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Ronnie Daniels  
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Dear Director Daniels,

I am writing a report on the growing needs of seniors facing the challenges of Alzheimer's in Washington County. Twenty three percent of the senior citizens of Utah currently reside in Washington County. I am aware of the financial difficulties your organization has faced in its efforts to keep a chapter office open in St George. The services you provide to Senior's and their caregivers in Utah are desperately needed in Southern Utah. It is my goal is to raise awareness and inspire local donations, so you can re-open and maintain an office in St. George.

There is a lack of awareness of the need for funding. Those with the disease cannot advocate for themselves, and their caregivers are too tired by the end of their day. Awareness truly begins when you have a family member diagnosed with dementia. Targeting a younger demographic is needed to bring up the level of awareness and the much needed funding.

There is a Silver Tsunami headed for St. George in the next 10-15 years, and we need more of our community members to actively support this cause. Support by giving time or giving money to organizations like the Alzheimer's Association who are making a difference in the lives of patients and caregivers afflicted by Alzheimer's.

I hope that my report will help illuminate areas of need, and inspire new ideas for fundraising that will enable your St. George chapter to re-open and remain open. I welcome any feedback you may have and would be happy to answer any questions that come up. I can be reached at the above number or email.

Sincerely yours,

Kay L. Reilly

Enclosure: Report

**EXAMINING THE NEEDS OF ALZHEIMER'S PATIENTS  
IN WASHINGTON COUNTY, UTAH**

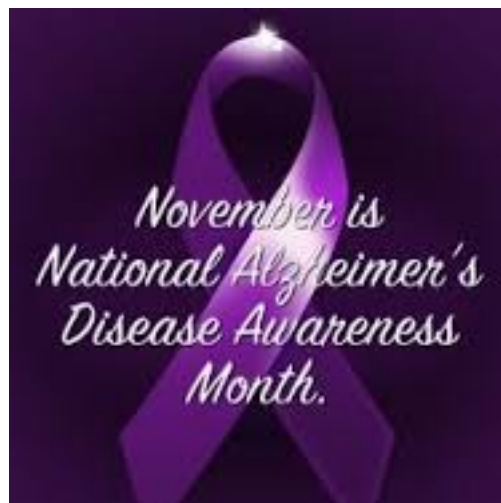
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**November 10, 2016**



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## **Abstract**

This report addresses the needs of the growing population of Alzheimer's and dementia patients in Washington County, Utah. The Alzheimer's Association had an office located in St. George, Utah, but was closed a few years back due to funding issues. There is tremendous demand for increased support services in St. George, as Washington County has the largest population of aging seniors, roughly 23 percent of the states senior citizens. There has not been much progress made medically, since the first Alzheimer's diagnosis in 1901. However, new concepts in treatment of the whole body, and changes in lifestyle are proving to be of greater success than those of just medication and nursing care alone. The greatest challenge is in providing adequate caregiving in the home, so that the patient can remain at home. Too often care is provided by family members who have to stay home from work. The issues of exhaustion, fatigue, burnout, and depression are common among those providing the care, often without pay or compensation. There are far too few resources available for these caregivers in terms of training, financial assistance or respite care. Additional funds are greatly needed to support caregivers and patients in our local community. We need the services that are offered by the Alzheimer's Association, and we need to make it feasible for them to re-open and maintain an office in St. George. The solution to this problem begins with improving awareness to middle aged and younger adults. We all need to learn to step up and share in the responsibility of this problem because it is going to affect all of us directly or indirectly as our baby boomers are all approaching senior citizen status. We can all help in bringing Alzheimer's Association back to our community, either by volunteering time or donating financially.

# Introduction

## Background

Alzheimer's disease is the most common form of dementia. Symptoms including short-term memory loss and disorientation usually begin to develop around age 65. Alzheimer's is now the 6<sup>th</sup> leading cause of death. ([www.alz.org](http://www.alz.org)) Experts do not yet know exactly what causes Alzheimer's, though many theories exist. Since the first Alzheimer's diagnosis made in 1901, very little has changed medically. Of the top ten diseases, this is the only one for which we have no prevention, no cure, or even a slowing of the disease process. It is currently the most expensive disease and the largest social and medical challenge of our generation. (Cohen, S, 2015) By 2050, the cost of treating dementia in this country may be at one trillion dollars. (<https://alz.org>, 2016) There is not enough financial support at the local or national level to meet the needs of the growing population of seniors. By the age of 65, 1 in 6 will be diagnosed with the disease. By age 85, 1 in 2 people will have the disease. If you plan on living that long, you will either be a patient or a caregiver for one. With the baby boomers all reaching 65 or older in the next decade or so, we have a Silver Tsunami heading our way. (L.Lundquist, personal interview, November 23, 2016)

## Problem

Alzheimer's Association, which has provided the greatest support to patients and caregivers is experiencing a lack of funding from donations, and has had to close their Chapter office in St. George. Donations had been on the decline for a number of years due in part to the economy. That seems to be on the rise again recently, so hopefully we are moving in the right direction. (<https://www.alz.org/forum>) Their absence has left a void in our community and a greater need for support services for patient, family and caregivers. The challenge is that these seniors with the disease cannot advocate for themselves. Their family or caregivers don't advocate for a couple of reasons. They are accustomed to not talking about this illness. The patients generally don't want anyone to know, as they feel some inadequacy in the early stages. (L.Lundquist, personal interview, November 23, 2016) The caregivers are just too overwhelmed, exhausted, and possibly depressed. When in the midst of caring for their loved one, they just don't have anything left at the end of the day.

## Purpose

This report is intended to begin to improve awareness of the problem facing our community with the potential for it to snowball over the next decade. I was greatly impacted by this illness in my family, and am seeing many of my friends and relatives facing the same hardships of caring for their own parents or grandparents, afflicted with dementia or Alzheimer's. With the baby boomers nearing 65 or older, the number of people being compromised by the disease is on the rise. (<https://alz.org>, 2016)

## Scope

I have chosen to report specifically on the awareness and funding issues facing the Alzheimer's Association with their operation having to shut its doors here in St. George. They were a tremendous resource and a great support for my mother and I, when we were in desperate need. Their services are an absolute necessity in our community. More services are what we need, not less. A portion of the funds raised or granted to the Alzheimer's Association goes to research. This is an important part of the whole picture if we are going to be able to get ahead of the Silver Tsunami headed for Southern Utah. We need all the services the Alzheimer's Association can provide in our local community as we house roughly 23% of the state's senior citizens. In ten years 1 in 3 persons in this area will be 65 or older. (L.Lundquist, personal interview, November 23, 2016)

## Discussion

### The Patient and Their Needs

Being diagnosed with Alzheimer's is a frightening experience. There are far more questions than there are answers. The needs of the patient are many, and vary with the stages of the illness. They need what we all need, which is love, comfort, identity, occupation, inclusion, and attachment. (Innes, A., & Hatfield, K, 2011) Too often they are left isolated when families are at a loss on how to begin to meet their needs. "Though medicine has advanced greatly, we can offer no more help today than we could 115 years ago" (when the first diagnosis of Alzheimer's was made by Dr. Alois Alzheimer) states research scientist Samuel Cohen in his recent *Ted Talks*. He is part of a team of scientists working to find a cure for the past decade. He goes on to say, "Alzheimer's is one of the biggest medical and social challenges of our generation. Today of the top ten causes of death worldwide, it is the only one we cannot prevent, cure, or even slow down. We understand less about the science of Alzheimer's than that of other diseases because we have invested less time and money into the research of it. The US government spends ten times more on cancer research, despite the fact that Alzheimer's costs us more and has a similar number of deaths each year as cancer".

A new area of research presented at the Alzheimer's Association International Conference, shows some promise in the area of reasonable lifestyle choices, including exercise, diet, sleep, stress relief, and targeted brain training. This was reported by Mandy Oaklander in her cover story for Time magazine this year. She stated, "When it comes to cognitive decline, simple lifestyle changes are finally being borne out by science".

Additionally, as reported by Chris McWilliams in a review of the book, *Healing Arts Therapies and Person-Centered Dementia Care*, "Service provision and resource planning ignores the person-centered aspects of care at the expense of medical and nursing care much too often"

In this country, there has been an insurgence of growth and interest in the use of healing art therapies. There is a growing body of research supporting the use of the arts, including dance, movement, music and visual art as therapeutic tools. Evidence shows that the arts provide an immeasurable sense of accomplishment, joy and improved

communication to person's who are ill, cognitively impaired or with neurological damage. (Innes, A., & Hatfield, K, 2011)

Person-centered care and healing art therapies make great partners in promoting wellness and growth to improve physical, emotional, and spiritual wellbeing. As detailed in the book, *Healing Art Therapies and Person-Centered Dementia Care*, some of the following outcomes can be anticipated:

- Increasing orientation and activation
- Facilitating reminiscence and remembering
- Increasing self-understanding and acceptance
- Developing meaningful interpersonal relationships
- Building communal spirit

Levels of awareness, and additional research about person-centered care and associated therapies are needed, so that totality of care is recognized and implemented.

In the absence of a local Alzheimer's Association chapter office, another non-profit organization called *Memory Matters* has opened an office in St. George. Their staff is comprised of the most dedicated employees of the former Alzheimer's Association office that closed a few years ago. I interviewed their founder and director, LuAnn Lundquist. They offer services in the area of support, education, activities, and consultation for the patients, families, and caregivers. LuAnn is very interested in opening an adult with dementia daycare here in St. George. It would serve to create activities and education for the seniors, while providing a break for the family or caregivers to attend to their own lives. Evidence exists that this type of care helps the patient to have a more purposeful, meaningful life and the activity helps them to sleep better at night, which sometimes means everyone in the family can sleep at night. (L.Lundquist, personal interview, November 23, 2016)

## **The Caregivers and Their Needs**

I became a caregiver for my mother with her Alzheimer's in 2011. She had been diagnosed a few years earlier, but the point where she needed 24-hour supervision came quickly. I was lost and alone and did not know where to turn. The Alzheimer's Association proved to be a life-saving resource for me in my quest for answers, education, emotional support, and respite care. I do not know how I would have coped without Mitzi Sullivan and the other workers in that office. They were available to me in my time of need and even went with me to look at care centers when that time came. I learned a lot during that experience and though one of the most challenging times of my life, I can look back at it as one of the most rewarding.

"Family caregiving can also take a personal and financial toll. Many caregivers lose earnings, pensions, and Social Security benefits and spend down their savings. You are providing care for a person that needs it, while impoverishing another," states Julia Martinez in her report for the State Legislature magazine. She notes the nationwide shift from institutionalized care to home-based care, and the lack of training, support and respite care.

The caregiver, particularly if it is a family member needs awareness, and education or training. When your loved one loses the memory of who they are, they can become very agitated and even aggressive. Caring for them is in some ways similar to

caring for a young child, except that they are in an adult sized, often very strong body. The caregiver too often has no backup or relief, and his or her own needs often get put on the back burner. In my case, I lived next door to my mother, so it was convenient for me to look after her. My son was 14-16 during the years that I cared for her. When it became necessary for me to be with her around the clock, my son was inadvertently, neglected by me. This did not become clear until after the fact, but I could see that there were aspects of caring for him, that I missed out on. He did not seem too concerned about my absence in our home, but I see the consequences of that now. During the time I was caring for mom, I was completely overwhelmed, exhausted, and consumed by her issues. A few months after she passed away, I was diagnosed with breast cancer for the second time in ten years. I believe it came back because I was not adequately caring for myself during that time.

## How We Can All Help

Support, awareness, funding, and more options for these Alzheimer adults are necessary in this community if we are going to be able to care for the growing numbers of individuals and families affected by this disease.

We can all help, and we can all make a difference. We can give of our time as volunteers, as caregivers, or helpers. We can donate money to the Alzheimer's Association, or inspire others in a position to do so. The fact that our community has such a large population of retirement-aged seniors increases the urgency of this situation. The city of St. George needs to step up and include some provisions for the growth in the local senior population, in their 5-year-plan for the city. (L.Lundquist, personal interview, November 23, 2016)





Research has shown that more care will be necessary for an aging population, and that a crisis will ensue if it is not made a top priority. (Martinez, J. 2015)

The Alzheimer's Association Advocacy Forum has been instrumental in raising awareness at the government level in Washington D.C. Due to their efforts we have had two years of historic funding increases at the National Institutes of Health for Alzheimer's disease research. We have great momentum for this effort at this time. (<https://alz.org/forum>, 2016)

## **Conclusion**

In order to be in position to care for the growing number of seniors who will be in need of care and service in Washington County, we need to act now. We all need to do our part to raise awareness and find the level at which we can participate in caring for our elders. The need is there and as evidenced in this report, will only expand exponentially in the coming decades, due to the high percentage of retirement population in our community. There are services available, but we need more. The services that can be provided by The Alzheimer's Association would be a tremendous asset to what is currently available. They need additional funding in order for this to be possible. We need to reach out to the younger residents and inspire them to get involved in this effort now.

## **Recommendations**

Implementation of the recommendations outlined in this report may be of benefit to the Alzheimer's Association in an effort to re-open their Chapter office in St. George. The need for their services at the local level is greater here than anywhere in the state.

- 1) Advertising and marketing targeted at a younger generation, appealing to their heart, by bringing awareness that it could be affecting their parents or grandparents in the not-so-distant future.
- 2) Increase fund-raising efforts locally by sponsoring a silent auction, perhaps in conjunction with another event such as the Walk to End Alzheimer's. This community has a large number of professional artists, and I know many who would donate art to this cause.
- 3) Sponsor a tea party at a local venue, and invite local senior women in a position to contribute financially. This community financially supports the local hospital in a very big way. Attracting some of those donors could be extremely beneficial.
- 4) Begin education on caregiving in high school, to raise awareness.
- 5) Provide training for caregiver's that includes education on person-centered care.
- 6) Implement a daycare program for seniors with Alzheimer's, with options for art therapy.

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- \* ([www.alz.org](http://www.alz.org))

\* Additional references, properly cited within the report, but not needed on reference page