Alzheimer's: A Disease Not A Disgrace™

Jim Mangi

Disease Not A Disgrace $^{\mathsf{TM}}$

Kathleen Then and Now



One of The World's Most Powerful Rivers



.....Denial

Disease Not A Disgrace ™

How Big a Problem?

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



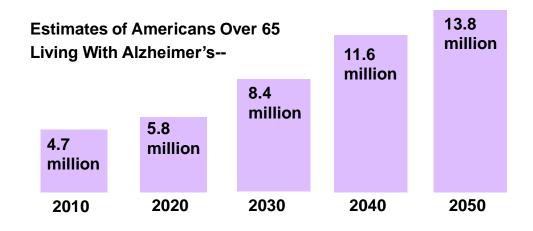
White? Black? Brown? Surely a Lot More Gray

US Population Over 65 % of total

2018: 51,000,000 15% 2030: 73,000,000 21%

Michigan has more seniors than the national average, and Washtenaw has about 48,000 of them.

More from *Alzheimer's Disease Facts and Figures 2018*Alzheimer's Association



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

Ten Early Signs Of Alzheimer's (from alz.org/10signs)

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 agerelated 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 agerelated 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

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

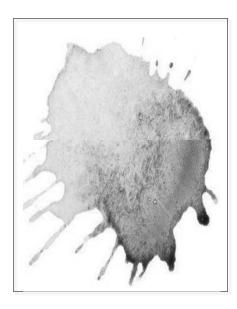
Why Aren't They "Paying Attention"?

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.







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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



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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.

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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?"

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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



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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

Do as I say, not as I did

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

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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)

Use RELIABLE information sources, not hucksters

I won't get it, because......

This is never a safe statement

Home

Food

Drugs

Medical Devices

Radiation-Emitting Products

Vaccines, Blood & Biologics

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Cosmetics

Tobacco Products

For Consumers

Home > For Consumers > Consumer Updates

Consumer Updates

Animal & Veterinary

Children's Health

Watch Out for False Promises About So-Called Alzheimer's Cures

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FDA TARGETS FAKE

A warning to \$40B supplements industry

he U.S. Food and Drug Administration warned 17 companies that sell dietary su stop making false claims that their prod vent or cure Alzheimer's disease. "These be ineffective, unsafe and could prevent a person fro appropriate diagnosis and treatment," according to ment released in February.

The agency has sought to reform the supplement taken aim at firms claiming their products can cure which affects more than 5 million Americans. So fa proved effective at stopping or treating the disease

These products may prevent a person from seeking an appropriate diagnosis and treatment. -The FDA

In the 25 years si passed a law givin regulatory authorit the dietary supplem has grown from a \$4 try to one that is wo \$40 billion, accordi Today, 4 in 5 olde take a supplement.

Outgoing FDA C Scott Gottlieb said that some products



U.S. FOOD & DRUG ADMINISTRATION

■ Home Food Drugs Medical Devices Radiation-Emitting Products Vaccines, Blood & Biologics Animal & Veterinary

A to Z Index | Follow FDA | En Es

For Consumers

Home > For Consumers > Protect Yourself > Health Fraud

Health Fraud For Consumers Warning Letters - Health Fraud Health Fraud Scams - Be Smart,

Be Aware, Be Careful (Video)

Public Notifications and Safety Alerts - Health Fraud

Recalls - Health Fraud

Seizures and Injunctions - Health Fraud

Press Announcements - Health

Unproven Alzheimer's Disease Products

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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 58 products, many that are sold as dietan which are unapproved new drugs and/or misbranded drugs that claim to prevent, treat or cure Ala and a number of other serious diseases and health conditions. These products, which are often s and social media platforms, have not been reviewed by the FDA and are not proven safe and effe diseases and health conditions they claim to treat. These products may be ineffective, unsafe and person from seeking an appropriate diagnosis and treatment.

For More Information

- · FDA takes action against 17 companies for illegally selling products claiming to treat Alzheir
- · Questions and Answers: FDA alerts companies to stop the illegal sale of products cla Alzheimer's disease

Some National Dementia Information and Help

- Alzheimers.gov<u>www.alzheimers.gov</u>
 - 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
- MedlinePlus https://medlineplus.gov/
 - Extensive library of diverse Alzheimer's articles, papers
- Area Agencies on Aging: 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 <u>alzfdn.org</u>
 - 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 Ibda.org
- Dementia Action Alliance daanow.org ("Nothing About Us Without Us")

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https://www.nia.nih.gov/health/alzheimers

Alzheimer's Disease & Related Dementias

Basics | Causes | Symptoms and Diagnosis | Treatment | Caregiving | Related Dementias | Resources for Health Professionals | Research and Clinical Trials

Alzheimer's Caregiving

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



Changes in Behavior and Communication



Everyday Care



Relationships and Alzheimer's



Safety and Alzheimer's



Caregiver Health



Legal and Financial Issues

Medlineplus.gov



alzheimers

GO

About MedlinePlus Site Map FAQs Customer Support

Health Topics

Drugs & Supplements

Videos & Tools

Español

Home → Search Results

Search Help

Related Topics

Alzheimer's Disease

Refine by Type

All Results (1,590)

- Health Topics (23)
- External Health Links (926)
- Drugs and Supplements (30)
- Medical Encyclopedia (43)
- MedlinePlus Magazine (48)
- Multiple Languages (11)
- National Institutes of Health (460)

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),

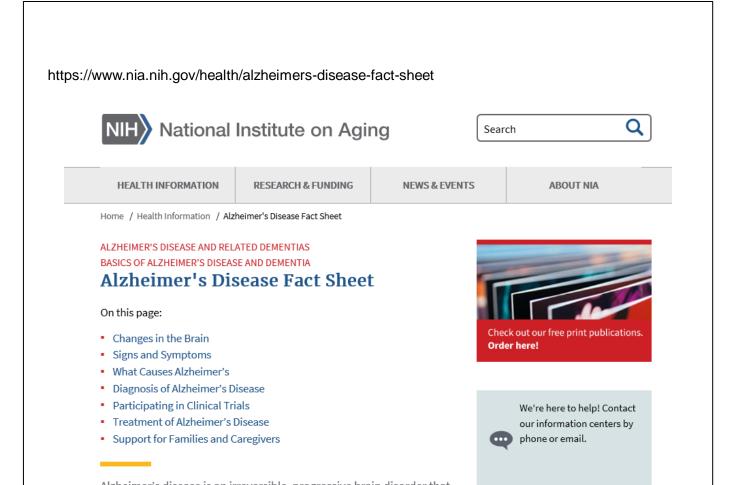


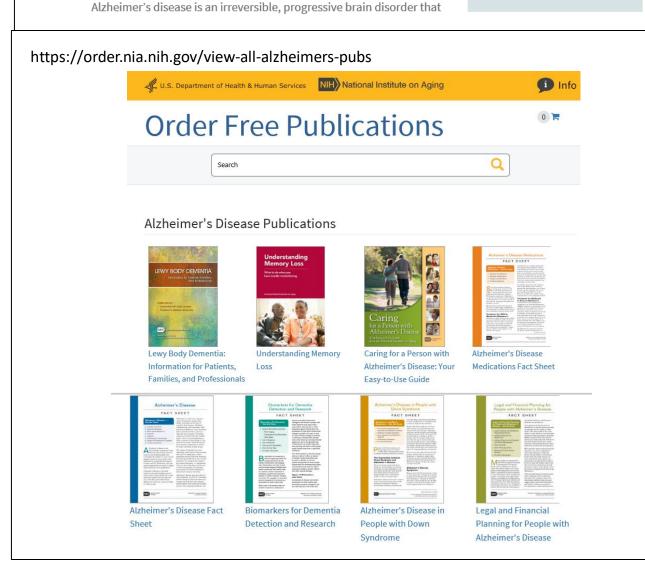
causes more memory problems than normal for people of the same age. Many, but not all, people with MCI will develop AD.

(Read more)

Results 1 - 10 of 1,112 for alzheimers

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 ...



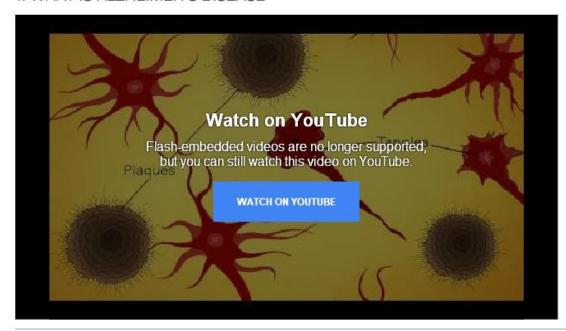


FIVE 'POCKET' FILMS TO INCREASE UNDERSTANDING OF A 21ST CENTURY EPIDEMIC

한국어 الحريب 北方話 北方话 أخرس 타元리 日本語 português русский язык deutsch français español <mark>english</mark>

4SELECT LANGUAGE

WHAT IS ALZHEIMER'S DISEASE









3. The Race to the Cure







TAKE THESE FILMS - PLEASE!

ABOUT THE CREATORS

ALZHEIMER'S RESOURCES

These very-short "pocket" films are designed to be viewed anywhere at anytime: a doctor's office, a Congressional hallway, a family living room. Please take them. Put them on your own website or powerpoint presentation; play them on your phone or tablet. They are free for non-commercial use. Understanding Alzheimer's better will reduce stigma, improve care, and help the public fight against the disease.

- <u>David Shenk</u>, writer/director Author, *The Forgetting*

Options

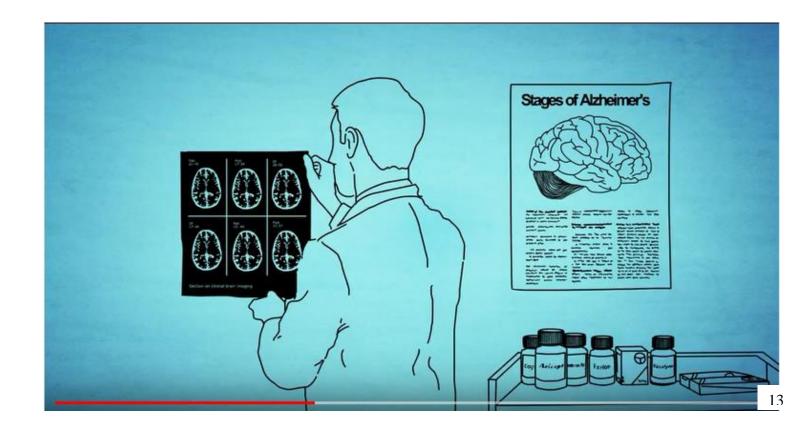
- » Download to iTunes (mp4)
- » Download to Desktop (Quicktime)
- » Download to Desktop (WMV)
- » Embed In Your Own Website
- » Purchase DVD for 70 cents (including shipping)
- » Contact us
- » Subscribe



Developed in partnership with Alliance

by a grant from

Made Possible 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

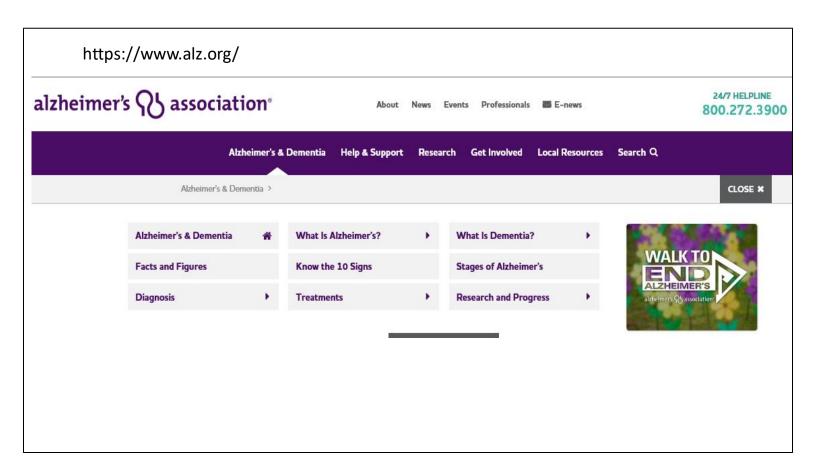
- Area Agency on Aging 1b
 - Government-funded non-profit
- Geriatric Care Managers (Fee-for-Service consultants; costs, services, qualifications vary)
 - A few examples:
 - SPS Consulting
- Kennedy Care
- Alivity Care Advocates
- See also: MyAlzheimersGuide.com
- Home Care Agencies (Quality, services, costs vary)
 - A few examples:
 - EHM Shared Care
- Visiting Angels
- Senior Helpers
- Axiom Home Care
- Elder Care Attorneys and Financial Advisors (Costs, qualifications vary)
 - A few examples
- Dykema
- Legacy Law
- See also National Academy of Elder Law Attorneys:

Bassett Law naela.org

- Adult Day/Caregiver Respite Programs (Costs, services vary)
 - A few examples
 - Brecon Village
- The Oaks Ann Arbor
- Silver Club U of M
- See also National Respite Network: archrespite.org

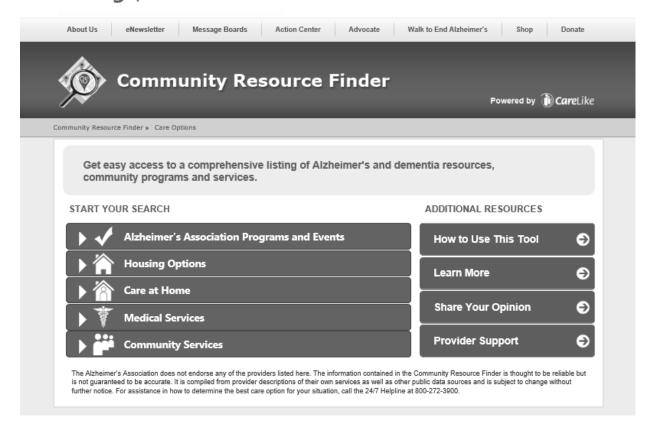
Area Agency on Aging 1B https://aaa1b.org

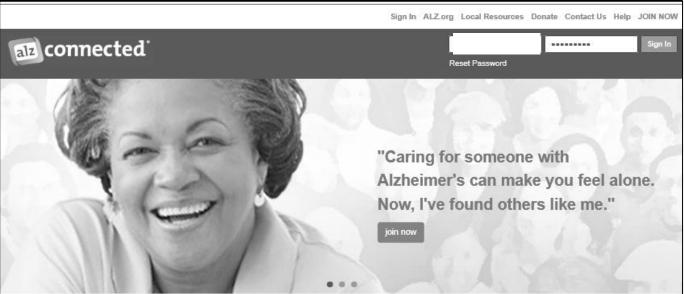




https://www.communityresourcefinder.org/

alz.org® alzheimer's \$\\ association





View Message Boards from others like you

Caregivers Forum

Moving Advice

My mom was recently diagnosed with mild-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.

I have Alzheimers

Screening

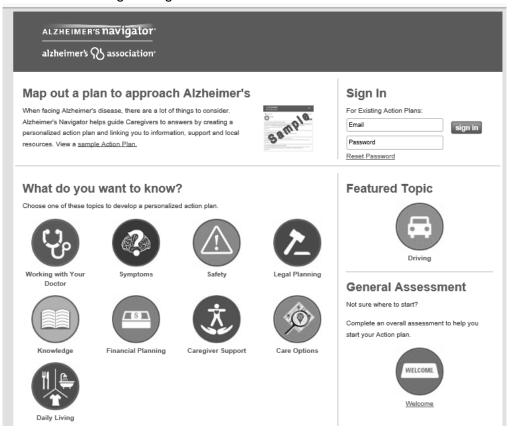
I pestered the Neuro office and they at least told me that I won't be scheduled for another screening until late fall/early winter. I understand this can be good - maybe the forgetfulness, etc. was due to another cause and it could work itself out by that time.

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.

https://www.alzheimersnavigator.org/



Eldercare.gov



Home About Resource

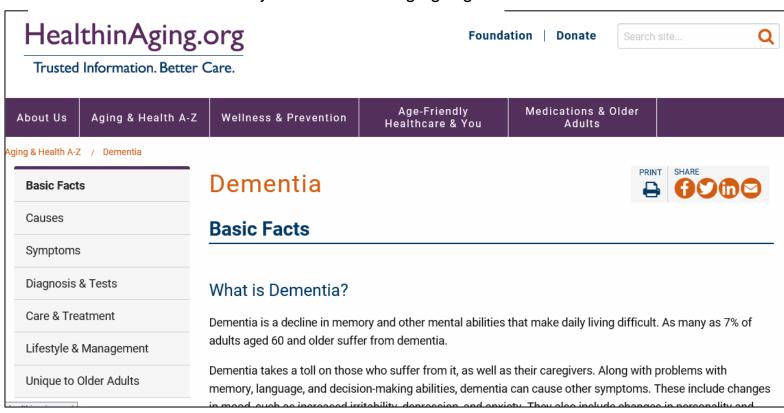
1-800-677-1116

Find help in your community by entering your zip code OR city and state.

Zip Code City/State

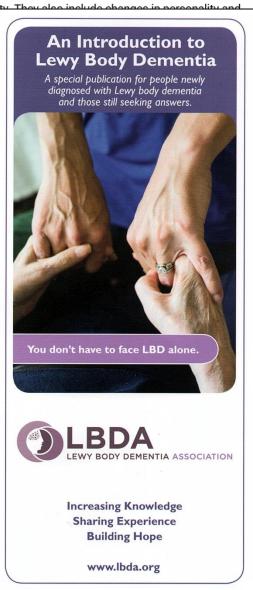
Enter zip code Search



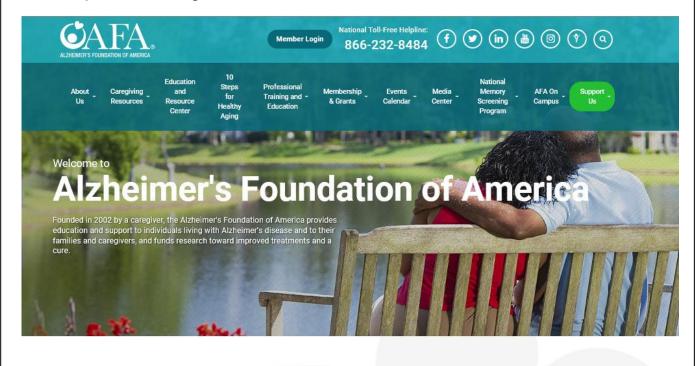


About one of the less common types of dementia



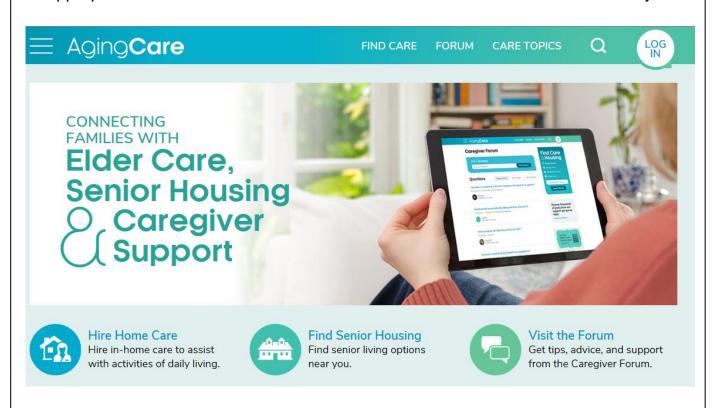


https://alzfdn.org/ A separate outfit from the Alzheimer's Association



We Are The Alzheimer's Foundation of America

Agingcare.com Example of commercial entities offering help in locating local appropriate resources. This one also has an extensive forum and online library.





alzstore.com

MY ACCOUNT WISH LIST CONTACT US

Search our store GO

SHOP BROWSE

ASK THE EXPERT

NEW PRODUCTS

RESOURCES

BLOGS

Find the best products designed for those living with Alzheimer's, dementia and for the ones caring for them!

Save on Tax

Sales tax added to orders shipped to FL or NJ only

Free Shipping

Pay only a flat handling rate of \$3.90 per order

*Free shipping on most orders under 15lbs & in the continental U.S.

SHOPPING FROM CANADA? Visit The Alzheimer's Store Canada ALZSTORE.CA for faster, low-cost shipping!

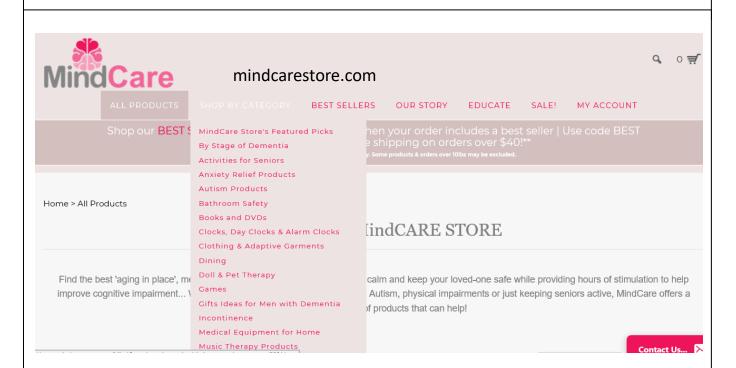
Home > SHOP > Safety for Seniors >

Please Be Patient Alzheimer's Cards



Price: \$15.00

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: http://michiganradio.org/post/what-it-s-watch-loved-one-early-onset-alzheimers-slowly-slip-away

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.



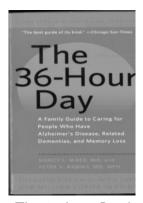
In 2016, Kathleen enjoyed seeing the Grand Canyon for the first time, again.

Disease Not A Disarace TM

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:

By STATESIDE STAFF - MAR 7, 2018

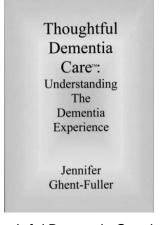


The 36 hour Day by Mace and Rabins. This is a standard, go-to, somewhat clinically written resource.

Visit the **In This Together** Display at the Saline Library



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.

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 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:

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

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