Case Statement

BakerRipley is advocating for better support of people living alone with dementia through strengthened community understanding of dementia, improved response from service providers, adoption of dementia capable policies, and funding to implement best practices in dementia care. Dementia Specific Case Management (DSCM) is a flexible solution for the complex challenges associated with living alone with Alzheimer’s disease and other related dementias. Using interventions focused on getting a diagnosis, medication management, establishing support systems, and getting access to services, clients are able to remain independent longer in a safer, more supportive environment. With the number of individuals with dementia rapidly growing and the cost of care increasing exponentially, solutions like DSCM that can improve quality of life for the individual while reducing costs are desperately needed.

What is Alzheimer’s Disease?

Alzheimer’s disease and other related dementias slowly affect an individual’s memory, judgment, reasoning, complex thinking and eventually his or her independence.

Level of Care Required

Those with dementia slowly lose their independence and require increasing levels of care to safely manage their lives, including support with:

- Activities of Daily Living (ADLs): eating, bathing, getting dressed, toileting, transferring and continence.
- Instrumental Activities of Daily Living (IADLs): Preparing meals, managing money, shopping, housework, laundry, and using a telephone.

Biggest Concerns

- There is no viable prevention or cure
- Many go undiagnosed and unreported
- Increasing numbers (Baby Boomers)
- The increasing costs to both individuals and the healthcare system

The Economic Impact of Dementia

“Total annual payments for healthcare, long-term care and hospice care for people with Alzheimer’s or other dementias are projected to increase from $277 billion in 2018 to more than $1.1 trillion in 2050 (in 2018 dollars). This dramatic rise includes more than four-fold increases both in government spending under Medicare and Medicaid and in out-of-pocket spending.” – Alzheimer’s Association

<table>
<thead>
<tr>
<th>Individuals without Alzheimer’s or other dementias</th>
<th>Individuals with Alzheimer’s or other dementias</th>
<th>% increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid</td>
<td>$358</td>
<td>$8,399</td>
</tr>
<tr>
<td>Inpatient Hospital</td>
<td>$3,509</td>
<td>$10,862</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>$749</td>
<td>$15,462</td>
</tr>
<tr>
<td>Skills Nursing Facility</td>
<td>$462</td>
<td>$6,750</td>
</tr>
<tr>
<td>Hospice</td>
<td>$153</td>
<td>$2,017</td>
</tr>
<tr>
<td>Home Health Care</td>
<td>$367</td>
<td>$2,525</td>
</tr>
<tr>
<td>Medicare</td>
<td>$7,415</td>
<td>$24,122</td>
</tr>
<tr>
<td>Medical Provider</td>
<td>$3,569</td>
<td>$5,792</td>
</tr>
<tr>
<td>Prescription Medications</td>
<td>$2,947</td>
<td>$3,436</td>
</tr>
</tbody>
</table>

Average Annual Per-Person Payments for Health Care & Long-Term Care Services Provided to Medicare Beneficiaries Age 65 or Older, with and without Alzheimer’s or Other Dementias, in 2017 Dollars

Total Lifetime Cost of Care $341,840 per person with dementia

83% of care comes from family, friends, and other unpaid caregivers.

18.4 billion hours of unpaid care across the country.

232 billion estimated in unpaid care across the country.
Like most older adults, people with dementia want to remain independent and prefer to live in their home, even if it means living alone. However, symptoms of dementia make it more challenging to live alone. As described by the Administration on Community Living, an individual living alone with dementia is at increased risk for a variety of health and safety concerns. Self-neglect is the Adult Protective Services’ highest reported and substantiated category of abuse and financial exploitation is also especially common in this population. Due to the common symptoms of impaired judgment, visual perception issues, and disorientation, the risk of falls doubles and the risk of death from accidental injuries increases when living alone with dementia as compared to living with someone. The common social isolation experienced by these individuals can also contribute to these and other negative health outcomes. For example, if an emergency arises, the individual may not know how to address it or may be unable to seek help, causing a delay in emergency response that may complicate treatment and increase associated costs.

Aging and health service providers are often regarded as the safety net for these individuals. Houston has a large network of aging services older adults can use to live independently and safely; however, some of these services are unaffordable or inaccessible for many individuals living alone with dementia because of financial or physical limitations. Additionally, these individuals have increased challenges accessing services because service providers’ policies often lack flexibility and their procedures are too complex for individuals with dementia to navigate. People with dementia have challenges with executive function, reasoning and judgment; therefore if the individual has no family or friends to assist them, they are frequently unable to access these services. Accordingly, the Houston community must provide comprehensive care coordination to and advocacy for individuals with dementia to ensure their safety and well-being.

“"The world of medical and social services is not dementia capable or equipped to respond to the needs of people with dementia. Even those entities charged with helping our society's most vulnerable population expect the service recipient to be capable of navigating complicated phone menus, complete lengthy applications, and follow through with instructions and proper procedures. Without someone to assist every step of the way, including being the contact person, persons with dementia slip through the cracks. It is important for service providers to consider 'exceptions to the rule' when the applicant or patient is a person with dementia.””

-Annemieke Pike-Luckey, Dementia Case Manager

1Physical limitations may include but are not limited to, residing outside of the defined service area, limited transportation options, or inability to initiate services because of medical conditions.
There is Hope...

The challenges of living alone with dementia are real, but there are initiatives focused on improving the lives of these individuals, including the **Houston Alliance to Address Dementia** project and the development of the BakerRipley Dementia Specific Case Management program.

**What is the Houston Alliance to Address Dementia?**

The Houston Alliance to Address Dementia project began in 2014 to respond to the increasing needs of families affected by dementia in the Houston area. Funded through the Administration on Community Living, this demonstration project **aimed to address the dementia-related knowledge and service gaps** within Houston's aging and community service networks and **provide better, more responsive services** for those living with dementia and their families. The Houston Alliance to Address Dementia project investigated how Houston responds to individuals with dementia and their families and developed the foundation for further exploration to improve our response to this population.

**Houston Alliance to Address Dementia**

---

**Who was involved?**

The Houston Alliance to Address Dementia **recruited over 27 partners** to better serve individuals affected by dementia and provided them with:

- Basic knowledge about dementia and available resources;
- Tools to assist identification of individuals with or at risk of developing dementia and their caregivers; and
- Tools to refer them to dementia-specific services

Once individuals were identified, partners could refer them to a series of evidence-based and evidence-informed dementia specific and caregiver support programs. Individuals with dementia and caregivers were connected to a variety of services, including the evidence-based Benjamin Rose Institute Care Consultation program, evidence-based caregiver self-care classes, online and in-person support and education groups and Dementia Specific Case Management for individuals with or at risk of dementia living alone.
Houston Alliance to Address Dementia Results

The project increased community knowledge of dementia and awareness about related resources and laid the groundwork for additional community level change. The project also prompted further conversation and exploration around the concept of “comprehensive care coordination” in better serving the needs of individuals living alone with dementia. This care coordination, demonstrated through Dementia Specific Case Management, can address client needs, allowing individuals with dementia living alone to remain independent longer in a safer, more supportive environment.

890 professionals from 27 agencies received training to increase organizational capacity to address the needs of individuals with or at risk of dementia and their caregivers. Partner agencies referred 752 individuals to dementia-specific community organizations.

1,046 caregivers received care consultation and education programs.

77 individuals who live alone with or at risk of dementia served through 2,672 hours of Dementia Specific Case Management. This intervention successfully addressed more than 75% of client's needs.

What is Dementia Specific Case Management?

Care coordination and active disease management have proven effective in reducing unmet needs of individuals with dementia. However, for individuals living alone with dementia, additional advocacy is needed to assist the individual in navigating the various systems of care. BakerRipley’s Dementia Specific Case Management (DSCM) program combines care coordination, active management, and advocacy in a flexible framework to better address the needs of individuals living alone with dementia. The goal of the DSCM model is to provide person-centered care through community-based solutions while addressing key safety and wellness concerns. By implementing community-based interventions, there are greater opportunities to personalize care to meet an individual’s needs or preferences while creating safe and supportive environments that also maximize independence. Our DSCM model addresses common case management goals, but more importantly focuses on addressing four primary areas that specifically affect the safety and independence of individuals living alone with dementia:

Active Management

Active Management of Alzheimer’s has a positive impact on the quality of life of the individual. Active management means

- Appropriate use of available treatment options.
- Effective management of coexisting conditions.
- Coordination of care among physicians, other health care professionals and lay caregivers.
- Participation in activities that are meaningful and bring purpose to one’s life.
- Having opportunities to connect with others living with dementia; support groups and supportive services are examples of such opportunities.
- Becoming educated about the disease.
- Planning for the future.

Alzheimer’s Association 2018 Facts and Figures

- Accurate diagnosis, allowing access to the appropriate treatments;
- Medication management plans that ensure regimens are adhered to;
- Support system identification and engagement; and
- Development of future plans when remaining independent may not be possible.
This model uses a multimodal assessment to evaluate cognition and executive function as well as basic health and safety through a holistic assessment process. In conjunction with the individual, a team of social workers and case aides develops a care plan to respond to needs identified in the assessment. To ensure developed plans are initiated, services are accessed, safety is maintained, and needs are addressed, the DSCM team provides ongoing monitoring and advocacy.

Each individual served through the DSCM program has a unique set of needs; some only have one or two needs, others have as many as 20 needs that require intervention. However, the most commonly presented needs are related to personal safety, physical health, medication management, and planning for the future. The DSCM team uses a variety of methods to address these needs, from the installation of home safety equipment to recruiting family members and friends to provide additional care and support. The goal is to implement interventions that allow the individual to maintain as much independence as safely possible. For example, if a client has been identified as needing additional support developing future plans and managing daily tasks, we aim to find family or friends that can provide assistance before pursuing legal actions, such as court-appointed guardianship. Through these and similar interventions, the DSCM team is able to meet the majority of the needs of the individuals they serve.

Common Dementia Specific Case Management Interventions

- Arranging and providing transportation to diagnostic testing and other medical appointments
- Initiating in-home health and assistive services, such as personal attendant services.
- Setting up safety measures, such as enrollment in MedicAlert SafeReturn.
- Purchasing and setting up automatic medication aids
- Assisting with the creation of advanced directives and future plans, such as Power of Attorney documents.

This intensive intervention and monitoring can require service delivery lasting as long as 2.5 years. Additionally, the DSCM team spends an average of 35 hours per client per year. This is 4 times greater than the time spent with general geriatric case management clients, approximately 5 to 8 hours per client.

Financial Impact

Despite the time intensity of this intervention, the DSCM model has the potential for future cost savings. Participants in similar community based interventions, such as MIND At Home, have shown significant delays in nursing home placement compared to control groups. Although further study is needed, the Baker Ripley DSCM intervention has similar potential to delay nursing home placement, possibly saving individuals and the healthcare system approximately $50,000 to $80,000 per year. This model also has the potential to positively influence other major health care cost drivers, such as medication non-adherence, emergency room visits, and hospitalizations. However, additional funding for the DSCM program is needed to support additional evaluation of such financial outcomes and cost savings.

---


2 2017 Annual Cost of Nursing Home Care in Greater Houston Area: $58,984 (Semi Private) and $86,688 (Private). https://www.berwalt.com/aging-and-you/finances/cost-of-care.html; Average annual cost of DSCM Intervention is $4,000.
What Do We Know Now?

The Houston Alliance to Address Dementia project and the development of the Dementia Specific Case Management (DSCM) model provided key learnings that can influence how Houston and our region can better respond to individuals with dementia.

Individuals living alone with dementia need personal support and advocacy from trained experts.

A primary component of the dementia specific case management intervention is navigating the complex network and intake of aging and health services. This care coordination not only involves communication and collaboration with other agencies, it also requires client advocacy from professionals who understand the challenges of living with dementia and understand the complex network of services.

“We tried to secure personal assistance services for a client; however, this client was contacted without our presence and denied a need for services. The agency then removed her from the list and prohibited her from accessing any agency services in the future based on this denial. We advocated with a variety of agency employees over many weeks to reinstate her eligibility.” – Dementia Specific Case Manager

Organizational policies need to be more flexible to accommodate dementia-related needs.

Restrictions in policy often inhibit the ability to protect the best interest of individuals living alone with dementia. We recognize policies are in place to ensure appropriate service utilization, improve efficiencies, and to prevent fraud and waste. However, they often present barriers to service access and do not account for the flexibility required to address dementia-related issues. Legislation and policy development and implementation, especially for programs designed to serve older adults, must include provisions for dementia populations to ensure swifter access to services.

“We identified a client as being unsafe to live at home alone because their inability to manage their activities of daily living caused major health risks. When we tried to initiate emergency services, we received feedback that the individual needed to be within a "few days of death" for the agency to move her to a safer environment.”

– Dementia Specific Case Aid

Coordinated efforts across organizations and health systems are necessary to serve individuals with dementia.

Common practice for service coordination includes a hand-off of cases from one agency to another instead of collaborative intervention between them. This often presents challenges when serving an individual with dementia as they may not be able to communicate what services have already been established or they may struggle with developing a relationship with a new service provider. As discovered through the DSCM program, an effective way to serve this population is through continued service provision, even when another agency begins services. This means that community based organizations and other service providers must engage in conversations about our roles in serving this population and legislation and policies must support this collaboration.

“We initiated guardianship for a client who was no longer able to safely live alone. The standard operating procedures for the process were never communicated with us or the client. We were left out of communication with the client and she was left unprepared for the next steps. Accordingly, we engaged in conversation with the guardianship program to better coordinate care for future clients.” – Dementia Care Program Manager
Where Do We Go from Here?

Though the Houston Alliance to Address Dementia project and BakerRipley’s Dementia Specific Case Management program positively influenced how individuals living alone with dementia are supported, Houston must develop a stronger response to this growing population. BakerRipley has over 30 years of dementia experience and continually advocates for better care and support by sharing our knowledge and practices with other organizations and key regional leadership. We strongly believe that partnership is the key to serving families affected by dementia and have helped nearly 30 agencies and organizations become more dementia capable. With additional support of programs like the BakerRipley Dementia Specific Case Management program, we have the opportunity to improve the quality of life of individuals living alone with dementia while potentially reducing costs in our healthcare system.

Living with dementia is hard; living alone with dementia is nearly impossible.

Join us to make a difference.
713.685.6577
dementia@bakerripley.org

BakerRipley exists to keep Greater Houston a welcoming place of opportunity where everyone can earn, learn, belong and be well. BakerRipley’s Senior Services promote the dignity and independence of older adults through service and advocacy and support for caregivers. At our dementia-specific adult day center, senior centers, and in the homes of seniors, we provide holistic programs and services that impact health, wellness, engagement and connection, helping older adults to remain physically active, maintain a sense of purpose, engage in meaningful relationships with others, and contribute and give back to help others and the community.

Katie Scott, MPH, is the Sr. Director of Dementia and Caregiver Services of BakerRipley in Houston, TX and leads regional and statewide initiatives to improve care and support for families affected by dementia.