


THE ECONOMIC BURDEN OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS IN SAN DIEGO COUNTY

APRIL 2018



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THE ECONOMIC BURDEN OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS IN SAN DIEGO COUNTY

County of San Diego
Health and Human Services Agency

Aging & Independence Services
Public Health Services

April 2018

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THE ECONOMIC BURDEN OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS IN SAN DIEGO COUNTY

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Dear San Diego County Residents:

Rising costs of health care affects all of our senior residents, especially those with a diagnosis of Alzheimer's Disease or Related Dementias (ADRD). These individuals are disproportionately affected, with costs of long-term care before and after hospitalization contributing to the financial burden faced by ADRD patients and their families.

The numbers are staggering; more than 84,000 of our own residents now have ADRD. It is the third leading cause of death among San Diego County residents. The average cost of one hospitalization for a person with ADRD is higher than one year in assisted living with specialized dementia care.

Launched by the San Diego County Board of Supervisors in 2014, The Alzheimer's Project is one of the boldest and most innovative initiatives in the nation aimed at addressing ADRD awareness, care, and research leading to a cure. In the years since the project began, the effort has already made progress towards reducing the toll ADRD takes on our residents and their families, but there is still a lot of work to be done. Those 65 years and older are the fastest-growing age group in our region, and many of them will develop dementia, resulting in a significant toll on taxpayers, caregivers, and the healthcare system as a whole.

This report outlines the costs of care, formal and informal, for those in our community who are suffering from this devastating group of diseases. It provides a snapshot of the increasing burden we face, and will help guide our ongoing efforts to reduce the burden of ADRD in our community.

Kristin Gaspar
Chairwoman, 3rd District

Dianne Jacob
Vice-Chairwoman, 2nd District



County of San Diego

NICK MACCHIONE, FACHE
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April 12, 2018

Dear San Diegans:

The County of San Diego Health and Human Services Agency is proud to release the second edition of *Economic Burden of Alzheimer's Disease and Related Dementias in San Diego County*. This group of diseases, their effects, and the care needed for those suffering from them has a significant effect on the local economic burden, but also on the financial burden faced by patients and their families.

The San Diego County Board of Supervisors adopted *Live Well San Diego* in 2010. This regional vision aligns the efforts of government, community partners, and individuals to help all San Diego County residents be healthy, safe, and thriving.

In May 2014, The Alzheimer's Project was adopted by the Board of Supervisors. A partnership between Supervisor Dianne Jacob, San Diego Mayor Kevin Faulconer, philanthropist Darlene Shiley, Sheriff Bill Gore, and Alzheimer's San Diego, along with local research collaboratives, The Alzheimer's Project created a roadmap to addressing Alzheimer's Disease and Related Dementias (ADRD) within our community, and emphasized working together to find a cure.

This report contributes an important component to understanding the monetary cost of ADRD in San Diego County – the financial impact it has on taxpayers, patients, and their families. This report describes the financial cost of ADRD in our community for the lifetime of an individual with ADRD, the average costs should they need to be hospitalized, the value of unpaid care given by informal (family) caregivers, and the costs associated with long-term care.

Currently over 84,000 San Diegans are suffering from ADRD. If nothing changes, that number is expected to increase to 115,000 by 2030. Understanding the cost of this devastating disease to those who suffer from it is an essential part of the County's *Live Well San Diego* vision. This report brings the real dollar amount cost of ADRD to light.

NICK MACCHIONE, FACHE
Agency Director

CHUCK MATTHEWS, PhD., Interim Director
Aging & Independence Services

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FOREWORD

Live Well San Diego is a regional vision adopted by the San Diego County Board of Supervisors in 2010 that aligns the efforts of County government, community partners and individuals to help all San Diego County residents be healthy, safe, and thriving. The vision includes three components. Building Better Health, adopted on July 13, 2010, focuses on improving the health of residents and supporting healthy choices; Living Safely, adopted on October 9, 2012, focuses on protecting residents from crime and abuse, making neighborhoods safe, and supporting resilient communities; and, Thriving, adopted on October 21, 2014, focuses on cultivating opportunities for all people to grow, connect and enjoy the highest quality of life. Live Well San Diego encompasses community engagement on all levels. It starts with individuals and families who are leading efforts to be healthy, safe and thriving and grows through County-community partnerships to convene working groups, conduct program activities, and leverage each other's resources and capabilities to improve the health, safety and overall well-being of residents throughout San Diego County.

In alignment with the Live Well San Diego vision, the San Diego County Board of Supervisors adopted The Alzheimer's Project in 2014. In the years since, progress has been made towards increasing awareness of Alzheimer's Disease and Related Dementias (ADRD), educating clinicians on providing appropriate dementia care, implementing programs to keep our seniors safe, and working collaboratively with our academic and research-oriented partners to find a cure.

This report was created provide an understanding of how many of our residents have been directly affected by ADRD and understanding the financial burden the disease and accompanying complications pose to those patients and their families. It describes the cost of hospitalization for our residents with ADRD, determines the cost of unpaid care given by friends and families of those affected, and describes the cost of long-term care, should it become necessary.

As more members of our community develop dementia, caring for those affected will have a larger impact on our local economy, and also on our healthcare systems. The information within this report can be used to provide a complete picture of the impact that ADRD has on our community.



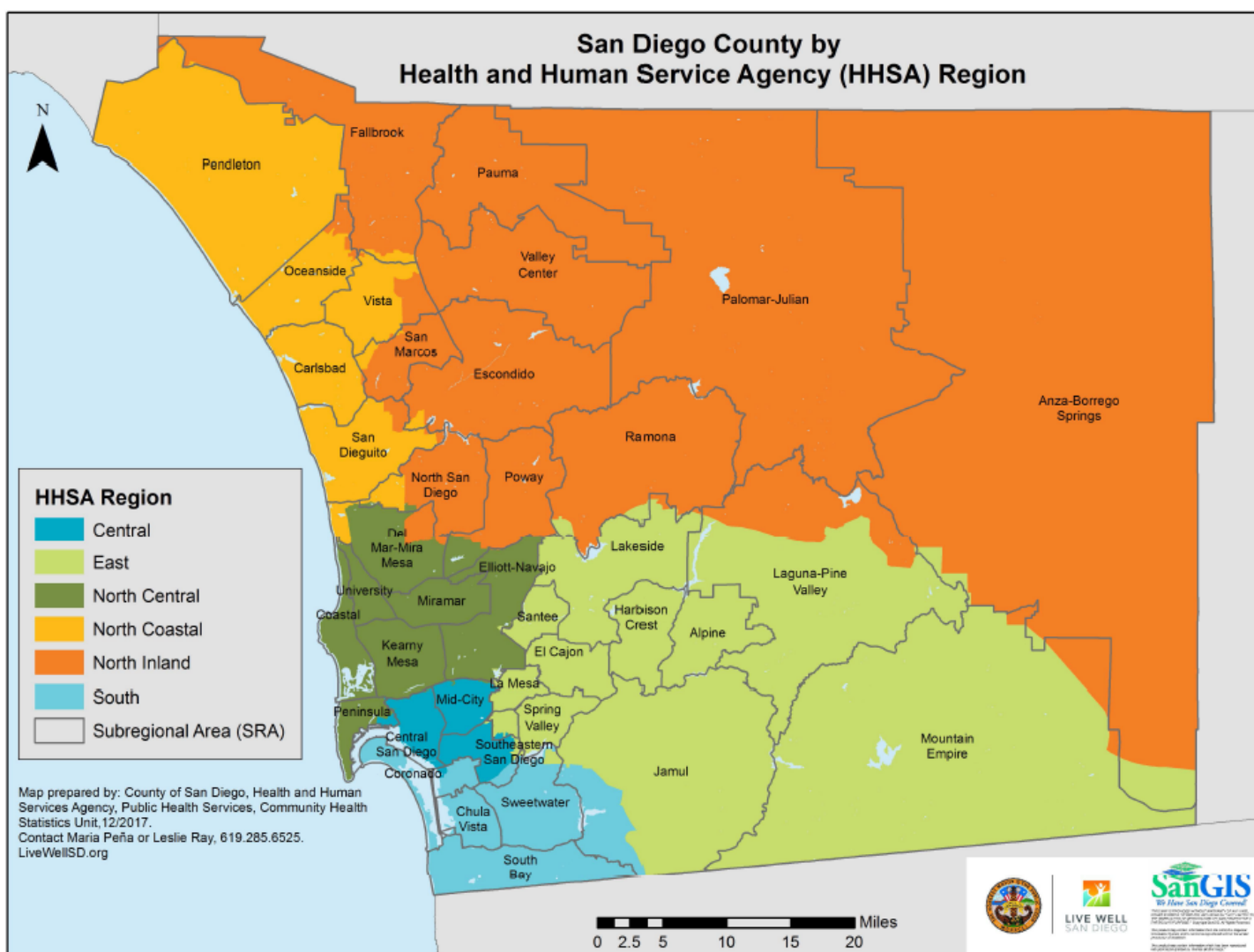
WILMA J WOOTEN, M.D., M.P.H.
Public Health Officer
Director, Public Health Services

EXECUTIVE SUMMARY

ALZHEIMER'S DISEASE AND RELATED DEMENTIAS IN SAN DIEGO COUNTY

Alzheimer's disease was the sixth leading cause of death in the United States and third leading cause of death among San Diego County residents in 2015.¹ An estimated 84,400 San Diego County residents, aged 55 and older, were living with Alzheimer's disease and related dementias (ADRD) this same year. San Diegans can expect to see this number grow by 36.5%, or to over 115,000 residents in 2030.

The County of San Diego Health and Human Services Agency is divided into six different service delivery regions based on geographic boundaries. These regions are Central, East, North Central, North Coastal, North Inland, and South.



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East Region had the largest number of people, 55 and older, with ADRD and is expected to remain the largest, going from 21,901 in 2015 to nearly 28,000 individuals in 2030. However, South Region is projected to be the fastest growing, with a 57.2% increase, surpassing Central Region as the second largest Health and Human Services Agency (HHSA) Region with residents, age 55 and older, living with ADRD.



COMMUNITY COSTS

The costs associated with the care for patients with dementia are staggering and have a sizeable financial burden on society.² Although the annual costs due to dementia vary by year, RAND estimated the average cost to be \$64,750 per year (2015 dollars).³ This estimate included direct and indirect medical costs as well as loss of income and productive services to the market economy. Literature suggests individuals 65 and older with Alzheimer's disease survive, on average, four to ten years after diagnosis or onset.³⁻⁹ When taking into account the midpoint, or a seven-year survival, the estimated community cost of ADRD for San Diego County residents, age 55 and older, was \$38.3 billion dollars in 2015 and will exceed \$52 billion dollars by 2030, assuming current trends continue. Due to its high prevalence of ADRD among residents 55 and older, the East Region faced a \$9.9 billion dollar impact from ADRD which is expected to grow to \$12.6 billion dollars in 2030.

An estimated 84,400 San Diego County residents, aged 55 and older, were living with ADRD. San Diegans can expect to see this number grow by 36.5%, to over 115,000 residents in 2030.

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LIFETIME COSTS

A more recent study in 2017 developed a model to estimate the annual variance in net lifetime cost for an average U.S. dementia patient. The study found that for an average 83-year-old, with a projected five-year survival after diagnosis, the net lifetime cost due to dementia amounted to \$321,780 (2015 dollars). Furthermore, researchers found this exceeded the cost for a non-dementia patient by 57.3%, or \$184,500, with the primary difference being the value of unpaid, or informal, caregiving required for dementia patients. Additionally, average net costs vary by year, with the patient receiving costlier in-home care in the first five-years after diagnosis, followed by care in a long-term care facility as the patient progresses in their illness in years six to ten. Annual net costs peak in year five at \$72,404, with over half coming from the value of unpaid caregiving and nearly one-quarter from out-of-pocket expenditures.³

The study found that for an average 83 year old, with a projected five-year survival after diagnosis, the net lifetime cost due to dementia amounts to \$321,780 (2015 dollars).



LONG-TERM CARE COSTS

Two-thirds of Americans turning age 65 will need long-term services and supports (LTSS), or assistance with activities such as bathing, dressing, incontinence, or assistance with eating, for an average of three years.¹⁰ Two in five individuals who receive this type of care at home will utilize some sort of paid care. In 2017, the annual median costs of care in San Diego County ranged from \$20,540 for adult day care to \$136,875 for nursing home care. Median annual costs for assisted living facilities in San Diego County were \$54,000, with memory care costing, on average, \$1,150 more per month (2016 dollars–national average).¹⁷ By 2035, costs associated with home health care and assisted living are projected to exceed \$90,000.¹¹

The lifetime cost for LTSS is approximately \$138,000, with over half covered by individuals out-of-pocket, and the remaining covered by public coverage or private insurance.¹² However, public coverage like Medicare only covers the initial diagnosis, evaluation and treatment of Alzheimer's disease, and medically necessary nursing home care³⁰ (limited to up to 100 days in a skilled nursing

EXECUTIVE SUMMARY



facility).¹³ Additionally, some ADRD patients may be covered by Medi-Cal, which covers LTSS with chronic disabilities, but requires individuals to meet income qualifications and other eligibility criteria. Private long-term care insurance exists, and typically covers adult day care, hospices, respite care, assisted living facilities, Alzheimer's special care facilities and nursing homes.¹⁴ However, less than 5% of adults in San Diego County purchased long-term care insurance in 2016 and those that did paid \$120 million dollars in premiums.¹⁵

HOSPITALIZATION CHARGES

In 2015, approximately one in seven hospitalizations, or 18,888 hospital discharges, among San Diego County residents 55 years and older, occurred for patients with any mention of ADRD. Over one-quarter of these patients were readmitted to a hospital in 2015 with any mention of ADRD. The total direct charges due to these hospitalizations was approximately \$1.3 billion dollars in 2015.

- After accounting for outliers, the average charge for a single hospitalization with any mention of ADRD was \$72,193 in 2015.
- The median length of stay for a hospitalization with any mention of ADRD was 4.0 days.
- Nearly 60% of hospitalizations with any mention of ADRD resulted in the patient being discharged to skilled nursing facility or home health service organization.

After accounting for outliers, the average charge for a single hospitalization with any mention of ADRD was \$72,193 in 2015.

Hospitalizations with ADRD as a secondary diagnosis (any mention of ADRD, aside from principal diagnosis) accounted for 95% of all ADRD hospitalizations among residents age 55 and older in San Diego County. Hospital admissions with principal diagnosis of ADRD had a median length of stay of 5.0 days; one full day longer than hospitalizations with a secondary mention of ADRD. Additionally, hospital stays for patients with a secondary diagnosis of ADRD, age 55 and older, were more likely to end with the patient being transferred to a skilled nursing facility, compared to hospitalizations with a principal diagnosis of ADRD (41.7% and 31.2%, respectively).

EXECUTIVE SUMMARY

By 2030, ADRD hospitalizations among residents 55 and older are expected to increase by 56%, from 18,888 to 29,450, with a resulting increase in direct hospitalization charges of \$1.3 billion dollars in 2015 to a little over \$2.1 billion dollars in 2030 (2015 dollars).

In 2015, the three most frequently occurring principal diagnoses among hospitalizations with any mention of ADRD for residents age 55 years and older were septicemia, urinary tract infections and hip fractures. In general, ADRD complicates routine medical care. All three co-occurring conditions (septicemia, UTIs and hip fractures) are preventable and illustrate the environmental impacts, as well as the complexities that functional limitations pose for patients with ADRD. Patients with ADRD and these three leading co-occurring conditions may be discharged later or, more frequently, and sent to a skilled nursing facility or home health service organization in greater proportions. Studies show the average annual payment for an individual with ADRD treated at a skilled nursing facility was fourteen times higher than the cost of individuals without ADRD.¹⁸

In 2015, the three most frequently occurring principal diagnoses among hospitalizations with any mention of ADRD for residents age 55 years and older were septicemia, urinary tract infections and hip fractures.

CAREGIVING COSTS

In 2015:

- There were more than 214,300 San Diegans providing unpaid care to an estimated 84,400 individuals age 55 years and older living with ADRD in San Diego County. These caregivers provided an estimated 244 million hours of unpaid care, representing 1,139 hours of care per caregiver per year, valued at \$3.1 billion dollars (2015 dollars).
- In San Diego County, the health care cost to caregivers due to the physical and emotional impact of caregiving was approximately \$133.8 million dollars (2015 dollars).
- East Region had the highest proportion of caregivers, with 25.9% of the 214,300 unpaid caregivers in the county caring for residents. Central Region had 16.9% of unpaid caregivers.

EXECUTIVE SUMMARY

In 2030:

- More than 292,500 unpaid caregivers will provide nearly 333.1 million hours of care to the projected 115,000 San Diegans living with ADRD.
- These caregivers will provide an estimated \$4.2 billion dollars worth of care (2015 dollars).
- The health care costs of unpaid caregivers will increase to \$182.7 million dollars a year (2015 dollars).



COST COMPARISON

Below is a comparison of costs of ADRD on the local, state, and national level.

COSTS	SAN DIEGO COUNTY	CALIFORNIA	UNITED STATES
HOSPITALIZATION			
PRINCIPAL DIAGNOSIS			
Median Charge Per Hospitalization	\$73,823	-	-
Total Charges	\$65.6 million	-	-
SECONDARY MENTION OF ADRD			
Median Charge Per Hospitalization	\$71,833	-	-
Total Charges	\$1.2 billion	-	-
CAREGIVING	\$3.1 billion	\$23.0 billion	\$230.1 billion

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INTRODUCTION

In May 2014, the San Diego County Board of Supervisors voted to launch the Alzheimer's Project to address the devastating effects of the disease on affected individuals, their families and the region's health care system. The Alzheimer's Project brings together the region's caregivers, researchers, clinicians, advocacy groups and leadership to inventory and improve caregiver resources and provide support for local efforts to find a cure. The Alzheimer's Project includes six major components:

- Cure: enhancing the awareness, partnerships and funding for Alzheimer's disease research
- Care: development of a countywide plan to improve the network of services for those afflicted with the disease and their caregivers
- Clinical: addresses improving medical care for patients with ADRD
- Education/Awareness: development of a multi-faceted education and public awareness campaign
- Legislation: support legislation that increases funding for Alzheimer's disease research and provides resources for caregivers, family members, and those directly affected by the disease
- Funding: identify and pursue opportunities for additional resources to support the Alzheimer's Project

The Alzheimer's Project supports the *Live Well San Diego* vision, which encourages residents to live healthy, safe, and thriving lives. *Live Well San Diego* is a comprehensive, long term vision to advance the health and well-being of all San Diegans through the collective efforts of residents, community, faith-based organizations, businesses, schools, law enforcement, as well as local, city and tribal jurisdictions and the County of San Diego.

The Alzheimer's Project inventories and improves resources for San Diegans living with ADRD and their caregivers in order to enhance their ability to live healthy, safe, and thriving lives. Improving coordination of care for someone living with ADRD, and raising awareness of these conditions so that they may be diagnosed earlier, improves the health of San Diegans with ADRD. An inventory of resources and facilities with designated ADRD programs, and education on environmental modifications for those living with ADRD, will ensure the safety of those living with the disease. Connecting and improving the entire network of services enhances the quality of life for San Diegans living with ADRD and for their caregivers, allowing them to thrive through all stages of the disease. For more information, please visit www.LiveWellSD.org.

INTRODUCTION

WHY ALZHEIMER'S DISEASE AND RELATED DEMENTIAS?

Alzheimer's disease and related dementias (ADRD) includes conditions caused by the degeneration of brain cells. Alzheimer's disease is the most common form of dementia (60-80% of cases), but all dementias can be characterized by a decline in thinking skills, memory loss, and reduced ability to perform everyday activities. These diseases often require increasing levels of care as the disease progresses.¹⁶ While dementia is more common among the older population, ADRD is increasingly diagnosed at an earlier age. Therefore, information on ADRD is discussed for the 55 years and older age group unless otherwise noted.

The specific definition of ADRD was developed and modeled after review of publications and national standards for reporting ADRD by the Alzheimer's Association. Following definitional changes by the Alzheimer's Association in the 2017, and the International Classification of Disease (ICD) coding changes from the 9th version to the 10th in 2015, the definition of ADRD was further expanded to include additional dementia diagnoses. This allows for more precise estimates of ADRD. Additionally, all people suffering from dementia need access to similar types of resources, such as caregivers and health care professionals trained in the treatment of dementia. The definition includes major causes of dementia such as Alzheimer's disease, frontotemporal dementia, and vascular dementia. Related forms of dementia include senility and mild cognitive impairment. For a complete list of conditions included in the definition of ADRD, and the corresponding International Classification of Disease (ICD)-9 and ICD-10 codes, refer to the Data Guide and Definitions section.

Where possible, data on ADRD is provided. However, national and state publications frequently only provide information on Alzheimer's disease or on dementias individually. Prevalence estimates, hospitalization and caregiving data for San Diego County all refer to the expanded definition of ADRD.



INTRODUCTION

BURDEN OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

Alzheimer's disease is the sixth leading cause of death in the U.S.,²⁰ third leading cause of death in California,¹ and the third leading cause of death in San Diego County.¹ Estimates show there are currently 5.5 million Americans suffering from Alzheimer's disease, a majority of whom are age 65 years and older.¹⁸ Furthermore, the Centers for Disease Control and Prevention estimated that Alzheimer's disease caused more than 110,651 deaths in the U.S. in 2015.²⁰

Additionally, there was an 89% increase in Alzheimer's deaths in the U.S. between 2000-2014. Heart disease, the leading cause of death in the U.S., declined during this time while Alzheimer's deaths nearly doubled.¹⁹

The economic costs of medical care due to Alzheimer's disease are staggering. In 2017, Alzheimer's disease cost the U.S. an estimated \$259 billion in direct medical costs. Medicaid expenditures for ADRD is estimated to be \$44 billion this year (in 2017 dollars).¹⁹ By 2030, Alzheimer's disease is expected to cost Californians an estimated \$98.8 billion in direct and indirect medical costs, including traditional medical and social supports, such as doctor visits, hospital stays, skilled nursing facility stays, and home health services.²¹

In 2015, Alzheimer's disease was the third leading cause of death in San Diego County.⁷



Direct medical costs for ADRD were estimated at \$259 billion in the United States in 2017.¹⁹

INTRODUCTION

WHAT IS ECONOMIC BURDEN?

Economic burden is best described by two measures: direct costs and indirect costs.

DIRECT COSTS

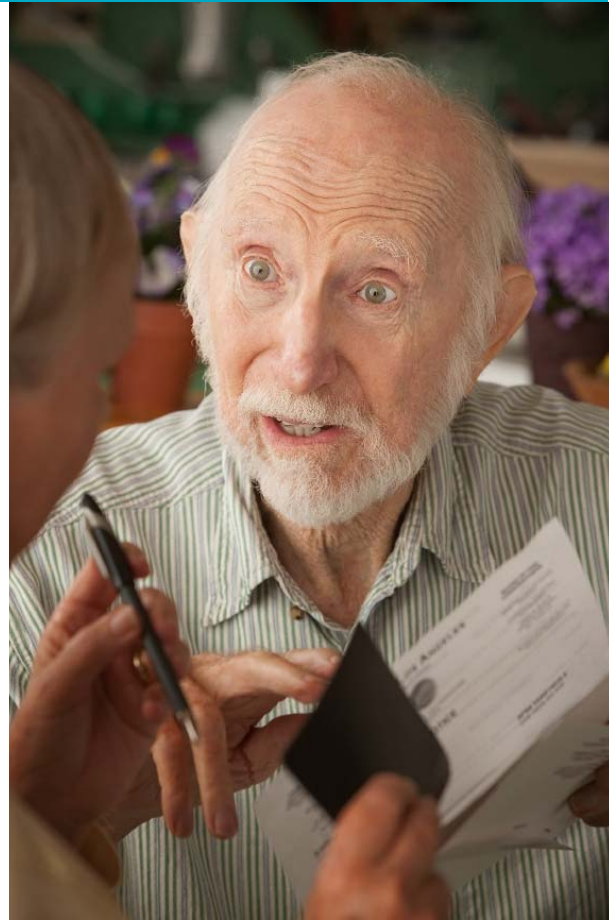
Direct costs are the actual costs of medical treatment incurred, and are represented by both service and product costs. Service costs include physician or other healthcare professional procedures, hospital or other inpatient care, outpatient care, and nursing home stays. Product costs include prescription and nonprescription drugs. Direct costs are also called treatment expenditures. This report estimates the direct hospitalization charges, or treatment expenditures, of ADRD.

INDIRECT COSTS

Indirect costs can be incurred by both the sick person and their caregivers, and represent the impact on the workplace. These indirect costs result from the costs of absenteeism (work missed due to sick days) and efficiency losses from presenteeism (lost productivity while at work). An ill employee who continues to work in order to avoid sick days is unlikely to perform as well as a healthy worker. Productivity loss due to presenteeism is enormous.

The direct costs of ADRD among San Diego County residents were estimated using the 2015 Office of Statewide Health Planning and Development Patient Discharge Data. Statistics from the Alzheimer's Association, peer reviewed journals articles, and other published reports were also used to estimate direct costs in San Diego County. However, only the indirect costs incurred as a result of caregiving for residents living with ADRD in San Diego County were estimated. Indirect costs are likely to be much higher than direct costs.

Along with direct and indirect costs, information on the prevalence of people living with ADRD and the rate of ADRD in the population is provided. Prevalence refers to the number of people living with ADRD at a specific point in time. These numbers represent the burden on the medical care and social systems established for caring for those with ADRD. The rate of ADRD represents the risk to an individual within the population.



COMMUNITY COSTS

PREVALENCE OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

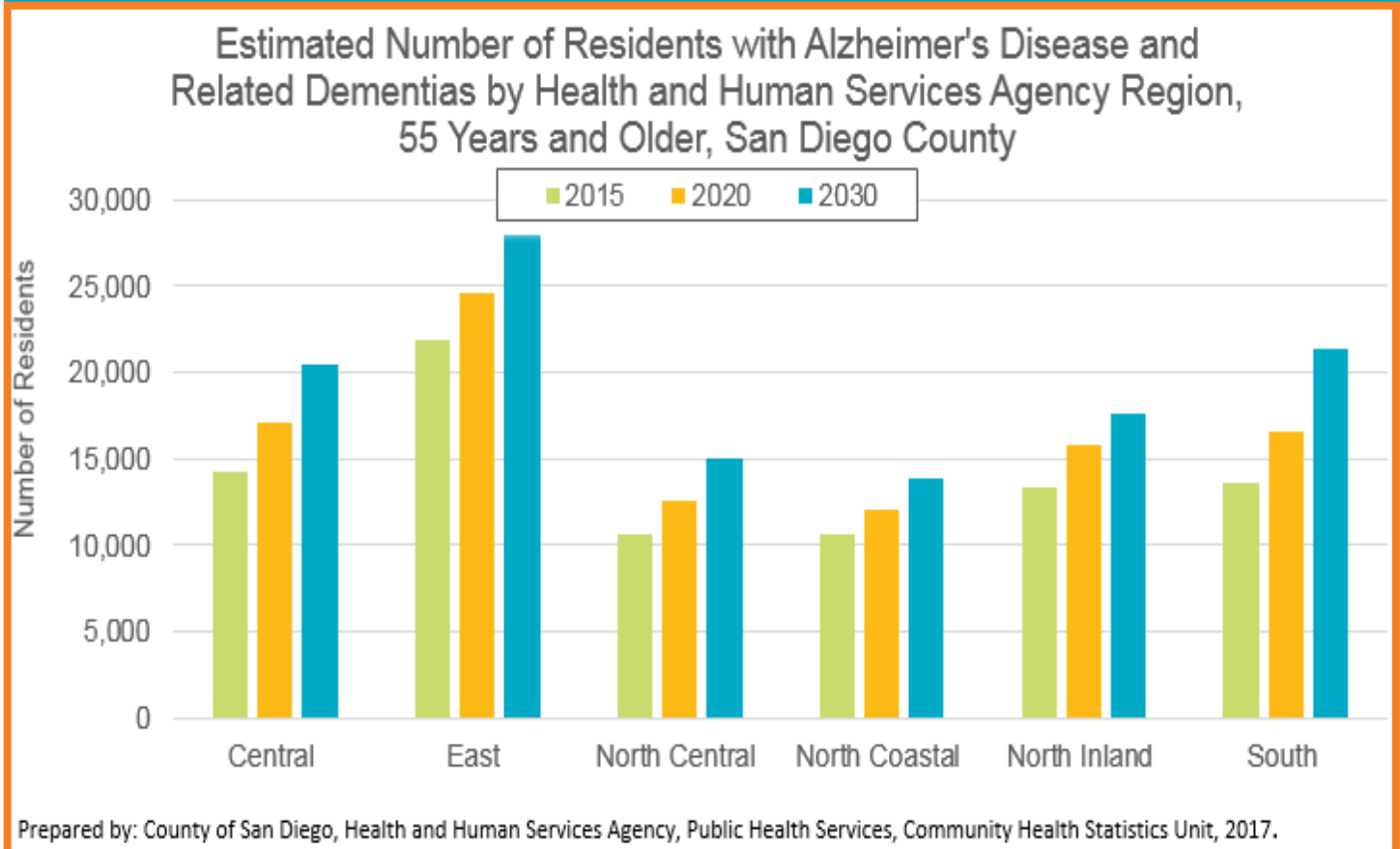
Prevalence is the number of people living with the disease. Based on national and state estimates, and using local data, an estimated 84,400 San Diego County residents age 55 years and older were living with ADRD in 2015. As those with ADRD age through the end of their disease, prevalence estimates depend on additional newly diagnosed individuals.

84,400 San Diego County residents aged 55 years and older were living with ADRD in 2015.

Locally, prevalence may increase as the rate of disease increases, as San Diegans live longer, and as the tail end of the 'baby boom' population ages. Between 2015 and 2030, the population 55 years and older will increase to nearly 1.1 million in San Diego County. ADRD prevalence among San Diegans, age 55 years and older, is expected to increase from 84,400 to 115,000 in 2030.



COMMUNITY COSTS



Among the Health and Human Services Agency (HHSA) Regions, East Region had the highest number of people, age 55 years and older, living with ADRD in 2015 (21,901), followed by Central Region (14,235). The HHSA Region with the lowest prevalence of ADRD in 2015 was North Coastal, with 10,626 individuals. However, in 2030, East and South Regions are projected to surpass Central Region in the number of individuals, age 55 years and older, living with ADRD, with 27,894 and 21,408 individuals, respectively.

CURRENT AND PROJECTED COMMUNITY COSTS BY HHSA REGION

Community costs refer to the combined monetary and societal costs incurred by a group of individuals. In this report, community costs for individuals with ADRD were estimated to be the paid or unpaid value of caregiving, the costs paid by public coverage programs like Medicare or Medicaid for hospitalizations or skilled nursing care, as well as the costs associated with long-term care. Dementia contributes a significant burden on society in the form of a community cost, on par with the financial burdens associated with both cancer and heart disease.² The annual average cost for a person with ADRD varies by year, but it is estimated to be \$64,750 per year (in 2015 dollars).³ This estimate takes into account direct and indirect medical costs, as well as loss of income and

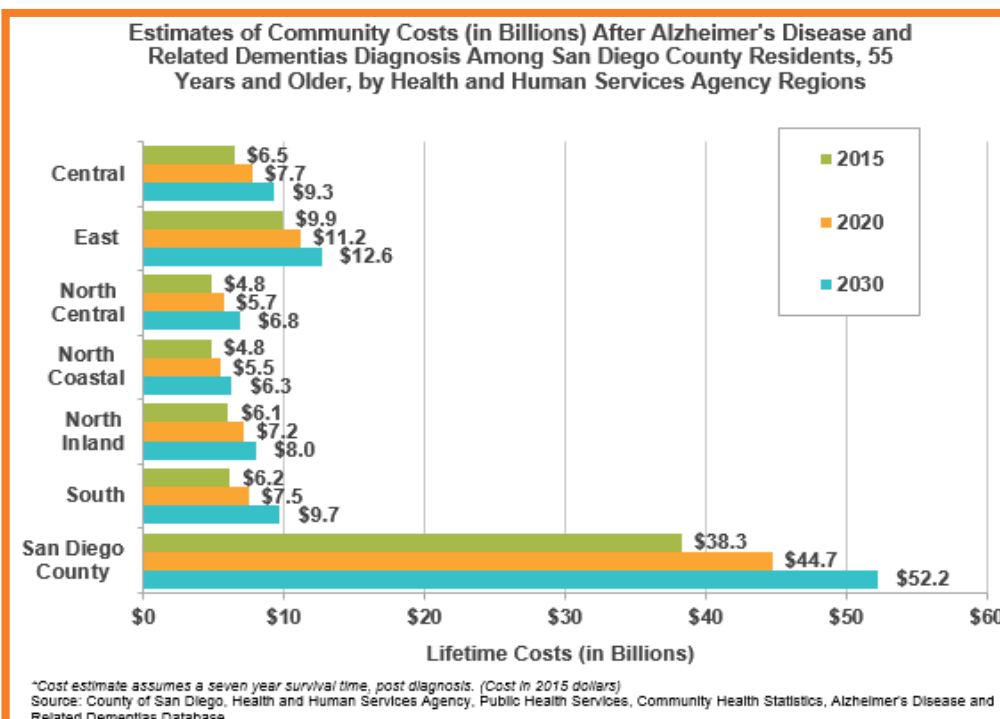
COMMUNITY COSTS

productive services to the market economy. To calculate community costs for San Diego County residents age 55 years and older living with ADRD, the annual cost of \$64,750 was used to account for the costs of informal care, which are often difficult to estimate. Furthermore, studies show individuals 65 and older with Alzheimer's disease survive, on average, four to ten years after diagnosis or onset.³⁻⁹ The shorter midpoint survival time of seven years after diagnosis was used to estimate community costs due to ADRD. This cost was estimated for 2015 and projected for 2020 and 2030, both countywide and by HHSA Regions.



In 2015, the estimated community cost for San Diego County residents age 55 years and older with an ADRD diagnosis was \$38.3 billion dollars. Compared to the other HHSA Regions, East Region had the highest estimated community cost for ADRD, at nearly \$10 billion dollars. This cost is indicative of its larger ADRD population. This was nearly \$3.5 billion dollars more than the HHSA Central Region, which had the second largest estimated lifetime cost for ADRD.

When using the seven year life expectancy after diagnosis, the community cost for residents age 55 years and older with ADRD in San Diego County is expected to increase nearly \$6.5 billion dollars from 2015, reaching \$44.7 billion dollars in 2020. This cost will continue to increase, reaching over \$52.2 billion dollars by 2030.



In 2015, the estimated community cost due to ADRD among San Diego County residents, 55 and older, was \$38 billion dollars.

COMMUNITY COSTS

As in 2015, East Region will continue to be the region with the highest community costs due to ADRD in both 2020 and 2030. By 2030, East Region is expected to reach a cost of \$12.6 billion dollars.

As in 2015, East Region will continue to be the region with the highest community costs due to ADRD in both 2020 and 2030. By 2030, East Region is expected to reach a cost of \$12.6 billion dollars. However, South Region is projected to surpass Central Region as the region with the second largest community costs due to ADRD.

These estimates mirror the prevalence estimates, as they are influenced by the estimated number of people age 55 years and older living with ADRD in each region of San Diego County. When using the longer survival time of ten years to estimate the community costs of ADRD after diagnosis, among those age 55 years and older in San Diego County, the cost increases to nearly \$55 billion dollars for 2015.

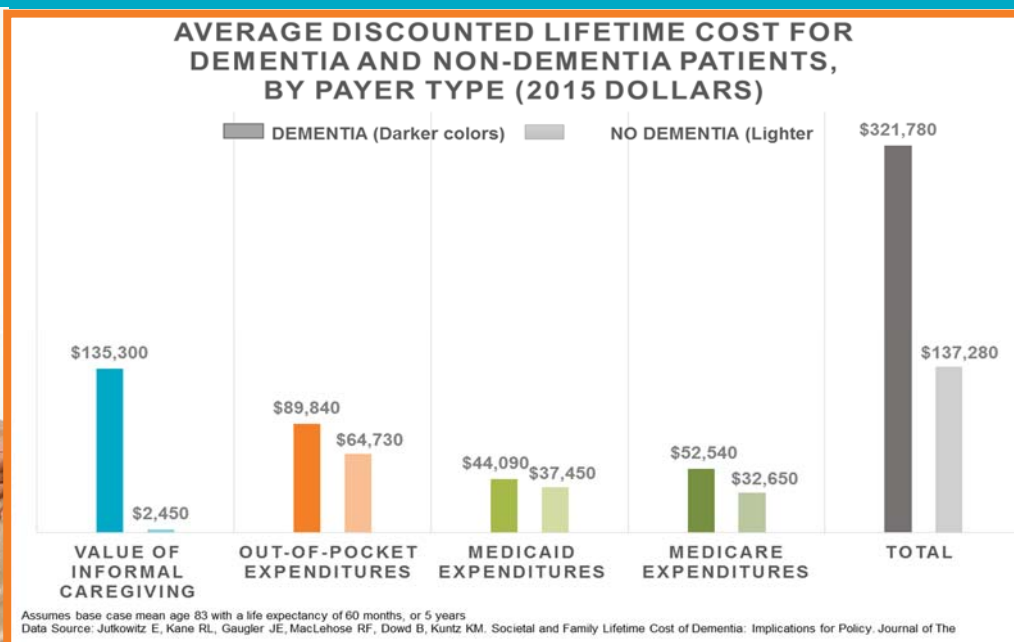
Change in Community Costs (in Billions) Based on Ten-year Life Expectancy After Diagnosis of Alzheimer's Disease and Related Dementias Among San Diego County Residents, 55 Years and Older, 2015



**Cost in 2015 dollars*

Source: County of San Diego, Health and Human Services Agency, Public Health Services, Community Health Statistics, Alzheimer's Disease and Related Dementias Database.

LIFETIME COSTS



INDIVIDUAL LIFETIME COST

Lifetime cost refers to the monetary costs incurred during the years of survival after onset or after receiving a diagnosis for an individual. These costs include the value of informal care, paid care, out-of-pocket expenditures, as well as costs to health insurance (e.g. Medicare or Medicaid). In a 2017 study, researchers developed a mathematical model estimating the total net lifetime cost for an average U.S. dementia patient (83-year-old with a five-year life expectancy post-diagnosis). Researchers estimated the average individual net lifetime cost for a person with dementia was \$321,780 (2015 dollars).³ The largest share of lifetime costs for individuals with dementia was due to the value of informal caregiving received (42%), followed by out-of-pocket expenditures (28%), and finally Medicaid and Medicare expenditures (14% and 16%, respectively).

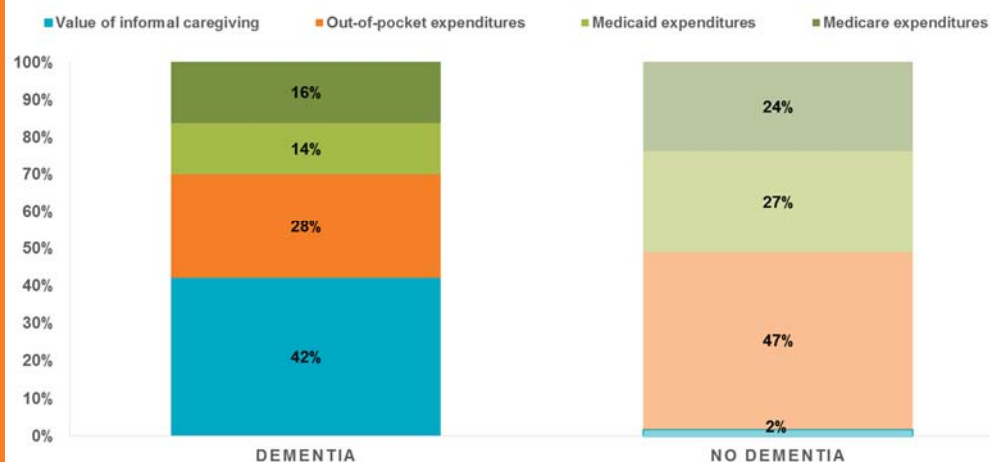
Additionally, researchers also found that the extra lifetime cost for a person with dementia was \$184,500, or 57.3% more than someone without dementia.³ Dementia patients incurred more net lifetime costs across all categories, but most notably experienced the largest expenditures due to the

The average individual net lifetime cost for a person with dementia is \$321,780 (2015 dollars) [...]
Researchers also found that the extra lifetime cost for a person with dementia was \$184,500, or 57.3% more than someone without dementia.³

LIFETIME COSTS

Dementia patients receive, on average, \$135,300 worth of informal caregiving, while non-dementia patients receive only \$2,450 in a lifetime. Additionally, dementia patients experienced nearly 30% greater out-of-pocket costs than non-dementia patients (\$89,840 vs \$64,730).³

PERCENT OF AVERAGE DISCOUNTED LIFETIME COST FOR DEMENTIA AND NON-DEMENTIA PATIENTS, BY PAYER TYPE



Assumes base case mean age 83 with a life expectancy of 60 months, or 5 years. (2015 dollars)
Data Source: Jutkowitz E, Kane RL, Gaugler JE, MacLehose RF, Dowd B, Kuntz KM. Societal and Family Lifetime Cost of Dementia: Implications for Policy. Journal of The American Geriatrics Society 2017; 65:2169-2175.

value of unpaid, or informal, caregiving and out of pocket expenditures. Dementia patients receive, on average, \$135,300 worth of informal caregiving, while non-dementia patients receive only \$2,450 in a lifetime. Additionally, dementia patients typically experienced nearly 30% greater out-of-pocket costs than non-dementia patients (\$89,840 versus \$64,730).³

Research has shown that those with dementia receive \$168,990 more in lifetime care than an individual with one physical limitation, \$130,510 more than an individual with three physical limitations, and \$70,670 more than an individual with five physical limitations. These patients had no cognitive, behavioral, or psychological limitations.³



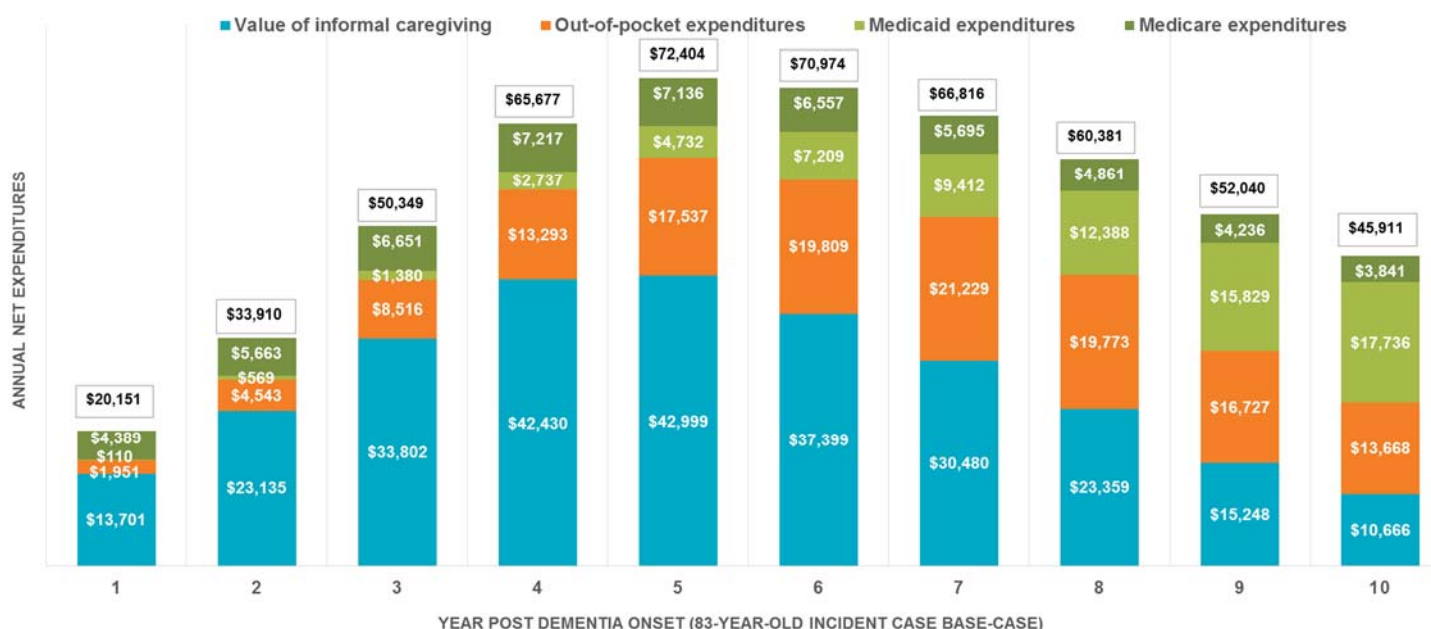
LIFETIME COSTS

With the outstanding financial burden and the subsequent increased cost of caregiver healthcare, expenses for a patient peak in year five at \$72,404.



This study also indicates that annual average net costs for dementia patients vary. For the first five years after diagnosis, the average patient remains in the community receiving in-home care. This type of care, generally provided by family and unpaid caregivers, is of high financial burden and health consequence to the family. With the outstanding financial burden and the subsequent increased cost of caregiver healthcare, expenses for a patient peak in year five at \$72,404. As the patient progresses in their illness from year six to year ten, they often enter long-term care facilities. While this care is still an out-of-pocket and Medicaid/Medicare expense, the cost is less than that of direct and indirect costs of informal caregiving. This leads to overall costs decreasing in the last four years of the ten-years post diagnosis for a dementia patient.³

Annual Average Net Costs of Dementia for an 83-Year-Old with 10 Years Post Onset Life Expectancy, by Care Type (2015 Dollars)



Assumes base case mean age 83
Data Source: Data Source: Jutkowitz E, Kane RL, Gaugler JE, MacLehose RF, Dowd B, Kuntz KM. Societal and Family Lifetime Cost of Dementia: Implications for Policy. Journal of The American Geriatrics Society 2017; 65:2169-2175.

LONG-TERM CARE COSTS

LONG-TERM SERVICES AND SUPPORTS

Long-term services and supports (LTSS) is the general name for assistance provided to people who are unable to perform one or more Activities of Daily Living (ADLs) on their own, due to cognitive limitations, functional limitations, or both. These activities range from bathing, dressing, incontinence care and assistance with eating. Other types of long-term care service and supports can provide assistance with everyday tasks, also known as Instrumental Activities of Daily Living (IADL). These tasks can include housework, budget management, medication adherence, pet care, assistance with mobile devices, shopping and response to home emergencies. A recent U.S. report states that approximately two-thirds of Americans turning age 65 will need LTSS due to serious disability, often requiring assistance for an average of three years.¹⁰ LTSS may be provided by trained professionals as paid or formal care, or as unpaid care by family or friends. Paid services can be provided in a variety of settings such as the individual's home, community-based or in a residential facility.⁴² Options for paid care range from adult day care, to assisted living, where residents typically need help with less than two activities ADLs, to skilled nursing care provided by trained medical staff, for those who need help with three or more ADLs.²²



LONG-TERM CARE COSTS

Local, Annual Costs for Long-term Care and Coverage Options, by Care Type, 2017

Care Type	2017 San Diego County Annual Median Costs	Coverage Notes
Home Health Care	\$54,866	Based on 44 hours per week for 52 weeks. Medi-Cal may cover home health services that are medically necessary for qualified individuals.
Adult Day Care	\$20,540	Based on 5 days per week for 52 weeks. Not covered by Medicare. May be subsidized by Medi-Cal managed care, if qualified.
Assisted Living	\$54,000 (private, one bedroom)	Based on 12 months of care. May be covered by private long-term care insurance. Typically not covered by traditional health insurance. ²⁷ An Assisted Living Waiver (ALW) in San Diego County exists for those on full-scope Medi-Cal who require care and are willing to reside in assisted living instead of a nursing facility. ²⁸
Assisted Living Memory Care	An average of \$1,150 per month higher than assisted living alone (2016 dollars– National Average) ²⁶	May be covered by private long-term care insurance. Typically not covered by traditional health insurance. ²⁷ An ALW in San Diego County exists for those on full-scope Medi-Cal who require care and are willing to reside in assisted living instead of a nursing facility. ²⁸
Nursing Home	\$102,565 (semi-private room) \$136,875 (private room)	Based on 365 days of care. Medicare Part A covers up to 100 days of skilled nursing facility care post-hospital stay. Days 1-20 require no coinsurance by the patient. Days 21-100 have coinsurance of \$167.50 per day (in 2018). The patient is required to cover all costs starting on day 101 of his or her stay. ¹³

Source: Genworth Survey. Compare Long term care Costs across the United States: Annual Costs, California (2017). <https://www.genworth.com/about-us/industry-expertise/cost-of-care.html>. Accessed December 11, 2017.

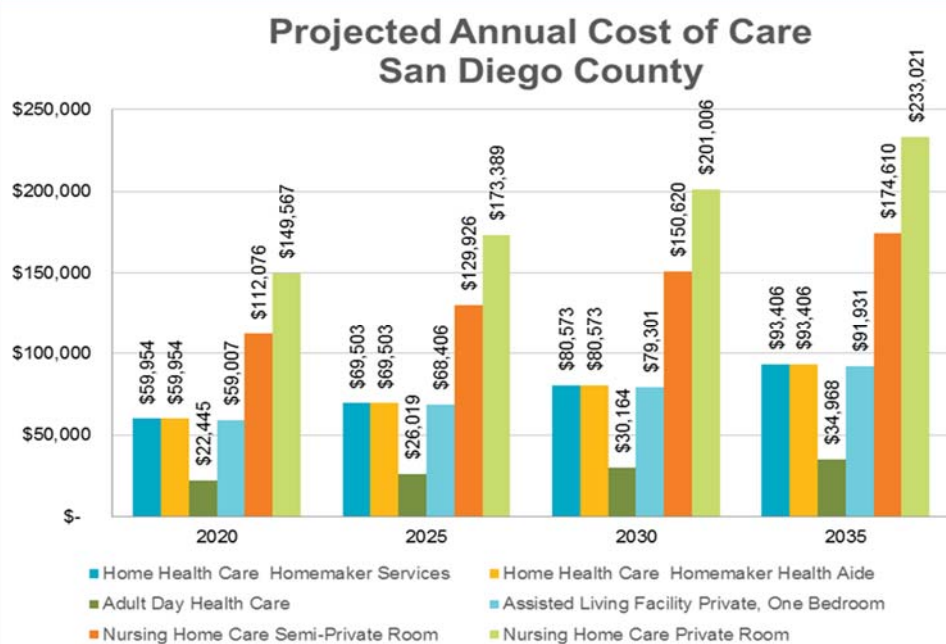
Prepared by: County of San Diego, Health and Human Services Agency, Public Health Services, Community Health Statistics Unit, 2017.

COSTS OF PAID CARE

Forty-two percent of people who receive care at home will receive some sort of paid care.¹⁰ In 2017, the cost of care in San Diego County for one adult senior was substantial. For in-home care homemaker services and for homemaker health aide services costs averaged \$54,866 annually. These services allow seniors to remain in their homes by providing assistance with meals, housekeeping, bathing and dressing. The annual cost for adult day health care was \$20,540. Day care provides a safe, engaging and supportive environment for a senior allowing a spouse or family care giver to continue working or handling other responsibilities.²³ The average annual cost of an assisted living facility with a private, one bedroom space was \$54,000. Assisted living facilities generally provide congregate dining, community activities, laundry and light housekeeping services as well as medication management, assistance with and transportation to medical appointments.²⁵ The average annual cost of a nursing home for a semi-private room was \$102,565 and a private room was \$136,875. The costs associated with nursing home care may be covered

The average annual cost of a nursing home for a semi-private room was \$102,565 and a private room was \$136,875.

LONG-TERM CARE COSTS



By 2035, costs associated with home health care and assisted living are projected to exceed \$90,000 annually.¹¹

under health insurance, Medicare or Medi-Cal, depending on the treatment needed. When compared to California and the U.S., San Diego County long-term care costs were generally higher, except for home health care. By 2035, costs associated with home health care and assisted living are projected to exceed \$90,000 annually.¹¹

Local, State and National Annual Median Costs for Long-term Care, 2017

Care Type	San Diego County	California	United States
Home Health Care	\$54,866	\$57,200	\$47,934 (Homemaker Services) \$49,192 (Homemaker Health Aide)
Adult Day Care	\$20,540	\$20,020	\$18,200
Assisted Living	\$54,000 (private, one bedroom)	\$ 51,300 (private, one bedroom)	\$45,000 (private, one bedroom)
Assisted Living Memory Care	An average of \$1,150 per month higher than assisted living alone (2016 dollars–National Avg.) ²⁶	An average of \$1,150 per month higher than assisted living alone (2016 dollars–National Avg.) ²⁶	An average of \$1,150 per month higher than assisted living alone (2016 dollars.) ²⁶
Nursing Home	\$102,565 (semi-private room) \$136,875 (private room)	\$97,367 (semi-private room) \$116,435 (private room)	\$ 85,775 (semi-private room) \$97,455 (private room)

Source: Genworth Survey. Compare Long term care Costs across the United States: Annual Costs, California (2017). <https://www.genworth.com/about-us/industry-expertise/cost-of-care.html>. Accessed December 11, 2017.

Prepared by: County of San Diego, Health and Human Services Agency, Public Health Services, Community Health Statistics Unit, 2017.

LONG-TERM CARE COSTS

COVERAGE OPTIONS

According to a U.S. report released in 2016, the lifetime cost for LTSS is approximately \$138,000 (with \$72,000 covered by the individual themselves, out of pocket, and the remaining covered by public programs and private insurance).⁴¹ These coverage options may include public insurance such as Medicare or Medicaid, or privately purchased long-term care insurance.

Coverage for certain services by Medicare changes for those with diagnosed Alzheimer's disease. Medicare will cover the initial diagnosis, evaluation and treatment for Alzheimer's disease. Even though mental health services are typically covered under Part B, some mental health & rehabilitation services will not be covered for those with Alzheimer's disease. Medicare may determine that the patient will not benefit from these services.³⁴ It does not cover over-the-counter nutritional supplements and vitamins. It does not cover adult day care, respite care (except under Part A hospice benefit), personal aid assistance (except as provided under the home health care benefit), custodial care in a nursing home (non-medical care help with ADLs), or incontinence supplies. Additionally, Medicare Part A covers up to 100 days of skilled nursing facility (SNF) care post-hospital stay. Days 1-20 require no coinsurance by the patient. Days 21-100 have coinsurance of \$167.50 per day (in 2018). The patient is required to cover all costs starting on day 101 of his or her stay.¹³ New to Medicare in 2017, is coverage for cognitive assessments and care planning sessions with a medical professional.³⁵ The Department of Veterans Affairs and the Older Americans Act may cover long-term care services, but only for specific populations and in certain circumstances.

Some ADRD patients will also be covered by Medi-Cal, California's Medicaid program. Although Medicaid covers LTSS with chronic disabilities, individuals are only eligible if they meet certain in-



[Medicare] does not cover adult day care, respite care (except under Part A hospice benefit), personal aid assistance (except as provided under the home health care benefit), custodial care in a nursing home (non-medical care help with ADLs), or incontinence supplies.

LONG-TERM CARE COSTS

Long-term Care Insurance Uptake & Total Household Dollars spent on LTC Insurance, by Community, 2016

Region	Percent of Adults with Long-term Care Insurance	Aggregate Amount Households spend on Long-term Care Insurance Annually
Central	3.62%	\$11,746,688
East	4.31%	\$17,057,245
North Central	5.26%	\$30,778,126
North Coastal	4.64%	\$21,916,009
North Inland	5.00%	\$26,274,704
South	3.71%	\$11,905,354
San Diego County	4.47%	\$119,678,126

Source: ESRI Market Potential Database, 2016; ESRI Consumer Expenditure Survey, 2016.

Prepared by: County of San Diego, Health and Human Services Agency, Public Health Services, Community Health Statistics Unit, 2017.

come and qualifying criteria. Additionally, in California, hospitals that serve a large number of Senior Medi-Cal beneficiaries and uninsured patients are eligible for Disproportionate Share Hospital (DSH) funding. There is an annual DSH allotment to each state from the federal government, based on the previous year's allotment, inflation, and the total amount of Medicaid expenditures in that state.³⁷

Privately available LTSS insurance exists, but less than 8% of Americans have purchased this insurance, in part due to high and rising premiums.⁴¹ Private policies will typically cover services provided at adult day care centers, hospice facilities, respite facilities, assisted living facilities, Alzheimer's special care facilities and nursing homes.¹⁴ In 2016, there were 92 of these long-term care facilities in San Diego County.³¹ People who currently use long-term care services or already have a diagnosis of ADRD may not be able to purchase long-term care insurance; however, if they purchase the insurance prior to developing the condition, then any long-term care they need as a result of that condition will be covered under their policy. The average age of a person purchasing long-term care insurance is 60 years.³³ In San Diego County, 5.1% of people in San Diego County were likely to purchase long-term care insurance in 2014.²⁴ San Diegans spent almost \$130 million dollars on long-term care insurance in 2014, or an average of \$1,034 per household that



Less than 5% of adults in San Diego County have actually purchased long-term care insurance.

LONG-TERM CARE COSTS

According to a recent brief released in 2016, individuals who ever used paid LTSS saw the average cost at approximately \$266,000, with \$140,000 paid by the individuals, out of pocket.⁴¹

year.²⁹ Less than 5% of adults in San Diego County have actually purchased long-term care insurance. San Diego households spent almost \$120 million dollars in long-term care insurance premiums in 2016. The likelihood of having purchased long-term care insurance is correlated with residing in a higher income community and age.¹⁵

According to a recent brief released in 2016, individuals who ever used paid LTSS saw the average cost at approximately \$266,000, with \$140,000 paid by the individuals, out of pocket.⁴¹ When other coverage options are unavailable, individuals may also choose to use another private payment option to finance their care, such as a reverse mortgage, some types of life insurance policies, and annuities.³² These options require paying out-of-pocket, but individuals may “spend down” until they are income-eligible for Medicaid. The Congressional Budget Office projects LTSS expenses will double by 2050 to 3% of gross domestic product (GDP).⁴¹



HOSPITALIZATION CHARGES

HOSPITALIZATION CHARGES WITH ANY MENTION OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

In 2015, approximately one in seven hospitalizations, or 18,888 hospital discharges, among San Diego County residents, age 55 and older, occurred for patients with any mention of ADRD. Nearly 28% of these patients were readmitted to a hospital in 2015, either due to ADRD or a secondary co-occurring condition.

When outliers were removed, patients with any mention of ADRD averaged \$72,193 in direct charges per hospital stay.

The financial impact of these hospitalizations was quite significant with nearly \$1.3 billion dollars in total direct hospitalization charges accrued in 2015. When outliers were removed, patients with any mention of ADRD averaged \$72,193 in direct charges per hospital stay. A majority of these charges (approximately 90%), were billed to Medicare. The median length of stay for a hospitalization with any mention of ADRD was approximately 4.0 days. A little over 41% of these hospitalizations resulted in the patient being transferred to a skilled nursing facility and 16.7% to a home health service organization; only one in five (21.6%) of these hospitalizations resulted in discharge to home or self-care.

Approximately, 900 of these hospitalizations were due to ADRD as the primary reason of admission. Hospital discharges with a principal diagnosis of ADRD accounted for 4.7% of total discharges with any mention of ADRD, and totaled \$65.6 million dollars in direct charges, with an average charge of \$73,823 per stay (accounting for outliers). A little over 80% of these hospitalizations were billed to



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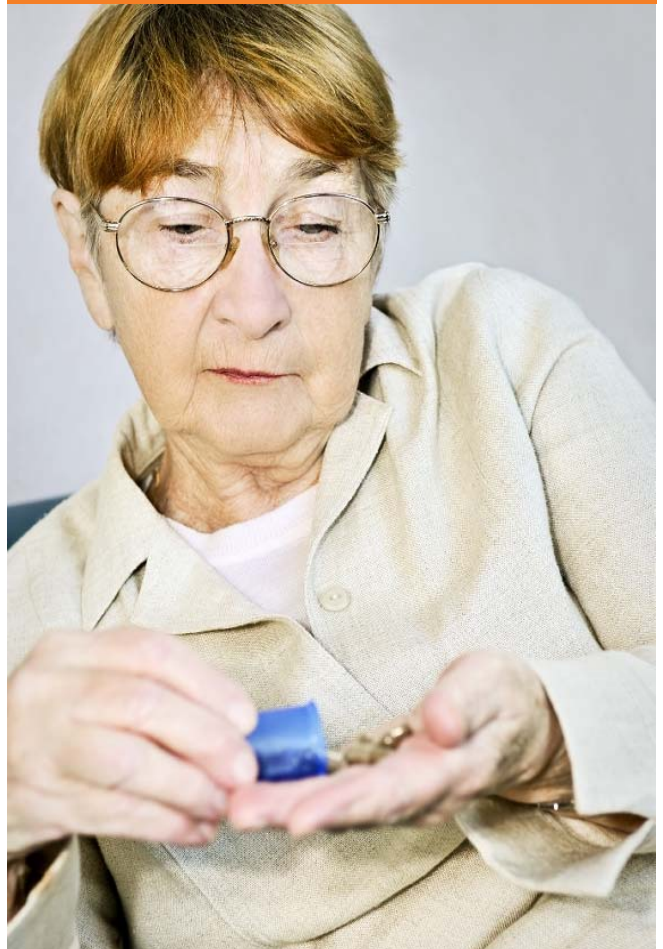
HOSPITALIZATION CHARGES

Medicare, while 8.6% were covered by private coverage, followed by 6.7% with Medi-Cal. San Diegans with a principal diagnosis of ADRD, age 55 years and older, were admitted for a median length of stay of 5.0 days. Less than one in three hospitalizations resulted in patients being discharged to a skilled nursing facility. Eleven percent were discharged to a home health service organization and nearly 30% were discharged to home or self-care.

In 2015, approximately 18,000 hospitalizations (95% of any mention of ADRD) among San Diego County residents 55 years and older had ADRD mentioned as a secondary diagnosis (any mention of ADRD, aside from principal diagnosis). The total direct charges for these hospitalizations was over \$1.2 billion dollars, averaging \$71,833 per discharge (accounting for outliers). The majority of hospitalizations were billed to Medicare (89.5%), followed by Medi-Cal (5.8%) and private insurance (3.8%). The median length of stay for these patients was 4.0 days with two in five hospitalizations ending in the patient being transferred to a skilled nursing facility and 17.0% to a home health service organization. Only one in five, or 21.3%, of these hospitalizations resulted in discharge to home or self-care.

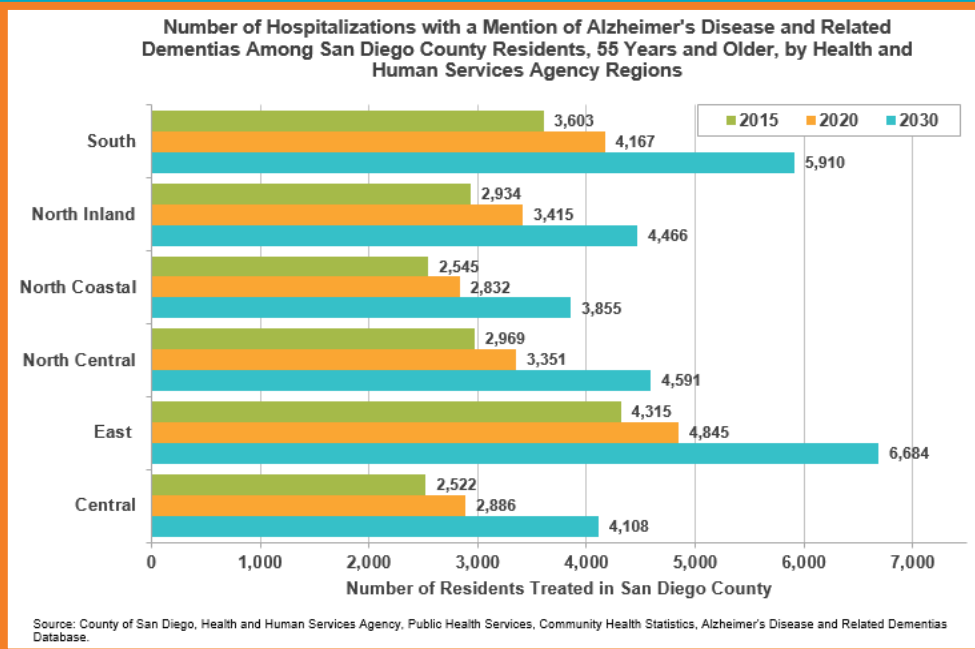
Among the HHSA Regions, East Region had the highest number of ADRD hospitalizations and total charges among residents, age 55 years and older, at nearly \$290 million dollars and 4,315 hospitalizations; this was followed by South Region at \$241 million dollars and 3,603 hospitalizations. North Inland Region had the next highest total in direct charges at \$237 million dollars, but the fourth highest number of ADRD hospitalizations among San Diego County residents, aged 55 and older, at 2,934. North Central Region had the third highest number of hospitalizations at 2,969 with \$191 million dollars in direct hospital charges in 2015.

The total direct charges for these hospitalizations [with ADRD mentioned as a secondary diagnosis] was over \$1.2 billion dollars, averaging \$71,833 per admission (accounting for outliers).



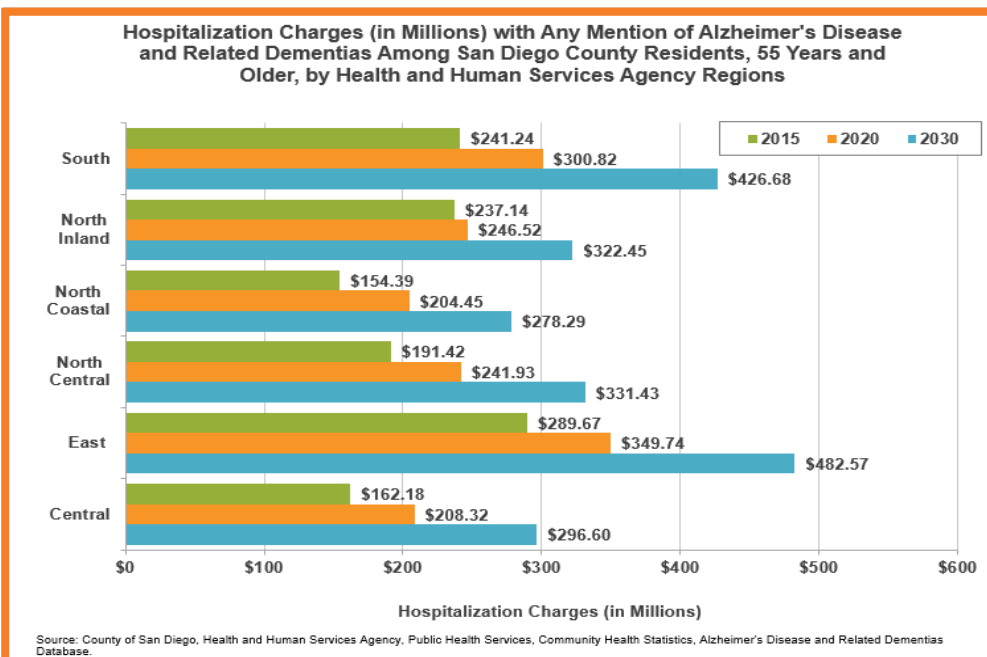
HOSPITALIZATION CHARGES

[...] By 2030, direct hospitalization charges will increase by 67%, from \$1.3 billion to \$2.1 billion dollars (2015 dollars).



Hospitalizations for San Diego County residents, ages 55 and older, with ADRD are expected to grow by 56% in 2030, from 18,888 to 29,450. Assuming similar trends, by 2030, direct hospitalization charges will increase by 67%, from \$1.3 billion to \$2.1 billion dollars (2015 dollars).

By 2030, East Region is expected to remain at the top with the highest amount of direct charges and number of hospitalizations with any mention of ADRD among residents age 55 years and older at \$483 million dollars and 6,684 admissions. South Region will have the second highest amount of hospitalization charges, with more than \$426 million in direct charges and 5,910 ADRD hospitaliza-



HOSPITALIZATION CHARGES

tions among residents 55 and older. By 2030, assuming current trends continue, South and Central Regions will experience the largest increases in projected ADRD hospitalizations among residents 55 and older, at 64.0% and 62.9%, respectively.

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TOP THREE PRINCIPAL DIAGNOSES AMONG HOSPITALIZATIONS WITH ANY MENTION OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

Individuals with ADRD are more likely to have co-occurring medical conditions than those without ADRD. These coexisting conditions result in higher health care utilization than those without such conditions. Older adults with ADRD also typically have higher health care costs than those without these conditions.¹⁷



HOSPITALIZATION CHARGES

In 2015, the top three principal diagnoses for a hospitalization among San Diegans, age 55 years and older with any mention of ADRD, were septicemia (infection resulting from the presence of bacteria in the blood), urinary tract infections, and hip fractures.

HOSPITALIZATION DUE TO SEPTICEMIA

In 2015, there were 2,727 hospitalizations with a principal diagnosis of septicemia that included a secondary diagnosis of ADRD among San Diegans age 55 years and older. Median charges for septicemia hospitalization with a mention of ADRD was about \$4,000 less than hospitalization charges for septicemia without ADRD (\$47,794 vs. \$51,936). However, the median length of stay was longer, by a full day, for septicemia with a mention of ADRD (5.0 days) compared to septicemia hospitalizations without ADRD (4.0 days). Discharges to a skilled nursing facility occurred 42.1% of the time for those patients, compared to septicemia without ADRD at 24.3%. Moreover, a larger percentage of septicemia hospitalizations with a mention of ADRD resulted in a discharge due to death (16.5%) compared to hospitalizations without a mention of ADRD (12.3%). One-quarter of hospitalizations for patients 55 and older admitted for septicemia with a mention of ADRD, arrived from a skilled nursing, intermediate care or a residential facility; whereas, only 8.8% of patients with septicemia

without a mention of ADRD arrived from these facilities. Additionally, a greater proportion of septicemia hospitalizations, among residents aged 55 and older with a mention of ADRD, were billed to Medicare (89.7% vs. 71.7%). More septicemia hospitalizations without a mention of ADRD were billed to private coverage (13.6%) and Medi-Cal (12.7%), compared to septicemia hospitalizations with a mention of ADRD (3.4% and 5.9%, respectively).

In 2015, the top three principal diagnoses for a hospitalization among San Diegans, age 55 years and older with any mention of ADRD, were septicemia (infection resulting from the presence of bacteria in the blood), urinary tract infections, and hip fractures.



HOSPITALIZATION CHARGES



The median charge per hip fracture hospitalization for patients 55 years and older was greater by over \$1,700 for any mention of ADRD at \$72,619, than without a mention of ADRD, at \$70,877.

HOSPITALIZATION DUE TO URINARY TRACT INFECTION

In 2015, there were 939 hospitalizations with a principal diagnosis of urinary tract infection (UTI) that included a secondary diagnosis of ADRD among San Diegans age 55 years and older, making it the second most common reason for admission among ADRD hospitalizations. The median hospitalization charge for UTI with a mention of ADRD was approximately \$700 more than the charges for UTI hospitalizations without a mention of ADRD (\$29,287 and \$28,557 respectively). Median length of stay was similar for both hospitalization types at 3.0 days. Nearly one in five, or 18.5%, UTI hospitalizations with a mention of ADRD had patients arriving from a skilled nursing, intermediate care or residential care facility, compared to only 6.4% of UTI hospitalizations without a mention of ADRD arriving from these facilities. Nearly two-thirds (65.4%) of all UTI hospitalizations with a mention of ADRD were discharged to skilled nursing or home health service organization, versus only 45.7% for UTI hospitalizations without a mention of ADRD. Medicare was overwhelmingly the primary payment source for UTI hospitalizations with a mention of ADRD at 93.2%, as compared to no mention of ADRD (75.9%) among residents aged 55 years and older.

HOSPITALIZATION DUE TO HIP FRACTURES

In 2015, there were 761 hospitalizations with hip fractures as the principal diagnosis with a secondary mention of ADRD among San Diego County residents age 55 years and older. The median charge per hip fracture hospitalization for patients 55 years and older was greater by over \$1,700 for any mention of ADRD at \$72,619, than without a mention of ADRD, at \$70,877. Median length of stay was similar for both hospitalization types at 4.0 days. One in five hip fracture hospitalizations with a mention of ADRD had patients arriving from a skilled nursing, intermediate care or residential care facility, compared to only 3.6% of hip fracture hospitalizations with no mention of ADRD. Both types of hospitalizations resulted in a majority of discharges to a skilled nursing or home health ser-

HOSPITALIZATION CHARGES

vice organization (approximately 85%). In the case of hip fractures, there is no difference seen in disposition due to the severity of the hip fracture which, by itself, requires a higher level of post-discharge medical care.

In general, ADRD complicates routine medical care. All three co-occurring conditions (septicemia, UTIs and hip fractures) are preventable and illustrate the environmental impacts, as well as the complexities that functional limitations pose for patients with ADRD. Patients

with ADRD and these three leading co-occurring conditions may be discharged later or, more frequently, sent to a skilled nursing facility or home health service organization in greater proportions. These facilities provide a high level of care for patients while they recover from their illness. Additionally, ADRD patients with these three conditions were admitted to the hospital from either a skilled nursing, intermediate care, or residential care facility in greater proportions when compared to those with the same conditions, but without a mention of ADRD. Patients with ADRD may have either been temporarily placed in a skilled nursing or intermediate care facility or permanently reside in a residential facility, but require hospitalization from time to time, only to be discharged back to a facility.

Studies have shown that the average yearly Medicare payment for an individual with ADRD in a skilled nursing facility was nearly fourteen times higher than the payments to individuals without ADRD.¹⁹ Thus, as the course of care moves out of the hospital and into care facilities such as a skilled nursing, home health or residential care facilities, the cost of care for patients with ADRD becomes much greater when the time spent in those facilities is taken into account.

All three co-occurring conditions (septicemia, UTIs and hip fractures) are preventable and illustrate the environmental impacts, as well as the complexities that functional limitations pose for patients with ADRD.

Patients with ADRD and these three leading co-occurring conditions may be discharged later or, more frequently, sent to a skilled nursing facility or home health service organization in greater proportions.

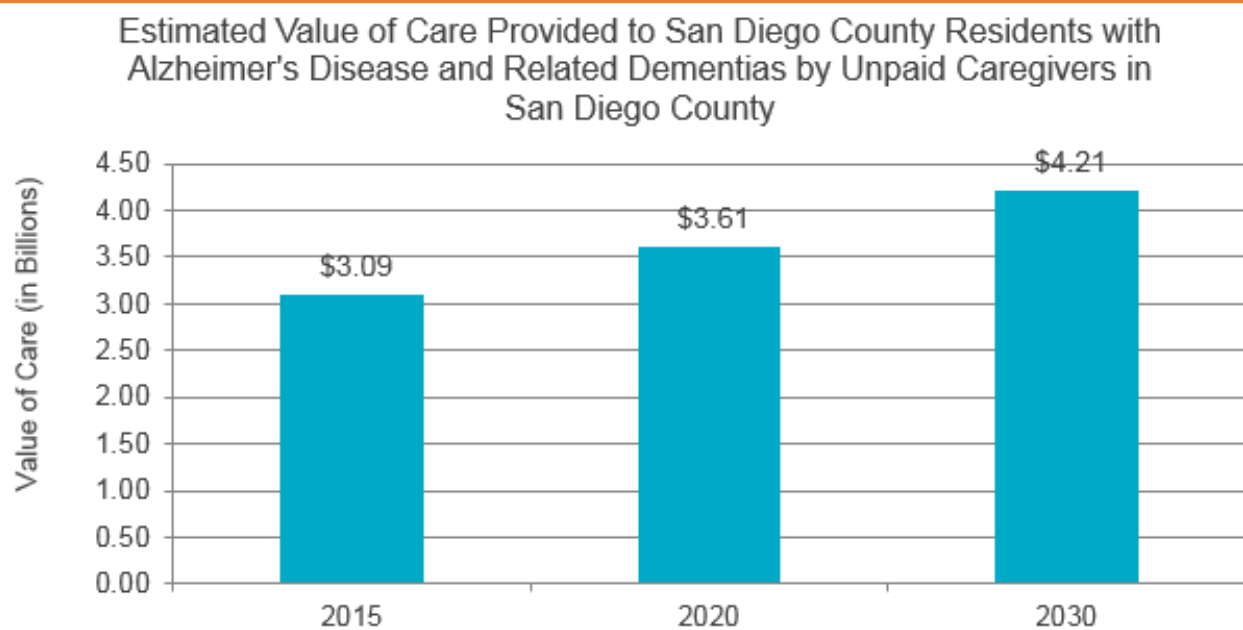
CAREGIVER COSTS

In 2015, there were more than 214,300 San Diegans providing unpaid care for an estimated 84,400 people living with ADRD in San Diego County. These caregivers provided an estimated 244 million hours of unpaid care in 2015. This number represents an average of 21.9 hours of care per caregiver per week, or 1,139 hours of care per caregiver per year.

The economic value of this care is estimated to be worth \$3.1 billion dollars (in 2015 dollars). If nothing else changes, by 2030 there will be approximately 115,000 people age 55 years and older with ADRD in San Diego County. The increase in San Diegans living with ADRD will require more than 292,500 unpaid caregivers to provide nearly 333.1 million hours of care a year. The economic value of this care is estimated to be worth \$4.2 billion dollars (in 2015 dollars).



The work required of all caregivers, including physical tasks, organization, and planning can lead to increased emotional stress, depression, and financial hardships. Financial hardships can result from both personal finances used to cover costs of care and loss of wages due to missing work.



Source: County of San Diego, Health and Human Services Agency, Public Health Services, Community Health Statistics, Alzheimer's Disease and Other Dementias Database.

In 2015, more than 214,300 San Diegans provided an estimated 244 million hours of unpaid care for those living with ADRD in San Diego County.

CAREGIVER COSTS

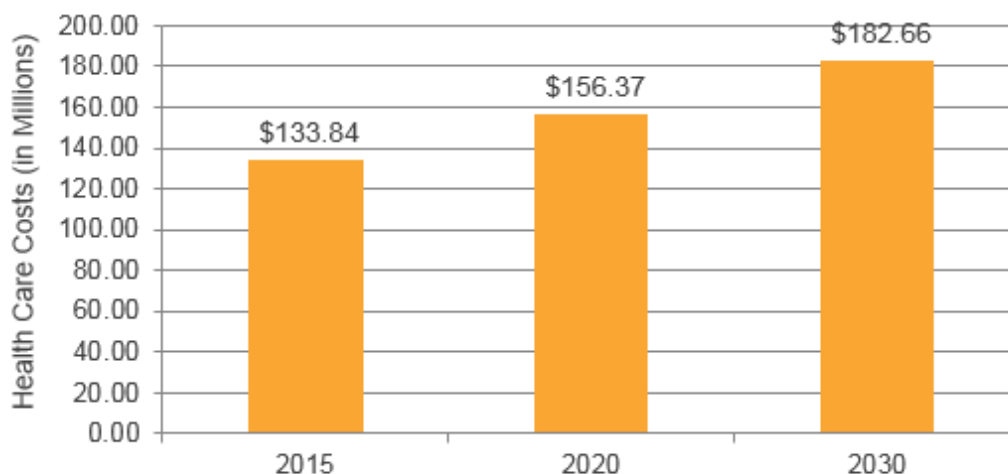
These stressors can result in poor health for caregivers. In addition, the added demands on caregivers of people living with ADRD can leave little time for managing their own health. The health care costs to caregivers due to the physical and emotional impact of caregiving were approximately \$133.8 million dollars in San Diego County for 2015. By 2030, if nothing else changes, the health care costs of unpaid caregivers will increase to \$182.7 million dollars a year (in 2015 dollars).



The distribution of unpaid caregivers providing services to those with ADRD is unequally spread throughout the Health and Human Service Agency Regions. East Region had the highest proportion of caregivers at 25.9% of the 214,300 unpaid caregivers residing in San Diego County in 2015, followed by Central Region at 16.9%. Following this trend, East Region caregivers provided the highest estimated amount of care of all the regions at 63.3 million hours of unpaid care in 2015, with an estimated economic value of \$801.1 million dollars. Similarly, the health care costs due to the physical and emotional impact of caregiving were highest in East Region, with health care costs to caregivers averaging nearly \$34.7

By 2030, if nothing else changes, the health care costs of unpaid caregivers in San Diego County will increase to an estimated \$182.7 million dollars a year.

Estimated Health Care Costs to Caregivers of San Diego County Residents Living with Alzheimer's Disease and Related Dementias, San Diego County



Source: County of San Diego, Health and Human Services Agency, Public Health Services, Community Health Statistics, Alzheimer's Disease and Other Dementias Database.

CAREGIVER COSTS

million dollars in 2015. If nothing else changes, by 2030 there will be approximately 27,900 people age 55 years and older with ADRD in East Region requiring more than 70,800 unpaid caregivers to provide nearly 80.7 million hours of care a year. The economic value of this care is estimated to be worth \$1.0 billion dollars (in 2015 dollars).

Central Region caregivers provided the second highest estimated amount of care at 41.2 million hours of unpaid care in 2015, with an estimated economic value of \$520.7 million dollars. Central Region had the second highest health care costs to caregivers at an estimated total of \$22.6 million dollars. If nothing else changes, by 2030 there will be approximately 20,400 people age 55 years and older with ADRD in the Central Region requiring more than 52,000 unpaid caregivers to provide nearly 59 million hours of care a year. The economic value of this care is estimated to be worth \$749.4 million dollars (in 2015 dollars).

**Central Region
had the
second
highest health
care costs to
caregivers
at an estimated
total of \$22.6
million
dollars in 2015.**

2015 Regional Estimates

Location	Number of Alzheimer's Disease and Other Dementias Caregivers	Hours of Unpaid Care	Value of Unpaid Care	Higher Health Care Costs of Caregivers
San Diego County	214,362	244,104,619	\$ 3,087,213,357	\$ 133,842,214
Central Region	36,152	41,167,866	\$ 520,653,757	\$ 22,572,282
East Region	55,623	63,340,132	\$ 801,068,419	\$ 34,729,304
North Central Region	27,108	30,869,534	\$ 390,409,805	\$ 16,925,721
North Coastal Region	26,987	30,731,308	\$ 388,661,657	\$ 16,849,933
North Inland Region	33,913	38,618,530	\$ 488,412,063	\$ 21,174,485
South Region	34,579	39,377,249	\$ 498,007,656	\$ 21,590,489

2030 Regional Projections

Location	Number of Alzheimer's Disease and Other Dementias Caregivers	Hours of Unpaid Care	Value of Unpaid Care	Higher Health Care Costs of Caregivers
San Diego County	292,556	333,147,833	\$ 4,213,350,991	\$ 182,664,481
Central Region	52,034	59,254,232	\$ 749,393,667	\$ 32,489,011
East Region	70,843	80,672,376	\$ 1,020,270,895	\$ 44,232,549
North Central Region	38,282	43,593,810	\$ 551,334,893	\$ 23,902,424
North Coastal Region	35,238	40,126,932	\$ 507,488,963	\$ 22,001,539
North Inland Region	44,672	50,870,556	\$ 643,364,556	\$ 27,892,253
South Region	54,369	61,912,689	\$ 783,015,416	\$ 33,946,639

SUMMARY

In 2015, approximately 84,400 San Diego County residents were living with ADRD. As a result, San Diego County experienced an economic impact of \$38.3 billion dollars, including both direct and indirect costs due to ADRD. Individually, the estimated net lifetime costs for an average dementia patient with five years to live after diagnosis totaled \$321,780.³ When compared to a non-dementia patient, dementia patients incurred an extra \$184,500 in costs, mainly attributed to the value of unpaid, or informal, care.³

ADRD patients received 244 million hours of unpaid care from 214,300 caregivers that same year. These caregivers experienced \$133.8 million dollars in health care costs themselves due to the emotional and physical demands of caregiving.

San Diego County residents, 55 years and older with ADRD, were hospitalized 18,888 times in 2015, accounting for nearly \$1.3 billion dollars in direct hospitalization charges. Nearly one-third of these patients were readmitted the same year. Patients with a principal diagnosis of ADRD were hospitalized for median length of stay of 5.0 days- one full day longer than patients with a secondary mention of ADRD. When accounting for outliers, hospitalization charges averaged \$73,823 per stay.



SUMMARY

Two in five hospitalizations ended with the patient being discharged or transferred to a skilled nursing facility or home health service organization.

Moreover, individuals with ADRD were more likely to have co-occurring medical conditions than those without ADRD, often complicating care.¹⁹ Coexisting conditions result in higher health care utilization for those with ADRD, compared to patients without ADRD.¹⁹ In 2015, the three most frequently co-occurring principal diagnoses among ADRD hospitalizations for residents 55 year and older, treated in San Diego County, were septicemia, urinary tract infections (UTIs), and hip fractures. These conditions are typically preventable and demonstrate how physical and cognitive limitations can pose challenges for patients with ADRD. Hospitalizations with any mention of ADRD and these co-occurring diagnoses was more likely to result in a discharge to a skilled nursing or intermediate care facility for further care. Studies indicate that dementia patients often transition between nursing facilities, hospitals and the home which creates challenges for care coordination.¹⁹



Long-term care needs are growing as more Americans turning age 65 and require assistance with everyday tasks. Patients with ADRD are more likely to need assistance as their disease progresses. The 2016 annual median costs for long-term care options ranged from \$20,540 for adult day care to \$136,875 for nursing home care (private room) in San Diego County. Median annual costs for assisted living were \$54,000, with memory care costing an average of \$1,150 more per month (2016 dollars–national average).¹¹ With home health care and assisted living costs expected to exceed \$90,000 by 2035, affordability remains a challenge for individuals with ADRD.

Public coverage for long-term supports and services is far from comprehensive. Medicare only covers the initial diagnosis, evaluation and treatment of Alzheimer's disease, and medically necessary care. Medicare does not cover custodial care, or non-medical care. Furthermore, Medicare will only cover up to 100 days of medically necessary care such as services provided in a skilled nursing facility. Medicaid, or Medi-Cal in California, may cover custodial care if care is provided in an assisted living facility, rather than a nursing facility; however, individuals must first meet income and eligibility criteria to receive Medi-Cal. This leaves little options for patients who do not meet eligibility criteria

SUMMARY

for Medi-Cal. Privately available long-term care insurance exists, however, this insurance is only available to individuals who do not have a current diagnosis of ADRD. If an individual purchases insurance prior to diagnosis, then typically any long-term care will be covered under their policy. In 2016, less than 5% of adults purchased this insurance in San Diego County.¹⁵ With coverage options exhausted, individuals must resort to private payment options to finance their care, such as a reverse mortgage, some types of life insurance policies, or annuities.³²

Looking ahead in the next two decades, ADRD prevalence is expected to increase by 36.5%, from 84,400 in 2015 to over 115,000 in 2030. As a result, community costs are projected to exceed \$52 billion dollars by 2030. An additional 78,194 caregivers will be needed by this time, totaling 292,556 individuals who are estimated to provide 333.1 million hours valued at \$4.2 billion dollars. These caregivers will experience \$182.7 million in higher health care costs themselves as a result of the physical and emotional toll of caregiving for patients with ADRD.

Furthermore, ADRD hospitalizations among residents 55 and older are expected to increase by 56%, from 18,888 to 29,450, with direct hospitalization charges going from \$1.3 billion dollars to almost \$2.1 billion dollars in 2030 (2015 dollars).

The costs of ADRD among the local, state, and federal levels are compared in the table below:

COSTS	SAN DIEGO COUNTY	CALIFORNIA	UNITED STATES
HOSPITALIZATION			
PRINCIPAL DIAGNOSIS			
Median Charge Per Hospitalization	\$73,823	-	-
Total Charges	\$65.6 million	-	-
SECONDARY MENTION OF ADRD			
Median Charge Per Hospitalization	\$71,833	-	-
Total Charges	\$1.2 billion	-	-
CAREGIVING	\$3.1 billion	\$23.0 billion	\$230.1 billion

With one in every ten adults, 55 and older, living with ADRD in 2015, patients, caregivers, their families and the region's medical resources are experiencing a significant economic burden due to ADRD. Despite the challenges ahead, the region as a whole can work together to mitigate the impact of ADRD with the power of collective impact to ensure that all residents can live healthy, safe and thriving lives.

DATA GUIDE AND DEFINITIONS

Data Guide

Caution must be used when exploring data from multiple sources or even the same data prepared by different analysts; comparisons may not be appropriate. Attention to accompanying information is important in order to note differences, including, but not limited to: data sources, data preparation, diagnoses/case definitions, rate constant (i.e., per 100,000 or 1,000), geographic units, persons included in the data (i.e. location of occurrence vs. location of residence, or among live births not total pregnancies).

Geography: Understanding Geographic Units Used in Health Data

Many different geographic units are used throughout San Diego County. In this document, Health and Human Service Agency Region (HHSA Region) boundaries are based on zip codes.

Numbers, Proportions, Prevalence, and Rates

The data in this report includes numbers, proportions, and crude rates (from this point forward referred to as rates) for Regional level data:

The number and proportion (or percent) represent the burden to the community for which the data is being reported.

The prevalence is the estimated number of people with a particular condition. In the case of this report, prevalence is the estimated number of people living with ADRD.

A rate is the number of cases divided by the population, usually multiplied by a constant. For example 987 cases, divided by population of 654,321 multiplied by 100,000 would be a rate of 150.8 per 100,000 population. The rate can be interpreted as an individual's risk and the odds of an outcome occurring.

Medical Encounters

Any mention of ADRD in a medical record refers to review of the 25 diagnosis fields within a medical record to find if any of the identified International Classification of Diseases (ICD)-9 codes or ICD-10 codes associated with ADRD are reported in any of the 25 fields. A principal diagnosis of ADRD was determined using the principal diagnosis field in the 2015 patient discharge database (PDD). A secondary diagnosis of ADRD was determined using the 24 other diagnosis fields in the PDD.

Population Estimates and Projections

Population estimates and projections were obtained from the San Diego Association of Governments (SANDAG) website at <http://www.sandag.org/>.

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Prevalence Estimates

Analysis of local data shows that individuals visit the emergency department at least once every five years. Additionally, using median survival time and age, individuals with ADRD can live between four years (post-diagnosis) and ten years after symptoms first appear or diagnosis.³⁻⁹ Utilizing this information, seven years was established as the mid-point for the median survival time. Emergency department discharges (EDD) and patient discharge data (PDD) with any mention of ADRD were merged to find the number of unique number of San Diego County residents, treated in San Diego County, with ADRD over a five-year period. An average number of unique users per year was calculated and multiplied by seven (for the seven year survival time) to estimate the prevalence of San Diego County residents, age 55 and over, currently living with ADRD. This analysis yielded 84,405 individuals. The distribution of individuals with hospital discharges and emergency department discharges with any mention of ADRD in 2015 was applied to the county-wide estimate of 84,405 individuals to estimate the prevalence of residents currently living with ADRD by Health and Human Services Agency Regions and sub-regional areas.

Projections

SANDAG 2020 and 2030 projections were used to calculate the percent change in population from 2015, by age group. The 2015 to 2020 percent change for the 55-64, 65-74, 75-84, and 85 years and older age group populations of each sub-regional (SRA) was applied to the 2015 ADRD prevalence estimates and ADRD medical encounters for the corresponding SRA to obtain the 2020 ADRD prevalence estimates and ADRD discharges by SRA and Health and Human Services Agency Regions. ADRD projections for SRAs within each region were summed to find the projection for the corresponding Health and Human Services Agency Region. The regions' populations were summed to determine the projection for San Diego County. This method was repeated using the 2030 population projections to obtain the 2030 ADRD prevalence estimates. The same methodology was applied to the hospitalizations and emergency department discharges to obtain medical encounter projections for 2030. Additionally, the same methodology was applied to caregiving to find the 2030 projections of caregiving costs, value of care, and caregiver health care costs for San Diego County and the Health and Human Services Agency Regions.

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Cost or Charge Estimates

To estimate the current and projected lifetime costs for ADRD, the prevalence estimates for the regions and the county were multiplied by a published annual, per person estimate of the monetary cost attributable to dementia after diagnosis.³ This annual cost (in 2015 dollars) included the direct and indirect medical costs, as well as loss of income and productive services to the market economy, including valuation of forgone caregiver wages.

Hospitalization charges for San Diego County residents, treated in San Diego County, were calculated using the 2015 patient discharge total charges. Charges were summed by Health and Human Services Agency Regions and county-wide using the patient's zip code of residence. Median charges were calculated based on total reported charges per hospitalization. Average charges were reported only when both upper and lower outliers for these total charges were removed. To project hospitalization charges, the current 2015 average charge for ADRD discharges among residents 55 years and older was multiplied by the 2020 and 2030 hospitalization projections.

The same methodology was used as foundation for caregiving costs estimates. A proportion was used to estimate the caregiving costs for each of the Health and Human Services Agency Regions from the known San Diego County value.

International Classification of Disease (ICD)-9 and ICD-10 Codes

The ICD-9 CM codes used to define Alzheimer's disease and related dementias are listed in the table below:

ICD-9 Codes	ICD-9 Name
290	DEMENTIAS
294	PERSISTENT MENTAL DISORDERS DUE TO CONDITIONS CLASSIFIED ELSEWHERE
331	OTHER CEREBRAL DEGENERATIONS
332	PARKINSON'S DISEASE
797	SENILITY WITHOUT MENTIONAL OF PSYCHOSIS

DATA GUIDE AND DEFINITIONS

The ICD-10 CM codes used to define Alzheimer's disease and related dementias are listed in the table below:

ICD-10 Codes	ICD-10 Name
A81.00-.09	CREUTZFELDT-JAKOB DISEASE
F01	VASCULAR DEMENTIA
F02	DEMENTIA IN OTHER DISEASES CLASSIFIED ELSEWHERE
F03	UNSPECIFIED DEMENTIA
F04	AMNESTIC DISORDER DUE TO KNOWN PHYSIOLOGICAL CONDITION
F06.0	PSYCHOTIC DISORDER WITH HALLUCINATIONS DUE TO KNOWN PHYSIOLOGICAL CONDITION
F06.8	OTHER SPECIFIED MENTAL DISORDERS DUE TO KNOWN PHYSIOLOGICAL CONDITION
G10	HUNTINGTON'S DISEASE
G20	PARKINSON'S DISEASE
G21.11	NEUROLEPTIC INDUCED PARKINSONISM
G21.19	OTHER DRUG INDUCED SECONDARY PARKINSONISM
G21.8	OTHER SECONDARY PARKINSONISM
G30	ALZHEIMER'S DISEASE
G31.01-.09	FRONTOTEMPORAL DEMENTIA
G31.1	SENILE DEGENERATION OF BRAIN, NOT ELSEWHERE CLASSIFIED
G31.83	DEMENTIA WITH LEWY BODIES
G31.84	MILD COGNITIVE IMPAIRMENT, SO STATED
G91.2	(IDIOPATHIC) NORMAL PRESSURE HYDROCEPHALUS
G94	OTHER DISORDERS OF BRAIN IN DISEASES CLASSIFIED ELSEWHERE
R41.81	AGE-RELATED COGNITIVE DECLINE

The ICD-10 mortality codes used to define Alzheimer's disease and related dementias are listed in the table below:

ICD-10 Codes	ICD-10 Name
A81.0	CREUTZFELDT-JAKOB DISEASE
F01	VASCULAR DEMENTIA
F03	UNSPECIFIED DEMENTIA
F04	ORGANIC AMNESIC SYNDROME, NOT INDUCED BY ALCOHOL/OTHER PSYCHOACTIVE SUBSTANCES
F05.1	DELIRIUM SUPERIMPOSED ON DEMENTIA
F06.7	MILD COGNITIVE DISORDER
F06.8	OTHER SPECIFIED MENTAL DISORDERS DUE TO BRAIN DAMAGE AND DYSFUNCTION AND TO PHYSICAL DISEASE
F06.9	UNSPECIFIED MENTAL DISORDER DUE TO BRAIN DAMAGE AND DYSFUNCTION AND TO PHYSICAL DISEASE
G10	HUNTINGTON'S DISEASE
G20-G21	PARKINSON'S DISEASE & SECONDARY PARKINSONISM
G30	ALZHEIMER'S DISEASE
G31	OTHER DEGENERATIVE DISEASES OF NERVOUS SYSTEM, NOT ELSEWHERE CLASSIFIED
G91.2	NORMAL-PRESSURE HYDROCEPHALUS
R54	SENILITY

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The ICD-9 codes used to define Septicemia, as defined by the Agency for Healthcare Research and Quality's Clinical Classification Software, are:

3.1, 20.2, 22.3, 36.2, 38, 38.1, 38.10, 38.11, 38.12, 38.19, 38.2, 38.3, 38.4, 38.41, 38.42, 38.43, 38.44, 38.49, 38.8, 38.9, 54.5, 449, 790.7, 995.91, 995.92, 771.81

The ICD-9 codes used to define Urinary Tract Infections, as defined by the Agency for Healthcare Research and Quality's Clinical Classification Software, are:

32.84, 590.0, 590.01, 590.1, 590.11, 590.2, 590.3, 590.8, 590.81, 590.9, 595.0, 595.1, 595.2, 595.3, 595.4, 595.81, 595.82, 595.89, 595.9, 597.0, 597.8, 597.81, 597.89, 598.0, 598.01, 599.0

The ICD-9 codes used to define Hip Fractures, as defined by the Agency for Healthcare Research and Quality's Clinical Classification Software, are:

820.00, 820.01, 820.02, 820.03, 820.09, 820.10, 820.11, 820.12, 820.13, 820.19, 820.20, 820.21, 820.22, 820.30, 820.31, 820.32, 820.8, 820.9, 905.3, V54.13, V54.23

The ICD-10 codes used to define Septicemia, as defined by the Agency for Healthcare Research and Quality's Clinical Classification Software, are:

A021, A207, A227, A267, A327, A392, A393, A394, A400, A401, A403, A408, A409, A4101, A4102, A411, A412, A413, A414, A4150, A4151, A4152, A4153, A4159, A4181, A4189, A419, A427, A5486, B007, B377, I76, P360, P3610, P3619, P362, P3630, P3639, P364, P365, P368, P369, R6520

The ICD-10 codes used to define Urinary Tract Infections, as defined by the Agency for Healthcare Research and Quality's Clinical Classification Software, are:

A3685, N10, N110, N111, N118, N119, N12, N136, N151, N3000, N3001, N3010, N3011, N3020, N3021, N3030, N3031, N3040, N3041, N3080, N3081, N3090, N3091, N340, N341, N342, N343, N35111, N35112, N35113, N35114, N35119, N3512, N37, N390, Z87440

The ICD-10 codes used to define Hip Fractures, as defined by the Agency for Healthcare Research and Quality's Clinical Classification Software, are:

M84350K, M84350P, M84351A, M84351D, M84351G, M84351K, M84351P, M84351S, M84352A, M84352D, M84352G, M84352K, M84352P, M84352S, M84353A, M84353D, M84353G, M84353K, M84353P, M84353S, M84359A, M84359D, M84359G, M84359K, M84359P, M84359S, S72001A, S72001B, S72001C, S72001D, S72001E, S72001F, S72001G, S72001H, S72001J, S72001K, S72001M, S72001N, S72001P, S72001Q, S72001R, S72001S, S72002A, S72002B, S72002C, S72002D, S72002E, S72002F, S72002G, S72002H, S72002J, S72002K, S72002M, S72002N, S72002P, S72002Q, S72002R, S72002S, S72009A, S72009B, S72009C, S72009D, S72009E, S72009F, S72009G, S72009H, S72009J, S72009K, S72009M, S72009N, S72009P, S72009Q, S72009R, S72009S, S72011A, S72011B, S72011C, S72011D, S72011E, S72011F, S72011G, S72011H, S72011J, S72011K, S72011M, S72011N, S72011P, S72011Q, S72011R, S72011S, S72012A, S72012B, S72012C, S72012D, S72012E, S72012F, S72012G, S72012H, S72012J, S72012K, S72012M, S72012N, S72012P, S72012Q, S72012R, S72012S, S72019A, S72019B, S72019C, S72019D, S72019E, S72019F, S72019G, S72019H, S72019J, S72019K, S72019M, S72019N, S72019P, S72019Q, S72019R, S72019S, S72021A, S72021B, S72021C, S72021D, S72021E, S72021F, S72021G, S72021H, S72021J, S72021K,

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