Alzheimer’s:
A Disease Not A Disgrace™

Jim Mangi

Kathleen Then and Now

2000

2016

2019
How Big a Problem?

More than 7 million Americans have Alzheimer’s or another dementia: more than the combined populations of these states:

Ten years from now, add the equivalent of Nebraska’s population


<table>
<thead>
<tr>
<th>US Population Over 65</th>
<th>% of total</th>
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<tbody>
<tr>
<td>2018: 51,000,000</td>
<td>15%</td>
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<tr>
<td>2030: 73,000,000</td>
<td>21%</td>
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Michigan has more seniors than the national average, and Washtenaw has about 48,000 of them.
How common is it?

- Roughly every minute, another American develops Alzheimer’s dementia
- 10% of Americans over 65 have it.
- 190,000 Michiganders

Alzheimer’s $$$ Impacts

Our most expensive disease, by far

- Annual nationwide government and private costs: $277,000,000,000 (Several times more than we spend on all cancers combined)
- Annual value of unpaid caregiving: $232,000,000,000
- Provided by 16 million unpaid caregivers, working over 10 million full time equivalent jobs
- Estimated lifetime cost of care for a person with dementia: $340,000
1. **Memory Loss That Disrupts Daily Life.**
Forgetting recently learned information; asking for the same information over and over, and increasingly needing to rely on reminder notes and devices.

What's a typical age-related change? Sometimes forgetting names or appointments, but remembering later.

2. **Challenges In Planning Or Problem Solving.**
Changes in ability to make and follow a plan, work with numbers, follow recipes, or keep track of bills. Persons may have difficulty concentrating and take much longer to do things than formerly. Typical age-related change: Occasional checkbook errors.

3. **Difficulty Completing Familiar Tasks**
Trouble driving to a familiar location, managing a budget, or remembering the rules of a favorite game.

Typical age-related change: Occasionally needing help to use the microwave or record a television show.

4. **Confusion With Time Or Place.**
Losing track of dates, seasons and the passage of time. Trouble understanding things not happening immediately. Forgetting where they are or how they got there.

Typical age-related change: Forgetting day of the week.

5. **Trouble Understanding Visual Images and Spatial Relationships.**
Difficulty reading, judging distance, and determining color or contrast, which may cause problems with driving.

Typical age-related change: Vision changes from cataracts.

6. **New Problems With Words.**
Trouble following or joining a conversation. The person may stop in the middle of a conversation, or repeat themselves. They may have problems finding the right word. Typical age-related change: Occasional trouble finding the right word.

7. **Misplacing things and inability to retrace steps**
Putting things in unusual places; losing things and accusing others of stealing. This may become more frequent. Typical age-related change: Misplacing things occasionally.

8. **Decreased or Poor Judgment.**
Changes in judgment or decision making such as giving large amounts of money to telemarketers or con artists. Persons may pay less attention to grooming and hygiene.

Typical age-related change: Occasional bad decisions.

9. **Withdrawal From Work Or Social Activities**
Withdrawal from hobbies, social life, work projects or sports. Trouble keeping up with a favorite team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced. Typical age-related change: Sometimes feeling weary of work, and social obligations.

10. **Changes In Mood Or Personality.**
Person can become confused, suspicious, depressed, fearful, anxious; easily upset at home, at work, or where they are out of their comfort zone. Typical age-related change: Developing very specific ways of doing things.

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**Dementia vs Alzheimer’s**

Dementia---The General name for:

- loss of memory or other mental function that impairs daily life
- Caused by any of several diseases or conditions—100 different possible causes
- Some are treatable, even curable

Specific Causes of Dementia:
- Alzheimer’s Disease (about 70% of dementia cases)
- Vascular dementia i.e. strokes (about 10% of dementia cases)
- Lewy body dementia (10%)
- Frontotemporal dementia
- Parkinson’s disease (sometimes)
- Huntington’s disease
- Alcohol/drug abuse
- Thyroid and vitamin disorders
- Depression
- Hypoglycemia
- Medication interactions
Why Aren’t They “Paying Attention”?

In persons with Alzheimer’s, brain cells responsible for memory are damaged.

It’s like trying to take notes on paper you’ve just spilled coffee on.

Good luck with that.

Memory Storage Devices

Even when they do “record” new memories, the brains of persons with Alzheimer’s sometimes work like Magic Slates—wiping the new memories all clean in an instant.

Pfftt!!
Actually, The Glass Is Full
You can see the water, not the air, but it’s there.

Just so with people.

Look beyond what’s obviously missing; see what’s still there.

You should always talk to us. We’re still in there. Know that you have reached us even if we don’t look at you or respond

-A man with Alzheimer’s, quoted in Facing Alzheimer’s With Strength and Grace, AgingCare.com

Alzheimer’s: Storm Damage In the Brain (But It Can’t Be Cleaned Up)

- The normal brain handles high speed thought traffic
- Changing thoughts/lanes is easy
- An Alzheimer’s-damaged brain, not so much.
- Don’t expect a quick response to your question.
- Don’t change topics suddenly; they won’t follow you.
**Finessing dressing**

- “You have your gloves on the wrong hands!”
- “You have your gloves on backwards!”
- “I will put your gloves on for you!”
- “Those might be more comfortable the other way around …………
  want me to help adjust them a little?”

**Mysterious Mirrors**

- “I can’t use the bathroom, there’s some old lady in there”
- “The lady in the window said I could go outside now”
- Get help from the Klingons
  - Temporarily cover mirrors, artwork, at home, or on travel
Other Considerations

- Consult Elder Law Attorney/Financial Advisor
  - Power of Attorney (POA)
  - Advance Medical Directive and Do Not Resuscitate (DNR) Directive
  - Finances
  - Don’t wait too long….. like I did

- Take care of yourself—the “Second Patient”
  - (S)he needs you at your best
  - Don’t wait for your trip to the ER as a warning
  - Take advantage of all available help:
    - That’s not weakness, it’s being human

- Learn about and watch out for Urinary Tract Infections (UTI)
  - I almost lost Kathleen

Alzheimer’s Disease: No Cure Yet

- There’s never been a documented cure
- No proven, surefire preventive diet or supplement
- But, healthy eating and living probably lower risk
- Family history/genetics are no guarantee either way
  
  (don’t look to DNA testing)

  I won’t get it, because……..

  This is never a safe statement
Watch Out for False Promises About So-Called Alzheimer’s Cures

In the News

The U.S. Food and Drug Administration has warned 17 companies that sell dietary supplements to stop making false claims that their products can prevent or cure Alzheimer’s disease. “These products are ineffective, unsafe and could prevent a person from getting appropriate diagnosis and treatment,” according to the agency’s statement released in February.

The agency has sought to reform the supplement industry and taken aim at firms claiming their products can cure diseases, which affects more than 5 million Americans. So far, the FDA has improved effective at stopping or treating the disease.

In the 25 years since the U.S. passed a law giving the regulatory authority over dietary supplements, the business has grown from a $4 billion industry to one that is worth $40 billion, according to the agency. Today, 4 in 5 older adults take a supplement.

Outgoing FDA Commissioner Scott Gottlieb said that some products

For Consumers

Unproven Alzheimer’s Disease Products

The U.S. Food and Drug Administration issued 12 warning letters and 5 online advisory letters to domestic companies that are illegally selling more than 56 products, many of which are sold as dietary supplements which are unapproved new drugs and/or misbranded drugs that claim to prevent, treat or cure Alzheimer’s disease and a number of other serious diseases and health conditions. These products, which are often sold online and on social media platforms, have not been reviewed by the FDA and are not proven safe and effective for these diseases and health conditions they claim to treat. These products may be ineffective, unsafe, or even dangerous to patients who are seeking an appropriate diagnosis and treatment.

For More Information

• FDA takes action against 17 companies for illegally selling products claiming to treat Alzheimer’s disease
• Questions and Answers: FDA alerts companies to stop the illegal sale of products claiming to cure Alzheimer’s disease
Some National Dementia Information and Help

- Alzheimers.gov [www.alzheimers.gov]
  - Feds’ main portal for Alzheimer’s information
- National Institutes of Health (NIH)/National Institute on Aging (NIA)
  - Extensive information & free pubs
  - [https://order.nia.nih.gov/publication](https://order.nia.nih.gov/publication)
- MedlinePlus [https://medlineplus.gov/]
  - Extensive library of diverse Alzheimer’s articles, papers
- Area Agencies on Aging: [aaa1b.org](http://aaa1b.org)
  - Government-funded non-profits
  - Help with training, respite care, referrals, other assistance

- Alzheimer’s Association [alz.org/]
  - Information/publications
  - Training
  - 24/7 Volunteer helpline:
  - On-line Support/Message Boards
  - Monthly support groups
- Alzheimer’s Foundation [alzfdn.org]
  - Information/factsheets
  - Training
  - Helpline
  - Monthly support groups
- Fisher Center For Alzheimer’s Research [alzinfo.org]
  - Library of Research articles
- Alzheimer Society of Canada [alzheimer.ca]
- Association For Frontotemporal Degeneration [theaftd.org]
- Lewy Body Dementia Association [lbda.org]
- Dementia Action Alliance [daanow.org]
  (“Nothing About Us Without Us”)
Alzheimer's Disease & Related Dementias

Alzheimer's Caregiving
Learn how to respond to changes in communication and behavior, provide everyday care, and get help when needed.

Medlineplus.gov

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Alzheimer's Disease
Alzheimer's disease (AD) is the most common form of dementia among older people. Dementia is a brain disorder that seriously affects a person's ability to carry out daily activities.

AD begins slowly. It first involves the parts of the brain that control thought, memory and language. People with AD may have trouble remembering things that happened recently or names of people they know. A related problem, mild cognitive impairment (MCI), causes more memory problems than normal for people of the same age. Many, but not all, people with MCI will develop AD.

(Read more)

Results 1 - 10 of 1,112 for alzheimers

1. Alzheimer's Disease (National Library of Medicine)
Alzheimer's disease (AD) is the most common form of dementia among older people.

Dementia is a brain...
Alzheimer's Disease Fact Sheet

On this page:

- Changes in the Brain
- Signs and Symptoms
- What Causes Alzheimer's
- Diagnosis of Alzheimer’s Disease
- Participating in Clinical Trials
- Treatment of Alzheimer’s Disease
- Support for Families and Caregivers

Alzheimer’s disease is an irreversible, progressive brain disorder that
FIVE ‘POCKET’ FILMS TO INCREASE UNDERSTANDING OF A 21ST CENTURY EPIDEMIC

A QUICK LOOK AT ALZHEIMER’S

1. WHAT IS ALZHEIMER’S DISEASE

Watch on YouTube
Flash-embedded videos are no longer supported, but you can still watch this video on YouTube.

WATCH ON YOUTUBE

OPTIONS
- Download to iTunes (mp4)
- Download to Desktop (Quicktime)
- Download to Desktop (WMV)
- Embed in Your Own Website
- Purchase DVD for $9.95 (including shipping)
- Contact us

Developed in partnership with
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Alliance for Aging Research
MetLife Foundation
Some Other Information Resources

- Long term care planning (Medicaid, Insurance etc.):
  Longtermcare.gov
- Legal and Financial Planning:
  nia.nih.gov/topics/legal-and-financial-planning
  National Academy of Elder Law Attorneys: www.naela.org
  American Bar Association, Consumer's Toolkit for Health Care Advance Planning americanbar.org
  Legal Services Corporation lsc.gov
- Caregiver resources:
  Caregiver Action Network caregiveraction.org
  Family Caregiver Alliance caregiver.org
  Aging Life Care Association aginglifecare.org.
- Driver safety:
  National Institute on Aging:
  nia.nih.gov/health/publication/older-drivers
  Hartford Insurance: the hartford.com/talkwitholderdrivers
- The AlzForum: Research-oriented website for scientists, but also links to popular films and documentaries.
  alzforum.org/films-about-alzheimers

Sampler of Locally Available Help

- Area Agency on Aging 1b
  - Government-funded non-profit
- Geriatric Care Managers (Fee-for-Service consultants; costs, services, qualifications vary)
  - A few examples:
    - SPS Consulting
    - Alivity Care Advocates
    - Kennedy Care
    - See also: MyAlzheimersGuide.com
- Home Care Agencies  (Quality, services, costs vary )
  - A few examples:
    - EHM Shared Care
    - Senior Helpers
    - Visiting Angels
    - Axiom Home Care
- Elder Care Attorneys and Financial Advisors (Costs, qualifications vary )
  - A few examples
    - Legacy Law
    - Bassett Law
    - Dykema
    - See also National Academy of Elder Law Attorneys: naela.org
- Adult Day/Caregiver Respite Programs (Costs, services vary)
  - A few examples
    - Brecon Village
    - Silver Club U of M
    - The Oaks Ann Arbor
    - See also National Respite Network: archrespite.org
Area Agency on Aging 1B  https://aaa1b.org

E.g. Confident Caregivers Course

https://www.alz.org/
Get easy access to a comprehensive listing of Alzheimer’s and dementia resources, community programs and services.

START YOUR SEARCH

- Alzheimer’s Association Programs and Events
- Housing Options
- Care at Home
- Medical Services
- Community Services

ADDITIONAL RESOURCES

- How to Use This Tool
- Learn More
- Share Your Opinion
- Provider Support

The Alzheimer’s Association does not endorse any of the providers listed here. The information contained in the Community Resource Finder is thought to be reliable but is not guaranteed to be accurate. It is compiled from provider descriptions of their own services as well as other public data sources and is subject to change without further notice. For assistance in how to determine the best care option for your situation, call the 24/7 helpline at 800-272-3900.

"Caring for someone with Alzheimer’s can make you feel alone. Now, I’ve found others like me.”

View Message Boards from others like you

- Caregivers Forum
- I have Alzheimers

Moving Advice
My mom was recently diagnosed with mild to moderate Alzheimer’s disease and was started on Aricept. We have convinced her to move into an independent living facility. As you can imagine she initially agreed and now does not want to go.

Tell me I'm not alone
Hi, I just stumbled upon this discussion board tonight and thought it would be a great way to help cope with my mother’s recent diagnosis of early onset Alzheimer’s.

Screening
I passed the Neuro exam and they at least told me that I won’t be scheduled for another screening until late fall/early winter. I understand this can be good - maybe the forgetting, etc. was due to another cause and it could work itself out by that time.

Early-onset Alzheimer’s Disease
I am new to this site, however I just recently started a blog about Early-onset Alzheimer’s, as my mother was diagnosed a couple years ago at age 52.

ALZConnected® (alzconnected.org), powered by the Alzheimer’s Association®, is a free online community for everyone affected by Alzheimer’s or another dementia, including:
- People with the disease
- Caregivers
- Family members
- Friends
- Individuals who have lost someone to Alzheimer’s
Dementia

Basic Facts

What is Dementia?

Dementia is a decline in memory and other mental abilities that make daily living difficult. As many as 7% of adults aged 60 and older suffer from dementia.

Dementia takes a toll on those who suffer from it, as well as their caregivers. Along with problems with memory, language, and decision-making abilities, dementia can cause other symptoms. These include changes in mood, such as increased irritability, depression, and anxiety. They also include changes in personality and...
A separate outfit from the Alzheimer's Association

Agingcare.com Example of commercial entities offering help in locating local appropriate resources. This one also has an extensive forum and online library.
Alzheimer's companion cards can also be downloaded from Alzheimer's Association and other sources.

Another commercial source offering a wide range of products for helping caregivers ensure the safety and contentment of their loved ones.

Amazon (you may have heard of them) as well as other companies, also offer various Alzheimer's products.
Jim Mangi’s Public radio interview:

Or: Google: Michigan Radio Stateside, then search Alzheimer’s

What it’s like to watch a loved one with early-onset Alzheimer's slowly slip away

Extended interview includes our daughter and her personal, and professional, perspective.

In 2016, Kathleen enjoyed seeing the Grand Canyon for the first time, again.

Jim’s Favorites
There are many good books on Alzheimer’s and dementia, (and some not so good, like the ones that promise preventions and cures). These three were the most useful I have read:

The 36 hour Day by Mace and Rabins. This is a standard, go-to, somewhat clinically written resource.

Creating Moments of Joy by Jolene Brackey. Series of very sensitively written brief chapters of practical ideas, especially, but not only, for later on in the disease, for bringing some brightness, even transitory, into the lives of folks facing increasing mental fog.

Thoughtful Dementia Care by Jennifer Ghent-Fuller. Don’t read this first, but definitely read it; it may be the most important. It explains, as best anyone can, how different “Our World” is from the “Alternate World” our Loved Ones with Dementia are forced to live in, and how we can best reach them and help them navigate their new environment. This is a very good, brief, but intense read.

Visit the In This Together Display at the Saline Library
We can’t yet cure Alzheimer’s, nor should we ignore it.

In partnership with the Alzheimer’s Association, Holy Faith Church is sponsoring a dementia awareness program to give individuals and their families reliable information about Alzheimer’s and other dementias, caregiving skills, and where to get information and help from multiple sources. With its emphasis on Alzheimer’s as a disease, not a personal failing, the program also seeks to dispel its social stigma.

To kick off this program on May 1 and May 4, we present “Alzheimer’s: A Disease, Not a Disgrace,” a talk by Saline resident Jim Mangi aimed at helping people and families learn about the disease, how to recognize it, how to acquire caregiving skills, and how to get help. He’ll do this within the narrative of his own 11-year long (so far) “Unwelcome Journey™” caring for his wife, who developed younger onset Alzheimer’s in her fifties.

Information booklets from the Alzheimer’s Association and the National Institutes of Health will also be available. **All talks and information booklets are free.**

Visit [www.holy-faith-church.org](http://www.holy-faith-church.org) for more information, or see our display at the Saline District Library.

You needn’t face dementia alone. The sessions in this program will discuss Alzheimer’s and other dementias, caregiving skills, and where to get information and help. Current planned presentations to be held at Holy Faith Church include:

- **May 8 - 7-8:30 pm** Know The Ten Warning Signs of Dementia*
- **May 15 - 7-8:30 pm** Understanding Alzheimer’s & Dementia*
- **May 22 - 7-8:30 pm** Effective Communication Strategies*
- **May 29 - 7-8:30 pm** A Family’s Journey: The Perspective of a Person Living with Dementia
- **June 5 - 7-8:30 pm** Conversations About Dementia*
- **June 12 - 7-8:30 pm** Understanding and Responding to Dementia-Related Behaviors*
- **June 19 - 7-8:30 pm** Legal and Financial Planning Concerning Persons Living with Dementia
- **June 26 - 7-8:30 pm** Brain Changes and Interaction Skills: Pt. 1
- **July 10 - 7-8:30 pm** Brain Changes and Interaction Skills: Pt. 2
- **July 17 - 7-8:30 pm** Envisioning a Dementia-Friendly Community

*Presentations in partnership with Michigan Great Lakes Alzheimer’s Association