



# Conquering the Specter of Alzheimer's Disease in South Carolina



**The Purple Ribbon  
Alzheimer's  
Task Force**

**March 1, 2009**



**State of South Carolina**  
**Office of The Lieutenant Governor**

André Bauer  
Lieutenant Governor

Office on Aging  
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**Transmittal Letter**

*To Members of the S.C. Senate and House of Representatives*

The Purple Ribbon Task Force was created by concurrent resolution S.1333 adopted by the General Assembly on June 3, 2008, requesting the Lt. Governor's Office on Aging convene this body to study the current and future impact of Alzheimer's disease in South Carolina and to assess the resources for and the needs of persons with Alzheimer's and related disorders (ARD) so as to develop a state strategy to address this health issue. In fulfillment of this endeavor the Purple Ribbon Task Force is pleased to submit our final report entitled "Conquering the Specter of Alzheimer's Disease in South Carolina".

It has been more than fifteen years since the Blue Ribbon Task Force submitted South Carolina's first state plan to address Alzheimer's disease and related disorders. From that initial plan the Alzheimer's Resource Coordination Center was created, along with a program to fund seed grants for respite and/or education programs within South Carolina. This initiative is housed within the Lt. Governor's Office on Aging. Great strides have been made in service to individuals with Alzheimer's disease and their families and caregivers. However, there is still much work to be done. The current Purple Ribbon Task Force adopted a multidisciplinary approach, through representation from the public and private sectors, to formulate recommendations in a holistic approach. The recommendations cover diverse topics and initiatives important to comprehensive services to individuals with Alzheimer's disease, their families and caregivers.

In light of the current economic situation, the Purple Ribbon Task Force is offering several recommendations that we believe can be carried out through existing infrastructure, thus lessening the fiscal impact to those involved. Full implementation of all of the recommendations in the report, however, will certainly require funding. This funding will enable local and statewide activities in furtherance of the objective to provide comprehensive, meaningful, and greatly needed services to individuals with Alzheimer's disease, their families and caregivers. As implementation progresses, the Alzheimer's Resource Coordination Center will utilize the collective expertise of stakeholders to provide an estimate of projected costs associated, ensuring that subsequent policy changes or additional requirement identify sufficient funding for implementation.

The Task Force appreciates the opportunity provided by the General Assembly to confront the specter of Alzheimer's disease in South Carolina. Dedicated Task Force members representing state agencies, academic institutions, and private entities and individuals brought a wealth of knowledge and experience to this vital undertaking. The

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Task Force would also like to take this opportunity to express their appreciation and thanks to Anne Wolf, Alzheimer's Program Manager for the Lt. Governor's Office on Aging, who functioned as the executive director of the task force. Her leadership and guidance were indispensable throughout this process. In addition, we thank Anne and Beth Murff Sulkowski for authoring the final document.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Tony Kester". The signature is fluid and cursive, with a long horizontal stroke extending to the left.

Tony Kester  
Interim Director, Lt. Governor's Office on Aging  
Chair, Purple Ribbon Task Force

## **The Purple Ribbon Task Force**

Comprised of individuals representing diverse public and private stakeholders, the Purple Ribbon Task Force conducted its work diligently toward their determined mission and vision. The Task Force held five full task force meetings as well as numerous subcommittee meetings over the course of the endeavor. Meeting minutes are available upon request from the Lt. Governor's Office on Aging, Alzheimer's Resource Coordination Center.

**The Mission** of the Purple Ribbon Task Force is to study the current and future impact of Alzheimer's disease and related disorders (ADRD) in South Carolina, assess the resources for and needs of persons with ADRD and their caregivers, and recommend a state strategy to address this public health issue.

**Our vision** is a comprehensive, coordinated, accessible system providing information, education and support to improve the lives of persons with ADRD and their caregivers.

### **Task Force Members:**

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## PREFACE

This is an extraordinary time in your lives and mine. We are poised at the precipice of change in preparing our state for the silver tsunami that is coming. The age wave has crashed to shore and we are not ready. Alzheimer's disease and the dementias are on the rise and we are not completely sure why. People are showing symptoms earlier and earlier and we can't seem to stop it.

But you have shown up and owned this challenge. You have created a task force of passionate and purposeful people who opened their hearts and minds and rolled up their sleeves to create a new, innovative plan for our state. There is not a more urgent cause. My family and I are very proud and deeply grateful for this opportunity for South Carolina to lead and set the standard for care and management of Alzheimer's disease. We honor the heroic souls who came together and worked so hard to present this plan.

As you read this, think about the day your child was born, your silver wedding anniversary, your baby's christening. Think about your mother's laugh, your father's embrace. Recall your college graduation or that first spin in the car after you got your driver's license. Now imagine all those memories are gone. Vanished, deleted from your mental bank. The places you've gone, the people you love, the dreams you have.....that's what makes us who we are ...that's our soulprint. It's unbearably cruel when Alzheimer's disease breaks in and steals the memories and rewrites the pages of our lives. Ronald Reagan, Carroll Campbell, my mom and the 5 million others who have faced death in slow motion stand as reminders of what we have failed to do.

When my mother grew up in our beautiful Palmetto state, she wanted to be a mom. That dream blossomed alongside my amazing father and they created a rich, full life and three children. In the end, she didn't know any of us. She didn't just forget our names, but the fact that we even existed. Memory by memory, she was taken over a period of 10 years and my brother, my sister and I watched a part of my Dad die too. Her laugh grew silent, her eyes vacant and her steps, unsteady. Then she hunched over and drooled through most of the day and fell off the bed at night until she finally slept on the floor getting up to have her diaper changed and be strapped into a chair for another day of nothing.

She knew where she was headed. She saw her own mother lose her battle with the thief. On the day of granny's funeral my mom had just been diagnosed with the disease that took her mother's life. The casket was open as wide as my mother's eyes as she looked at the lifeless figure there. I watched my mom as she watched over hers. A preview of things to come? The fog had rolled into the lives of two generations of women in my family and I was intent to find a way to make it burn off.

Mom had the steel magnolia strength that only women in the south seem to possess. She tempered it with kindness and encouragement. When she was diagnosed with Alzheimer's disease she stood alone in her empowerment for a time, while the rest of us pulled up the secure blanket of denial. As she headed deeper into the darkness of her disease, she somehow managed to get us to wake up and we became her caregivers and legacy keepers.

“You’ve reported on a lot of stories in your career, honey”, she told me. “Now go tell this one. Use it to inspire and make it count.”

That is where the Leeza Gibbons Memory Foundation really began; in my mom’s courage and her simple direction. I promised Mom that I would tell the story and we began to honor that promise through Leeza’s Place, where we offer free services to caregivers and their loved ones facing any chronic illness or disease. Our living room settings are much like mom’s kitchen-the door is always open and the coffee is always on.

In the years since we formed our nonprofit, I have become somewhat of a reluctant expert in Alzheimer’s disease. I have cried with many families and relied on faith and hope when it seemed answers were nowhere to be found. Being a caregiver means you carry a load that is extremely heavy and you often don’t see the burden it places on your own mind, body and soul.

My forward thinking parents taught me to embrace change. Every family who navigates through the treacherous waters of Alzheimer’s is intimate with change. We are ready to say that it’s no longer acceptable to wait for someone else to tackle this long goodbye. It’s no longer an option to look away and ignore how much it costs the state and how much it costs families in lost jobs, stress related disorders and frayed nerves. This disease bankrupts spiritually, emotionally, physically and mentally. Things have got to change.

I believe that those who are forgetting should not be forgotten and that no caregiver should ever be alone. I believe that a heart never forgets and that love is love...it transcends this heinous disease. I believe that it will take the brilliance and energy and innovation and dedication of this group and many others locking elbows and staring this thief down to create a world free of memory loss.

My brother and sister and I used to wonder if we would ever get Daddy back from the grips of this thief that had stolen his wife. All too often caregivers are the victims of compassion fatigue. Then Daddy engaged in the work of this task force and he’s walking on a new path now. It’s one where the next step is supported by like minded people all dedicated to the same goal; proudly presenting our great state with this comprehensive plan.

So here we are; looking at the next few years and wondering if we have done everything we can to offer comfort and care, help and hope to families who often feel frustrated and alone. Thanks to the work we present to you in this report, we can dig deep into our hearts and say, “We have done our best”. As my mom used to tell me, “that’s good enough for God and everybody”.

Ever forward,

A handwritten signature in dark ink, appearing to read 'Leeza Gibbons', written in a cursive style.

Leeza Gibbons

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## EXECUTIVE SUMMARY

On June 3, 2008 the General Assembly of South Carolina passed a concurrent resolution to form a Purple Ribbon Task Force to study the current and future impact of Alzheimer's disease in South Carolina and to assess the resources for and the needs of persons with Alzheimer's disease and related disorders (ADRD).

Building upon the groundwork laid by the Blue Ribbon Task Force in 1993, the Purple Ribbon Task Force studied the current infrastructure of services to Alzheimer's patients, their families and caregivers. Based on this information, the Purple Ribbon Task Force brought forth recommendations to fill gaps in services and to comprehensively address the wide-ranging needs of individuals with Alzheimer's disease, their families and caregivers. Recommendations cover diverse aspects of addressing Alzheimer's disease, as well as an estimated time frame to implement the recommendations and suggested parties to be responsible for implementation.

The most recent estimates from the Alzheimer's Association show that more than 5 million Americans are living with Alzheimer's disease. In South Carolina there are an estimated 67,000 individuals with Alzheimer's disease or a related disorder as of the year 2000. That number is expected to increase by 19% by the year 2010, at which point an estimated 80,000 South Carolinians will be living with the disease. In addition, in 2007 there were 159,221 family caregivers of individuals with dementia in South Carolina<sup>1</sup>.

The impact of Alzheimer's disease is felt beyond those who are directly impacted. Caregivers who have full time employment must often cut their work hours or discontinue working altogether to attend to the needs of their loved ones with ADRD. Nationally, the financial toll taken on Medicare, Medicaid and businesses is estimated by the Alzheimer's Association to be more than \$148 billion annually.

While there are an array of services and facilities in South Carolina, not all provide Alzheimer's specific programs and services. According to the records of the SC Department of Health and Environmental Control, there are currently 195 nursing homes in the state; of those, 28 reportedly provide Alzheimer's care and 18 report having an Alzheimer's unit. Of 488 community residential care facilities, 112 reportedly provide Alzheimer's care and 65 report having an Alzheimer's unit. There are also 97 adult day care centers reported, but no data is available on availability of dementia-related services<sup>2</sup>.

It is also significant to note that 70% of people with ADRD live at home, where family and friends provide most of their care and pay for it out of their own pockets<sup>3</sup>. Caregivers of family members with dementia face an enormous physical, emotional and financial impact associated with caring for a loved one, and local support services are vital to these family caregivers. While many resources are available in the state, it is often difficult for overwhelmed caregivers to identify and access these services.

The following recommendations were generated by four subcommittees within the Task Force, which focused on the areas of Medical and Long-Term Care, Outreach and Education, Data and Research, and Case Management and Assistance for Caregivers. The recommendations are divided by the suggested time frame for implementation.

The Alzheimer's Resource Coordination Center, housed within the Lt. Governor's Office on Aging, will act as the overall facilitator for the recommendations, with key participants proposed under each recommendation. The term "Responsible Party" identifies suggested agencies or entities that may be appropriate for assuming responsibility for implementation of these recommendations. The parties identified are by suggestion of the Task Force, and the agencies or entities named have not provided a formal review or approval of the recommendations.

*For full details and rationale, please view Chapter 3 of this report.*

### **For implementation in 1-2 years:**

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#### **Recommendation 1.**

Create a single point of entry for persons seeking assistance with Alzheimer's related needs utilizing a toll free number through the Lt. Governor's Office on Aging.

#### **Recommendation 2.**

Provide appropriate referrals for hospice care for people with Alzheimer's disease and aftercare for the caregivers of persons with ADRD.

#### **Recommendation 3.**

Expand the scope of data included in the Alzheimer's Disease Registry, to include increased sources of data and result in greater capacity to identify gaps in services available.

#### **Recommendation 4.**

Utilize existing health data dissemination infrastructure to integrate information on Alzheimer's disease and related disorders.

#### **Recommendation 5.**

Generate state level work with health disparities for minorities that is inclusive of Alzheimer's disease.

#### **Recommendation 6.**

Promote education and provide resource protection and tax credits for long term care planning and long term care insurance purchase.

#### **Recommendation 7.**

Implement a Silver Alert Program in South Carolina for the rapid recovery of adults with cognitive impairment who may wander and become lost.

**Recommendation 8.**

Establish standards for dementia-specific training for staff of any state licensed entity, including but not limited to nursing homes, community residential care facilities, home health agencies, hospice, or adult day care centers that provide for care of individuals with ADRD.

**Recommendation 9.**

Promote and support the use of home and community based services that enable families and caregivers to have the option to care for their loved ones with ADRD at home, allowing them to age in place for as long as practicable.

**For implementation in 3-5 years:**

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**Recommendation 10.**

Provide case management and person centered support services to persons with Alzheimer’s Disease and related disorders (ADRD) and their caregivers through a local/regional provider network.

**Recommendation 11.**

Identify and disseminate research findings on promotion of brain health and reduction of risk factors for Alzheimer’s disease.

**Recommendation 12.**

Track research being done in the state and educate the public so they will be knowledgeable and can be involved in research if that is their choice. Make available the Alzheimer’s disease research directory so that prospective participants could access current information on available opportunities.

**Recommendation 13.**

Conduct focus groups across the state with professionals and consumers, to include caregivers, as well as those with early stage Alzheimer’s disease so as to determine service needs and recommend system changes.

**Recommendation 14.**

Expand training on Alzheimer’s disease and related disorders (ADRD) and enhance accessibility for personnel in the justice system as well as first responders (i.e. EMS, firefighters).

**Recommendation 15.**

Incorporate mandatory training modules and continuing education on ADRD for medical school students, licensed doctors, and licensed nurses of all disciplines.

**Recommendation 16.**

Build on existing DHEC reporting requirements for specific criteria for designation as a Special Care Unit.

**Recommendation 17.**

Create public service announcements and advertisements to educate and enhance awareness of Alzheimer’s disease and available resources.

**Recommendation 18.**

Address the unique service needs of persons with ADRD who exhibit combative or other aggressive behaviors, to include:

- The consideration of publicly funded specialized services which meet Medicare standards for persons throughout the state who have a diagnosis of Alzheimer’s disease or related disorders (ADRD) and whose assaultive or combative behaviors preclude care in traditional nursing home settings.
- The consideration of an incentive for current providers that offer appropriate settings for short-term stabilization or rehabilitation.

**For implementation in 6-10 years:**

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**Recommendation 19.**

Create a brain bank in South Carolina for research purposes.

**Recommendation 20.**

Promote and support private and public sector businesses in addressing the needs of employees who are caregivers to persons with ADRD through the use of on-site respite, support groups, or other initiatives.

## Chapter 1

### Introduction to Alzheimer's Disease Background, Prevalence, and Impact on South Carolina Residents

#### Background

Alzheimer's (*AHLZ-high-merz*) disease is a complex, progressive disease that destroys cells in the brain. Contrary to a common misconception, Alzheimer's disease is not a normal part of aging. According to the Alzheimer's Association, common symptoms of the disease include gradual memory loss, problems with reasoning or judgment, disorientation, difficulty in learning, loss of language skills and decline in the ability to perform routine tasks. People with Alzheimer's also experience changes in their personalities and behavior, such as agitation, anxiety, delusions and hallucinations.

Alzheimer's is a terminal illness. The duration of the disease varies from three to 20 years; the average duration is about eight years<sup>4</sup>. The loss of brain cells typically begins with memory centers, gradually leading to the failure of other systems in the body. Eventually, the person with Alzheimer's will need complete care. In the absence of other serious illness, the loss of brain function itself will cause death; however, pneumonia and other illnesses are commonly found to be the primary cause of death for individuals with dementia.

Alzheimer's disease is the most common form of dementia, accounting for 50 to 70 percent of cases<sup>5</sup>. Dementia is a general term for a group of brain disorders that affect memory, judgment, personality and other mental functions. Vascular dementia, another common form, results from reduced blood flow to the brain's nerve cells. In some cases, Alzheimer's disease and vascular dementia can occur together in a condition called "mixed dementia." Other causes of dementia include, but are not limited to, frontotemporal dementia, dementia with Lewy bodies, Creutzfeldt-Jakob disease and Parkinson's disease.

#### Prevalence

According to the 2008 Alzheimer's Association *Alzheimer's Disease Facts and Figures*, there are as many as 5.2 million Americans living with Alzheimer's. In 2050, the number of people in the United States with Alzheimer's could reach 16 million. While age is the greatest known risk factor, the development of Alzheimer's disease is not limited to older people: an estimated 500,000 Americans in their 30s, 40s and 50s have Alzheimer's or a related dementia. When Alzheimer's is first recognized in a person under age 65, this is referred to as "early-onset" or "younger-onset" Alzheimer's.<sup>6</sup>

According to the latest statistics from the Centers for Disease Control and Prevention, Alzheimer's disease is currently the sixth-leading cause of death in the United States.

From 2000-2005 death rates have declined for most major diseases -- heart disease (-8.6 percent), breast cancer (-.8 percent), prostate cancer (-4.9 percent) and stroke (-14.4 percent), while Alzheimer's disease deaths continue to trend upward, increasing 45 percent during that period<sup>7</sup>.

In the state of South Carolina alone, there were an estimated 67,000 individuals with Alzheimer's or related dementia in the year 2000. It is expected that the number of people impacted will grow 19% by the year 2010, at which point an estimated 80,000 South Carolinians will be living with the disease<sup>8</sup>.

The South Carolina Alzheimer's Disease Registry, which records diagnosed cases of Alzheimer's disease and related dementia, acknowledges the difficulty of definitively knowing the number of South Carolinians affected. In its 2007 Annual Report, the Registry shows that 56,754 South Carolinians were living with a diagnosis of Alzheimer's or related dementia; the report, however, cites a study suggesting that the total number of individuals who have dementia may be nearly 50% greater than the number that have been diagnosed<sup>9</sup>.

The Alzheimer's Association estimates that the direct and indirect costs of Alzheimer's disease and other dementias to Medicare, Medicaid and businesses amount to more than \$148 billion annually. By 2030, when the baby boom generation is over age 65, the number of Americans with Alzheimer's will soar to levels that may exceed our ability to absorb the added cost and bankrupt our health care system<sup>10</sup>.

### **Causes and Risk Factors of Alzheimer's Disease**

Scientists regard two abnormal microscopic structures called "plaques" and "tangles" as the hallmarks of Alzheimer's disease. Amyloid plaques (AM-uh-loyd plaks) are clumps of protein fragments that accumulate between the brain's nerve cells. Tangles are twisted strands of another protein that form inside brain cells. Scientists have not yet determined the exact role that plaques and tangles may play, but most believe that these proteins play a key role in blocking neuron communication and otherwise disrupting vital cell processes<sup>11</sup>.

As a result, the cause of Alzheimer's disease remains unknown in a vast majority of cases. Most experts agree that Alzheimer's, as with other common, chronic conditions, likely develops as a result of multiple factors rather than a single cause. The greatest risk factor by far is increasing age. Most Americans with Alzheimer's disease are age 65 or older.

When Alois Alzheimer first described Alzheimer's disease in 1906, a person in the United States lived an average of about 50 years<sup>12</sup>. Few people reached the age of greatest risk. As a result, the disease was considered rare and attracted little scientific interest. However, as life span increased, scientists began to realize how often Alzheimer's strikes people in their 70s and 80s. In an analysis of data from 2005, the U.S.

Department of Health and Human Services recently estimated average life expectancy to be 77.8 years<sup>13</sup>.

A small percentage of Alzheimer's disease is caused by rare genetic variations found in a few hundred families worldwide. In these inherited forms of Alzheimer's, the disease tends to strike younger individuals. When Alzheimer's is first recognized in a person under age 65, this is referred to as "early-onset" or "younger-onset" Alzheimer's. It is estimated that up to 500,000 Americans are currently living with younger-onset Alzheimer's or another dementia<sup>14</sup>.

Lifestyle choices and chronic health conditions have also been observed to increase an individual's risk of developing Alzheimer's disease or related dementia. In a recent public awareness campaign specifically developed for African-American outreach, the American Heart Association, American Stroke Association, and Alzheimer's Association highlighted the interconnectivity of heart health and brain health. Because African-Americans have an increased risk of developing diabetes, high blood pressure, high cholesterol and stroke, they are also at increased risk of developing Alzheimer's disease and related dementia<sup>15</sup>. The South Carolina Alzheimer's Disease Registry clearly demonstrates the increased risk; African Americans, who comprised nearly 21% of the adult South Carolina population 65 years and older in 2005, made up 43% of documented Vascular dementia diagnoses and 33% of the overall Alzheimer's Disease Registry<sup>16</sup>.

### **Warning Signs of Alzheimer's Disease**

Some changes in memory are normal as we grow older, but symptoms of Alzheimer's disease are more than simple lapses in memory. Persons with Alzheimer's experience difficulties communicating, learning, thinking, and reasoning – problems severe enough to have an impact on daily life.

The Alzheimer's Association has developed the following checklist of common symptoms to help individuals, family members, and healthcare professionals recognize the warning signs of Alzheimer's<sup>17</sup>.

**1. Memory loss.** Forgetting recently learned information is one of the most common early signs of dementia. A person begins to forget more often and is unable to recall the information later.

*What's normal? Forgetting names or appointments occasionally.*

**2. Difficulty performing familiar tasks.** People with dementia often find it hard to plan or complete everyday tasks. Individuals may lose track of the steps involved in preparing a meal, placing a telephone call or playing a game.

*What's normal? Occasionally forgetting why you came into a room.*

**3. Problems with language.** People with Alzheimer’s disease often forget simple words or substitute unusual words, making their speech or writing hard to understand. They may be unable to find the toothbrush, for example, and instead ask for “that thing for my mouth.”

*What’s normal? Sometimes having trouble finding the right word.*

**4. Disorientation to time and place.** People with Alzheimer’s disease can become lost in their own neighborhoods, forget where they are and how they got there, and not know how to get back home.

*What’s normal? Forgetting the day of the week or where you were going.*

**5. Poor or decreased judgment.** Those with Alzheimer’s may dress inappropriately, wearing several layers on a warm day or little clothing in the cold. They may show poor judgment about money, like giving away large sums to telemarketers.

*What’s normal? Making a questionable or debatable decision from time to time.*

**6. Problems with abstract thinking.** Someone with Alzheimer’s disease may have unusual difficulty performing complex mental tasks, like forgetting what numbers are and how they should be used.

*What’s normal? Finding it challenging to balance a checkbook.*

**7. Misplacing things.** A person with Alzheimer’s disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl.

*What’s normal? Misplacing keys or a wallet temporarily.*

**8. Changes in mood or behavior.** Someone with Alzheimer’s disease may show rapid mood swings – from calm to tears to anger – for no apparent reason.

*What’s normal? Occasionally feeling sad or moody.*

**9. Changes in personality.** The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful or dependent on a family member.

*What’s normal? People’s personalities do change somewhat with age.*

**10. Loss of initiative.** A person with Alzheimer’s disease may become very passive, sitting in front of the TV for hours, sleeping more than usual or not wanting to do usual activities.

*What’s normal? Sometimes feeling weary of work or social obligations.*

## **Diagnosing Alzheimer’s Disease**

Early and accurate diagnosis of Alzheimer’s disease or other dementias is an important step to getting the right treatment, care and support. Timely identification enables individuals to take an active role in treatment decisions and planning for the future.



Available treatment options also offer the best possible quality of life when implemented early in the course of the disease.

Experts estimate that a doctor experienced in diagnosing Alzheimer's can make a diagnosis with more than 90 percent accuracy<sup>18</sup>. Because there is no single test for Alzheimer's, diagnosis usually involves a thorough medical history and physical examination as well as tests to assess memory and the overall function of the mind and nervous system. The doctor may ask a family member or close friend about any noticeable change in the individual's memory or thinking skills. Most diagnostic uncertainty arises from occasional difficulty distinguishing Alzheimer's disease from a related dementia.

It is important to consult a physician when there are memory concerns, because it is possible that symptoms may be due to a condition other than Alzheimer's. Depression, medication side effects, certain thyroid conditions, excess use of alcohol and nutritional imbalances are all potentially treatable disorders that may sometimes impair memory or other mental functions.

### **Impact of Living with Alzheimer's Disease**

Due to changes in the brain, people with Alzheimer's will eventually lose sense of who they are and the ability to care for themselves. The disease affects independence, relationships and the ability to express oneself. Individuals in the early stages of the disease often have difficulty coping with the diagnosis, and many experience periods of depression and denial.

Younger individuals who are diagnosed with the disease can also face other issues. If employed, the individual may have to reduce work hours or quit, leaving a gap in the family income and losing insurance coverage. Insurance and other benefits may be more difficult to get to help pay for care, due to age-minimums and mandatory waiting periods for program access. These difficulties are compounded when dependent children are still living at home.

### **Caring for Persons with Alzheimer's Disease**

Caregivers of family members with dementia face an enormous physical, emotional and financial impact associated with caring for a loved one. Seventy percent of people with Alzheimer's disease live at home, where family and friends provide most of their care and pay for it out of their own pockets.

In South Carolina alone, there were 159,221 family caregivers of individuals with dementia in the year 2007. These caregivers provided an estimated 137,439,556 hours of unpaid care for their loved ones, at a cumulative value of \$1,454,110,507<sup>19</sup>.

Caring for a person with Alzheimer's disease or another dementia poses unique challenges, with individuals requiring increasing levels of supervision and personal care. Many family caregivers commit multiple years to providing care, often to the detriment of their own physical, emotional and mental well-being. The *2008 Alzheimer's Disease Facts and Figures Report* found that one-third of these family caregivers have symptoms of depression, and that all were at increased risk to have high levels of stress hormones, reduced immune function, slow wound healing, new hypertension and new coronary heart disease. Caregiver stress, especially stress related to behavioral symptoms of the person with dementia, has been associated with nursing home placement<sup>20</sup>.

As Alzheimer's disease progresses, most families find that their loved ones require full-time professional care. According to the 2008 Alzheimer's Association *Alzheimer's Disease Facts and Figures Report*, there were 36,035 individuals living in skilled nursing facilities in South Carolina in the year 2006. Of those residents, 72 percent of them had some form of cognitive impairment<sup>21</sup>.

The US Census estimates that by 2015 South Carolina's elder population will increase by 45.6%. As the state's population ages, the demand for skilled care, whether in-home or residential, will grow tremendously. However, the Paraprofessional Healthcare Institute projects that by 2016, women aged 25–54 (the traditional labor pool for direct care workers) is projected to increase by less than 1 percent, down from over 18 percent just two decades ago<sup>22</sup>. With the number of those with some degree of cognitive impairment continuing to escalate, the need for direct care workers in the future will be more urgent than ever.

## **Stages of Alzheimer's Disease**

The general progression of Alzheimer's disease may be tracked by common patterns of symptoms and behaviors. While each person with Alzheimer's disease or related dementia will experience a unique progression of cognitive loss, generalized "scaling" methods have been developed that follow the progression of nerve cell degeneration.

The following stages of Alzheimer's disease progression are based on a system developed by Barry Reisberg, M.D., Clinical Director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center, and are currently used by the Alzheimer's Association<sup>23</sup>.

### **Stage 1: No cognitive impairment**

Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

### **Stage 2: Very mild decline**

Individuals at this stage feel as if they have memory lapses, forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems

are not evident during a medical examination or apparent to friends, family or co-workers.

### **Stage 3: Mild cognitive decline**

Early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms:

Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:

- Word- or name-finding problems noticeable to family or close associates
- Decreased ability to remember names when introduced to new people
- Performance issues in social and work settings noticeable to others
- Reading a passage and retaining little material
- Losing or misplacing a valuable object
- Decline in ability to plan or organize

### **Stage 4: Moderate cognitive decline**

(Mild or early-stage Alzheimer's disease)

At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- Decreased knowledge of recent events
- Impaired ability to perform challenging mental arithmetic. For example, to count backward from 100 by 7s
- Decreased capacity to perform complex tasks, such as marketing, planning dinner for guests, or paying bills and managing finances
- Reduced memory of personal history
- The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations

### **Stage 5: Moderately severe cognitive decline**

(Moderate or mid-stage Alzheimer's disease)

Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- Be unable during a medical interview to recall such important details as their current address, their telephone number, or the name of the college or high school from which they graduated
- Become confused about where they are or about the date, day of the week or season
- Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s
- Need help choosing proper clothing for the season or the occasion
- Usually retain substantial knowledge about themselves and know their own names and the names of their spouse or children
- Usually require no assistance with eating or using the toilet

### **Stage 6: Severe cognitive decline**

(Moderately severe or mid-stage Alzheimer's disease)

Memory difficulties continue to worsen, significant personality changes may emerge, and affected individuals need extensive help with daily activities. At this stage, individuals may:

- Lose most awareness of recent experiences and events as well as of their surroundings
- Recollect their personal history imperfectly, although they generally recall their own names
- Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces
- Need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet
- Experience disruption of their normal sleep/waking cycle
- Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly)
- Have increasing episodes of urinary or fecal incontinence
- Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding
- Tend to wander and become lost

### **Stage 7: Very severe cognitive decline**

(Severe or late-stage Alzheimer's disease)

This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak, and, ultimately, the ability to control movement.

- Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered
- Individuals need help with eating and toileting and there is general incontinence
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their heads up
- Reflexes become abnormal and muscles grow rigid
- Swallowing is impaired

## **Treatment and Prevention of Alzheimer's Disease**

There is currently no cure for Alzheimer's, but new treatments are on the horizon as a result of accelerating insight into the biology of the disease. The following medications approved by the U.S. Food and Drug Administration (FDA) may temporarily delay memory decline and treat Alzheimer's symptoms for some individuals, but none of the currently approved drugs is known to stop or prevent the disease.

Cholinesterase inhibitors are designed to prevent the breakdown of acetylcholine, a chemical messenger important for memory and learning. By keeping levels of

acetylcholine high, these drugs support communication among nerve cells. They delay worsening of symptoms for six to 12 months for about half of the people who take them<sup>24</sup>. Three cholinesterase inhibitors are commonly used to treat mild to moderate Alzheimer's:

Donepezil (Aricept®), FDA approved in 1996  
Rivastigmine (Exelon®), FDA approved in 2000  
Galantamine (Razadyne®), FDA approved in 2001

Another type of drug works by regulating the activity of glutamate, a different messenger chemical involved in information processing. Memantine (Namenda®) was approved by the FDA in 2003, and it is currently the only available drug in this class. Approved for treatment of moderate to severe Alzheimer's disease, memantine may also temporarily delay the worsening of symptoms for some people<sup>25</sup>.

Research has also shown that effective care and support can improve quality of life for individuals and their caregivers over the course of the disease from diagnosis to the end of life. An essential part of treatment is supportive care that helps individuals and their families come to terms with the diagnosis; obtain information and advice about treatment options; and maximize quality of life through the course of the illness.

An accelerating worldwide effort is under way to find better ways to treat the disease, delay its onset or prevent it from developing. Several drugs are in Phase III clinical trials, and many show great promise at slowing or stopping the progression of Alzheimer's disease. Some trials are being conducted locally in South Carolina, and opportunities are available for volunteers to participate in these studies (more information in Chapter 2).

### **Risk Reduction and Possible Prevention**

Many scientists consider the emerging field of prevention one of the most exciting recent developments in dementia research. Some of the most exciting preliminary evidence suggests that strategies for general healthy aging may also help reduce the risk of developing Alzheimer's. These measures include controlling blood pressure, weight and cholesterol levels; exercising both body and mind; eating a brain-healthy diet that is low in fat and includes fruits and vegetables; and staying socially active.

The Alzheimer's Association has developed Maintain Your Brain®, a public health and education campaign designed to help the public understand steps they can take now to make brain health part of their overall goals for healthy aging. These lifestyle changes boost mental health and may also reduce an individual's risk of developing Alzheimer's disease and other dementias. While there is strong evidence pointing to ways to support brain health and possibly reduce risk of dementia, there is currently no definitive way to prevent Alzheimer's, and these brain health tips cannot guarantee disease prevention.<sup>26</sup>

## **10 ways to Maintain Your Brain®**

### **1. Head first**

Good health starts with your brain. It's one of the most vital body organs, and it needs care and maintenance.

### **2. Take brain health to heart**

What's good for the heart is good for the brain. Do something every day to prevent heart disease, high blood pressure, diabetes and stroke — all of which can increase your risk of Alzheimer's.

### **3. Your numbers count**

Keep your body weight, blood pressure, cholesterol, and blood sugar levels within recommended ranges.

### **4. Feed your brain**

Research suggests that a diet rich in dark vegetables and fruits may help protect brain cells. Eat less fat and more antioxidant-rich foods.

### **5. Work your body**

Physical exercise keeps the blood flowing to the brain and may encourage new brain cells. Walking just 30 minutes a day can help keep both body and mind active.

### **6. Jog your mind**

Keeping your brain active and engaged strengthens brain cells and the connections between them, and may even trigger growth of new cells. Read, write, play games, learn new things, do crossword puzzles.

### **7. Connect with others**

Leisure activities that combine physical, mental and social elements may be most likely to prevent dementia. Be social, converse, volunteer, join a club or take a class.

### **8. Heads up! Protect your brain**

Take precautions against head injuries. Always wear a seat belt; unclutter your house to avoid falls; and wear a helmet when cycling.

### **9. Use your head**

Avoid unhealthy habits. Don't smoke, drink excessive alcohol or use street drugs.

### **10. Think ahead – start today!**

You can do something today to protect your tomorrow.

## Chapter 2

### Existing Infrastructure in South Carolina Programs, Services and Research Opportunities Currently Available to the Public

#### State Role and Infrastructure

In order to chart a future course to address Alzheimer's disease in South Carolina, it is vital to recognize the strides we have already made, as well as the tools currently available to face the journey ahead.

On April 22, 1993 Governor Carroll A. Campbell, Jr. signed Act 195 of the General Assembly, creating the Blue Ribbon Task Force. The Task Force was created to study the planning, coordination and delivery of services for individuals with Alzheimer's disease, their families and caregivers. Their work culminated in submission of the first state plan, "Gray Plague of the Twenty-first Century: Meeting the Needs of Individuals with Alzheimer's Disease, Their Families and Caregivers."

In this report, the Blue Ribbon Task Force identified five goals<sup>27</sup>:

1. To establish a single entry which shall facilitate the assessment, planning, and coordination of services to individuals with Alzheimer's disease and related disorders (ADRD), their caregivers and families.
2. To promote a comprehensive service system, with emphasis on community services in the least restrictive environment, meeting individual needs and maximizing independence. Services and strategies should be consumer focused and based on cultural sensitivity with knowledge of individual and caregiver needs.
3. To enhance data collection and utilization in order to improve the service delivery system and provide information for policy development.
4. To increase the numbers and training of professional caregivers with expertise in geriatrics and ADRD.
5. To assure that administrators of health care facilities and service providers utilize the appropriate staff and facility resources and provide staff training and continuing education relating to the special needs of ADRD individuals.

From the goals and recommendations made by the Blue Ribbon Task Force, legislation was written and enacted, creating the Alzheimer's Disease and Related Disorders Resource Coordination Center (Chapter 36, Title 44 of the 1976 Code of Laws of South Carolina, was amended by adding Article 3, Section 44-36-310 through 44-36-330). The duties of the center include:

1. To initiate the development of systems which coordinate the delivery of programs and services;
2. To facilitate the coordination and integration of research, program development, planning, and quality assurance;
3. To identify potential users of services and gaps in the service delivery system and expand methods and resources to enhance statewide services;
4. To serve as a resource for education, research, and training and provide information and referral services;
5. To provide technical assistance for the development of support groups and other local initiatives to serve individuals, families, and caregivers;
6. To recommend public policy concerning Alzheimer's disease and related disorders to state policy makers;
7. To submit an annual report to the Joint Legislative Committee on Aging and to the General Assembly.

The legislation also provided for the development of a grant program to assist communities and other entities in addressing problems relative to Alzheimer's disease and related disorders. It also created an Advisory Council for the Resource Center, comprised of representatives forming a multi-disciplinary approach to addressing Alzheimer's disease (Article 3, Sections 44-36-310 through 44-36-3300). This legislation also established the Special Care Disclosure Act, which states that facilities that provide special Alzheimer's care must provide information distinguishing Alzheimer's care from other levels of care (Article 5, Sections 44-36-510 through 44-36-520).

*To view the full text of Chapter 36, Title 44 of the 1976 Code of Laws of South Carolina, please see Appendix D.*

### **Existing State Programs**

At the initial meeting of the Purple Ribbon Task Force, an overview of the current infrastructure of aging services was provided. The following agencies, programs, and services were considered as they relate to the provision of services for individuals with Alzheimer's disease, their families and caregivers.

#### **SC Access:**

SC Access, [www.scaccesshelp.org](http://www.scaccesshelp.org), is an internet-based information resource designed to assist seniors, adults with disabilities, and their caregivers in locating a variety of services in their area and provide educational material on numerous issues. Ten regional Information and Referral Specialists, located at the Area Agencies on Aging provide personal assistance by phone or in person.



### **Aging and Disability Resource Centers:**

Created through a grant program, this cooperative effort of the Administration on Aging and the Centers for Medicare and Medicaid Services assists states in their efforts to create a single, coordinated system of information and access for all persons seeking long term support to minimize confusion, enhance individual choice, and support informed decision-making. ADRCs provide:

- Awareness & Information
  - Public Education
  - Information on Options
- Assistance
  - Referral
  - Crisis Intervention
  - Options Counseling
  - Benefits Counseling
  - Planning for Future Needs
  - Employment Options Counseling
- Access
  - Eligibility Screening
  - Private Pay Services
  - Comprehensive Assessment
  - Programmatic Eligibility Determination
  - Medicaid Financial Eligibility Determination
  - One-Stop Access to all public programs

There are currently five ADRCs in South Carolina, with offices in the following regions:

- Lower Savannah: Aiken, Allendale, Bamberg, Barnwell, Calhoun, Orangeburg
- Santee Lynches: Clarendon, Lee, Kershaw, Sumter
- Appalachia: Anderson, Cherokee, Greenville, Oconee, Pickens, Spartanburg
- Trident: Berkeley, Charleston, Dorchester
- Pee Dee: Chesterfield, Darlington, Dillon, Florence, Marlboro, Marion

### **Area Agencies on Aging:**

The Older Americans Act intends that the Area Agency on Aging (AAA) shall be the leader relative to all aging issues on behalf of all older persons in the planning and service areas (45CFR1321.53(c)). The AAA shall proactively carry out, under the leadership of the State Unit on Aging, a wide range of functions related to advocacy, planning, coordination, inter-agency linkages, information sharing, brokering, monitoring and evaluation, designed to create a comprehensive and coordinated community-based system. There are currently ten Area Agencies located throughout the state.

### **Family Caregiver Support Program:**

Administered through the Lt. Governor's Office on Aging and South Carolina's Area Agencies on Aging, the Family Caregiver Support Program provides services to help the caregiver with information, planning, problem solving, caregiver training, support groups, finding ways to take a break from caregiving (respite) and other services

designed to make caregiving a little easier, less stressful and more rewarding. The Family Caregiver Support Program helps unpaid family caregivers of adults age 60 and over; caregivers of adults with Alzheimer's disease; grandparents (55 or older) raising a grandchild under 19; and grandparents caring for an adult grandchild with a disability.

**Long Term Care Ombudsman:**

Investigates complaints and advocates for residents' rights in nursing homes, assisted living and residential care facilities as well as facilities operated or contracted for operation by the Department of Disabilities and Special Needs or the Department of Mental Health. The Friendly Visitor Program allows for "friendly visits" to residents of the facilities above who may have no family or friends.

**Community Long Term Care:**

South Carolina has provided Home and Community Based Services to older persons under the Community Long Term Care (CLTC) program since 1983. The CLTC program is housed within the SC Department of Health and Human Services, Bureau of Long Term Care Services. Community Long Term Care (CLTC) operates home and community-based waiver programs for persons eligible for institutional care such as nursing home care but who prefer to receive their services in the community. Through a process of case management and an individualized service package, waiver clients are able to successfully remain at home at a cost to Medicaid that is substantially less than the cost of institutional care.

**Alzheimer's Disease Demonstration Grant to States Project:**

In 2007, the SC Lieutenant Governor's Office on Aging received a federal grant from the Administration on Aging to provide outreach and services to individuals with Alzheimer's disease, their families and caregivers, targeting minority and/or rural populations in Charleston, Berkeley, and Dorchester counties. Outreach was focused on faith-based communities and volunteer Family Consultants were recruited to act as a bridge between the congregants and the grant partners to facilitate access to services for these minority populations. In 2008, a second federal grant was received to continue the services outlined above, as well as expand these services to provide outreach and education to primary care physicians who frequently represent the first point of contact for a newly diagnosed Alzheimer's patient.

**Alzheimer's Association - South Carolina Chapter:**

The Alzheimer's Association - South Carolina Chapter is a non-profit voluntary health organization providing resources for Alzheimer care, support and research. The mission of the Alzheimer's Association is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

The South Carolina Chapter has eight offices located throughout the state, providing:

- A 24-hour helpline (1-800-273-2555)
- Information and referral
- 90+ Caregiver support groups
- Early stage dementia support groups
- MedicAlert + Safe Return, a wanderers' safety and identification program
- Community and professional education
- Care consultation
- State and federal advocacy
- Promotion of brain health

Additionally, the Alzheimer's Association –South Carolina Chapter provides respite vouchers for full-time family caregivers through a grant from the Department of Mental Health. This program serves nearly 1500 families each year, allowing overburdened family members to take a temporary break and reduce their stress levels. Caregiver stress, especially stress related to behavioral symptoms of the person with dementia, has been associated with nursing home placement<sup>28</sup>. The goal of this program is to help full-time caregivers take needed short-term breaks, resulting in better health and, consequently, a better quality of life, both for themselves and for the individuals receiving care. By promoting the health and well-being of family caregivers, it is believed that persons with dementia will receive greater benefit from their companionship and assistance with activities of daily living.

The Alzheimer's Association website provides extensive information, including information on applying for caregiver respite: [www.alz.org/sc](http://www.alz.org/sc).

#### **South Carolina Alzheimer's Disease Registry:**

The Alzheimer's Disease Registry was established in 1988 to record specific information about South Carolinians who develop Alzheimer's disease and related disorders (ADRD). As the nation's most comprehensive registry of its kind, the Alzheimer's Disease Registry has maintained a record of diagnosed cases of ADRD in the state since 1988. On May 31, 1990, Governor Carroll A. Campbell, Jr., signed a state law authorizing the Registry. This law (R653, H4924) amended Title 44, Code of Laws of South Carolina 1976, relating to health, by adding Chapter 36 establishing a voluntary Statewide Alzheimer's Disease and Related Disorders Registry in the Arnold School of Public Health. The law has strict confidentiality requirements but does allow registry staff to contact the families and physicians of persons diagnosed as having Alzheimer's disease or a related disorder to collect relevant data and to provide information about public and private health care resources available to them<sup>29</sup>.

The Registry is maintained by the Arnold School of Public Health at the University of South Carolina, in cooperation with the SC Department of Health and Human Services, the SC Department of Mental Health, the USC School of Medicine, and the SC Office of Budget and Control. It draws from multiple data sources, including inpatient hospitalizations, mental health records, Medicaid, emergency departments, memory clinics, chart abstracts, vital records, and long-term care evaluations.

### **Alzheimer's Resource Coordination Center:**

The Alzheimer's Resource Coordination Center (ARCC) was created through legislation as a result of the Blue Ribbon Task Force report on Alzheimer's disease in 1993. The ARCC is guided by an Advisory Council and, in addition to serving as a clearinghouse for information on Alzheimer's disease and related disorders, manages a grant program to fund respite and education programs for individuals with Alzheimer's disease, their families and caregivers.

### **South Carolina State Plan on Aging, 2009-2012**

The Lieutenant Governor's Office on Aging, as the designated State Unit on Aging under the federal Older Americans Act, has in place a comprehensive State Plan on Aging, 2009-2012, which was submitted to the U.S. Administration on Aging. It builds on the U.S. Administration on Aging's Strategic Action Plan for FY 2007-2012 and addresses how South Carolina as a state will meet the five key goals of this plan:

- Goal 1:** Empower older people, their families, and other consumers to make informed decisions about, and be able to easily access existing health and long term care options
- Goal 2:** Enable seniors to remain in their own homes with high quality of life for as long as possible through the provision of home and community-based services, including supports for family caregivers
- Goal 3:** Empower older people to stay active and healthy through Older Americans Act services and the new prevention benefits under Medicare
- Goal 4:** Ensure the rights of older people and prevent their abuse, neglect and exploitation
- Goal 5:** Maintain effective and responsive management.

Within the State Plan on Aging is the plan to provide enhanced services and assistance for individuals with Alzheimer's disease and their families. The proposed strategies are:

- Expansion of the scope and mission of the ARCC to fulfill duties specified in original legislation.
- Continued funding to provide seed grants for education and/or respite programs, targeting underserved communities.
- Collaboration with the SC Alzheimer's Association on a state plan to assess current levels of activities and develop future strategies based on a global perspective of stakeholders.
- Collaboration with the Family Caregiver Support Program to obtain a comprehensive view of the need for assistance for caregivers specifically dealing with Alzheimer's disease.
- Collaboration with Aging and Disability Resource Centers to coordinate centralized service delivery for persons with Alzheimer's disease and their caregivers.

## Type and Availability of Existing Dementia Services

While there are an array of services and facilities in South Carolina, not all provide Alzheimer's specific programs and services. The following chart outlines the total numbers of nursing homes, community residential care facilities, and adult day care centers. Those facilities with an Alzheimer's unit or that provide Alzheimer's care are so designated.

**Table 1.** Dementia-Related Services Available In South Carolina<sup>30</sup>

Service Venue	Total # Served	# Facilities	Alzheimer's Care	Alzheimer's Units
Nursing Homes	19,647	195	28	18
Community Residential Care Facilities (CRCF)	16,375	488	112	65
Adult Day Care Centers	3,684	97	N/A	N/A

In addition to established facilities in South Carolina, the Alzheimer's Resource Coordination Center administers the seed grant program to fund respite centers and/or education programs for individuals with Alzheimer's disease, their caregivers and families. Table 2 shows the current grant recipients for the 2008-2009 grant year.

**Table 2.** Alzheimer's Resource Coordination Center seed grant service providers

Name of Provider	Type of Grant
Catawba Area Agency on Aging	Education
Golden Care Adult Day Care	Respite Care
Alzheimer's Family Services of Greater Beaufort	Respite Care
South Santee Senior and Community Center	Respite Care
The ARK	Education
Edisto Island Outreach Center	Respite Care
Low Country Management Services	Education
SC Respite Coalition	Education
Zion's Hill Missionary Baptist Church	Respite Care

## **Capacity of Public Safety and Law Enforcement to Respond to Persons with Dementia**

There is currently no mandatory uniform training for personnel in the criminal justice system. However, the South Carolina Criminal Justice Academy, in cooperation with the Alzheimer's Association –South Carolina Chapter, has implemented a training program for certified law enforcement officers in South Carolina. A three-hour film has been developed for training and includes information on how to approach and speak with persons with Alzheimer's disease and their families and satisfactorily resolve calls for service. The training encompasses sections on the basics of dementia as well as specific situational episodes, with response analysis. It is anticipated that this training film will be shown to 12,000 law enforcement officers in its initial release, along with 75 additional law enforcement departments.

### **Research Activities in the State**

As of January 2009, South Carolina was participating in fifteen research activities. Following is a listing of each research project, along with its sponsors and collaborators, and its location in South Carolina. All information was obtained from the National Institute on Aging (NIA) through their website at <http://nia.nih.gov/Alzheimer's/ResearchInformation/ClinicalTrials>.

1. Valproate in Dementia (VALID)  
Sponsors and Collaborators: National Institute on Aging (NIA), Alzheimer's Disease Cooperative Study (ADCS)  
Location: Medical University of South Carolina (MUSC) – North Charleston, Columbia, Florence
2. Observational Study on Costs and Caregiver Burden in Alzheimer's Disease  
Sponsors and Collaborators: AstraZeneca and i3 Innovus  
Location: Beaufort and Summerville
3. Depression in Alzheimer's Disease – 2 (DIADS – 2)  
Sponsors and Collaborators: National Institute of Mental Health (NIMH)  
Location: MUSC – North Charleston
4. A Phase 3 Study Evaluating Safety and Effectiveness of Immune Globulin Intravenous (IGVI 10%) for the Treatment of Mild to Moderate Alzheimer's Disease  
Sponsors and Collaborators: Baxter Healthcare Corporation, Alzheimer's Disease Cooperative Study (ADCS)  
Location: MUSC- North Charleston

5. Rosiglitazone (Extended Release Tablets) as Adjunctive Therapy in Subjects with Mild to Moderate Alzheimer's Disease  
Sponsors and Collaborators: GlaxoSmithKline  
Location: GSK Clinical Trials Call Center, Greer
6. Comparative Efficacy, Safety, and Tolerability of Rivastigmine 10 and 15 cm 2 Patch in Patients with Alzheimer's Disease (AD) Showing Cognitive Decline  
Sponsors and Collaborators: Novartis  
Location: Dorchester Medical Associates, Summerville; Coastal Neurology, Beaufort
7. Bapineuzumab in Patients with Mild to Moderate Alzheimer's Disease  
Sponsors and Collaborators: Elan Pharmaceuticals  
Location: MUSC – North Charleston
8. DHA (Docosahexaenoic Acid), An Omega 3 Fatty Acid, In Slowing the Progression of Alzheimer's Disease  
Sponsors and Collaborators: National Institute on Aging (NIA) and Martek Biosciences Corporation  
Location: MUSC – North Charleston
9. ADNI: Alzheimer's Disease Neuroimaging Initiative  
Sponsors and Collaborators: National Institute on Aging (NIA), National Institute for Biomedical Imaging and Bioengineering (NIBIB), Foundation for the National Institutes of Health, Alzheimer's Drug Discovery Foundation, and Alzheimer's Association  
Location: MUSC – North Charleston
10. Anti-Psychotic Discontinuation in Alzheimer's Disease  
Sponsors and Collaborators: National Institute on Aging (NIA), New York State Psychiatric Institute, Columbia University  
Location: MUSC – North Charleston
11. Evaluation of 3APS in Patients with Mild to Moderate Alzheimer's Disease  
Sponsors and Collaborators: Bellus Health, Inc.  
Location: MUSC – North Charleston
12. ELND005 in Patients with Mild to Moderate Alzheimer's Disease  
Sponsors and Collaborators: Elan Pharmaceuticals, Transition Therapeutics  
Location: Absher Neurology, Greenville
13. A Randomized, Clinical Trial of Vitamin E and Memantine in Alzheimer's Disease (TEAM – AD)  
Sponsors and Collaborators: Department of Veterans Affairs, Forest Laboratories, DSM Nutritional Products, Inc.  
Location: VA Medical Center – Charleston

14. A Phase 2 Study Evaluating the Efficacy and Safety of PF 04494700 in Mild to Moderate Alzheimer's Disease  
Sponsors and Collaborators: Pfizer, Alzheimer's Disease Cooperative Study (ADCS)  
Location: Pfizer Investigational Site, North Charleston
  
15. Effect of LY450139 on the Long Term Progression of Alzheimer's Disease  
Sponsors and Collaborators: Eli Lilly and Company  
Location: North Charleston



## Chapter 3

### Purple Ribbon Task Force Recommendations

The Purple Ribbon Task Force convened in August, 2008, and consensus was reached on the creation of subcommittees to address four aspects critical to provision of services to individuals with Alzheimer's disease, their families, and caregivers. The subcommittees created were Outreach and Education, Case Management and Assistance for Caregivers, Medical and Long Term Care, and Data & Research. Task Force members chose their respective subcommittees and each was responsible for bringing recommendations before the full task force.

The following recommendations, with their accompanying rationale, are the product of the four subcommittees with input from the full task force. The recommendations are divided by the suggested time frame for implementation.

The Alzheimer's Resource Coordination Center, housed within the Lt. Governor's Office on Aging, will act as the overall facilitator for the recommendations, with key participants proposed under each recommendation. The term "Responsible Party" identifies suggested agencies or entities that may be appropriate for assuming responsibility for implementation of these recommendations. The parties identified are by suggestion of the Task Force, and the agencies or entities named have not provided a formal review or approval of the recommendations.

#### **For implementation in 1-2 years:**

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##### **Recommendation 1.**

Create a single point of entry for persons seeking assistance with Alzheimer's related needs utilizing a toll free number through the Lt. Governor's Office on Aging.

**Rationale:** While many resources are available throughout the state, there is currently no publicized central public access point for consumers to obtain information about services and/or referrals. Families affected by Alzheimer's need a simple method to ascertain what assistance is available and how to gain access to these resources.

**Responsible Party:** Lt. Governor's Office on Aging, Area Agencies on Aging

##### **Recommendation 2.**

Provide appropriate referrals for hospice care for people with Alzheimer's disease and aftercare for the caregivers of persons with ADRD.

**Rationale:** Many caregivers need assistance adjusting to dramatic life changes when their loved ones with ADRD are placed in a facility and/or enter the end stages of the disease process. Likewise, caregivers could benefit from bereavement services following

the death of their loved ones with ADRD. To this end, caregivers should have information on the availability and benefits of hospice care.

**Responsible Party:** Area Agencies on Aging

**Recommendation 3.**

Expand the scope of data included in the Alzheimer’s Disease Registry, to include increased sources of data, resulting in greater capacity to identify gaps in services available.

**Rationale:** There currently exist several state databases which collect and store key information that may contribute to the accuracy and breadth of the Alzheimer’s Disease Registry. However, these databases are not currently integrated to include all sources of information. Such an integration of information will not only ensure maximum accuracy of all data, but will also assist in identifying gaps in services by overlaying areas of population with services available.

**Responsible Party:** Alzheimer’s Disease Registry, South Carolina Health Integrated Data Services (SCHIDS)

**Recommendation 4.**

Utilize existing health data dissemination infrastructure to integrate information on Alzheimer’s disease and related disorders.

**Rationale:** The development of Alzheimer’s disease has been shown to be strongly linked to cardiovascular disease as well as metabolic health. Current dissemination includes information on cardiovascular disease and metabolic disorders, but does not incorporate vital information about Alzheimer’s disease and risk reduction. As this infrastructure is currently in use, this initiative would require no new money for outreach.

**Responsible Party:** Office of Research and Statistics, SC Health Integrated Data Services (SCHIDS)

**Recommendation 5.**

Generate state level work with health disparities for minorities that is inclusive of Alzheimer’s disease.

**Rationale:** There currently exists a federal program through the US Health Resources and Services Administration to address health disparities but it does not include Alzheimer’s disease. South Carolina legislators could approach our U.S. representatives to add Alzheimer’s disease to the legislation, which in turn would provide access to monies not currently available for research.

**Responsible Party:** South Carolina General Assembly, Prevention Partners

**Recommendation 6.**

Promote education and provide resource protection and tax credits for long term care planning and long term care insurance purchase.

**Rationale:** Most consumers do not know that Medicare does not provide for anticipated long term care needs. Only 37% of adults report they have developed a plan to pay for long term care needs<sup>31</sup> and approximately 60% of adults over age 65 will require at least some type of long term care service during their lifetimes<sup>32</sup>. As many families spend down to Medicaid, there is increasing dependence on the already-strained Medicaid system to cover the costs of long term care.

**Responsible Party:** SC Department of Health and Human Services, SC Department of Insurance, Lt. Governor's Office on Aging, long term care providers

**Recommendation 7.**

Implement a Silver Alert Program in South Carolina for the rapid recovery of adults with cognitive impairment who may wander and become lost.

**Rationale:** Alzheimer's patients are at great risk for wandering: six out of ten persons with dementia will wander at some point in the disease progression, and many will wander repeatedly. Up to fifty percent of wanderers may succumb to serious injury or death if not found within 24 hours<sup>33</sup>. There is minimal cost for implementation within existing infrastructure.

**Responsible Party:** SC General Assembly, Silver Haired Legislature, Lt. Governor's Office on Aging, SC Alzheimer's Association, State Law Enforcement Division, local law enforcement agencies

**Recommendation 8.**

Establish standards for dementia-specific training for staff of any state licensed entity, including but not limited to nursing homes, community residential care facilities, home health agencies, hospice, or adult day care centers that provide for care of individuals with ADRD

**Rationale:** There is currently no standard curriculum for staff working with Alzheimer's patients. Consistent training will enhance delivery of care to Alzheimer's patients.

**Responsible Party:** SC Alzheimer's Association, SC Department of Health and Environmental Control, long term care providers, SC Technical College System, SC Department of Health and Human Services, USC Office for the Study of Aging

**Recommendation 9.**

Promote and support the use of home and community based services that enable families and caregivers to have the option to care for their loved ones with ADRD at home, allowing them to age in place for as long as practicable.

**Rationale:** Persons with ADRD, their families and caregivers should have choices about where they receive services. Most people with ADRD prefer to remain in their own homes for as long as possible. At any one time 70% of people with ADRD are living at home<sup>34</sup>. Aging in place reduces the need for relocation to a different living arrangement, and it is often a cost-effective option both for families and for public programs funding long term care.

**Responsible Party:** SC Department of Health and Environmental Control, SC Department of Health and Human Services/Community Long Term Care, Area Agencies on Aging, SC Alzheimer's Association, SC AARP

**For implementation in 3-5 years:**

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**Recommendation 10.**

Provide case management and person centered support services to persons with Alzheimer's Disease and related disorders (ADRD) and their caregivers through a local/regional provider network.

**Rationale:** Persons with Alzheimer's disease and related disorders and their caregivers frequently present compound critical needs, which are not necessarily limited to needs directly related to the disease. Publicly accessible case management is needed to provide comprehensive support services for persons with ADRD and their caregivers, ensuring that clients receive appropriate services through a process of ongoing assessment and coordination of resources. Ideally, such a system may be implemented within existing infrastructure.

**Responsible Party:** Area Agencies on Aging/Aging and Disability Resource Centers

**Recommendation 11.**

Identify and disseminate research findings on promotion of brain health and reduction of risk factors for Alzheimer's disease.

**Rationale:** Diabetes, hypertension, heart disease, and obesity increase the risk of Alzheimer's disease. Physical activity and mental activity are significant to maintaining brain health. Good nutrition is an integral component to overall physical health. Area libraries enable dissemination at no cost.

**Responsible Party:** Lt. Governor's Office on Aging, Office of Research and Statistics, SC Alzheimer's Association

**Recommendation 12.**

Track research being done in the state and educate the public so they will be knowledgeable and can be involved in research if that is their choice. Make available the Alzheimer's disease research directory so that prospective participants could access current information on available opportunities.

**Rationale:** The general public is not always aware of research opportunities. Persons with Alzheimer's disease and related disorders (ARD) and their families may not be aware of research taking place in other parts of the state. Many persons with dementia and their families are acutely interested in gaining access to potential treatments through clinical trials.

**Responsible Party:** Medical University of South Carolina (MUSC), SC Alzheimer's Association, SC Access database

**Recommendation 13.**

Conduct focus groups across the state with professionals and consumers, to include caregivers, as well as those with early stage Alzheimer's disease so as to determine service needs and recommend system changes.

**Rationale:** Caregivers have direct knowledge of what is lacking and what is needed in service to Alzheimer's patients and their caregivers. Early stage Alzheimer's patients provide personal experience on what is most needed from service providers. Physicians will provide feedback on what they need to address the needs of Alzheimer's patients from initial point of diagnosis.

**Responsible Party:** SC Alzheimer's Association partnering with appropriate institutes as well as the Lt. Governor's Office on Aging and the Area Agencies on Aging

**Recommendation 14.**

Expand training on Alzheimer's disease and related disorders (ARD) and enhance accessibility for personnel in the justice system as well as first responders (i.e. EMS, firefighters).

**Rationale:** Persons with ARD may display disruptive behaviors that are misunderstood by law enforcement officers, solicitors, judges, and/or corrections officers and first responders. Current training on ARD in these fields is very limited.

**Responsible Party:** SC Medical Association, SC Bar Association, SC Criminal Justice Academy, SC Summary Court Judges Association, SC Alzheimer's Association, SC Technical College System

**Recommendation 15.**

Incorporate mandatory training modules and continuing education on ADRD for medical school students, licensed doctors, and licensed nurses of all disciplines.

**Rationale:** There is limited mandatory training on dementia for physicians and health professionals; however, the field of dementia is continually changing, and patients rely on physicians and health professionals to provide them with up-to-date information, diagnostic tools and treatment options. As physicians frequently represent the initial point of entry for persons with ADRD, opportunities for continuing education on dementia will increase patient access to an accurate diagnosis and appropriate referrals. In addition, existing senior mentoring programs may be an appropriate vehicle for additional training on ADRD for medical students.

**Responsible Party:** SC Medical Association, SC Nurses Association, Medical University of South Carolina, USC School of Medicine, SC Technical College System, Primary Care Association with facilitation through the SC Alzheimer's Association and the Lt. Governor's Office on Aging

**Recommendation 16.**

Build on existing DHEC reporting requirements for specific criteria for designation as a Special Care Unit.

**Rationale:** The current DHEC definition does not include specific criteria for designation of an Alzheimer's facility, but relies on self-reporting. "Alzheimer's care" designation denotes the facility is stating they have sufficient staff to supervise Alzheimer's patients. "Alzheimer's unit" means the facility has a unit specifically designed to care for Alzheimer's patients, without stipulating what that design entails<sup>35</sup>.

**Responsible Party:** SC Alzheimer's Association, SC Department of Health and Environmental Control, long term care providers

**Recommendation 17.**

Create public service announcements and advertisements to educate and enhance awareness of Alzheimer's disease and available resources. Include information on minimizing risk factors, targeting at-risk populations to reduce health disparities.

**Rationale:** The number of people in South Carolina age 65 and over with Alzheimer's disease is projected to increase from 67,000 in 2000 to an estimated 80,000 in 2010<sup>36</sup>. As of 2007, South Carolina had 159,221 caregivers for persons with Alzheimer's disease<sup>37</sup>. One in 6 women and 1 in 10 men who live to be at least age 55 will develop Alzheimer's disease in their remaining lifetimes<sup>38</sup>. Information needs to be broadly distributed throughout South Carolina.

**Responsible Party:** Facilitated by the SC Alzheimer’s Association and Lt. Governor’s Office on Aging

**Recommendation 18.**

Address the unique service needs of persons with ADRD who exhibit combative or other aggressive behaviors, to include:

- The consideration of publicly funded specialized services which meet Medicare standards for persons throughout the state who have a diagnosis of Alzheimer’s disease or related disorders (ADRD) and whose assaultive or combative behaviors preclude care in traditional nursing home settings.
- The consideration of an incentive for current providers that offer appropriate settings for short-term stabilization or rehabilitation.

**Rationale:** Alzheimer’s patients who exhibit aggressive behaviors are frequently expelled from traditional residential care, leaving families with very few options for appropriate care. A study of family and other unpaid caregivers of more than 2,000 older people found that caregivers of people who had Alzheimer’s or other dementias without behavioral symptoms were 31% more likely than caregivers of other older people to have reduced their hours or quit work<sup>39</sup>. Caregivers of people who had Alzheimer’s or other dementias with behavioral symptoms were 68% more likely than caregivers of other older people to have reduced their hours or quit work<sup>40</sup>. Program implementation may be modeled after North Carolina’s Black Mountain Center, a state-sponsored facility operated through the NC Division of Mental Health, Developmental Disabilities, and Substance Abuse Services.

**Responsible Party:** SC General Assembly, SC Alzheimer’s Association, long term care providers, appropriate governmental agencies

**For implementation in 6-10 years:**

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**Recommendation 19.**

Create a brain bank in South Carolina for research purposes.

**Rationale:** Post mortem research is crucial for a greater understanding of Alzheimer’s disease, and there are currently limited means for South Carolina citizens to designate the donation of one’s brain to research upon death. Designation may potentially be incorporated into existing framework of the South Carolina Organ Donor Registry.

**Responsible Party:** Medical University of South Carolina, University of South Carolina School of Medicine, SC Organ Procurement Association, Donate Life South Carolina, SC Alzheimer’s Association, SC AARP, appropriate governmental agencies

**Recommendation 20.**

Promote and support private and public sector businesses in addressing the needs of employees who are caregivers to persons with ADRD through the use of on-site respite, support groups, or other initiatives.

**Rationale:** Seventy percent of people with ADRD are living at home, most of whom receive unpaid help from family members<sup>41</sup>. One study of family and other unpaid caregivers of people with ADRD found that 57% were employed full time or part time. Of those who were employed, two-thirds said they had to go in late, leave early or take time off because of caregiving; 18% had to take a leave of absence; 13% had reduced their hours; and 8% had turned down promotions<sup>42</sup>. Eight percent of caregivers in the study had quit work entirely because of caregiving. Another study of family and other unpaid caregivers of more than 2,000 older people found that caregivers of people who had Alzheimer's or other dementias without behavioral symptoms were 31% more likely than caregivers of other older people to have reduced their hours or quit work<sup>43</sup>. Caregivers of people who had Alzheimer's or other dementias with behavioral symptoms were 68% more likely than caregivers of other older people to have reduced their hours or quit work<sup>44</sup>.

**Responsible Party:** SC Alzheimer's Association, SC Chamber of Commerce, SC Better Business Bureau, SC Technical College System, SC Manufacturers Association



**South Carolina General Assembly  
117th Session, 2007-2008**

**S. 1333**

**STATUS INFORMATION**

Concurrent Resolution

Sponsors: Senator Setzler

Document Path: I:\council\bill\nbd\12283ac08.doc

Introduced in the Senate on April 29, 2008

Introduced in the House on May 29, 2008

Adopted by the General Assembly on June 3, 2008

Summary: Alzheimer's Task Force

**HISTORY OF LEGISLATIVE ACTIONS**

<b>Date</b>	<b>Body</b>	<b>Action Description with journal page number</b>
4/29/2008	Senate	Introduced SJ 5
4/29/2008	Senate	Referred to Committee on Medical Affairs SJ 5
5/28/2008	Senate	Committee report: Favorable with amendment Medical Affairs SJ 10
5/28/2008	Senate	Committee Amendment Adopted SJ 10
5/28/2008	Senate	Adopted, sent to House SJ 10
5/29/2008	House	Introduced HJ 3
5/29/2008	House	Referred to Committee on Medical, Military, Public and Municipal Affairs HJ 3
5/29/2008	House	Recalled from Committee on Medical, Military, Public and Municipal Affairs HJ 21
5/30/2008		Scrivener's error corrected
6/3/2008	House	Adopted, returned to Senate with concurrence HJ 162

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## VERSIONS OF THIS BILL

4/29/2008

5/28/2008

5/29/2008

5/30/2008

~~Indicates Matter Stricken~~

Indicates New Matter

RECALLED

May 29, 2008

## S. 1333

Introduced by Senator Setzler

S. Printed 5/29/08--H. [SEC 5/30/08 3:26 PM]

Read the first time May 29, 2008.

### A CONCURRENT RESOLUTION

TO REQUEST THE LIEUTENANT GOVERNOR'S OFFICE ON AGING TO CONVENE A PURPLE RIBBON ALZHEIMER'S TASK FORCE TO STUDY THE CURRENT AND FUTURE IMPACT OF ALZHEIMER'S IN SOUTH CAROLINA AND TO ASSESS THE RESOURCES FOR AND NEEDS OF PERSONS WITH ALZHEIMER'S AND RELATED DISORDERS SO AS TO DEVELOP A STATE STRATEGY TO ADDRESS THIS HEALTH ISSUE.

Whereas, Alzheimer's disease is a slow, progressive disorder of the brain that results in loss of memory and other cognitive function and, eventually, results in death; and

Whereas, with one in eight people over age sixty five and almost one in every two people over eighty five having Alzheimer's disease and related disorders, the number of South Carolinians with Alzheimer's disease or related dementia (with or without diagnosis) is expected to increase nineteen percent from 67,000 in 2000 to 80,000 in 2010; and

Whereas, an in-depth study of Alzheimer's and the needs and resources required to address this issue has not been conducted in this State in over fourteen years, and, consequently, it is incumbent upon the State to assess the current and future impact of Alzheimer's disease in South Carolina and the programs and services needed to ensure an integrated, comprehensive, coordinated, and up to date strategy to address the needs of this growing segment of the population. Now, therefore,

Be it resolved by the Senate, the House of Representatives concurring:

That the South Carolina General Assembly, by this resolution, requests the Lieutenant Governor's Office on Aging to convene a Purple Ribbon Alzheimer's Task Force to assess the current and future impact of Alzheimer's disease in South Carolina, to examine the existing services and resources addressing the needs of persons with Alzheimer's, their families and caregivers, and to develop a comprehensive strategy to provide a state response to this public health crisis.

Be it further resolved that the Purple Ribbon Alzheimer's Task Force is composed of 20 members appointed by the Lieutenant Governor to include:

- (1) one member of the South Carolina Senate;
- (2) one member of the South Carolina House of Representatives;
- (3) one person with Alzheimer's disease or a related disorder;
- (4) one caregiver of a person with Alzheimer's disease;
- (5) one member representing the State at-large;
- (6) one member from the nursing facility industry;
- (7) one member from the assisted living industry;
- (8) one member from the adult day services industry;
- (9) one member from the medical care provider community;
- (10) one member from the nursing community;
- (11) one member who specializes in Alzheimer's disease research;
- (12) one member representing the Alzheimer's Disease Registry;
- (13) one member representing the Alzheimer's Association;
- (14) the director of the SC Department of Mental Health or his designee;
- (15) the director of the Department of Disabilities and Special Needs or his designee;
- (16) the director of the Department of Health and Environmental Control or his designee;
- (17) the director of the Department of Health and Human Services or his designee;
- (18) the director of the Lieutenant Governor's Office on Aging;
- (19) one member representing the law enforcement community;
- (20) one member representing labor and workforce development.

The director of the Lieutenant Governor's Office on Aging shall serve as chairman of the task force. Members of the task force shall service without compensation. The Purple Ribbon Alzheimer's Task Force shall be so named for the color of Alzheimer's disease awareness.

Be it further resolved that the Purple Ribbon Alzheimer's Task Force include in its assessment and recommendations an examination of:

- (1) the Alzheimer's population needs, including, but not limited to, state policy and the role of the State in meeting these needs;

(2) existing services, resources, and capacity, for serving persons with Alzheimer's and related disorders;

(3) changes needed to state policies and resources, including, but not limited to, providing coordinated services and support to persons and families living with Alzheimer's and related disorders and strategies to address any identified gaps in services.

Be it further resolved that the Purple Ribbon Alzheimer's Task Force is requested to develop a report and date specific recommendations for responding to the task force findings, which the Office of Aging shall provide to the General Assembly and Governor no later than March 1, 2009, at which time the Office on Aging shall disband the task force.

Be if further resolved that the Office on Aging is requested to monitor the implementation of the recommendations of the Purple Ribbon Alzheimer's Task Force and to keep the General Assembly apprised of the progress of these matters.

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## **Appendix B**

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### **Purple Ribbon Task Force Subcommittees**

#### **Outreach and Education**

Dr. Warachal Faison  
Captain Patsy Lightle  
Marilynn Koerber  
Fran Emerson  
Pierce McNair  
Kay Hightower

#### **Case Management and Assistance for Caregivers**

Lois Park Mole  
Brenda Hyleman  
Dr. Carlos Gibbons  
Shawn Keith

#### **Medical and Long-Term Care**

Scott Middleton  
Dr. Edgar Weiss  
Bunny Runge  
Dr. Paul Switzer  
Tim Barresi

#### **Data and Research**

Dr. Michael Byrd  
Candace Porter  
Senator Mike Fair  
Representative Gilda Cobb-Hunter  
Carol Cornman  
Robert Coaxum

## Appendix C

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### Adjunct Contributors

The following individuals played vital roles in the formation of this state plan:

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Lt. Governor's Office on Aging

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Alzheimer's Association - SC Chapter

Joren Bartlett  
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Candace Porter  
Arnold School of Public Health  
University of South Carolina

Adelle Stanley  
Alzheimer's Association - SC Chapter

**South Carolina Code of Laws  
(Unannotated)  
Current through the end of the 2008 Session**

**Title 44 - Health**

**CHAPTER 36.  
ALZHEIMER'S DISEASE AND RELATED DISORDERS**

**ARTICLE 1.  
ALZHEIMER'S DISEASE REGISTRY**

SECTION 44-36-10. Establishment of Registry; purpose and functions; sources of data.

(A) There is established within the University of South Carolina School of Public Health the Alzheimer's Disease Registry to provide a central information data base on individuals with Alzheimer's disease or related disorders to assist in the development of public policy and planning.

(B) The functions of the registry include, but are not limited to:

(1) collecting data to evaluate the prevalence of Alzheimer's disease and related disorders in South Carolina;

(2) providing information for policy planning purposes; and

(3) providing nonidentifying data to support research on Alzheimer's disease and related disorders.

(C) In gathering data the registry shall rely upon, to the extent possible, data from existing sources; however, the registry may contact families and physicians of persons reported to the registry for the purpose of gathering additional data and providing information on available public and private resources. Patient contact following data received from the State Budget and Control Board Office of Research and Statistics must be done in accordance with regulations approved by the South Carolina Data Oversight Council and promulgated by the Office of Research and Statistics.

SECTION 44-36-20. Advisory committee; membership; duties; prohibition against compensation.

(A) The School of Public Health shall appoint an advisory committee to assist in maintaining this registry which must include, but is not limited to, a representative of:

- (1) South Carolina Alzheimer's Association chapters;
- (2) American Association of Retired Persons, South Carolina Chapters;
- (3) Clemson University;
- (4) Department of Disabilities and Special Needs;
- (5) Department of Health and Environmental Control;
- (6) Department of Mental Health;
- (7) Department of Social Services;
- (8) Department of Health and Human Services;
- (9) Medical University of South Carolina;
- (10) National Association of Social Workers, South Carolina Chapter;
- (11) South Carolina Adult Day Care Association;
- (12) South Carolina Association of Area Agencies on Aging;
- (13) South Carolina Association of Council on Aging Directors;
- (14) South Carolina Association of Nonprofit Homes for the Aging;
- (15) South Carolina Association of Residential Care Homes;
- (16) South Carolina Health Care Association;
- (17) South Carolina Home Care Association;
- (18) South Carolina Hospital Association;
- (19) South Carolina Medical Association;
- (20) South Carolina Nurses' Association;
- (21) Alzheimer's Disease and Related Disorders Resource Coordination Center, Office of the Governor, Division on Aging;
- (22) University of South Carolina;
- (23) South Carolina State University.



(B) The advisory committee shall assist the registry in:

(1) defining the population to be included in the registry including, but not limited to, establishing criteria for identifying patient subjects;

(2) developing procedures and forms for collecting, recording, analyzing, and disseminating data;

(3) developing protocols and procedures to be disseminated to and used by health care providers in identifying subjects for the registry;

(4) developing procedures for approving research projects or participation in research projects.

(C) Members of the advisory committee are not entitled to mileage, per diem, subsistence, or any other form of compensation.

SECTION 44-36-30. Confidentiality; release of identifying information upon consent.

(A) The School of Public Health and all persons to whom data is released shall keep all patient information confidential. No publication of information, biomedical research, or medical data may be made which identifies the patients. For purposes of maintaining this registry, the School of Public Health may access appropriate confidential data reported to the Office of Research and Statistics in accordance with Section 44-6-170.

(B) Except for use in collecting data on deaths from the Bureau of Vital Statistics, Department of Health and Environmental Control, no identifying information collected or maintained by the registry may be released unless consent is obtained from the subject or the subject's legal representative.

SECTION 44-36-40. Immunity from liability for divulging confidential information.

Neither the registry or the School of Public Health nor a person, medical facility, or other organization providing or releasing information in accordance with this article may be held liable in a civil or criminal action for divulging confidential information unless the person or organization acted in bad faith or with malicious purpose.

SECTION 44-36-50. Annual report requirement.

The registry shall submit an annual report to the Office of the Governor, Division on Aging, Alzheimer's Disease and Related Disorders Resource Coordination Center, the Department of Health and Environmental Control, and the Budget and Control Board, Division of Research and Statistics, Health Statistics.

### **ARTICLE 3.**

#### **ALZHEIMER'S DISEASE AND RELATED DISORDERS RESOURCE COORDINATION CENTER**

SECTION 44-36-310. Alzheimer's Disease and Related Disorders Resource Coordination Center created; purpose.

There is created in the Office of the Governor, Division on Aging, the Alzheimer's Disease and Related Disorders Resource Coordination Center to provide statewide coordination, service system development, information and referral, and caregiver support services to individuals with Alzheimer's disease and related disorders, their families, and caregivers.

SECTION 44-36-320. Duties of Center.

The center shall:

- (1) initiate the development of systems which coordinate the delivery of programs and services;
- (2) facilitate the coordination and integration of research, program development, planning, and quality assurance;
- (3) identify potential users of services and gaps in the service delivery system and expand methods and resources to enhance statewide services;
- (4) serve as a resource for education, research, and training and provide information and referral services;
- (5) provide technical assistance for the development of support groups and other local initiatives to serve individuals, families, and caregivers;
- (6) recommend public policy concerning Alzheimer's Disease and related disorders to state policymakers;
- (7) submit an annual report to the Joint Legislative Committee on Aging and to the General Assembly.

SECTION 44-36-325. Grant program development for Alzheimer's Disease and related disorders; condition to receipt of grant.

The Alzheimer's Disease and Related Disorders Resource Coordination Center shall develop a grant program to assist communities and other entities in addressing problems relative to Alzheimer's disease and other related disorders. In awarding grants, consideration must be given to recommendations made by the advisory council to the

Alzheimer's Disease and Related Disorders Resource Coordination Center regarding priority needs and criteria for selecting grant recipients. As a condition to receiving a grant, the community or other entity shall provide matching funds or an in-kind contribution equal to the amount of funds awarded in the grant.

SECTION 44-36-330. Advisory council; membership; compensation of members.

(A) The Alzheimer's Disease and Related Disorders Resource Coordination Center must be supported by an advisory council appointed by the Governor including, but not limited to, representatives of:

- (1) Alzheimer's Association Chapters;
- (2) American Association of Retired Persons;
- (3) Clemson University;
- (4) Department of Disabilities and Special Needs;
- (5) Department of Health and Environmental Control;
- (6) Department of Mental Health;
- (7) Department of Social Services;
- (8) Department of Health and Human Services.
- (9) Medical University of South Carolina;
- (10) National Association of Social Workers, South Carolina Chapter;
- (11) South Carolina Adult Day Care Association;
- (12) South Carolina Association of Area Agencies on Aging;
- (13) South Carolina Association of Council on Aging Directors;
- (14) South Carolina Association of Nonprofit Homes for the Aging;
- (15) South Carolina Association of Residential Care Homes;
- (16) South Carolina Health Care Association;
- (17) South Carolina Home Care Association;
- (18) South Carolina Hospital Association;

(19) South Carolina Medical Association;

(20) South Carolina Nurses' Association;

(21) Statewide Alzheimer's Disease and Related Disorders Registry;

(22) University of South Carolina;

(23) South Carolina State University.

(B) Members of the advisory council are not entitled to mileage, per diem, subsistence, or any other form of compensation.

## **ARTICLE 5.**

### **SPECIAL CARE DISCLOSURE**

SECTION 44-36-510. Short Title.

This article may be cited as the "Alzheimer's Special Care Disclosure Act"

SECTION 44-36-520. Information respecting form of Alzheimer's care or treatment provided.

A nursing home, community residential care facility, or day care facility for adults licensed by the Department of Health and Environmental Control which offers to provide or provides an Alzheimer's special care unit or program must include in its policies and procedures and disclose to the responsible party seeking a placement within the Alzheimer's special care unit or program, the form of care or treatment provided that distinguishes it as being especially applicable to or suitable for persons with Alzheimer's disease. The information that distinguishes the form of care or treatment shall include criteria for admission, transfer, and discharge; care planning; staffing patterns; staff training; physical environment; resident and participant activities; family role in care; and unique costs to the resident or participant associated with specialized service delivery.

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**Endnotes:**

<sup>1</sup> *2008 Alzheimer's Disease Facts and Figures Report*. © 2008 Alzheimer's Association, p.9, 13, and 20.

<sup>2</sup> Source: South Carolina Department of Health and Environmental Control.

<http://scdhec.gov/health/licen/hrfsum.pdf>

<sup>3</sup> *2008 Alzheimer's Disease Facts and Figures Report*. © 2008 Alzheimer's Association, p.17.

<sup>4</sup> *Stages of Alzheimer's Disease – Topic Sheet*. © 2007 Alzheimer's Association, p.1.

<sup>5</sup> *Basics of Alzheimer's: What it is and what you can do*. © 2005 Alzheimer's Association, p.8.

<sup>6</sup> *2008 Alzheimer's Disease Facts and Figures Report*. © 2008 Alzheimer's Association, p.9.

<sup>7</sup> *2008 Alzheimer's Disease Facts and Figures Report*. © 2008 Alzheimer's Association, p.29.

<sup>8</sup> *2008 Alzheimer's Disease Facts and Figures Report*. © 2008 Alzheimer's Association, p.13.

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<sup>9</sup> 2007 Annual Report, South Carolina Alzheimer's Disease Registry. Arnold School of Public Health, University of South Carolina, Columbia, SC. December, 2007, p.5, 8. (LE Hebert et al. Alzheimer's disease in the US population: Prevalence estimates using the 2000 Census. Archives of Neurology, 2003; Vol 60, 11191122.)

<sup>10</sup> 2008 Alzheimer's Disease Facts and Figures Report. © 2008 Alzheimer's Association, p.21, 27.

<sup>11</sup> Basics of Alzheimer's: What it is and what you can do. © 2005 Alzheimer's Association, p.11.

<sup>12</sup> Basics of Alzheimer's: What it is and what you can do. © 2005 Alzheimer's Association, p.28.

<sup>13</sup> *Life Expectancy*. FASTSTATS, National Center for Health Statistics, U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. <http://www.cdc.gov/nchs/fastats/lifexpec.htm>

<sup>14</sup> 2008 Alzheimer's Disease Facts and Figures Report. © 2008 Alzheimer's Association, p.9.

<sup>15</sup> *Facts: Brain Health, Heart Health and African Americans*. American Heart Association, American Stroke Association, Alzheimer's Association, 2008.

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<sup>16</sup> *2007 Annual Report, South Carolina Alzheimer's Disease Registry*. Arnold School of Public Health, University of South Carolina, Columbia, SC. December, 2007, pp.13-14.

<sup>17</sup> *Basics of Alzheimer's: What it is and what you can do*. © 2005 Alzheimer's Association, pp.6-7.

<sup>18</sup> *Basics of Alzheimer's: What it is and what you can do*. © 2005 Alzheimer's Association, p.15.

<sup>19</sup> *2008 Alzheimer's Disease Facts and Figures Report*. © 2008 Alzheimer's Association, p.20.

<sup>20</sup> *2008 Alzheimer's Disease Facts and Figures Report*. © 2008 Alzheimer's Association, p.17.

<sup>21</sup> *2008 Alzheimer's Disease Facts and Figures Report*. © 2008 Alzheimer's Association, p.26.

<sup>22</sup> *Occupational Projections for Direct-Care Workers 2006–2016*. © Paraprofessional Healthcare Institute, April 2008.

<sup>23</sup> *Stages of Alzheimer's Disease – Topic Sheet*. © 2007 Alzheimer's Association, pp.1-3.

<sup>24</sup> *Basics of Alzheimer's: What it is and what you can do*. © 2005 Alzheimer's Association, p.24.

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- <sup>25</sup> Basics of Alzheimer's: What it is and what you can do. © 2005 Alzheimer's Association, p.25.
- <sup>26</sup> *Brain Health – Topic Sheet*. © 2007 Alzheimer's Association
- <sup>27</sup> Gray Plague of the Twenty-first Century: Meeting the Needs of Individuals with Alzheimer's Disease, Their Families and Caregivers. The South Carolina Blue Ribbon Task Force Report, 1993, p. 1.
- <sup>28</sup> 2008 Alzheimer's Disease Facts and Figures Report. © 2008 Alzheimer's Association, p.17.
- <sup>29</sup> *2007 Annual Report, South Carolina Alzheimer's Disease Registry*. Arnold School of Public Health, University of South Carolina, Columbia, SC. December, 2007, p.7)
- <sup>30</sup> South Carolina Department of Health and Environmental Control, <http://scdhec.gov/health/licen/hrfsum.pdf>.
- <sup>31</sup> *State Plan on Aging 2009-2012*, Lt. Gov's Office on Aging, p. 86. *Long Term Care: The Public's View*. Peter D. Hart Research Associates and American Viewpoint. National Academy of Social Insurance, Health and Income Security Brief, November 2005, No.8, p.3.



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<sup>32</sup> *State Plan on Aging 2009-2012*. Lt. Gov's Office on Aging, p. 86. *Own Your Future: Planning guide for long term care*. US Department of Health and Human Services, Centers for Medicare and Medicaid Services, 2002.

<sup>33</sup> Alzheimer's disease: Guide for law enforcement. Alzheimer's Association, 2007.

<sup>34</sup> 2008 Alzheimer's Disease Facts and Figures, Alzheimer's Association, p. 24.

<sup>35</sup> SC Department of Health and Human Services, <http://www.scdhec.gov>.

<sup>36</sup> Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; and Evans, DA. "State-specific projections through 2025 of Alzheimer disease prevalence." *Neurology* 2004; 62:1645. As reported in *2008 Alzheimer's Disease Facts and Figures*, Alzheimer's Association, p. 13.

<sup>37</sup> 2008 Alzheimer's Disease Facts and Figures, Alzheimer's Association, p. 20.

<sup>38</sup> 2008 Alzheimer's Disease Facts and Figures, Special Report: Lifetime Risk, Alzheimer's Association, p. 33.

<sup>39</sup> Covinsky, KI; Eng, C; Liu, L-Y; Sands, LP; Sehgal, AR; Walter, LC; et al. Reduced Employment in Caregivers of Frail Elders: Impact of Ethnicity, Patient Clinical Characteristics, and Caregiver Characteristics. *Journal of Gerontology: Medical Sciences* 2001; 56A (11): M707-713.

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<sup>40</sup> 2008 Alzheimer's Disease Facts and Figures, Alzheimer's Association, p. 18.

<sup>41</sup> 2008 Alzheimer's Disease Facts and Figures, Alzheimer's Association, p. 24.

<sup>42</sup> *Families Care: Alzheimer's Caregiving in the United States*. Alzheimer's Association and National Alliance for Caregiving, 2004, Accessible at [www.alz.org](http://www.alz.org).

<sup>43</sup> Covinsky, KI; Eng, C; Liu, L-Y; Sands, LP; Sehgal, AR; Walter, LC; et al. Reduced Employment in Caregivers of Frail Elders: Impact of Ethnicity, Patient Clinical Characteristics, and Caregiver Characteristics. *Journal of Gerontology: Medical Sciences* 2001; 56A (11): M707-713.

<sup>44</sup> 2008 Alzheimer's Disease Facts and Figures, Alzheimer's Association, p. 18.