Alzheimer’s Disease: Walking the Path of Science, Medicine, and Caregiving

COMPILED AND CURATED BY KATE E. BRIGHT
The Science

- What is Alzheimer’s Disease?
- What is Dementia?
- Causes for Dementia
- Plaques and Tangles

https://www.alz.org/braintour/blood_vessels.asp
WHAT IS ALZHEIMER’S DISEASE?

Alzheimer’s Disease is the most common form of dementia and is the slow decline of cognitive abilities affecting memory, thinking and behavior.

• 60 to 80% of dementia cases are diagnosed as Alzheimer’s Disease and mostly affect individuals who are 65 or older. Increasing age is the greatest risk factor and is not considered a normal part of aging.

• Alzheimer’s is a progressive disease. As time passes, symptoms will gradually worsen from mild memory loss to the inability to function and respond.

• Though Alzheimer’s Disease affects mostly older individuals, around 200,000 people in the U.S. have been diagnosed with early-onset Alzheimer’s.

https://www.alz.org/alzheimers_disease_what_is_alzheimers.asp
WHAT IS DEMENTIA?

Dementia is a general term for the decline in mental faculties to the point where it interferes with daily life.

- “Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities.”

- Damage to brain cells is the cause of dementia. These brain cells then can no longer function or communicate properly with each other. “When brain cells cannot communicate normally, thinking, behavior and feelings can be affected.”

https://www.alz.org/what-is-dementia.asp
THE SCIENCE

“The brain has many distinct regions, each of which is responsible for different functions (for example, memory, judgment and movement). When cells in a particular region are damaged, that region cannot carry out its functions normally.”

• Scientists are not completely certain how Alzheimer’s Disease originates in the brain. Made up of billions of neurons, a normally functioning brain is able to give and receive signals. Alzheimer’s seems to be the direct effect of the disruption of these processes.

• “In the Alzheimer's brain... the cortex shrivels up, damaging areas involved in thinking, planning and remembering. Shrinkage is especially severe in the hippocampus, an area of the cortex that plays a key role in the formation of new memories. Ventricles (fluid-filled spaces within the brain) grow larger.”

https://www.alz.org/what-is-dementia.asp
https://www.alz.org/braintour/healthy_vs_alzheimers.asp
THE SCIENCE

This image shows the marked difference between a health brain and a brain with advanced Alzheimer’s. This difference is the direct result of extensive loss of healthy cells in the brain.

https://www.alz.org/braintour/healthy_vs_alzheimers.asp
PLAQUES AND TANGLES

“To do their work, brain cells operate like tiny factories. They receive supplies, generate energy, construct equipment, and dispose of waste. Cells also process and store information and communicate with other cells. Keeping everything running requires coordination as well as large amounts of fuel and oxygen.” It is believed that Alzheimer’s develops when this normal flow of information is disrupted by the build-up of plaques and tangles.

Under the microscope, scientists see distinct changes in cells.

https://www.alz.org/alzheimers_disease_what_is_alzheimers.asp#tangles
PLAQUES AND TANGLES

“Though autopsy studies show that most people develop some plaques and tangles as they age, those with Alzheimer’s tend to develop far more and in a predictable pattern, beginning in the areas important for memory before spreading to other regions.”

• As these proteins build up, they block communication and vital processes that are necessary for cells to survive. Nerve cells begin to die off, “causing memory failure, personality changes, problems carrying out daily activities and other symptoms of Alzheimer’s disease.”

https://www.alz.org/braintour/plaques_tangles.asp
**PLAQUES**

**Plaques** are a type of protein called “beta-amyloid” (BAY-tuh AM-uh-loyd) that accumulates between brain cells.

Formed from the fatty membrane surrounding nerve cells, Beta-amyloid “is chemically ‘sticky’ and gradually builds up into plaques.”

Groups of beta-amyloids that are made up of several pieces are suspected to be more damaging than the plaques themselves. “The small clumps may block cell-to-cell signaling at synapses. They may also activate immune system cells that trigger inflammation and devour disabled cells.”

https://www.alz.org/braintour/plaques_tangles.asp
TANGLES

Tangles, shaped like twisted fibers, are another type of protein called “Tau” that develop inside brain cells.

Tangles destroy a vital cell transport system made of proteins.

https://www.alz.org/braintour/plaques_tangles.asp
Another way Alzheimer’s Disease affects brain function is by disrupting the activity of neurotransmitters and the way electrical charges travel within cells.

Signals that form memories and thoughts move through an individual nerve cell as a tiny electrical charge.

Nerve cells connect to one another at synapses. When a charge reaches a synapse, it may trigger release of tiny bursts of chemicals called neurotransmitters. The neurotransmitters travel across the synapse, carrying signals to other cells.

https://www.alz.org/braintour/synapses_neurotransmitters.asp
All of these actions result in nerve cell death and tissue loss throughout the brain. As time passes, “the brain shrinks dramatically, affecting nearly all its functions.”

https://www.alz.org/braintour/severe_stage.asp
A Public Health Issue

• What is Public Health/ Why Alzheimer’s is a Public Health Issue
• Quick Facts
• Alzheimer’s in Vermont
• Impact on Families and Caregiver Health
• Social and Work Impact
• Doctors Making a Difference in Our Community
**WHAT IS PUBLIC HEALTH?**

Public health works on a population level to protect and improve the health and safety of an entire community or group of people. Public health promotes healthy lifestyles, prevents illnesses and injuries, and detects and controls diseases. By working with diverse communities, public health supports the health and impact of health care efforts.

**Public Health at Work:**

- Vaccinations to prevent disease
- Quit smoking campaigns
- Emergency preparedness
- Safe drinking water
- Prevent and encourage healthy behaviors
- Improve management of health conditions to avert complications
- Prevent injuries
- Prevent epidemics and spread of disease
- Protect against environmental hazards

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**WHY ALZHEIMER’S IS A PUBLIC HEALTH ISSUE**

“Alzheimer’s is the most under-recognized threat to public health in the 21st century.”

Dr. David Satcher, former U.S. Surgeon General and former CDC Director

While Alzheimer’s has traditionally been seen as an aging issue, Alzheimer’s is a public health issue because:

- **The burden is large and growing larger.**
  - More than five million people are living with Alzheimer’s, and we know that the number of people with the disease is projected to triple, to as many as 16 million by 2050.

- **The impact is major.**
  - Annual costs exceed quarter of a trillion dollars ($355 billion in 2017) and costs are expected to rise to $1.1 trillion in 2050.

- **There are ways to intervene.**
  - Among people with dementia, one in every four hospitalizations is preventable.
  - More than 15 million caregivers have over $10 billion in additional health care costs each year due to caregiver burden.

- **Promoting prevention –** regular physical activity, attention to heart health, and reduction of the risk of cognitive decline and may reduce risk of Alzheimer’s.
- **Promoting early detection and diagnosis –** so many as half of people with Alzheimer’s are not diagnosed, and less than half of the diagnosed are aware of the diagnosis.
- **Data collection –** Collecting data on subjective cognitive decline and Alzheimer’s caregiving can help identify the burden and impact in each state.

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[alzheimer’s association logo]
ALZHEIMER'S DISEASE IS THE 6TH LEADING CAUSE OF DEATH IN THE UNITED STATES

MORE THAN 5 MILLION AMERICANS ARE LIVING WITH ALZHEIMER'S BY 2050, THIS NUMBER COULD RISE AS HIGH AS 16 MILLION

EVERY 66 SECONDS someone in the United States develops the disease

MORE THAN 15 MILLION AMERICANS provide unpaid care for people with Alzheimer's or other dementias

IN 2016 these caregivers provided an estimated 18.2 BILLION HOURS of care valued at over $230 BILLION

IN 2017, Alzheimer's and other dementias will cost the nation $259 billion. By 2050, these costs could rise as high as $1.1 TRILLION

35% of caregivers for people with Alzheimer's or another dementia report that their health has gotten worse due to care responsibilities, compared to 19% of caregivers for older people without dementia

1 IN 3 seniors dies with Alzheimer's or another dementia

Since 2000, deaths from heart disease have decreased by 14% while deaths from Alzheimer's disease have increased by 89%

IT KILLS MORE THAN breast cancer and prostate cancer COMBINED
Cognitive Decline in Vermont

Data from the 2016 Behavioral Risk Factor Surveillance System

In Vermont, 9.8 percent of those aged 45 and over report experiencing confusion or memory loss that is happening more often or is getting worse ("subjective cognitive decline").

More than half of them have not talked to a health care professional about it.

For those with worsening memory problems, 47.3 percent say it has created "functional difficulties" — that is, caused them to give up day-to-day activities and/or interfere with work or social activities.

65+ Number of People Aged 65 and Older
With Alzheimer's by Age

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Percentage change from 2017: 41.7%

U.S. Statistics

- 5 million Americans are living with Alzheimer's, and as many as 36 million will develop the disease in 2050.
- The cost of caring for those with Alzheimer's and other dementias is estimated to total $259 billion in 2017, increasing to $1.1 trillion (in today’s dollars) by mid-century.
- Nearly one in every three seniors who die each year has Alzheimer's, or another dementia.

Hospice

- # of people in hospice with a primary diagnosis of dementia: 363
- % of people in hospice with a primary diagnosis of dementia: 16%

Medicaid Costs of Care for People with Alzheimer's, 2017

$98 MILLION

Medicaid costs increased 44.3% from 2017 to 2025.

Number of Deaths from Alzheimer's Disease in 2016

- # of deaths from Alzheimer's Disease: 266
- % increase in Alzheimer's deaths since 2000: 99%

For more information, view the 2017 Alzheimer's Disease Facts and Figures report at alz.org.
IMPACT ON FAMILIES AND CAREGIVER HEALTH

43.5 million caregivers are giving care to a person at least 50 years old.

Along with old age, Alzheimer’s disease is one of the top reasons recipients need care.

More than 15 million people provide unpaid care to individuals with Alzheimer’s disease or other dementias.

Care totals 17.4 billion hours of unpaid caregiving, valued at $216 billion.

Alzheimer’s Disease, Elder Care and the Workplace

> 67 percent of caregivers are between the ages of 35-64 years.4
> As many as 70 percent of caregivers are women.5
> About 60 percent are employed full or part time.5
SOCIAL AND WORK IMPACT

Caregivers of Alzheimer’s patients reported having to make major changes to their work schedules because of caregiving responsibilities.

Caregivers commonly experience high levels of emotional stress and depression.

Caregivers, on average, provide care for people with Alzheimer’s for longer amounts of times than those who care for other older adults.

Working and Providing Care for Individuals with Alzheimer’s Disease
DOCTORS MAKING A DIFFERENCE IN OUR COMMUNITY

Michael LaMantia, M.D. M.P.H.

Article: Ongoing Medical Management to Maximize Health and Well-being for Persons Living With Dementia

This article, published in *The Gerontologist*, Dr. Michael LaMantia, in collaboration with colleagues, addresses the complex care needs of individuals with dementia and stress the importance of “person-centered care.”

“This article provides eight practice recommendations intended to promote understanding and support of the role of nonphysician care providers in educating family caregivers about ongoing medical management to improve the wellbeing of persons living with dementia.”

Dr. LaMantia was just recently named the Director of the UVM Center on Aging and is an associate professor of medicine and neurological science, as well as the head of geriatric medicine.

DOCTORS MAKING A DIFFERENCE IN OUR COMMUNITY

William Pendlebury, M.D.
Professor Emeritus, Department of Pathology and Laboratory Medicine
Professor, Department of Neurological Sciences
Larner College of Medicine

“Since I began my career as a faculty member in the Departments of Pathology and Neurological Sciences at the University of Vermont 35 years ago, my professional life has been rewarded by and focused on research, clinical practice, and community service related to Alzheimer's disease (AD). I have been fortunate to witness and be part of the explosion of knowledge that we have witnessed during that time as we gained insight into the possible etiologies and pathogenesis of this disorder. In the 1990s, I was part of the research team that led to the approval of several pharmaceutical agents that are currently used to treat AD. In 1991, together with my colleague Dr. Janis Peyser, I founded the UVM Medical Center Memory Program, currently located on the Fanny Allen Campus in Colchester. Our staff has grown to include 14 dedicated professionals who strive to provide evidence based clinical care to patients with AD and their families. I have also been privileged to lecture locally, regionally and nationally to lay and professional audiences on more than 200 occasions about various topics related to AD, and in that way have disseminated the latest, up-to-date information regarding AD clinical care and treatment. In 2012, I was honored to receive the Community Leadership and Activist Award from the Alzheimer's Association. I continue to have enthusiastic dedication to education and clinical practice for AD patients and family caregivers.”
Research, Initiatives, Movements, and Programs

• The Longest Day
• The Walk to End Alzheimer’s
• Health Brain Initiative
• Trial Match
• Virtual Library
• Services in the Community
THE LONGEST DAY

This initiative helps raise awareness and funds for Alzheimer’s disease by asking participants to set aside time on the longest day of the year, the summer solstice in support of funding and research. Based on the idea that there are not enough hours in the day to best care for those with Alzheimer’s disease, participants pick any activity that is meaningful to them, raise money, and do this activity on the summer solstice. Go to the Alzheimer’s Association Website to get ideas on how to participate: www.alz.org
The Walk to End Alzheimer’s

• Every year, in more than 600 communities in the U.S., the Alzheimer’s Association Walk to End Alzheimer’s raises awareness and funds for care, support and research. It is the world’s largest fundraiser for Alzheimer’s disease.

• 2018 Champlain Valley Walk: Shelburne Museum, Shelburne, VT

• Sunday, September 16, 2018

THE HEALTHY BRAIN INITIATIVE

The Alzheimer’s Association, in partnership with the Centers for Disease Control and Prevention, in their Healthy Aging Program, have published a Road Map “to advance cognitive health as a vital, integral component of public health.” This Road Map “identifies 35 specific action items that public health agencies can do over the next five years to promote cognitive functioning, address impairment, and help meet the needs of caregivers.”

https://www.alz.org/publichealth/road-map.asp
TRIALMATCH

TrialMatch is a service that assists in connecting Alzheimer’s disease patients, caregivers, healthy volunteers, and physicians with free clinical studies throughout the country and online.

To assist in the search for better treatments, prevention and a cure, clinical trials and studies are crucial. To learn more, visit alz.com/TrialMatch or call 800.272.3900
The Alzheimer’s Association has a virtual library devoted specifically to enhancing knowledge about Alzheimer’s Disease and related dementias. Visit the library at https://www.alz.org/library
Vermont Telephone Caregiver Support Group
Presented by: Alzheimer’s Association, Vermont Chapter

Join us for a new caregiver support group from the comfort of your own home or office.

Held monthly on the 2nd Tuesday 4:00-5:30PM.

Facilitated by:
Nan Rogers and Eileen Lawson,
Volunteer Facilitators

Space is limited. If you are interested in learning more or registering for this support group, please reach out to Pamela Beidler, Director of Programs and Outreach: pbeidler@alz.org or 802.316.3839 x8011.

Build a support system with people who understand.

Alzheimer’s Association® telephone support groups provide emotional, educational and social support for caregivers through regularly scheduled meetings. Held via telephone to accommodate individuals who are unable to travel to a meeting site, these groups help participants develop coping methods and encourage them to maintain their personal, physical and emotional health.

To extend your network of support, call our 24/7 Helpline: 800.272.3900 or visit ALZConnected®.

24/7 Helpline: 800.272.3900 | alz.org®
SERVICES IN THE COMMUNITY

https://alz.org/we_can_help_24_7_helpline.asp
Aliceheimer’s: Alzheimer’s Through the Looking Glass
A Graphic Medicine Book by Dana Walrath

• About Dana Walrath
• Aliceheimer’s (excerpts)
• What is Graphic Medicine?
• Artwork from Aliceheimer’s
• Other Work by Dana Walrath
• Thank you to...
• Citations
Dana Walrath is a medical anthropologist, writer, and artist who lives in Vermont. Until 2008, she taught medical students at the UVM College of Medicine.

She grew up in New York City interested in art and science, spending more time outside running and playing than inside reading and writing. She started teaching at a young age, studied at Barnard College and Columbia University, drawn to both visual art and biology, and earned a PhD in the anthropology of childbirth from the University of Pennsylvania. Anthropology was a means for her to connect creativity with her interests in life, science, and writing.

“Since moving to the mountains of Vermont with my husband and three sons in the summer of 2000, I’ve used stories and art to teach medical students at the University of Vermont’s College of Medicine. Creative writing and artwork was done mostly during hours stolen from sleep and squeezed between other responsibilities. The balance tipped toward creative work shortly after my mother, Alice, and dementia moved in with us. Alice had always wanted me to be a doctor. When she stood in my kitchen in early 2008, admiring the cabinet knobs I had hand painted and said, ‘You should quit your job and make art full time,’ I listened, and I haven’t looked back. When Alice lived with us, I had the great pleasure of earning an MFA in writing from Vermont College of Fine Arts.”

http://www.danawalrath.com/about/
Aliceheimer’s is an exploration of Dana’s experiences caring for her mother, Alice Mashoian Walrath. It is a navigation through Alzheimer’s, the rituals that ground Alice, the stories and memories that transport her to different times, the childlike understanding while grappling with a present world she can’t remember. It is a circuitous, fluid journey between the present and the past, following the meanderings of Alice’s Alzheimer’s, from seeing her late husband up in a tree outside Dana’s Vermont farmhouse to trips back to World War II and food rationing. Dana puts her expertise to work to help deal with her mom’s memory loss, time traveling, emotions, and sense of security.
“Aliceheimer’s found me rather than the other way around. In February of 2008, for the second time in the space of six months, my mother, Alice, had just been kicked out of her apartment. The reason? Her Alzheimer’s disease. My sister and I looked for alternatives around New York City, her life-long home. We were hoping to keep her near the relatives to which she was the closest, near to her friends. Instead, she moved hundreds of miles north to live with me and my family in the Vermont woods. Vermont winters are long and cold. She hated snow. I was the daughter who got on her nerves. The feeling was mutual…

If Alzheimer’s disease brought humor and clarity into our lives, does this mean that our lives were utterly crazy beforehand? Perhaps it was a bit of insanity that led me to move Alice, into our home just as our nest was about to empty, just as she was losing her marbles. But with a community of help that included pirates, good neighbors, a cast of characters from space-time travel, and my dead father hovering in the branches of the maple trees that surround our Vermont farmhouse, Aliceheimer’s let us write our own story daily—a story that, in turn, helps rewrite the dominant medical narrative of aging.”
WHAT IS GRAPHIC MEDICINE?

The official definition of Graphic Medicine is “the use of comics in medical education and patient care.” Graphic Medicine novels have recently been recognized as a useful tool in the medical field spurred by a resurgence in comic popularity. Dr. Ian Williams, comics artist and physician, comments that graphic medicine plays an important role in:

• Reflecting or changing cultural perceptions of medicine
• Relating the subjective patient/carer/provider experience
• Enabling discussion of difficult subjects
• Helping other sufferers or carers

https://www.graphicmedicine.org/why-graphic-medicine/
“Graphic storytelling captures the complexity of life and death, of sickness and health. Going back and forth between the subconscious and conscious, between the visual and the verbal, lets us tap into our collective memory, an essential element of storytelling.”

“Graphic medicine gives us ways to see the world through the eyes of others. We can better understand those who are hurting, feeling their stories, and redraw and negotiate those social boundaries. Most of all, it gives us a way to heal and to fly over the world as Alice does.”

—Dana Walrath
ARTWORK FROM ALICEHEIMER’S
OTHER WORK BY DANA WALRATH

SCIENCE, STORYTELLING, AND RACE SCROLL, 1ST PAGE, BY DANA WALRATH

GRAPHIC MEDICINE MEDICAL ANTHROPOLOGY SCROLL, 1ST PAGE, BY DANA WALRATH
THANK YOU TO...

• Nancy Bianchi, for acting as consultant and for always being so supportive
• Kate Birnbaum, for her hard, diligent work
• Pamela Beidler, for her guidance and for the wealth of information provided by the Alzheimer’s Assoc. of VT
• Dr. William Pendlebury, for his enthusiasm and contribution
• Dana Walrath, for her story and creativity
CITATIONS:

Websites and Links:

https://alz.org/
http://www.danawalrath.com

Books, Articles and Interviews:


