physical fitness) and libraries (promote mental fitness).
- Partner with media outlets to offer public service announcements, as well as incorporating messages about early identification in existing programs focused on brain health (especially those that already promote brain health products).

## **2. EARLY IDENTIFICATION OF ALZHEIMER'S AND RELATED DEMENTIAS**

### **Introduction**

Growing societal attention to Alzheimer's and related dementias is bringing much needed awareness to early identification of the disease, but we must prevent unwanted and counterproductive fears. The public at large needs to learn how to differentiate healthy aging from dementia and when and where to seek a medical evaluation and diagnosis.

It is important to note with regard to diagnosing early stage dementia that there is no consensus about how to diagnose mild cognitive impairment (MCI), and experts debate the wisdom of general population screening for dementia. For example, the Alzheimer's Foundation of America calls for regular cognitive screenings after the age of 75, or 65 for people at high risk. The Alzheimer's Association is opposed to memory screenings for the general public at this time and instead promotes awareness of signs of cognitive decline that require medical attention. At such time as disease altering drugs become available, the notion of broad cognitive/memory screening will likely become less controversial, though still challenging to implement, especially in a highly ethnically and culturally diverse area such as San Francisco.

Public awareness should be raised about early signs of dementia and of screening by health care professionals. Broad screening at the population level should be considered if research demonstrates the benefits of doing so outweighs the costs. Screening would be used to assess the need for a more comprehensive evaluation, possibly including referral to a specialist for a thorough diagnosis. Dementia services should be provided as soon as there are symptoms of cognitive impairment.

## Content Areas

The following topics should be covered in education and prevention efforts related to early identification of dementia:

- What cognitive changes are normal through healthy aging?
  - It takes longer to learn new information in unfamiliar domains, such as using the latest technologies.
  - We experience—and joke about—our imperfect memories: we don’t remember the name of someone we met last week, we forget one or several of the many items we wanted to buy in the grocery store, which is why we tend to use lists.
- What cognitive changes may indicate early stages of dementia?
  - New and noticeable loss of cognitive functions that disrupts aspects of daily life.
  - Early dementia often manifests itself as loss of attention/executive capacities such as cognitive flexibility, self-monitoring, lack of judgment, and reasoning, in ways that raise concerns about the ability to live independently. These symptoms tend to precede impairment in perceptual and language functions- so just looking for perceptual, language, or “memory” problems doesn’t help with early identification.
- What factors other than dementia contribute to cognitive impairments?  
It is important to rule out other potential causes for the new cognitive problems experienced, such as:
  - High stress
  - Depression
  - Sleep disorder
  - Medications
  - B12 deficiency
  - Cardiovascular disease
  - Alcohol
  - Substance abuse
- When and where should a medical evaluation be sought?
  - See doctor/ primary care center to express concern and ask for evaluation or referral
  - Visit diagnostic centers, such as memory clinics, neuropsychologists, or geriatrics clinic
- What should be done after diagnosis?  
See Content Summaries for Education about Services and What to Expect as the Disease Progresses
- What services are available?

## Existing Services

- Alzheimer’s Association workshops, brochures, and new curriculum (e.g., “Understanding Memory Loss and Alzheimer’s” and “Know the 10 Signs”)  
Some specific early warning signs, based on Alzheimer’s Association’s new campaign on 10 Warning Signs of Alzheimer’s Disease, are:

- Asking for the same information repeatedly (shows difficulty in learning/memorizing new information)
  - New difficulties in managing a budget/ monthly bills (shows difficulty in solving problems and planning ahead)
  - Suddenly giving a large amount of money to telemarketers (shows difficulties in judgment)
- Family Caregiver Alliance fact sheets
  - Institute on Aging conferences for providers
  - DAAS trainings for service providers
  - Kaiser Permanente educational workshops & materials

### **Recommendations**

Ideally, the office that diagnoses dementia—generally the primary care provider—would have a social worker, nurse practitioner or physician’s assistant to make referrals. A model for this is On Lok, but this is unusual. The alternative is for the care provider to refer to a community agency that can make detailed referrals. The Alzheimer’s Association and Family Caregiver Alliance have a process where providers (physicians, social workers, nurses) can fax a HIPAA compliant referral to request follow-up for the patient and caregiver. Instead of the typical two-year lag between the time of diagnosis and accessing help, families receive immediate connections. This type of proactive contact is highly desirable. But both of these agencies have finite resources and they would require additional funding to handle increased use of this service.

### **Policy Implications**

The standard of care should be to refer people to services immediately upon identification of cognitive impairment. This should be a requirement for San Francisco contractors.

## **3. WHAT TO EXPECT AS THE DISEASE PROGRESSES**

### **Introduction**

A common challenge for diagnosed individuals, caregivers, and health care providers is understanding what to expect as dementia progresses. This is due to the variability in symptoms and progression in persons with the same diagnosis and to variability associated with different types of dementia. A common saying in the Alzheimer’s provider community is: “When you’ve met one person with Alzheimer’s disease you’ve met one person with Alzheimer’s disease.” Because of this variability, future planning is of critical importance as it is often unclear how long diagnosed individuals will have the capacity to make decisions for themselves.

There are no studies that demonstrate specifically the impact of training about what to expect as dementia progresses. There is, however, evidence that persons with dementia do better when they are identified earlier and when their caregivers access community resources, training, and support. While research shows that it continues to be rare for health care providers to refer patients and families for non-pharmacological services, persons with dementia who receive these referrals

experience better outcomes. There exists considerable information on the progression of dementia, but it can be challenging for families to find this information when they need it.

## Content Areas

The following topics to be covered in education and prevention efforts related to what to expect as the disease progresses:

- Common signs and symptoms in the early, middle, and late stages of dementia
- Importance of planning for the future
- Available treatments and interventions at each stage
- Identifying key helpers
- How to partner with medical and allied providers
- Safety issues
- Behavioral challenges
- Common co-morbidity issues and causes of delirium
- Supervision
- End of life decision making including Physicians' Orders for Life Sustaining Treatment (POLST), use of feeding tubes, and use of antibiotics

For each stage:

- In general, it's important to teach people to be realistic about what can and cannot be fixed. It's also important that people know that *it's not their fault*—it's normal for body systems to fail eventually.
- It is important to plan for the future in terms of finances, health care decision making, and advanced directives, including POLST—physicians' orders for life sustaining treatment. Recognize that at this point the diagnosed individual is able to actively participate in decision making and care planning.
- Learn what treatments/interventions are available at this point in the disease, how to access them, and how effective they are (e.g., at this point they are not disease altering but they may temporarily help with symptom reduction).

Specific to mild Dementia:

- Common signs and symptoms in the early stages of dementia include difficulties with memory, language, judgment and reasoning.
- Identifying key helpers is important. Is there a caregiver? An interested neighbor?
- How to partner with medical and allied providers for medical care and social services.

Moderate Dementia:

- Common signs and symptoms of the middle stages of dementia include increasing difficulty with memory, language, judgment, and reasoning.
- Clarify safety issues and behavioral challenges and how to deal with these issues if and when they arise.
- Learn the types of over the counter and prescription medications to avoid due to anti-cholinergic effects.
- Learn common co-morbid issues and causes of delirium, how to spot them, and how and when to get help.
- Identify key helpers and resources. Consider daycare and in-home care.
- Supervision of the individual becomes critical.

#### Advanced Dementia:

- Common signs and symptoms in the advanced stages of dementia include increasing personal care needs, incontinence, frailty, behavioral symptoms, and wandering for persons who are physically able.
- If it hasn't already happened, it may be necessary to have the individual conserved in order to access care and services on their behalf if no other legal planning has taken place. Medi-Cal eligibility and other financial planning are necessary if it hasn't already taken place.
- In many cases, providers may need to address when to stop treatments/interventions.
- Identify key helpers and resources (consider assisted living, nursing home care, hospice etc.)
- Discuss end of life decision making including POLST, use of feeding tubes, use of antibiotics.

#### Existing Services

- Alzheimer's Association
- Family Caregiver Alliance
- Institute on Aging
- Department of Aging and Adult Services
- Medical providers including Kaiser Permanente and California Pacific Medical Center
- UCSF Memory and Aging Clinic
- Veterans Administration Medical Center
- California Association of Nursing Home Reform & Legal Aid Society

#### Approaches to Education and Prevention

- Written materials in multiple languages widely distributed through health fairs, city offices, library and hospital systems and community agencies
- Workshops and classes
- Websites

#### Recommendations

- Centralize information about available resources, but also create decentralized access points to this information (e.g., in public libraries, health fairs, city offices, hospital systems, and community agencies), so that it is easily accessible.
- Consider having simple information on the DAAS website or having a diagnosis hotline.
- Offer annual in-service trainings on dementia for DAAS's Integrated Intake Unit, the Network of Support for Community Living, and 211 personnel.
- Aim to have every person with dementia in San Francisco prepare advanced directives, including POLST (Physician Orders for Life Sustaining Treatment).

#### 4. SERVICES AND RESOURCES

All too often, persons with dementia are not diagnosed until late in the disease, and when they are diagnosed, they may not be referred to critical services. A tremendous gap exists between available services and those who might use them.

There already exists considerable information about the progression of dementia but it is a challenge for family audiences to find what they need when they need it.

There are no studies that specifically show the impact of educating people about what to expect as dementia progresses. There is, however, evidence that persons with dementia who are identified earlier and whose caregivers access community resources, training, and support do better than those identified later or whose caregivers do not access these resources. While research shows that it continues to be rare for health care providers to refer patients and families for non-pharmacological services, those that do experience better outcomes.

##### Content Areas

The following topics should be covered in education and prevention efforts related to information about services and resources:

- Services available for persons who need to get a diagnosis:
  - Where to get a diagnosis and what does it entail?
  - What about non-English speaking individuals?
  
- Services available for early stage dementia:
  - Medical care and treatments
  - Social support and services
  - Education and training for diagnosed individuals and care partners
  - Early stage support groups
  - Financial and legal planning
  - Safety services, (e.g., MedicAlert + Safe Return and earthquake preparedness)
  - Home care and day care services
  - Housing
  - Financial aid
  - Brain health and fitness programs
  - Exercise programs
  - Senior centers
  
- Services available for middle stage dementia:
  - Medical care and treatments
  - Social support and services
  - Education and Training for caregivers
  - Caregiver support groups
  - Financial and legal planning
  - Safety services (e.g., MedicAlert + Safe Return and earthquake preparedness)
  - Home care and day care services
  - Housing, residential and nursing home care
  - Financial aid, Medi-Cal eligibility



- Services available for late stage dementia:
  - Medical care and treatments
  - Social support and services
  - Education and Training
  - Caregiver support groups
  - Financial and legal planning
  - Safety services (e.g., MedicAlert + Safe Return and earthquake preparedness)
  - Home care and day care services
  - Housing, residential care home and nursing homes
  - Financial aid
  - Hospice care

### **Existing Services**

San Francisco offers an array of community services for people with dementia including: UCSF's Memory and Aging Center and other diagnostic clinics; private and public home care agencies; day care centers for older adults including people with dementia; residential care facilities for the elderly; PACE (Program of All Inclusive Care for the Elderly) programs; support groups on early stage dementia and other related topics; workshops and conferences; a 24-hour helpline; and counseling.

#### Service Providers Include:

- Alzheimer's Association
- Family Caregiver Alliance
- Institute on Aging
- Department of Aging and Adult Services
- Medical providers including Kaiser Permanente and California Pacific Medical Center
- UCSF Memory and Aging Clinic
- Veterans Administration Medical Center
- California Association of Nursing Home Reform & Legal Aid Society

NOTE: See Appendix II for a comprehensive list of services and supports.

### **Approaches to Education and Prevention**

- Written materials in multiple languages widely distributed through health fairs, city offices, library and hospital systems and community agencies
- Workshops and classes
- Websites

### **Recommendations**

- Centralize information about available resources. Fortunately, to do this, the service delivery network can use the DAAS Integrated Intake Unit as the central door of the “no wrong door” strategy to access information about services and resources. This is available for older adults and adults with disabilities, including adults with MCI or dementia of any kind.

- Create decentralized access points for information (e.g., in public libraries, health fairs, city offices, hospital systems, and community agencies), so that it is easily accessible.
- Consider having simple information on the DAAS website or having a diagnosis hotline.
- Offer annual in-service trainings on dementia for DAAS's Long Term Intake and Screening Unit, the Network of Support for Community Living, and 211 personnel.
- Aim to have every person with dementia in San Francisco prepare advanced directives, including POLST (Physician Orders for Life Sustaining Treatment).
- Educate the staff of 211, the United Way's Community Service Information telephone service, about existing resources. This could be provided by the Alzheimer's Association.
- Place information on resources on the DAAS website, or on the Network of Support for Community Living website. Doing so will require an evaluation of this website and working with its administrators so that all dementia resources are very visible and very easily accessed.
- Ensure that all websites with dementia resources have a link to the Alzheimer's Association fact sheet on dementia.
- Be certain all decentralized access points that provide information about services and resources also address the stigma connected to Alzheimer's and related dementias, in community-based education centers, possibly located in neighborhood public libraries.
- Ensure that DAAS will promote awareness of all existing services and resources.

## 5. CAREGIVER WELLNESS AND SUPPORT

### Introduction

Caring for a person with dementia is often stressful and demanding as the caregiver watches memories disappear and skills erode. For both caregivers and their loved ones, this often produces difficulties in communication and an emotional wall of confusion, anger and sadness. Caregivers usually learn through trial and error the best ways to communicate with the person with dementia and to help maintain routines for eating, hygiene, and other activities at home.

### Content Areas

The following topics should be covered in education and prevention efforts related to caregiver wellness and support:

- Unique challenges and rewards for caregivers

#### Challenges:

- Overwhelming emotions as capabilities lessen.
- Fatigue and exhaustion as caregiving demands increase.
- Isolation and loneliness as independence disappears.
- Financial and work complications as cost rise and resources are challenged.
- Lack of education about disease and supportive services.
- Conflicts with other family members regarding who will provide care.
- Living with uncertainty and ambiguity.

#### Rewards:

- Bonds deepen through care, companionship and service.
  - Problem solving and relationship skills grow through experience.
  - New relationships form through education and support.
  - Unexpected rewards develop through compassion and acceptance.
- How to develop skill in coordinating services for the person with dementia
  - How to support caregivers and protect them from exhaustion/burnout during dementia care, including warning signs of caregiver burnout and tips for self care

#### Planning support for Alzheimer's caregivers

- Balancing the enormous task of caring for a cognitively impaired adult with other responsibilities requires skill, attention and diligent planning.
- Planning for one's own care is also vitally important.
- How to handle the unexpected.

Because care giving is such a hard work, one must learn to protect oneself. Warning signs of caregiver burnout or exhaustion include:

- Excessive stress and tension.
- Debilitating depression.
- Persistent anxiety, anger, or guilt.
- Extreme irritability or anger with the patient.
- Decreased overall life satisfaction.
- Relationship conflicts and social isolation.
- Lower immunity and greater need for health care services.
- Excessive use of medications, drugs, or alcohol.

#### Tips for self care:

- Schedule mini workouts throughout the day.
  - Take time to play.
  - Try something new.
  - Keep them laughing. Humor is a well-known antidote to stress, sadness, and illness.
  - Join a support group or find another caregiver with whom to converse. In addition to emotional support, you'll likely pick up practical tips as well. Professionals network with each other all the time to get emotional support and find answers to problems or situations they face. You can do this too.
- How to be an effective advocate with the health care system and social services and with public officials

#### What is an advocate?

- Personal advocate on behalf of the person with dementia
- Social advocate on behalf of all affected

#### How to become your own care coordinator

- Educate yourself on the nature of the disease or disability with which you're dealing.
- Write down your observations of the present situation including:
- Your loved one's ability to function independently, both physically and mentally.

- The availability of family and/or friends to form a support network to share the care.
- The physical environment: is it accessible or can it be adapted at reasonable cost?
- Your other responsibilities at work, at home, and in the community.
- Your own health and physical abilities.
- Your financial resources, available insurance, and the existence of health care or end-of-life documents.

Three ways to become an effective Alzheimer's/dementia advocate:

- Develop your own advocacy pitch. Before contacting anyone, decide what you are going to say. It's always important to share your own story about how Alzheimer's has affected you, your loved one, and/or other family members and friends. Also choose one or two policy recommendations to focus on, such as increased research funding, more support for caregivers, or better access to affordable long-term care for people with Alzheimer's disease.
- Contact your elected officials. You can find them by using the Alzheimer's Association's Elected Official Search Tool. Contact them in a way that's most comfortable to you, such as by phone, letter, email, or personal visit, if you can schedule one. Many elected officials can now be contacted through their own websites, which means you can make your voice heard at any time from the comfort of your own computer.
- Contact the Obama-Biden Administration, which has set up an unprecedented online system for the public to contribute thoughts and ideas about policy. At the Administration's health care page, advocates can share why they think health care is important and what should be included in health care reform. Be sure to share your personal story along with your recommendations.

The Alzheimer's Association has created a National Alzheimer's Advocate Network to keep advocates informed of advocacy-related issues and to provide guidance for becoming an effective Alzheimer's advocate. It's free to join and it's a great way to connect with other Alzheimer's advocates so that our collective voice can be heard loud and clear.

- How to understand the job of the caregiver

### **Existing Services**

- Alzheimer's Association (e.g., "Savvy Caregiver" program; pilot program on mindfulness for caregivers)
- Family Caregiver Alliance (e.g., "It Takes Two" program)
- Institute on Aging
- National Family Caregivers Association

### **Approaches to Education and Prevention**

- Websites
- Workshops and classes on the subject of caregiving.
- Support groups, including faith-based and social support groups.
- Pilot mindfulness program for caregivers as a way of reducing stress.
- Consider doing a needs assessment relating to specific content areas to cover in support groups, how best to do outreach, need for culturally specific groups; and where to hold

groups to make them accessible; could lead to expanded training for group facilitators or focus on different content areas (e.g., stress reduction techniques).

## **Recommendations**

- Expand resources for caregiver education. More awareness in the community will generate support.
- Create more support groups that are social or faith based.
- Offer workshops or classes for caregivers to equip them with skills to be effective caregivers and at the same time protect themselves from exhaustion/burnout.
- Increase local and state government resources available to support caregivers.
- Train facilitators in stress reduction techniques for caregivers.

## **6. DISEASE MANAGEMENT FOR MILD, MODERATE & ADVANCED DEMENTIA, INCLUDING END OF LIFE CARE**

### **Introduction**

Research shows that effective management of early and moderate dementia can slow the advance of cognitive impairment, reduce the impact of co-morbidity on persons with dementia and their caregivers, and delay entry into institutional care.

Persons who are in the late stages of dementia are totally dependent for all activities of daily living and need total supervision as they are unable to remain in the community without 24/7 care. They are not able to communicate their needs and rely totally on external support from either informal or formal caregivers.

Special needs occur at the end of life that must be addressed by medical personnel, hospice, and family caregivers. These include management of co-morbidities such as incontinence, nutrition, hydration, pain, and other chronic conditions, as well as follow through on advance care planning decisions. People in the late stages of dementia often require placement in a skilled nursing facility or an assisted living facility or board and care until the end of life.

Research clearly demonstrates the benefit of disseminating knowledge about the management and treatment of the disease, community resources, and caregiver education and support.

### **Content Areas**

The following topics should be covered in education and prevention efforts related to disease management:

- Consistent knowledge of and use of effective pharmacological interventions, and in particular, issues related to over-treatment at end of life and under-treatment of pain
- Consistent knowledge of and use of effective non-pharmacological interventions
- Early and effective symptom reduction
- Management of co-morbidity throughout the disease

- Special issues include management of incontinence, nutrition, hydration, pain, skin integrity, reduced mobility, and other co-existing medical conditions.
- Pharmacological and Non-pharmacological Interventions
- Interventions for difficult behaviors and psychotic symptoms need to be readily available for professionals with the most current effective treatments recommended. A resource: is [psychguides.com](http://psychguides.com). End of life care, including pain, skin integrity, incontinence, and nutrition (tube-feeding)
- End of life care, including pain, skin integrity, incontinence, and nutrition (tube-feeding)
- Caregiver supports and training, including the disease process, community resources, communication and advocacy with medical settings, placement, and spiritual needs
- Placement Issues:
  - Caregivers of persons with dementia need support and information regarding when, where, and how to place a person with dementia in the level of care that is the least restrictive and provides the highest quality of life possible. (Resources: Alzheimer's Association and Family Caregiver Alliance.)
  - Persons with late stage dementia need a place that provides quality care that can manage their needs on an ongoing basis without the threat of their having to move to another setting.
  - Available affordable assisted living, board and care, or skilled beds are essential for maintaining the care of persons with late stage dementia who have special needs at the end of life.
  - Persons at end of life must have access to hospice services or at the least palliative care.
- Coordination of care along the disease continuum, including utilization of advanced care planning
  - Case management services must be available to provide follow through and consistency with advance directives and care planning needs of caregivers and persons with dementia.
  - Continued discussion of special issues around decision-making such as tube-feeding, pain management, use of antibiotics, and flu shots needs to occur with health care professionals throughout the disease process and especially near the end of life. A team approach including a physician, social worker, nurse case manager, and spiritual advisor is best.
- Identification of criteria for hospice eligibility for persons with dementia

## **Audiences**

- Family caregivers need education regarding the disease process in late stage dementia and support for continued care planning and decision-making.
- Professional caregivers need education regarding the disease process and management of special needs and challenges that occur in the late stages of dementia and requirements for following advance directive of persons with dementia.
- First responders need education regarding POLST, to understand clearly with home caregivers and facility personnel regarding advance directives. They also need training on how to communicate with persons with dementia in distress.
- Physicians, social workers, nurses, and therapists need coordination of care services and information about best practices.

## **Approaches to Education and Prevention**

- Workshops, written materials and web-based programs and information
- Team-based coordinated care (see research section IV.C, pp. 25-30)
- Use of capitated, managed care (models: On Lok, PACE)
- Use of evidence based care practices (see research section IV.L, pp. 57-58)
- Case management to provide educational, psychosocial and spiritual support for informal caregivers and persons with dementia
- Hospice and palliative care at end of life
- Case consultation for individual cases carried out by a multidisciplinary team; this could be done by specific agencies or a resource center

## **Existing Services**

Education regarding late stage and end stage dementia is available through the following agencies:

- 211 - United Way's Community Services Telephone Information Line
- Alzheimer's Association
- American Society on Aging
- California Association for Nursing Home Reform
- Department of Aging and Adult Services
- Family Caregiver Alliance
- Hospice organizations in San Francisco such as Zen Hospice
- Institute on Aging
- Bay Area End of Life Task Force
- National Hospice Organization
- Physician Orders for Life Sustaining Treatment (POLST)
- On Lok
- Stanford Geriatric Education Center
- Laguna Honda Hospital (a best practice provider; see research p. 58, lines 28-35)
- Jewish Home (a best practice provider; see research p. 58, lines 28-35)

## **Service Gaps**

- Adult day center, assisted living, and SNF placements are all available but taxed by increasing demand; limited availability of low cost/affordable care
- Education of physicians and associated medical personnel regarding appropriate efficacy and use of pharmacological interventions, especially regarding over-treatment
- Education for professionals and family caregivers on special needs of persons with late stage dementia and end of life care
- No central website for best practices and guidelines in late stage dementia care
- Lack of knowledge regarding over-treatment and disease process at end of life
- Need for better pain management and management of co-morbidity throughout the late stages and end of life
- Need for increased case management services for informal caregivers of persons with dementia throughout the disease process
- Identification of needs and services available for homeless persons with dementia

## Recommendations

- Provide a central website for primary care physicians to find information quickly regarding best practices in pharmacological and non-pharmacological management of late stage dementia.
- Assist physicians to better understand the benefit of certain medications during late stage dementia.
- Provide comprehensive care coordination services that assist persons with dementia and their caregivers to manage persons at home and to navigate the placement process.
- Increase the number of available slots for adult day care.
- Increase the number of affordable assisted living and skilled nursing beds.
- Require minimum levels of dementia care training that includes specific issues regarding late stage dementia and end of life care, especially for professional caregivers, facility staff, physicians, registered nurses, certified nursing assistants, social workers, therapists, and other direct service providers.
- Identify and make available criteria for end of life and hospice care.
- Educate family members about changes and needs of persons with dementia at end of life and make support available.
- Educate Adult Protective Services, emergency personnel, ER personnel, and police regarding end of life issues that can be misinterpreted as neglect, such as management of pressure sores and nutrition challenges.

## Policy Recommendations:

- Identify Best Practices standard for city including:
  - Creating a central website for MD's, family caregivers, professionals
  - Requiring a set number of hours of training for providers
  - Provide a "best practices resource center" to provide technical assistance and consultation on dementia-related cases and programs.
- Utilize existing training resources to provide state of the art training to city agencies and staff, especially adult day centers, clinics, and staff in assisted living, skilled nursing, home health care, including person-centered care.
- Offer specialized training in co-morbidity, pharmacology by UCSF, California Pacific Medical Center, Stanford Hospital, and the VA Medical Center.
- Provide case manager, care coordination training at San Francisco State University, DAAS, and Stanford.
- Enhance informational resources from 211 and 311.
- Support periodic update conferences California Association for Nursing Home Reform, American Society on Aging, Alzheimer's Association, Family Caregiver Alliance.
- Provide funding for existing training institutions and agencies to train personnel
- Fellowship at UCSF in Geriatric Practice.
- Internships for city case managers, registered nurses, social workers.
- Develop an incentive program from the city to reinforce approved training and encourage agencies to provide training.
- Educate Adult Protective Services, emergency personnel, and police about end of life issues that can be misinterpreted as neglect, such as management of pressure sores and nutrition challenges.



- Expand primary care physician training related to end of life care to include issues regarding over-treatment (unnecessary procedures) and under-treatment (pain management) and hospice criteria for persons with dementia.
- Include a spiritual component to care to address the needs of caregivers and persons with dementia at all stages of the disease process.

## 7. ADVANCED CARE PLANNING

### Introduction

Advance care planning (ACP) is a process in which persons, anticipating a time in the future when they may not be able to make medical decisions, document preferences and requests that can guide health care providers and surrogate decision-makers. Encouraging ACP can help foster greater patient and caregiver understanding of the patient's medical condition, can help foster more patient-centered care, and can help ensure that a person's preferences are honored at the end of life.

Every older person should engage in ACP and identify a surrogate decision-maker. Completing an advance directive and completing a Durable Power of Attorney for Health Care are the two most common components of ACP. Unfortunately, despite efforts to improve the rates of ACP in the general population, most people do not engage in ACP prior to becoming incapacitated.

Although all dementia guidelines recommend ACP at the time of diagnosis and regularly thereafter, there is little published research on ACP in early to mid dementia; most of the research has been on people in nursing homes or at the very end of life.

Since dementia eventually causes people to lose capacity to make medical decisions, it is especially important that people with a diagnosis of early dementia engage in ACP promptly, while they still have the mental faculties to do so. Engaging newly diagnosed people with dementia in ACP is universally recommended in dementia guidelines, but in practice often does not occur. The barriers are many, but two stand out: providers lacking time to guide patients through the process; provider discomfort with the subject; and patient reluctance, which may be cultural and/or related to limited health literacy. A recent systematic review concluded that there is moderate evidence supporting the value of ACP led by skilled facilitators who engage key decision makers.

In some health care settings, advance care planning may be carried out by social workers. Although social workers do bring valuable skills to this task, many experts now recommend that physicians and other providers be closely involved in the ACP process, since an adequate understanding of a person's underlying health status and prognosis is necessary for the person to plan appropriately. Research has shown that people often have an inadequate understanding of dementia and its overall prognosis.

Many people are most familiar with instructional advance directives, in which a person specifies which procedures they would or would not want to have. These types of documents, however, often fit poorly with the complex decision-making situations that often occur at the end of life. Experts therefore now tend to recommend that people focus on articulating preferences and goals rather than specific directions regarding procedures and interventions. This allows surrogates and providers more flexibility when choices ultimately must be made, while still providing guidance about how to honor the person's preferences.

## Content Areas

The following topics should be covered in education and prevention efforts related to advanced care planning:

- What is Advanced Care Planning (ACP)?
  - A process of making plans for a future time when one won't be able to make medical decisions.
  - Recommended for everyone, but especially important for people who are older or chronically ill.
  - The products of ACP include advance directives and Durable Powers of Attorney for Health care
  - Products may also include pre-hospital DNRs and/or POLST (Physician Orders for Life-Sustaining Treatment).
  - Includes early planning, such as creating the basic care network, and determining whether the family should put the PWD in a home or not.
- Why is it especially important that people with dementia engage in ACP?
  - ACP is especially important for people diagnosed with dementia, because dementia eventually causes people to lose the mental capacity needed to make medical decisions and other complex decisions.
  - People diagnosed with dementia need to think ahead so that health care providers and surrogates will later be able to provide care in accordance with their preferences.
- Who should be involved in the ACP process and why?
  - A primary care provider or other provider, because people with dementia need to have an adequate understanding of their underlying health status, their prognosis (which may be very uncertain), and their treatment options before they can engage in meaningful and appropriate advance care planning.<sup>8</sup>
  - Caregivers, close family, and/or people likely to become surrogate decision-makers.
- What specific issues should be covered during ACP?
  - The list can vary, however at very least it should include identification of a surrogate decision-maker. Preferences regarding life support and CPR in the setting of a terminal illness are also usually covered. A more sophisticated process can address what would constitute a good death.
  - Hospice and palliative care.
- What are the steps involved in ACP?
  - The need to engage in ACP should be raised by health care providers. It can also be raised by empowered patient or caregiver.
  - A guided discussion should be planned.
  - Information regarding underlying health status, prognosis, and treatment options should be offered and clearly understood. A recent study found that showing people videos helped them understand what having advanced dementia is like.<sup>9</sup>
  - Goals and preferences should be elicited.

- Advanced directives and other paperwork documenting the advance care planning should be completed.
- Goals, preferences, and advance directives should be periodically reviewed and revised, especially after a significant change in medical condition.
- ACP is a longitudinal and iterative process. Providers and patients should expect to revisit ACP periodically, since preferences and goals can change over time.
- What is POLST?
  - POLST (physicians order for life sustaining treatment) is a physician’s order that outlines a plan of care reflecting the patient’s wishes concerning care at life’s end. The POLST form is voluntary and is intended to assist physicians, nurses, health care facilities, and emergency personnel to honor patients’ wishes for life-sustaining treatment. See <http://finalchoices.org/polst-consumers.html#faq>.
- Code status while in hospital
  - People are often taken by surprise when they are asked about code status when hospitalized.

### **Approaches to Education and Prevention**

- Improving participation rates of ACP is known to be difficult. Educational initiatives targeting health care consumers, people with dementia, and health care providers are unlikely to have an impact unless they are combined with other efforts to systematically encourage and facilitate ACP.<sup>10</sup> Examples of systematically facilitating ACP including providing a trained nurse facilitator in clinic<sup>11</sup> and reimbursing providers for spending time on ACP.
- Written materials in multiple languages widely distributed through health fairs, library and hospital systems and community agencies
- PSAs and other television, radio and print ads
- Workshops and classes
- Websites
- Completion of advance directives is monitored by the Veterans Administration; San Francisco could consider similar monitoring and feedback to providers to promote ACP.

### **Existing Services and Service Gaps**

- California Coalition for Compassionate Care has a good website: <http://finalchoices.org/acp-talking.html>
- California Health Care Foundation is currently paying to promote POLST
- The Institute for Health care Advancement has an easy-to-read California Advance Directive form available on their website, in English, Spanish, and Chinese. <http://www.iha4health.org/index.cfm/CFID/26763611/CFTOKEN/87482075/MenuItemID/266.htm>
- California Association for Nursing Home Reform (CANHR) offers free assistance with advance directives
- Legal Aid Society offers free assistance with advance directives
- AARP has a publication called “Prepare to Care” that addresses ACP

## Recommendations

- Systematically encourage and facilitate ACP through such means as providing a trained professional in clinics or reimbursing providers for spending time on ACP.
- Make informational/educational materials available in print and online.
- Consider a public education campaign to raise awareness of what ACP is and why it's important.
- Because the research on how best to engage elders and people with dementia in ACP is ongoing, the plan to educate providers and health care consumers needs to be dynamic.

## Policy Implications

- Currently many people with dementia die in the hospital after receiving fairly intensive medical care. Many people, however, when given comprehensive information about their underlying health status, prognosis, and treatment options, express a preference for more comfort-oriented care at the end of life. There is the potential for some cost-savings if unwanted intensive medical care is avoided at the end of life.
- A standard of care mandated by San Francisco could require providing resources to help ACP occur or to make sure it has occurred.

## 8. ETHICAL ISSUES

### Introduction

Persons diagnosed with Alzheimer's and related dementias, their families and professional care providers face ethical issues throughout the course of the disease. Dementia of any kind can be difficult and taxing—for both the person with the diagnosis and the primary caregiver. Changes in the person's ability to understand, to make decisions and to control behavior make caregiving challenging. The traditional approach to decision-making involves the person with dementia, the individual's primary care physician, and his or her spouse, life partner, or other family member.

Basic to decisions by the physician, the designated caregiver and others involved in the person with dementia's care is the need to know the value and attitudes of the person before becoming unable to make decisions. If the person presents for care without an advanced directive, physicians must consider the value to the person of palliative care versus restorative care. The value of the care to the person's quality of life needs to be part of any decision—making the physician undertakes on the individual's behalf in the absence of an advanced directive.

Alzheimer's and related dementias can bring up ethical questions, including:

- Obtaining and discussing a dementia diagnosis (e.g., Is it okay not to share the diagnosis with the patient?)
- Appropriate care at different stages of disease (e.g., When is treatment prolonging suffering rather than improving quality of life?) and,
- Who should be responsible for overseeing care over the course of the disease (e.g., What happens when individuals are alone or have uninvolved family?).
- What happens when the patient's and his/her significant other's relationship is not legally recognized or culturally accepted by formal care providers, who traditionally have not recognized non-blood relationships?

- Who should make care decisions in the absence of a designated representative? How can a decision making process avoid conflicts?
- When are restraints appropriate?
- Situations involving sexuality and intimacy between persons with limited capacity to make such decisions (Who decides whether an individual with dementia living in a care home can consent to an intimate relationship with another resident? What happens if the family is opposed to the decision?)
- How do we balance the rights of the individual to independence versus the need for public and personal safety (e.g., driving, living alone, wandering)?
- Who determines whether a person with dementia can take part in research studies?

### Existing Resources

The Alzheimer's Society of Canada developed ethical guidelines in 1997, and then revised them six years later "to provide information and guidance to persons with Alzheimer's and related dementias, their families, health care professionals and researchers as they navigate the difficult issues raised by Alzheimer's disease." These guidelines are available on the Internet at [alzheimer.ca/english/care/ethics.htm](http://alzheimer.ca/english/care/ethics.htm).

The Alzheimer's Association has several helpful fact sheets on the following topics:

- An Alzheimer's Bill of Rights (for persons with a diagnosis)
  - Every person diagnosed with Alzheimer's disease or a related disorder deserves:
  - To be informed of one's diagnosis.
  - To have appropriate, ongoing medical care.
  - To be productive in work and play as long as possible
  - To be treated like an adult, not a child.
  - To have expressed feelings taken seriously.
  - To be free from psychotropic medications if at all possible.
  - To live in a safe, structured and predictable environment.
  - To enjoy meaningful activities to fill each day.
  - To be out-of-doors on a regular basis.
  - To have physical contact including hugging, caressing, and hand-holding.
  - To be with persons who know one's life story, including cultural and religious traditions.
  - To be cared for by individuals well-trained in dementia care.
- Principles of a Dignified Diagnosis (for providers making and disclosing the diagnosis)
  - Talk directly to the person with dementia.
  - Tell the truth.
  - Test early.
  - Take concerns seriously, regardless of age.
  - Deliver the news in plain but sensitive language.
  - Coordinate with other care providers.
  - Explain the purpose of different tests and what you hope to learn.
  - Give tools for living with this disease.
  - Work on a plan for healthy living.
  - Recognize individuality and variability in disease.
  - Alzheimer's is a journey, not a destination.

- End of life decision-making
- Clinical Studies (how to participate)
- Genetic Testing (pros and cons)
- Love, Sex & Alzheimer’s (workshops and materials)
- Driving [http://www.alz.org/living\\_with\\_alzheimers\\_driving.asp](http://www.alz.org/living_with_alzheimers_driving.asp)
- Guidelines for Quality Dementia Care:  
[http://www.alz.org/national/documents/brochure\\_DCPRphase3.pdf](http://www.alz.org/national/documents/brochure_DCPRphase3.pdf)
- [http://www.alz.org/national/documents/brochure\\_DCPRphases1n2.pdf](http://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf)

Physicians Orders for Life Sustaining Treatment (POLST)—described in the Advanced Care Planning section of this document)

Existing processes—5150, conservatorship, public guardian, etc. —have gaps (5150 is short term, Adult Protective Services and the Public Guardian are often overwhelmed. Durable Powers of Attorney for Health Care can determine answers for some treatment issues, but many people may not have them in place.

**Content Areas:**

- Values and Guiding Principles
- Communicating the Diagnosis
- Driving
- Living alone
- Decision-making/ capacity to give consent
- Sexuality & Intimacy
- Quality of life
- Participation in clinical trials and research

Phases of clinical trials

- Preclinical studies
- Phase I trials
- Phase II trials
- Phase III trials
- Phase IV trials
- Ensuring accuracy of study results
- Designs for clinical trials: “placebo-controlled” or “double-blinded”
- Monitoring safety behind the scenes—how to decide whether to take part
- Informed consent: Knowing what to expect
- Matching participants to studies
- How to find a study near you

- Genetic testing
  - Having the APOE-e4 gene does not mean a person has or will develop Alzheimer’s disease.
  - The presence of a gene associated with Alzheimer’s disease should not be used to deny access to housing, employment, health care, insurance or any other goods and services.

- The presence of a gene associated with Alzheimer's disease does not qualify an individual for disability-related benefits. Disability support should be based on functional criteria rather than a genetic test.
- Because of possible social consequences or discrimination, anonymous testing should be available, thereby making the fact of and results of genetic testing for Alzheimer's disease invisible on an individual's medical records.
- If performed, genetic testing for Alzheimer's should be done with pre- and post-test counseling, which includes a full discussion of the implication of the test and provides the individual with all information necessary to make an informed decision. All genetic counseling and information should be provided in culturally and linguistically appropriate formats and should take into account an individual's literacy level.

- Restraints

### **Approaches to Education and Prevention**

- Workshops, conferences & classes
- Printed and web based materials
- Case consultation groups and discussions

### **Recommendations:**

- The City should explore the creation of an independent ethics panel to assist in decision-making. This body could provide advice and counsel in situations in which acute needs of involuntary treatment are present. An ethics panel might also make policy recommendations on related issues. Research should be undertaken that includes: (1) the existing ethics project in San Francisco; and (2) models already developed in Santa Clara, Contra Costa, and Alameda Counties. A workgroup should be established to investigate this option.
- Discuss/review ethical issues in case-based education for providers and having the Geriatric Fellows provide consultation on these issues.
- Consider a new model for handling 5150s in a demented, geriatric population (look to other counties such as San Mateo as a model).

## **9. EMERGENCY PREPAREDNESS AND SAFETY**

A disaster situation, such as an earthquake or power outage, can significantly add to the stress and confusion of someone with Alzheimer's or related dementias. This can lead to unsafe and distressing behaviors, such as wandering or agitation. Sixty percent of persons with dementia will wander away from home at some point in their illness and 70% will do so repeatedly.

If not found within 24 hours, up to 46% will be seriously injured or even die. These incidences occur in both community and institutional settings. In a study of nursing home elopement insurance claims, 70% of elopement claims involve the death of a resident; 45% of elopements occurred within the first 48 hours of admission; and 80% of elopements involved chronic wanderers.

Wandering is one of the leading factors that cause caregivers to place the person with dementia in assisted living or nursing home settings. Research indicates that simply delaying by one month entry into skilled nursing facilitated would result in savings by 2020 of \$1.3 billion annually in combined out of pocket state and federal expenditures .

There are no studies that specifically show the impact of training to address emergency preparedness and safety issues. However there is evidence that caregivers who have received training on approaches to managing difficult behaviors experience better outcomes.

## Content Areas

The subcommittee identified the following topics to be covered in education and prevention efforts related to emergency preparedness and safety:

- What are the unique needs of persons with dementia in emergency situations?
  - The impact memory and language impairment has during emergencies
  - Wandering behaviors/getting lost
  - Frail elders with dementia
  - Younger persons with dementia
  - Examples from Katrina
  
- What kinds of emergencies do we need to prepare for?
  - Earthquakes, fire, flood, tsunamis
  - Wandering episodes/getting lost
  - Flu or other epidemics
  - Power outages or other extreme conditions
  - Caregiver injury leaving PWD unattended at home
  
- How to plan ahead
  - Create an emergency plan, including legal documents such as advanced directives and powers of attorney.
  - Communicate the plan
  - Steps to do ahead of time:
    - Enroll the person in MedicAlert® + Alzheimer's Association Safe Return®, a 24-hour nationwide emergency response service for individuals with Alzheimer's or related dementia who wander or who have medical emergencies.
    - If the PWD lives in a residential facility, find out about its disaster and evacuation plan. Ask who will be responsible for evacuating the PWD.
    - Make sure evacuation plans address the specific needs of the PWD.
    - Prepare an emergency kit. Keep it in a watertight container and store it in an easily accessible location.
    - What to do if a pending disaster is about to occur
    - What to do during an evacuation
    - Tips for preventing agitation
  
- Addressing day-to-day safety
  - Wandering prevention
  - Home modification
  - Crime prevention
  - Poison control
  - Agitation and aggression



## **Approaches to Prevention and Education**

- Partner with the Red Cross and others to piggyback on their efforts with messages specific to persons with memory impairment.
- Public service announcements and other television, radio and print ads.
- Written materials in multiple languages widely distributed through health fairs, city offices, police and fire departments, libraries, hospital systems, and community agencies
- Workshops and classes
- Websites

## **Existing Services**

- Alzheimer's Association DVD's, curricula, materials in print and online
- MedicAlert & Safe Return Program
- Training DVD's for family caregivers and police officers
- Family Caregiver Alliance
- Institute on Aging
- Department of Aging and Adult Services
- [alzonline.phhp.ufl.edu/en/topics/fact sheets on emergency preparedness and wandering](http://alzonline.phhp.ufl.edu/en/topics/fact%20sheets%20on%20emergency%20preparedness%20and%20wandering)
- [www.annalsoflongtermcare.com/article/6200](http://www.annalsoflongtermcare.com/article/6200) includes an article on Disaster Preparedness for Long-Term Care Facilities
- [www.preparenow.org](http://www.preparenow.org)
- [www.72hours.org](http://www.72hours.org)
- San Francisco Community Agencies Responding to Disaster - [www.sfcard.org](http://www.sfcard.org)

## **Recommendations**

Share information with the Red Cross, SF Card and 72hours.org to see if they can incorporate dementia specific information into their materials, workshops and on the web. They have some great tips already for disabled persons but nothing on memory impaired individuals.

## **Policy Implications**

Ideally every person with dementia in San Francisco should be enrolled in the MedicAlert Safe Return program, though cost is a barrier (\$55 one-time enrollment and \$25 per year thereafter).

The fire and police departments should have annual in-services on how to respond to wandering and other situations involving persons with dementia (accidental shoplifting).

Some states are considering a silver alert system to notify the public of a missing person with dementia; San Francisco could consider implementing this type of program.

## Appendix IV: Finance Detail

As part of this effort, the Finance Subcommittee reviewed the results of a comprehensive study and analysis of the costs of services for individuals with Alzheimer's and other dementias.<sup>134</sup> This study examined the total formal and informal care costs attributable to Alzheimer's disease for persons living in the community as well as for individuals living in institutions in San Francisco. Data for the study were collected from ninety-three non-institutionalized Alzheimer's disease patients and their primary care-givers and from ninety-four institutionalized Alzheimer's disease patients, their primary caregivers, and staff of the institutions in which the patients resided. Special efforts were made to obtain broad representations by age, gender, socioeconomic status, race, and ethnicity.

Individuals with co-morbid conditions that might also result in dementia were excluded so that costs specific to Alzheimer's disease could be isolated. Primary caregivers were identified as unpaid persons who had primary responsibility for helping the patient with activities of daily living (ADLs), instrumental activities of daily living (IADLs), or both. This person provided more hours of care to the individual than anyone else. In an effort to further isolate costs attributable to Alzheimer's disease, caregivers were asked to describe only services used above and beyond what the patient would require if he or she were not demented. The researchers and Finance Subcommittee members recognized that the study population is not a random sample and may not be representative of the overall Alzheimer's population. Nevertheless, a broad range of Alzheimer's patients and their caregivers are included in this study, which represented the largest primary data collection effort to date using a sample of persons with Alzheimer's disease studied for cost implications.

A baseline interview of all primary caregivers in their homes included demographic, caregiving, and service use questions about themselves and the patients. Primary caregivers of non-institutionalized patients were also asked to assess the patient's capacities in ADLs. During the baseline interview a Mini-Mental State Examination (MMSE) was administered to patients who resided in the community. Patients in institutional settings were administered the MMSE during a separate visit, and facility staff familiar with the abilities of the patient were asked to assess ADL functioning. Caregivers were provided a calendar to record time spent on tasks related to caring for the patient, formal services used, formal costs associated with caring for the patient, and reimbursement received from Medicare, Medicaid, or private insurance. These data were obtained from caregivers through twelve monthly telephone interviews conducted by trained interviewers.

The economic cost of Alzheimer's disease represents the value of resources used or forgone as a result of the disease. Both formal and informal care services are estimated. Formal services refer to those rendered for a price in the traditional medical and social service marketplace, where dollars are explicitly exchanged for services. Informal services refer to services rendered outside those markets and for which providers are not reimbursed. Because the present study focuses on the cost of care rather than the total cost of the disease, indirect productivity losses are not estimated, however other studies have identified significant indirect productivity losses for both the individual with dementia and the informal caregiver. The incremental costs associated with caring for a demented person and attributed to the disease were measured. To exclude costs associated with conditions other than Alzheimer's disease, primary caregivers determined whether a formal service or an aspect of informal care was required because of the patient's demented condition. Billing records were also requested from primary caregivers and formal service providers for all formal services. Included in

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134 The Economic Burden Of Alzheimer's Disease Care by Dorothy P. Rice, Patrick J. Fox, Wendy Max, Pamela A. Webber, David A. Lindeman, Walter W. Hauck, and Ernestine Segura

formal care costs are expenditures for hospital and nursing home care, physician services, social services, medications, and other items or services used for the care of the person as a direct result of Alzheimer's disease. Social services are those that do not require the delivery of skilled medical care but that contribute to the health and welfare of the patient.

For most of these services, charges are used as a proxy for costs. Informal care provided to the patient as a result of Alzheimer's disease is valued using a replacement cost approach by imputing a market value for services performed. An alternative approach is to estimate the opportunity costs of caregivers' services by estimating the dollar value of their time had they been employed or engaged in other activities. Data were collected on missed wages and job and lifestyle changes that resulted from caregiving responsibilities.

Applying a common opportunity wage to all caregivers, as has been done elsewhere, would not consider the varying circumstances of the caregiver. Furthermore, market wages undervalue the time of women, the elderly, and minorities, who suffer from labor market discrimination. Thus we selected the replacement cost approach as the preferable methodology.

Monthly data on the hours spent per week on fourteen possible services that an informal caregiver might perform were collapsed into four broad categories: assistance with ADLs and IADLs, behavioral management, social/recreational activities, and other activities. If the patient had no system of informal support, similar services would have been performed by a paid employee appropriate to that need for services. An appropriate wage for each type of worker was used, reflecting 1990 California wages (including fringe benefits), which was updated to 2007 wage levels for this process as were the projected costs for formal, assisted living, and institutional care.

## Appendix V: Inventory of Plans in Other Jurisdictions

### Plans Relating to or Focused on Alzheimer's Disease: Elements and Themes

Senate Bill 491, Alquist, Statutes 2008, charges the Alzheimer's Advisory Committee to review existing documents when making policy and planning recommendations. The Committee is to: "Consider recommendations of other state plans, including but not limited to, the Olmstead Plan, the Long-Range Strategic Plan on Aging, and the California Department of Aging's State Plan on Aging."

This document organizes recommendations of several plans, including: the Strategic Plan for an Aging California Population and the California Olmstead Plan as well as Alzheimer's Disease Plans from Iowa, Kentucky and Vermont as well as two counties. The California Department of Aging will be issuing a draft State Plan on Aging for 2010 for comment during the spring of 2010. Recommendations of the plans reviewed thus far fall into several broad themes, including:

- Medical and Health Care
- LTC and Caregiver Support
- Data and Research
- Outreach and Education
- Legal Issues

For the complete text of the plans referenced, please see citations:

#### **CALIFORNIA:**

CA: Strategic Plan for an Aging California Population: Getting California Ready for the Baby Boomers (2003) <http://www.ccoa.ca.gov/pdf/population.pdf>

CA Olmstead: California Olmstead Plan (2003) <http://www.chhs.ca.gov/initiatives/Olmstead/Documents/01Section%20I%20-%20V%20combined.pdf>

Marin: An Emerging Need: Alzheimer's Disease & Dementia Care in Marin County, California (2002) [http://www.co.marin.ca.us/depts/HH/main/ag/PDFs/Alzheimer\\_Study.pdf](http://www.co.marin.ca.us/depts/HH/main/ag/PDFs/Alzheimer_Study.pdf)

SF: San Francisco Alzheimer's Advisory Committee Meeting Recommendations

#### **IOWA:**

IA: Iowa Alzheimer's Disease Task Force Final Report (2007) [http://www.legis.state.ia.us/lisadocs/Docs\\_Filed/2008/DFJYD077.PDF](http://www.legis.state.ia.us/lisadocs/Docs_Filed/2008/DFJYD077.PDF)

#### **KENTUCKY:**

KY: Setting a Roadmap to Address Alzheimer's in the Commonwealth: A Report on the Assessment of the Current and Anticipated Future Impact of Alzheimer's Disease and Related Dementias on Kentuckians with Recommendations for Action (2008) <http://chfs.ky.gov/NR/rdonlyres/DF111120-71BB-4461-850D-02F8AB159AC9/0/StateAlzheimerPlan.pdf>

#### **VERMONT:**

Vermont: Vermont State Plan on Dementia: Executive Summary (2008) <http://www.ddas.vermont.gov/ddas-publications/publications-dementia/publications-dementia-documents/state-plan-dementia-exec-summary>

#### **MICHIGAN:**

MI: Michigan Dementia Plan Update (2009) [http://www.dementiacoalition.org/members/pdfs/mi\\_dementia\\_plan\\_update.pdf](http://www.dementiacoalition.org/members/pdfs/mi_dementia_plan_update.pdf)

## Medical and Health Care

### Health Promotion

- Promote health and reduce the risk for developing Alzheimer's disease or related disorder. (LA)*
  - Provide physical and mental activity programs using evidence-based programs designed for older adults such as EnhanceFitness, Eat Better & Move More, and Healthy Aging.
  - Provide chronic disease self management programs using evidence-based health promotion programs such as Stanford Chronic Disease Self Management.
  - Promote dietary quality for older adults through provision of nutrition education programs such as Eat Better & Move More.
  - Provide nutrition counseling by registered dietitians to older adults determined to be at high nutrition risk.
  - Provide brain health education programs to help Iowans reduce their risk of Alzheimer's disease or related disorders.
- Encourage primary care doctors to perform an annual first level Alzheimer/ dementia assessment for their patients over 65 years of age to identify early markers of Alzheimer's disease so diagnosis can be made prior to manifestation of symptoms (CA)*
- Promote dementia case detection and assessment. (MI)*

### Acute care

- Enhance capacity of services to meet needs of persons with Alzheimer's disease or related disorder. (LA)*
  - Provide technical assistance to current service providers to enable the diversification of their service base.
- Require and provide training and the subsequent provision of evidence based practices in programs and services supported by State funds. (KY)*

### Chronic disease care

- Pilot new care models where providers offer chronic care management to individuals, particularly those with dementia, who are incapable of managing their own chronic conditions, and need that assistance. (CA)*

### Mental Health

- Dementia recognized as MH issue with access to available services (Marin)*
- Advocate for legislation mandating coverage for dementia under Community Mental Health. (Marin)*
- Advocate for the development of a Med-Psych unit for differential diagnosis (Marin)*
- Require mental health parity. (KY)*
- Convene a workgroup on a regular basis to address psychogeriatric needs of persons with Alzheimer's disease in Iowa. The workgroup would be tasked with identifying mechanisms for funding of in-patient mental health services, expanding the statewide availability of services, establishing education pathways for providers, and enhancing the availability of emergency crisis intervention. (LA)*
- Better gero-psychiatric services in the community to avoid institutionalization (SF)*
- Improve pharmacology mismanagement*
- Support a pilot demonstration project to address the problem of facility discharges of residents exhibiting challenging behavior. (KY)*

### *End of life care*

- *Create a cadre of academic faculty trained in the principles of palliative care at all of the state's medical schools, teaching hospitals and schools for related medical professionals (ie. Social workers, nurses, etc.) This training curriculum should include non-cancer diagnoses, persons with dementia, and working with caregivers as it relates to palliative care. (CA)*

### *Care Management and Quality Improvement*

- *Establish a dementia quality initiative to direct efforts to measure and improve dementia care across health care settings, including home-based care, and promote person and family centered services (Vermont).*
- *Advocate for integrated systems of healthcare and support that are effective for individuals with Alzheimer's disease or related dementias and their families. (e.g. disease management strategies, practice guidelines, home and community based care, hospice care and chronic care management) (KY)*
- *Support and assist the rapidly increasing numbers of individuals with Alzheimer's disease or related disorder by providing a wide array of home and community based services such adult day services, respite care, and affordable transportation as well as assisted living, occupational therapy, speech therapy, social work services, dieticians, and others as these may delay premature nursing facility placement. (LA)*
- *Subject to funding, establish the Geriatric Comprehensive Care Management Program for persons over 60 with more than one chronic condition. Components of the program should include: (CA)*

A continuum of integrated accessible service options

A nurse/social worker geriatric team as part of every primary health delivery system

Development of a care plan with the consumer that considers the person or caregiver's ability to follow the plan based on their mobility, cognitive status, mental health, medication management status, transportation and nutrition needs

Consideration of the needs of family caregivers

Early diagnostic tests for Alzheimer's

- *Correlate stages of Alzheimer's disease or related disorder with interventions to assist caregivers and service providers to make care decisions and to navigate the delivery system through the: (LA)*

Identification of intervention

Identification of service needs

Identification of safety needs (including home environments)

Identification of caregiver needs

- *Enhance capacity of services to meet needs of persons with Alzheimer's disease or related disorder. (LA)*

Develop recommendations which reflect Alzheimer's disease or related disorder capable and friendly practices.

- *Identify and promote wide use of evidence based practices through the development of an Evidence-Based Practice Guide specific to Alzheimer's Care. (KY)*

- *Establish Alzheimer's disease and related disorder Diagnostic Centers of Excellence strategically throughout the state that would serve as multi-disciplinary centers to serve patients with Alzheimer's disease or related disorder and their caregivers. (LA)*

The ideal center would have physician services, social services, nursing, and special interest in the care of persons with Alzheimer's disease or related disorder.

Various organizations focused on patient needs in this area could join forces to ensure efficiency and effectiveness. For example, existing memory centers could joint venture with the Alzheimer's Association and mental health advocate organizations to establish multiple centers across the state that would provide easy access to comprehensive services. These services would include history, physical, lab, x-ray, social support, and treatment.

- *Provide timely assessments for persons in institutions to determine supports and services needed for individuals to transition and live successfully in the community. Provide assessments for persons living in the community, who are at risk of placement in an institution or more restrictive setting, to remain in the community in the least restrictive setting. Assessments should result in an informed choice for the consumer as to the most appropriate and integrated setting. (CA Olmstead)*
- *Continually improve quality of services based on desirable outcomes and measures and increase the level of consumer satisfaction. (CA Olmstead)*

#### *Medical and Health Care Workforce Issues*

- *Create an optional specialized certification for health and human services professionals to provide quality care and improve the quality of life for people with Alzheimer's disease or related disorders. (LA)*
- *Engage in initiatives which increase supply, distribution and quality of the dementia care workforce. Dementia care workforce may include conventional health care professionals and paraprofessionals as well as first responders, police, area agency on aging staff, housing providers and other critical workforce professions. (Vermont)*
- *Require mandatory dementia-specific training for emergency room staff including nurses, physicians and related services technicians such as radiology. (KY)*
- *Fund public awareness efforts and educational efforts for providers, caregivers, and state oversight and monitoring personnel. (LA)*
- *Implement a statewide campaign to educate health and human services professionals regarding early detection instruments, such as AD8 and Mini-Cog, as early detection could prepare patients and families for what to expect. (LA)*
- *Address the preparedness of the workforce to provide care and services in support of persons with Alzheimer's disease or related disorder and their caregivers. (LA)*

Recruit and retain workers across care settings.

Maximize the utilization of information technology to expand the access and availability of health professionals.

Promote the interdisciplinary team approach for planning and care delivery.

- *Support an interdisciplinary effort to develop a core set of geriatric competencies and a common language across the health, mental health and social service professions. (CA)*

These should include patient-centered care, the bio/psycho/social needs of the aging, evidence-based practice, interdisciplinary teams, quality improvement and problem solving.

Train providers on core competencies in order to encourage patient centered care

Core competencies should incorporate caring for people with dementia.

- *Promote training requirements in dementia issues for health professionals and other persons who are likely to be interacting with or providing care to persons with Alzheimer's. These professionals include but are not limited to, mental health professionals, residential facility and personnel (including assisted living and skilled nursing), and emergency room and other in-patient hospital staff. (CA)*

- *Work with the universities to develop specific training and recruitment options including: (KY)*

The development of optimal training content standards for licensed health professionals; target Kentucky's professional schools to integrate it into curricula. Create a "Bucks for Brains" program to recruit and train geriatric psychiatrists, geriatricians, and other geriatric specialists.

The development of residencies or fellowships for training of geriatric psychiatrists, geriatricians, and other geriatric specialists.

The development of a specific track on Alzheimer's disease related dementias and dementia related diseases for medical students and residents.

Institute State policies and procedures to provide additional support to ensure the health, safety and welfare of individuals with Alzheimer's and Related Dementias Related Disease. (KY)

- *Establish a certification process for trainers and educators of the standard curriculum model. (LA)*

- *Increase the spectrum of educational resources available by using on-line courses, community colleges and make subsidized educational opportunities available for those wishing to specialize in this field. (LA)*

- *Encourage geriatrics and gerontology studies in every curriculum regardless of specialty. Encourage all physicians, nurses, pharmacists and other healthcare professionals to know how to care for older patients, including patients with dementia. (CA)*

- *Initiate a forum for dialogue among providers serving this population (Marin)*

- *Disseminate information on services and related activities for individuals with Alzheimer's disease and related dementias to the medical and healthcare community, academic community, primary family caregivers, advocacy associations and general public (KY)*

- *Broaden the spectrum of people who are required to receive training specific to Alzheimer's disease or related disorders to those who work in direct contact with people diagnosed with Alzheimer's disease including but not limited to administrators, directors, dietary staff, administrative and management staff, hospital direct care staff, state employees with responsibility for long term care oversight/ monitoring, and ombudsmen. (LA)*

- *Fund public awareness efforts and educational efforts for providers, caregivers, and state oversight and monitoring personnel. (LA)*

- *Require mandatory dementia-specific training as part of DOCJT yearly in-service training for emergency personnel (e.g. firefighters, emergency medical technicians, police officers). (KY)*

- *Promote use of Primary Care Dementia Network (PCDN) education modules. (MI)*

- *Support dementia component of the Geriatric Education Center of Michigan (GECM) inter-disciplinary community geriatric team outreach and education project in eight communities: Marquette, Traverse City, Grand Rapids, Lansing, Saginaw, Flint, Detroit, and Kalamazoo. (MI)*

- *The GECM and PCDN developed five educational modules for primary care physicians and identified and distributed numerous other resource materials to primary care practices. Available at [www.dementiacoalition.org](http://www.dementiacoalition.org) (MI).*



## Financing

- Explore options to increase insurance coverage for individuals with Alzheimer's and Related Dementias (KY)
- Explore changes needed to ensure Medicaid eligibility for individuals with early onset Alzheimer's Disease or Related Dementias (KY)
- Explore potential for Medicaid waiver specific to Alzheimer's Disease and Related Dementias. (KY)
- Review the current Medicaid programs to ensure "dementia friendly" approaches and policies. (KY)
  - Review the "Resource Utilization Groups" (RUGs) system to determine values of behavior management and evidenced based interventions
  - Increasing opportunities for self-determination.
  - Identify challenges to admission and eligibility requirements
- Explore services and options available under private insurance entities. (KY)
- Given that the Medicaid Waiver is a long process, undertake a three-step approach to address the needs of persons with Alzheimer's disease or related dementia: (LA)
  - Step 1: Allow individuals with a diagnosis of early on-set Alzheimer's disease or related disorders to be served in excess of the current maximum number of clients under the Ill and Handicap Waiver.
  - Step 2: Increase the expenditure limits under the Elderly Waiver to give parity with other waivers including but not limited to the Ill and Handicapped Waiver, the Brain Injury Waiver, and the Mental Retardation Waiver for persons with a diagnosis of Alzheimer's disease or related disorder. (This recommendation affects patients older than 65)
  - Step 3: Establish an Alzheimer's disease or related disorder specific waiver to place greater importance on the issue and needs comparable to the Brain Injury Waiver and the HIV/Aids waiver and without regard to the age of the person with Alzheimer's disease or related disorder.
- Determine the implications of funding and policy on niche populations including Down's syndrome and Young onset Alzheimer's disease or related disorder. (LA)
- Evaluate inequities in insurance and Medi-Cal reimbursement to providers. (CA)
  - Subject to the availability of resources, allow drug coverage for treatment of Alzheimer's and related disorders.
- Identify differential costs of mild/moderate/severely impaired individuals with dementia or related disorders (SF)
- Identify co-morbidity costs of individuals with dementia or related disorders(SF)
- Enhance capacity of services to meet needs of persons with Alzheimer's disease or related disorder. (LA)
  - Examine the caps on waiver funding.
  - Review current re-imbursement rates across all state programs.
- Explore changes needed to support the purchase and provision of evidence based practice training and education. (KY)

## Policy

- Establish policies, procedures, and incentives to incorporate evidence based practices into training, service, and program activities. (KY)

## Long Term Care and Support

### *Skilled Nursing Facilities*

- Support a pilot demonstration project to address the problem of facility discharges of residents exhibiting challenging behavior. (KY)*
- Develop regulations or waiver protocol inviting development of new approaches to facility design that preserve resident safety, recognize special needs of persons with memory loss and pursuant to evidence based practice show promise for improving the quality of their lives. (KY)*
- Divert individuals from entering institutions and ensure that they are served in the most integrated setting appropriate, based on informed consumer choice. (CA Olmstead)*
- Transition individuals from institutions to the most integrated setting appropriate, based on consumer choice. (CA Olmstead)*

### *Residential Care Facilities for the Elderly*

- Review overlapping requirements for licenses for personal care homes and assisted living facilities such as medication management including oversight, assistance, administration and monitoring and recommend appropriate regulation changes to accommodate the needs of persons with dementia. (KY)*

### *Home care and Community Services*

- Develop a demonstration to test the feasibility and cost-effectiveness of adult day care clients receiving services in other long- term care settings traditionally considered “institutional” in order to expand access and accommodate anticipated growth in demand. (KY)*
- Utilize the Council to evaluate state regulations on home care, adult day and home health to assure they are “dementia friendly”. (KY)*
- Expand the continuum of community-based services inside and outside the home throughout the state including, but not limited to: care coordination/ navigation, home health, home aid, in-home supportive services (IHSS), independent living centers (ILC) and day care, including Adult Day Health Care (ADHC) and Alzheimer’s Day Care Resource Centers (ADCRCs). (CA)*
- Develop a full array of community services so that individuals can live in the community and avoid unnecessary institutionalization, including participating in community activities, developing social relationships, and managing his or her personal life by exercising personal decisions related to, among other things, housing, health care, transportation, financial services, religious and cultural involvement, recreation and leisure activities, education, and employment. Services should be appropriate to individuals living with and without family or other informal caregivers. Increase capacity for local communities to divert consumers from institutionalization and re-institutionalization. Support family caregivers by providing an array of information and services that will allow them to support a family member with disabilities in their home. (CA Olmstead)*
- Expand the availability of housing options for persons with disabilities. Ensure the availability of housing options that can be augmented by supports that facilitate the full inclusion of the person into the community. (CA Olmstead)*
- Identify and promote use of best community caregiver assessment tools and practices, ie. develop a statewide Best Practices Award for dementia day services (MI)*

- Develop recommendations for community service agencies regarding provision of long-term care dementia information and assistance to avoid gaps, minimize unnecessary duplication, and ensure consumer needs are met. (MI)*

#### *Caregiver support*

- Develop respite care resources (Marin)*
- Utilize the Council and stakeholder community to revise the current definition, eligibility and service requirements for the provision of respite. (KY)*
- Develop incentives beyond tax incentives for caregivers (KY)*
- Provide Additional Support for Vulnerable Caregivers. (CA)*

Intensive intervention efforts should be targeted to vulnerable caregivers, including those who are poor, socially isolated or who have health problems of their own. Intervention should also target those who experience high stress levels, and care for persons with problematic behaviors, dementia, or a high level of daily dependency.

- Disseminate information on services and related activities for individuals with Alzheimer's disease and related dementias to the medical and healthcare community, academic community, primary family caregivers, advocacy associations and general public (KY)*
- Develop a profile of Michigan's home-based dementia caregivers to aid planning and advocacy efforts. (MI)*
- Promote existing tools and resource materials including Effective Caregiver Interventions, in-home and community-based respite best practices, technology lexicon/ assistive technology, and other selected resources. (MI)*
- Facilitate and promote access to in-home and community-based dementia respite care in Michigan. (MI)*
- Provide input in development and implementation of Alzheimer's Disease Demonstration Grant to States (ADDGS) home and community-based caregiver support services. (MI)*

#### *Case management / Infrastructure repairing and building*

- Support the development and sustainability of local, regional and statewide health and human service, dementia informed systems of care. These systems will include specialty clinics for the assessment and diagnosis of cognitive impairment, settings providing for the multidisciplinary care of persons with dementia within the home, community, residential and nursing home environments, plus hospitals and hospice programs. (Vermont)*
- Establish State Protocol on Appropriate Interface and Choices for Individuals with Alzheimer's and Related Dementias and Their Families. (KY)*
- Ensure system of care coordinators & benefit counselors in each of 15 ADD regions. (KY)*
- Develop a process/protocol to permit persons with dementia to remain in their current living environment despite a change in their condition (e.g. challenging behaviors or other disease symptom) that under existing regulations might otherwise promote their move to a different level of care; this protocol should assure that the provider can adequately demonstrate that the person's care needs can be safely and effectively met without the disruption of moving. (KY)*
- Require the Unit and Council to develop a protocol detailing how to interface with individuals with Alzheimer's and related dementias and their families. The protocol should include appropriate placement care options based on the stages of Alzheimer's and related dementias. (KY)*

- *Correlate stages of Alzheimer’s disease or related disorder with interventions to assist caregivers and service providers to make care decisions and to navigate the delivery system through the: (LA)*

Identification of intervention

Identification of service needs

Identification of safety needs (including home environments)

Identification of caregiver needs

- *Support and assist the rapidly increasing numbers of individuals with Alzheimer’s disease or related disorder by providing a wide array of home and community based services such adult day services, respite care, and affordable transportation as well as assisted living, occupational therapy, speech therapy, social work services, dieticians, and others as these may delay premature nursing facility placement. (LA)*

- *Establish a dementia quality initiative to direct efforts to measure and improve dementia care across health care settings, including home-based care, and promote person and family centered services (Vermont).*

- *Implement a comprehensive service coordination system that will improve the long-term care system so that California residents, regardless of disability, will have available an array of community service options that allow them to avoid unnecessary institutionalization. This comprehensive system would include elements such as the following (CA Olmstead):*

A standardized diversion process for individuals at risk of placement in institutions.

Multi-disciplinary teams will be used that include the appropriate expertise (e.g., dementia expertise for a person with Alzheimer’s Disease).

- *Provide timely assessments for persons in institutions to determine supports and services needed for individuals to transition and live successfully in the community. Provide assessments for persons living in the community, who are at risk of placement in an institution or more restrictive setting, to remain in the community in the least restrictive setting. Assessments should result in an informed choice for the consumer as to the most appropriate and integrated setting. (CA Olmstead)*

- *Provide comprehensive information regarding services to persons with disabilities in order to make informed choice and for service planners for planning purposes. No individual with disabilities should be prevented from living in the community due to a lack of information. Develop information, education, and referral systems, as needed, to meet this goal. (CA Olmstead)*

#### *LTC Workforce Issues*

- *Increase and enhance training and education requirements about Alzheimer’s disease or related disorders for all direct care employees including, but not limited to, long-term care settings, assisted living, elder group homes, residential care, adult day service facilities and home health care. (LA)*

Establish or broaden the number of hours for training for direct care staff to a minimum of 8 hours classroom instruction and a minimum of 8 hours of supervised interactive experience.

Establish or broaden the number of continuing education/in-service hours for direct care workers on the topic of Alzheimer’s disease or related disorders to a minimum of 8 hours annually.

Add a competency component following Alzheimer’s disease or related disorders training.

Establish a standard curriculum model that will include, but not be limited to: the diagnostic process, the progression of the disease, communication skills

(including the person with the diagnosis, family, friends and caregivers), family stress and challenges, nutrition and dining information, activities, daily life skills, caregiver stress, the importance of building relationships and understanding the personal history, expected challenging behaviors and non-pharmacologic interventions, and medication management.

- Develop and implement an evidence-based training curriculum and implementation strategies for Long Term Care facilities (KY)*
- Develop a portable certification program for para-professional direct caregivers with standardized content designed to enhance their understanding of memory impairment and their performance in caring for individuals with Alzheimer's and related dementias. (KY)*
- Require geriatric and dementia training/ education for all owners and managers of assisted living/ residential and nursing facilities. (CA)*
- Enhance capacity of services to meet needs of persons with Alzheimer's disease or related disorder. (LA)*

Ensure the availability of trained workers for facility and community based services.

- Require and provide training and the subsequent provision of evidence based practices in programs and services supported by State funds. (KY)*
- Broaden the spectrum of people who are required to receive training specific to Alzheimer's disease or related disorders to those who work in direct contact with people diagnosed with Alzheimer's disease including but not limited to administrators, directors, dietary staff, administrative and management staff, hospital direct care staff, state employees with responsibility for long term care oversight/ monitoring, and ombudsmen. (LA)*
- Fund public awareness efforts and educational efforts for providers, caregivers, and state oversight and monitoring personnel. (LA)*
- Engage in initiatives which increase supply, distribution and quality of the dementia care workforce. Dementia care workforce may include conventional health care professionals and paraprofessionals as well as first responders, police, area agency on aging staff, housing providers and other critical workforce professions. (Vermont)*
- Address the preparedness of the workforce to provide care and services in support of persons with Alzheimer's disease or related disorder and their caregivers. (LA)*

Recruit and retain workers across care settings.

Train caregivers across disciplines to meet the unique needs of persons with Alzheimer's disease or related disorder.

Promote the interdisciplinary team approach for planning and care delivery.

Integrate strategies for planned environmental interventions to aid staff, caregiver and person with Alzheimer's disease or related disorder.

- Promote training requirements in dementia issues for health professionals and other persons who are likely to be interacting with or providing care to persons with Alzheimer's. These professionals include but are not limited to, mental health professionals, residential facility and personnel (including assisted living and skilled nursing), and emergency room and other in-patient hospital staff. (CA)*
- Provide training to drivers in how to safely transport older adults with dementia. (CA)*
- Develop a dementia competencies self-assessment tool and dementia competencies guide for direct care workers, to be used by the LTC system to promote dementia competency among direct care providers. (MI)*

### *Quality Improvement*

- Establish Quality Care measures with system benchmarks for facility and community based care for persons with Alzheimer's disease or related disorder. (LA)*
- Enhance the capacity of services to meet the needs of persons with Alzheimer's disease or related disorder. (LA)*

Examine current administrative rules for nursing facilities, CCDI, assisted living, adult day services, home and community-based services, and Medicaid elderly waiver case management programs (administered by the departments of Human Services, Elder Affairs and Public Health).

- Continually improve quality of services based on desirable outcomes and measures and increase the level of consumer satisfaction. (CA Olmstead)*
- Identify and develop information focusing on key points to be made in advocacy for people with dementia as they pertain to the various long-term care workgroups and initiatives. (MI)*

### *Financing*

- Provide tax incentives for individuals who purchase long-term care insurance. (KY)*
- Make Medicaid Waivers a significant factor in helping address the many needs of individuals dealing with problems associated with Alzheimer's disease or related disorder, such as adult day services, assisted living, respite care, occupational therapy, speech therapy, social work services, dieticians, and affordable transportation as a means to delay premature institutionalization. (LA)*
- Explore changes in the certificate of need requirements in order to foster expansions of Alzheimer's and dementia specific services. (KY)*
- Enhance the capacity of services to meet the needs of persons with Alzheimer's disease or related disorder. (LA)*

Examine the caps on waiver funding.

Review current re-imburement rates across all state programs.

- Require training for providers and State staff associated with any of the Medicaid home and community based waivers. (KY)*
- Advocate for Medi-Cal to supplement SSI payments in residential care settings. (Marin)*
- Advocate for SSI beds and mixed income residential care facilities (Marin)*
- Request an increase in the Alzheimer's Respite Services line item in the State budget. (KY)*
- Support legislation for a caregiver tax credit for people who provide in-home care for dependent relatives who have little to no income, and have been diagnosed with Alzheimer's Disease and related dementias. (KY)*
- Offer tax credits to families for the purchase of locator devices. (KY)*
- Develop a "Money Follows the Individual" model to provide resources for individuals to live in the community rather than an institution. Seek opportunities to increase resources and funding options. (CA Olmstead)*

## Data and Research

### Surveillance

- Require the Alzheimer's and Related Dementias Unit to coordinate a statewide effort to develop, and implement a statewide data collection system. (KY)*
  - Collect data and monitor at a minimum the following data: (KY)*
    - The prevalence of dementia related diseases across the state;
    - The prevalence of dementia related diseases by county;
    - The prevalence of early onset dementia and related diseases across the state;
    - The prevalence of inpatient geriatric psychiatry beds;
    - The availability of geriatric services and specialists;
    - The availability of dementia related services and supports;
    - The availability of assessment services for Alzheimer's and related dementias;
    - The number and location (county) of individuals who are currently providing care in their home to a family member.
  - Develop an improved standardized minimum data set for each reporting entity from Planning and Service Areas (PSA) to nursing homes. Include disability and dementia data in order to fulfill Federal and State requirements, while simultaneously supporting care navigation and the longitudinal database. (CA)*
  - Develop Standard Definitions – Establish a team representing the range of long term care programs, public and private, to develop standard definitions for each data element to be collected across all sectors in California that provide services to the aging, persons with dementia and/or the disabled. Encourage collaboration with other data groups to keep abreast of other related efforts. (CA)*
  - Capture data on a 10% sample of client data from the gamut of long term care and service providers, including, but not limited to: Residential Care Facilities for the Elderly, Multipurpose Senior Services Program, Adults Day Services, Adult Day Healthcare Centers, Alzheimer's Day Care Resource Centers, and all home and community-based service providers. (CA)*
  - Direct the Council to study new technologies that can help locate missing persons and to make recommendations about implementation strategies. (KY)*
  - Compile an analysis of Iowa's population by county and age to determine current utilization and future service needs of caregivers and persons with Alzheimer's disease or related disorder to support development of programs and services. (IA)*
  - Review current trends and the impact in the Long Term Care rebalancing efforts affecting persons with Alzheimer's disease or related disorder. (IA)*
    - Bed occupancy, length of stay in a nursing facility, increase number in elderly waiver, acuity level of nursing facility residents, growth of assisted living programs.
    - Availability of adult day services.
    - Senior Living Coordinating Unit (SLCU) long-range plan (need to ensure strategies to include those to support service for persons with Alzheimer's disease or related disorder and their caregivers).
    - Determine impact of Direct Care Worker shortages on availability and access to services.
  - Modify existing community needs assessment process to include questions that would identify and quantify at-risk people with Alzheimer's disease or related disorder. This would include local public health*
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*community needs assessment, Area Agency on Aging area planning process, and other agencies that receive federal and state funding for services to the aging population. (IA)*

- Enhance the capacity of services to meet the needs of persons with Alzheimer's disease or related disorder. (IA)*

Task the Senior Living Coordinating Unit (SLCU) to formally examine the findings of the University of Iowa's Adult Day Services study (Sanders and Saunders), make recommendations, and track implementation progress across the Unit agencies.

- Improve information and data collection systems to improve the long-term care system so that California residents will have available an array of community care options that allow them to avoid unnecessary institutionalization. (CA Olmstead)*

#### Research

- Increase dementia-related research activities in the state by attracting scientific investigators, increasing grant-funded research and increasing participation in dementia-related research that can benefit State's population. (Vermont)*
- Explore processes for distributing state funds to University faculty and determine feasibility of designating state funds specifically toward Alzheimer's research. (KY)*
- Explore additional funding sources for Alzheimer's research through universities and other resources. (KY)*
- Identify and explore ways to further evaluate existing evidence based practices with populations. (KY)*
- Continue exploring grant opportunities to provide empirical evidence of nationally recognized evidence based practices as well as practices that are already occurring in the state (e.g., Best Friend's model of care). (KY)*
- Collaborative efforts are developed with state agencies, policymakers and academic centers are developed to engage in policy-related research activities which advance State's understanding, and improvements, in dementia care. (Vermont)*
- Provide input in development and implementation of Alzheimer's Disease Demonstration Grant to States (ADDGS) home and community-based caregiver support services. (MI)*
- Look for grants to support stated objectives and consider other appropriate objectives to match available funding opportunities. Support organizations that are seeking grant opportunities that match the workgroup's stated objectives.*

#### Outreach and Education

##### General public

- Design a broad based dementia and brain health public information campaign. (Vermont)*
- Design a grass roots information dissemination campaign. (Vermont)*
- Create a summary of resources specifically addressing Alzheimer's and dementia care programs and services. (Marin)*
- Increase public visibility of the Adult & Aging Information and Assistance Number (Marin)*
- Promote educational resources for better understanding Long Term Care financing. (KY) Enhance the DAIL website to include Alzheimer's information and links. (KY)*



- *Develop an Integrated, One-Stop Consumer Information System (CA)*

Enhance and improve the user friendliness of CalCareNet. For example, consider the use of intuitive/illustrative icons similar to the American Automobile Association hotel guides, to describe the features of RCFEs or nursing homes. Include information on RCFE's having dementia waivers.

- *Establish initiatives which promote a sense of responsibility and provide the necessary resources to support active involvement in advocacy, care and self management. (Vermont)*
- *Establish Alzheimer's disease and related disorder Diagnostic Centers of Excellence strategically throughout the state that would serve as multi-disciplinary centers to serve patients with Alzheimer's disease or related disorder and their caregivers. (LA)*

The public could initially access information about the Centers through an 800-number manned by a non-profit entity (such as the Alzheimer's Association).

Various organizations focused on patient needs in this area could join forces to ensure efficiency and effectiveness. For example, existing memory centers could joint venture with the Alzheimer's Association and mental health advocate organizations to establish multiple centers across the state that would provide easy access to comprehensive services. These services would include history, physical, lab, x-ray, social support, and treatment.

- *Disseminate information on services and related activities for individuals with Alzheimer's disease and related dementias to the medical and healthcare community, academic community, primary family caregivers, advocacy associations and general public (KY)*
- *Educate communities regarding the Olmstead decision. Provide background information on the Americans with Disabilities Act, the Fair Housing Amendments Act, and other related federal and state laws, to community decision makers, to ensure that they take the needs of individuals with disabilities into account when making decisions regarding public services and resources. Provide information to California communities so that community planning can be conducted to address the needs of that community's individuals with disabilities. (CA Olmstead)*
- *Explore with Alzheimer's Association Chapters, the Office of Long-Term Care Supports and Services, and the Primary Care Dementia Network how best to maintain and disseminate information on dementia assessment providers. (MI)*
- *Continue to provide quarterly newsletters with Network updates, dementia news, and information about dementia resource materials. (MI)*
- *Work with Geriatric Education Center of Michigan (GECM) community geriatric teams to identify, develop and disseminate materials that help increase public awareness. (MI)*
- *Promote dissemination of information through eblasts: (MI)*

Update eblast database.

Promote Michigan Dementia Coalition participant dissemination of eblasts.

- *Prepare public awareness talking points and slides for dropping in PowerPoint presentations and promote their use among Michigan Dementia Coalition participants. (MI)*
- *Promote broad dissemination of WorriedAboutMemoryLoss (WAML) cards. (MI)*
- *Enhance WAML website with additions and more frequent updates. (MI)*
- *Expand educational outreach (for example, to Local Health Departments, medical professional*

*associations, and Medicaid managed care organizations).* (MI)

*First encounter and other non-medical/LTC service providers*

- Establish an office for Alzheimer's disease or related disorders within state government. This office would not replace or duplicate any services currently offered by the Area Agencies on Aging, the Alzheimer's Association, or other agencies, but would act as a referral source to local services. This office would: (LA)*
  - Increase public awareness for services currently available at the local or state level.*
  - Collaborate with various stakeholders including serving as a point of contact for people diagnosed with the disease, caregivers, professionals and consumers for information, education, training and referrals.*
  - Create a senior alert program for local, regional or statewide notification of missing senior adults.*
  - Coordinate efforts to continue the work of this task force and research the work of experts in both national and international settings.*
  - Create an advocacy system for people not currently living in long-term care facilities who have been diagnosed with Alzheimer's disease or related disorder and their families.*
  - Be guided by a multi-disciplinary commission (board) to continue the work of this task force.*
- Broaden the spectrum of people who are required to receive training specific to Alzheimer's disease or related disorders to those who work in direct contact with people diagnosed with Alzheimer's disease including but not limited to administrators, directors, dietary staff, administrative and management staff, hospital direct care staff, state employees with responsibility for long term care oversight/ monitoring, and ombudsmen. (LA)*
- Work with law enforcement to implement a coordinated protocol or swift and appropriate action upon report of a missing adult with dementia. (KY)*
- Identify specific training resources for targeted audiences across the state. (KY)*
- Develop relationships with police and community partners to develop and implement training (such as, but not excluding including but not limited to, bankers, attorneys, police, emergency personnel, etc.). (KY)*
- Develop and implement an evidence-based training curriculum and implementation strategies for targeted audiences (i.e. Department for Mental Health and Mental Retardation, Office of Inspector General surveyors, Comprehensive Care Centers, family caregivers, etc.). (KY)*
- Increase training for state adult protective services workers on Alzheimer's dementia. (KY)*
- Use stakeholders to promote innovation and a proactive approach to emerging issues in dementia care. (Vermont)*
- Establish a strategy to link and coordinate services and activities of State agencies, other service providers, advocacy groups and other entities throughout the State such as emergency personnel, police, universities and attorneys and other staff associated with the legal system. (KY)*
- Require the Unit and DAIL to provide training to staff within the Cabinet for Health and Family Services on the protocol including but not limited to adult protective services workers, guardianship/ social workers, and staff from the Office of Inspector General and the Department for Mental Health and Mental Retardation on the protocol. (KY)*

- Require mandatory dementia-specific training as part of DOCJT yearly in-service training for emergency personnel (e.g. firefighters, emergency medical technicians, police officers). (KY)*
- Educate Police and Fire Departments as potential population safety net (Marin)*
- Ensure that all task force recommendations coalesce with other initiatives and programs within the state, such as the Direct Care Worker Task Force Recommendations, Alzheimer's Association, Area Agencies on Aging, the Hartford Center Grant, Iowa Respite and Crisis Care Coalition and the UI Center on Aging and Geriatric Education Center. (LA)*
- Help plan the dementia conference day of the annual Issues on Aging Conference. (MI)*

#### *Financing*

- Establish Alzheimer's disease and related disorder Diagnostic Centers of Excellence strategically throughout the state that would serve as multi-disciplinary centers to serve patients with Alzheimer's disease or related disorder and their caregivers. (LA)*

The state would provide funding to support establishment of new centers.

- Explore funding for public education messages for community groups like Faith in Action to use. (MI)*
- Ask major health plans to participate in campaign. (MI)*
- Ask major health plans, Employee Health Plans, and drug companies to add WAML link to their websites. (MI)*

**Appendix VI: California Workgroup and  
Alzheimer's Association of Northern California and Northern Nevada  
Guideline for Alzheimer's Disease Management**

**2008 California Guideline for  
Alzheimer's Disease Management**

This new California Guideline updates and expands the 2002 version. This guideline was developed by the California Workgroup on Alzheimer's Disease Management through a collaborative effort of healthcare providers, consumers, academicians, and representatives of professional and volunteer organizations that included a review of scientific evidence supplemented by expert opinion when research has been unavailable or inconsistent.

**What is covered in the Guideline:**

- Support for a team approach to quality management of Alzheimer's disease
- Importance of an accurate assessment
- Treatment options - including a new class of medication
- Approaches to patient and caregiver education and support  
-including evidence that links positive patient outcomes to caregiver education and support
- Legal considerations
- New evidence on management of the disease in very early and end stages

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Please view the entire document at:

[http://www.alz.org/californiasouthland/in\\_my\\_community\\_professionals.asp#Clinical\\_guidelines](http://www.alz.org/californiasouthland/in_my_community_professionals.asp#Clinical_guidelines)

## Appendix VII: United Kingdom National Dementia Strategy

### **LIVING WELL WITH DEMENTIA: A NATIONAL DEMENTIA STRATEGY**

This strategy provides a strategic framework within which local services can:

- Deliver quality improvements to dementia services and address health inequalities relating to dementia;
  - Provide advice and guidance and support for health and social care commissioners and providers in the planning, development and monitoring of services; and
  - Provide a guide to the content of high-quality services for dementia.
- 

Please view the entire document at:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_094058](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058)

- [Download Living well with dementia: a National Dementia Strategy \(PDF, 1560K\)](#)
  - [Download accessible summary \(PDF, 681K\)](#)
  - [Implementation plan](#)
  - [Download impact assessment \(PDF, 400K\)](#)
  - [Download equality impact assessment \(PDF, 92K\)](#)
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## Appendix VIII: Additional Standards and Guidelines

Following are excellent resources for compiling such a set of standards and guidelines, which have been identified by the Evidence-Based Practice and Emerging Research Subcommittee:

- ***Guideline for Alzheimer's Disease Management, Final Report. California Department of Public Health.*** Provided perhaps the most current analysis of evidence-based practice in assessment, diagnosis, and community-based care. Published in 2008, it contains specific guidelines for virtually every aspect of care and treatment.  
[http://www.caalz.org/PDF\\_files/Guideline-FullReport-CA.pdf](http://www.caalz.org/PDF_files/Guideline-FullReport-CA.pdf)
- ***Practice parameter: management of dementia (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology.*** According to the guideline developer, this guideline has been reviewed and is still considered to be current as of October 2003. This review involved new literature searches of electronic databases followed by expert committee review of new evidence that has emerged since the original publication date. This review identified over 2500 studies, 380 of which met the criteria for inclusion in the meta-analysis. Practices then were rated: Standard (highest evidence of benefit), Guideline (moderate level of documented benefit) and Practice Option (where there was significant uncertainty of benefit).

[http://www.guideline.gov/summary/summary.aspx?ss=15&doc\\_id=2818&nbr=2044](http://www.guideline.gov/summary/summary.aspx?ss=15&doc_id=2818&nbr=2044)

- ***Guideline 86: Management of Patients with Dementia: A National Clinical Guideline, Scottish Intercollegiate Guidelines Network, National Health Service, Feb. 2006.***

Guideline 86 is a national clinical guideline from Scotland with evidence-based recommendations for diagnosis, pharmacological and non-pharmacological treatments, and services for patients and caregivers.

<http://www.sign.ac.uk/guidelines/published/support/guideline86/index.html>

- ***Improving Services and Support for People with Dementia, National Audit Office, July 2007***

This document is a very current and exhaustive summary of the literature relating to services and supports for caregivers of individuals with cognitive impairments.

[http://www.nao.org.uk/publications/0607/support\\_for\\_people\\_with\\_dement.aspx](http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx)

- ***The National Evaluation of the Aged Care Innovative Pool Dementia Pilot: Final Report., Australian Institute of Health and Welfare, 2006.***

This document is a nearly 500-page review of the Australian system's national demonstration project. The document includes both literature citations, reviews of randomized clinical trials, and evaluations of outcomes on four short-term case management-caregiver education demonstrations and four long-term case management models.

<http://www.aihw.gov.au/publications/index.cfm/title/10288/>

Following are some questions that could be considered by the Guidelines and Standards Workgroup in assembling a set of guidelines related to dementia care:

What are the parameters of excellence in dementia care?

- Do they include an assessment of the person with dementia and the caregiver that is person-centered and not diagnoses-centered?
- Do they focus on assessment, care and treatment, and patient and family education and support?
- Do they include humane ways to intervene when adverse behaviors arise from group living experiences?
- Do they include state of the art pharmaceuticals and good medical model of care?
- Do they include staff ratios of three residents to one staff for all shifts, with consistent assignment of caregiver staff?
- Do they include physical plant, landscaping and architectural inputs?
- Do they include guidelines related to minimal chemical restraints?
- Do they include a schedule of follow-up by medical providers for chronic care issues that arise in co-morbid complex care?
- Do they include advanced discussion of feeding and hydration issues, with adequate stand-by assist for eating?

These and many other questions will be posed and answered in the process of assembling a set of guidelines. Likely, the process will be ongoing with a set of core guidelines established initially and others being added over time.

## **Appendix IX: Managed Chronic Care Demonstration Project Requirements**

A managed chronic care demonstration project in San Francisco would need to be based on a combination of federal Medicaid waivers such as: (1) a 1915(c) Home & Community-Based Services Waiver; and (2) a 1115 Demonstration Waiver. Both of these federal waivers would provide access to Medicaid (Medi-Cal in California) funds for covered home and community-based services because they waive the normal Medicaid requirements that focus more on covering the costs of institutional care. The cost of this managed chronic care program would have to be equal to or less than the cost of services provided without the waivers.

The combination of an 1115 Demonstration Waiver with an expanded version of the 1915(c) Home and Community-Based Services Waiver can:

- Expand the array of funded community-based services beyond what MSSP now offers;
- Enhance flexibility in use of existing services, e.g., share IHSS workers in cluster housing arrangements;
- Create new funding mechanisms, like capitation and block grants, to allow use of current nursing home;
- Provide funds to support some of these community services; and
- Operate a system alternative on a community-wide basis without restrictions on enrollment caps.

Initially, San Francisco could target people coming out of Laguna Honda Hospital (LHH) and people being diverted from nursing home placement. The intent would be to take 90% of what Medicaid paid for nursing home care at LHH and use that to cover the cost of community-based care.

Many details would have to be addressed in defining precisely the target population, eligibility criteria, and services covered. For example, should the demonstration project assume responsibility for nursing home care? If not, what process would be needed to allow individuals to dis-enroll once a need for nursing home care or hospital care arose? The Oversight Committee will need to convene a workgroup to investigate the feasibility of this recommendation and, if feasible, develop a proposal that addresses these and other issues.



## Appendix X: Key Informant Interviews

As part of an investigation into current approaches to Alzheimer's and dementia-related services in San Francisco, the research team conducted a series of key informant interviews with recognized local experts, service providers, caregivers, and administrators. The objectives were to: 1) improve our understanding of the demographic context of the current demand for the full spectrum of services and supports needed for all stages of cognitive impairment; 2) appreciate how effectively the current array of services is meeting the existing demand; and 3) shed light on the current state of family and informal caregiver support. Interviews were designed to supplement input from the Expert Panel and subcommittee meetings on current network capacities, practices, strengths and challenges. In conjunction with a variety of other quantitative and qualitative data sources, the key informant interviews provide context and rationale for the Expert Panel's recommendations.

The research team conducted a total of 42 interviews. Eighteen (18) interviews focused on family and informal care giving, 22 interviews focused on the components of a network of care, and two interviews, with Catherine Dodd, Former Deputy Chief of Staff of the Mayor's Office, and Mitch Katz, M.D., Director of Health, Department of Public Health, focused on administration and oversight. Interviewees were selected in an effort to garner representation from the widest range of service components and institutions, including governmental, for-profit and not-for-profit, large and small. In light of the Expert Panel's interest in responding to the needs of caregivers, nearly half the interviews specifically focused on this group of stakeholders.

Each interviewee responded to a series of standardized questions. The first set of questions asked respondents to describe the services provided by their agency, organization or department; service delivery methods and best practice models; target populations; and capacities to meet current demand for services. The second set of questions asked respondents to broaden their perspectives and describe other agencies/organizations providing similar services within San Francisco; how well they communicated and shared resources; and the strengths and challenges of the current service delivery network. The final set of questions asked respondents to consider the full spectrum of services and supports offered to persons with Alzheimer's and related dementias and their caregivers within San Francisco, and how successfully they collaborate, communicate and share resources and best practices. Respondents were asked how easy or difficult it is for individuals and caregivers to understand and access the full array of available services and supports

The themes, strengths and weaknesses summarized below reflect: (1) the key-informant interviews; (2) the notes taken at all Expert Panel and Subcommittee meetings ; (3) topics focused upon in research, data, local, and national and international reports; and most importantly, (4) the extensive knowledge and experience of the Panel members themselves.

## Key Informants

**Jason Adamek**, Integrated Intake Unit Manager, DAAS  
**Adam Boxer, MD, PhD**, Alzheimer's Disease Researcher & Assistant Professor of Neurology, UCSF Memory & Aging Center  
**Cynthia Davis**, Former Executive Director, North and South of Market Adult Day Health  
**Catherine Dodd, PhD, RN**, Former Deputy Chief of Staff, Mayor's Office  
**Elizabeth Edgerly, PhD**, Chief Program Officer, Alzheimer's Association  
**Robert Edmondson**, Executive Director/CEO, On Lok  
**Linda Fodrini-Johnson**, Executive Director and Founder, Eldercare Services  
**Janet Gillen**, Director of Social Services, Laguna Honda Hospital  
**Jerome Goldstein, MD**, Director, San Francisco Alzheimer's and Dementia Clinic  
**Anne Hughes, RN**, Laguna Honda Hospital  
**Gay Kaplan, RN**, Director of Services, Curry Senior Center  
**Mitch Katz, MD**, Director of Health, Department of Public Health  
**Susan Koster**, Executive Director, Rhoda Goldman Plaza  
**Kate Lacey**, Intake Coordinator, Institute on Aging  
**Jay Luxenberg, MD**, Medical Director, Jewish Home, San Francisco  
**Tracy McCloud**, Program Director, Adult Day Health Services, Institute on Aging  
**Bruce Miller, MD**, Director, UCSF Memory & Aging Center  
**Benson Nadell**, San Francisco Ombudsman Program  
**Bob Newcomer, PhD**, Independent Researcher, UCSF Institute for Health & Aging  
**Cindy Rasmussen**, Adult Protective Services Supervisor, DAAS  
**Tessa ten Tusscher, PhD**, Vice President of Clinical Services, Institute on Aging

## Caregiver Interviews (professionals and family members)

**Margaret Baran**, Executive Director, In-Home Supportive Services Consortium  
**Cindy Barton, RN**, VA Medical Center and UCSF Memory & Aging Center  
**Patty Clement**, Program Director, Catholic Charities CYO  
**Laurel Etheridge**, Director of Services, Eldercare Services  
**Karen Garrison**, Senior Services Director, Bernal Heights Neighborhood Center  
**Janet Gillen**, Director of Social Services, Laguna Honda Hospital  
**Heather Gray**, Alzheimer's Association  
**Willard Harris, RN**, Caregiver  
**Mary Hulme**, Veteran Affairs Medical Center  
**Eileen Kunz**, Director of Policy and Government Relations, On Lok  
**Judy Lynch, RN**, Director, Seniors-At-Home  
**Sherrie Matza**, Alzheimer's Association  
**Timothy Patriarca**, Executive Director, Maitri Compassionate Care  
**Donna Schempp**, Program Director, Family Caregiver Alliance  
**Kim Schoen**, Central City Older Adults  
**John Timbs**, Alzheimer's Association  
**Betty Williams**, Executive Director, Network for Elders  
**Nelu Zia**, San Francisco Adult Day Services Network

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## Challenges in San Francisco: Caregiver Issues



## Informal Care The Backbone for Dementia Care

Informal care is uncompensated care for individuals with dementia.



# Informal Care

## The Backbone for Dementia Care

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- Informal care is provided by immediate and extended “family” members or other loved ones.
- “Family” includes domestic partners, extended family and informal family structures, including neighbors and caring friends.
- 75% of caregivers are women.



## Informal Caregivers

### Caregiver Concerns

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- Responsibilities change as the condition advances.
- Caregivers report that the first stages are the most demanding.
- The lack of information and understanding of the future creates tremendous uncertainty.



## What do caregivers do? Early-Stage

- Obtain information about dementia and how it progresses;
- Obtain information about resources, insurance coverage, legal issues;
- Navigate access to services;
- Begin long-term planning;
- Provide emotional support; and
- Support daily living needs.

## What do caregivers do? Mid-Stage

- Increase the level of in-home support;
- Seek formal in-home support;
- Seek respite and adult day program options;
- Arrange and manage other care, including primary and specialty care for other medical conditions;
- Manage increasingly difficult behavioral symptoms; and
- Plan for assisted living care.



## What do caregivers do? Late-Stage

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Often individuals remain in the community requiring virtually round-the-clock support, or once this is no longer possible, caregivers:

- ❑ Support the individual in assisted living, nursing home or hospital setting;
- Negotiate with health care staff about services, treatments and interventions;
- Ensure adherence to advance directives; and
- Manage end-of-life care and/or facilitate access to hospice.

## Informal Caregiving

### What would it cost if we paid for informal care?

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Research conducted by Patrick Fox and Brooke Hollings from UCSF indicate that if informal care were paid for at prevailing wage rates it would cost:

- \$63,000 per year while an individual is living in the community with mild-moderate impairment; and
- \$71,500 per year while an individual is living in the community with severe impairment.
- For 2008, for the estimated 20,000 San Franciscans living in the community with dementia, **this amounts to \$1.2 billion in uncompensated care.**

# Informal Caregiving

## How does providing care impact the caregiver?

Research indicates that fiscal costs are not the only caregiver burden:

- Caregivers are at extreme risk of developing cardiovascular disease, depression, stress and anxiety;
- It is estimated that for every year of caregiving, caregiver life expectancy is reduced by one year; and
- As a result, often caregivers do not outlive their loved ones with dementia.



# Informal Caregiving

## What Caregivers Say

During interviews caregivers said:

- *“There is so much information—it is confusing. When agencies work together there is a real benefit to us.”*
- *“We face so many decisions like, ‘Should we buy this vitamin?’ I worry about things being overstated in the brain fitness area. But who do I ask?”*

## Informal Caregiving

### What Caregivers Say

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During interviews caregivers said:

- *“Respite helped me have moments for myself. It also helped me get used to someone else caring for my husband.”*
- *“I broke my back for my dad and then when I had to put him in nursing care, I felt like I’d failed him.”*

## Informal Caregiving

### The Importance of Support

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Research indicates that you can reduce caregiver stress and co-morbidity and improve outcomes for the individual with dementia if you promptly deliver:

- Comprehensive caregiver assessment,
- Education and information; and
- Coordinated, easy access to community services and caregiver support.



## Informal Caregiving The Importance of Support

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Social support for caregivers has been linked to greater well-being and lower risk for depression for both caregivers and individuals with dementia.

Atienza, A. A., Collins, R., & King, A. C. (2001).

## Informal Caregiving The Importance of Support

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Seamless services and facilitated access to critical services is essential for both people with dementia and their caregivers.

Callahan, C.M, MD et al, JAMA. May 2006; 295:2148-2157.

## Informal Caregiving

### The importance of Support

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Counseling, support group participation and access to phone support may preserve caregiver health and delay institutionalization.

Report from a National Consensus Development Conference (Vol.1). San Francisco: Author.Mittelman, M. S., Haley, W. E., Clay, O. J., & Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*, 67, 1592-1599.

## Informal Caregiving

### What Resources are Available?

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A range of caregiver assessment, education, referral and support services is available for caregivers.

It is unfortunate that referral to these resources is not an automatic 'next step' when a person is diagnosed with dementia.

***A list of specific resources is included in handouts provided by the Family Caregiver Alliance.***

## Informal Caregiving

### What happens when there is no caregiver?

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In the absence of an involved caregiver:

- Individuals with dementia must access paid in-home support; or
- Must enter assisted living, nursing home or hospital placement prematurely.
- Since there is no public funding for assisted living, this inevitably means placement in nursing homes or hospitals for moderate to low-income individuals

## Informal Caregiving

### What happens when there is no caregiver?

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San Francisco has a growing number of individuals with no loved one nearby:

- An estimated 40% of older adults in San Francisco have no relative within a 20 minute drive of San Francisco.
- In the absence of a system to provide in-home support, these individuals face the prospect of being institutionalized prematurely.

# Informal Caregiving

## What happens when there is no caregiver?

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Models for volunteer and peer-based support exist, however:

- None have been developed explicitly to address the needs of individuals with dementia.
- Models for other populations would require significant modifications and while worth exploring may be impractical given the extensive needs for support even in early stages.

# Informal Caregiving

## What happens when there is no caregiver?

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Public costs increase significantly when an individual is placed in assisted living or institutional care:

- Assisted living expenses are **twice** the formal care costs incurred when an individual lives in the community.
- Hospital and nursing home care costs **five times** as much as all formal care when an individual lives in the community.

## Informal Caregiving

### What happens when there is no caregiver?

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The Finance Subcommittee of San Francisco's Expert Panel for Dementia Care estimated that:

- If each of the San Franciscans with dementia were to delay being institutionalized by just one month, care costs would be reduced by \$6 million.

## Informal Caregiving

### What happens when caregivers are supported?

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A Finnish study found that those enrolled in a program of systematic comprehensive support by a nurse or dementia family care coordinator remained living in the community over 250 days longer than the control group.

- Eloniemi-Sulkava U, Notkola IL, Hentinen M, Kivela SL, Sivenius J, Sulkava R. Effects of supporting community-living demented patients and their caregivers: a randomized trial [comment]. *J Am Geriatr Soc.* 2001;49(10):1282-7.

## Informal Caregiving

### What happens when caregivers are supported?

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In another study, when caregivers received “comprehensive caregiver support,” 65% of individuals with dementia were living at home after 30 months compared to 26% in the control group.

- Brodaty H, Gresham M, Luscombe G. The Prince Henry Hospital dementia caregivers training programme. *Int J Geriatr Psychiatry* 1997;12(2):183-92.

## Informal Caregiving

### What happens when there is no caregiver?

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While there are good reasons for placing an individual in assisted living or institutional care, these placements should be delayed until behaviors or medical conditions require it.

## Informal Caregiving

### What must we do?

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San Francisco faces a significant challenge:

- Develop a capacity to deliver timely, comprehensive caregiver support; **and**
- Develop easier access to services and supports; **and**
- Develop approaches that provide in-home support to individuals without informal caregivers; **OR**

## Informal Caregiving

### What must we do?

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**Face an increasing and expanding crisis in dementia care.**

# Informal Caregiving

## What must we do?

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Fortunately, we know what needs to be done.

- Caregivers have told us what they need.
- Research has provided models; and

The ***Strategy for Excellence in Dementia Care*** provides a roadmap to get it done.



## Appendix XIII:

### Comments from external review team consisting of: (1) Andrew Scharlach, PhD, School of Social Welfare, UC Berkeley; and (2) Kristine Yaffe, MD, Chief of Geriatric Psychiatry and Director of the Memory Disorders Clinic at the San Francisco VA Medical Center

Overall, this is an excellent report, and all those who have contributed to it are to be congratulated for their work. The report is comprehensive, well-documented, and surprisingly detailed given the time frame and diverse constituencies involved. The case is made very well in this report for the unmet and growing needs of those with dementia and caregivers of those with dementia in San Francisco. The vision for integrated care is quite compelling.

As the report notes, San Francisco is especially vulnerable to the effects of dementia, in part because of its comparatively old population and its large number of single-person households. A community-wide effort comparable to the City's response to the AIDS epidemic is indeed justified.

#### Following are additional thoughts to consider during the implementation of this report:

1. As noted, dementia includes a wide range of conditions and symptoms. While some attention is given to the stages of dementia, more could be said about the types of supports needed at each stage and by individuals suffering from non-Alzheimer's related dementia. Especially important is differentiating between cognitive impairments and behavioral disturbances. Such disturbances are considerably more problematic, but also more responsive to a variety of interventions.
2. More attention could be given to the possibilities of enhancing functioning and quality of life, rather than just maintaining safety. There are a wide variety of evidence-based interventions that can preserve or even enhance cognitive functioning and/or reduce behavioral disturbances, so as reduce excess disability. Just one simple example: MaeLynn's problem (presented as part of the human face of dementia) forgetting to turn off the stove could easily be solved with an automatic shut-off valve. Environmental accommodations such as this are an inexpensive yet overlooked solution to a number of common problems.
3. Goals might include maximizing quality of life for afflicted people and loved ones, preserving personal autonomy to the extent possible, reducing barriers to active community participation, maximizing continued contributions to the lives of families and communities, etc.
4. Greater reference could be provided in relation to cultural variations regarding the meaning of the disease, family roles, access to services, community-based supports, etc. Supporting existing cultural strengths is an economical way to reach underserved individuals.
5. Mention is made of public educational and some other service provider aids. Given the explosion of information and communication technologies, more of this information could be put in the hands of individuals and their families, thereby lessening the burden on professionals.
6. The point of diagnosis is an important time of intervention, and more care coordination and information dissemination could occur at that point. Referrals to other organizations is a start, but even better would be health care-based multidisciplinary care teams (e.g., nursing, social work, OT, family support, social networks) that are activated seamlessly.

7. Beds could be reserved at Laguna Honda Hospital for short-stay residential care, a huge asset for families. Something like 50% of NH admissions in Australia are for short-stay respite and assessment.
8. Skilled nursing facilities are poorly equipped for residents who have cognitive impairment but relatively little physical impairment. Residential Care Facilities for the Elderly and Green House models make a lot more sense and are more economical.
9. How about a city-wide number to call for information or advice about dementia?
10. While the recommendations and associated action plan involve a wide range of potential partners, the emphasis is primarily on the provision of services. Especially in light of state and local budget constraints and associated program limitations, it would seem advisable to consider more carefully how to use limited public resources to support and enhance voluntary and communal support structures that may already be in place at the local level (e.g., churches, community centers, cultural groups). The most obvious example would be the development of neighborhood-based support structures that enhance and focus existing social capital; while San Francisco Village is a notable example, many San Francisco neighborhoods and communal organizations have a lengthy history of social support.
11. The private sector receives little mention other than health care providers, yet a comprehensive solution must reflect its interests and involvement as well. Employer health care and leave policies, for example, have a substantial impact on caregiving family members. Even more fundamentally, "dementia-friendly" companies would be good places for people with dementia to work and to do business.
12. One might well imagine a "dementia-friendly" community, where individuals with dementia are not unnecessarily discriminated against. Following the example of Americans with Disabilities Act (ADA) curb cuts, the focus would be on modifying the built environment to provide cognitive accommodations as well as physical accommodations, so that individuals who are "cognitively challenged" can function as fully as possible. We need to begin to see ourselves as "temporarily mentally fit," and embrace our commonality with those who are less mentally fit at any given time. Only then will we be willing (as individuals and as a community) to invest in the changes that are truly needed, many of which are identified in this excellent report.
13. A concern: this is an enormous undertaking. How this will plan really get implemented? This will require an extremely well orchestrated effort over an extended period of years.
14. Finally, long term care service providers should already be "dementia capable". While we know that this is variable, the recommendation begs the question, why aren't they already dementia capable if 50% of their population has cognitive impairment? In other words, if they have not become so yet, why not - and how do you accomplish this from this point forward?



