



# Introduction to the Dementia Caregiver Resources Website

Jaye McLaren, OTR/L & Dat Hoang-Gia, RN, CNS

# What is GRECC-Connect?

- GRECC-Connect/Virtual Geriatrics is an Office of Rural Health (ORH) funded National GRECC collaborative
- Offers rural CBOC (Community-Based Outpatient Clinic) and other VA clinicians access to specialty care in geriatrics using telehealth modalities
  - Inter-professional clinical consultation
  - Video telehealth to rural CBOCs and to home
  - Ongoing case-based training/Case Conference Series



# POLL QUESTION

How do you give educational resources to your older patients and/or caregivers ?

(Select all that apply)

- Send link or attachment via email
- Send link or attachment via My Health eVet secure messaging
- Download a physical copy to hand to patient/caregiver during clinic
- Give professional handouts/pamphlets/guides that are already in the clinic (most likely sent by author)
- Print and send through the snail mail
- Write down website on paper and hand to patient/caregiver in clinic
- Referring to another agency but not offering a link
- None of the above

# Background

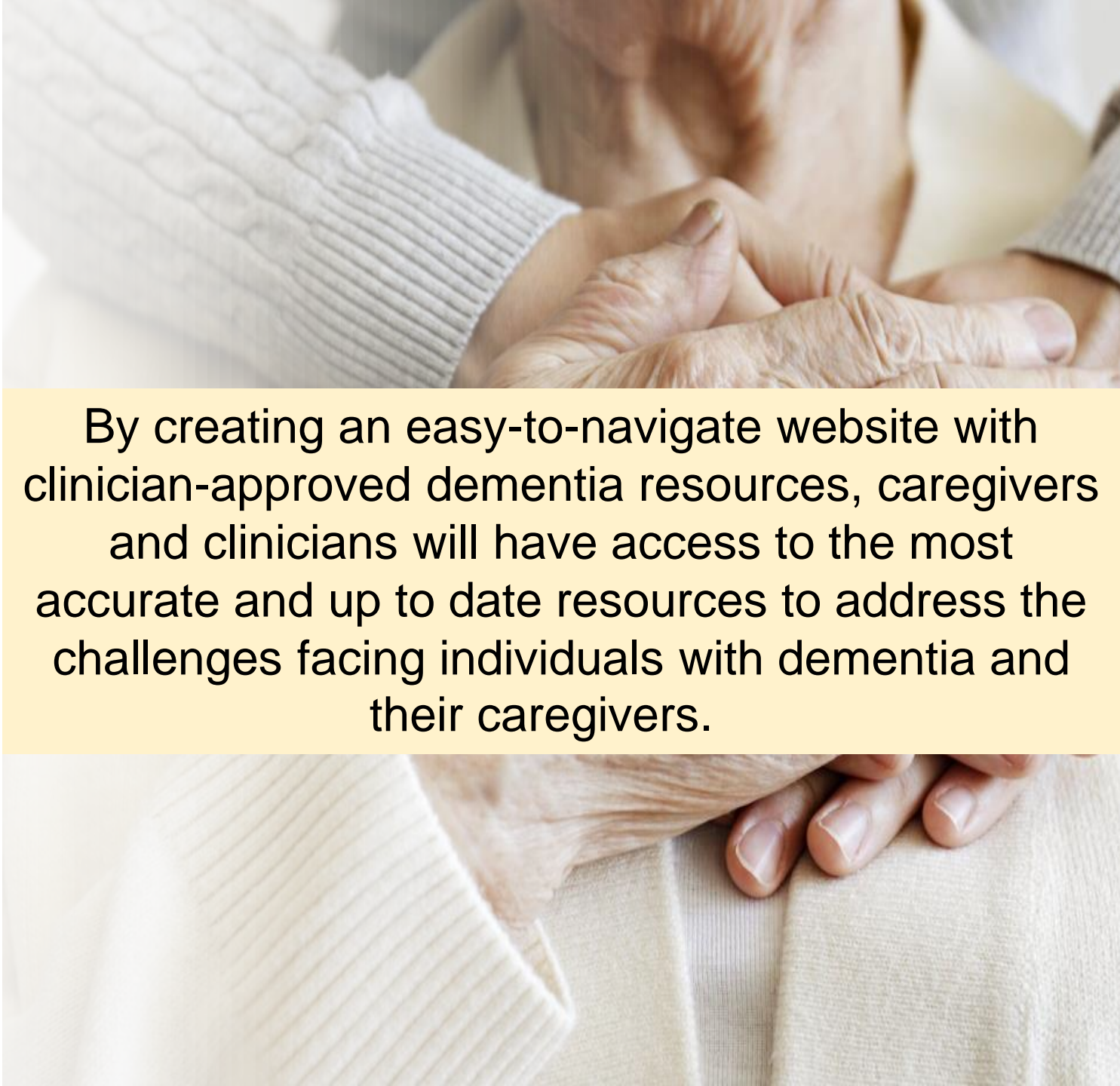
There are 11 million unpaid dementia caregivers in America providing over 16 billion hours of unpaid care.

(Alzheimer's Association Facts & Figures, 2021)

These caregivers report high levels of

- Stress
- Burden
- Depression
- hypertension and impaired immune function

Individuals with dementia and their caregivers living in rural areas face additional barriers in accessing specialty dementia care.



By creating an easy-to-navigate website with clinician-approved dementia resources, caregivers and clinicians will have access to the most accurate and up to date resources to address the challenges facing individuals with dementia and their caregivers.

# Dementia Resources for Caregivers and Families

Clinician Reviewed VA and Non-VA Resources for Families Caring for Veterans with Dementia

- VA GRECC-Connect team of content experts reviewed over 100 online dementia resources and selected the best options.
- Informative & easy to use resources in varied formats (brochure, booklet, video etc.)
- Resources can be printed from the pdf, or the direct link shared via email or chat.





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# Content Experts

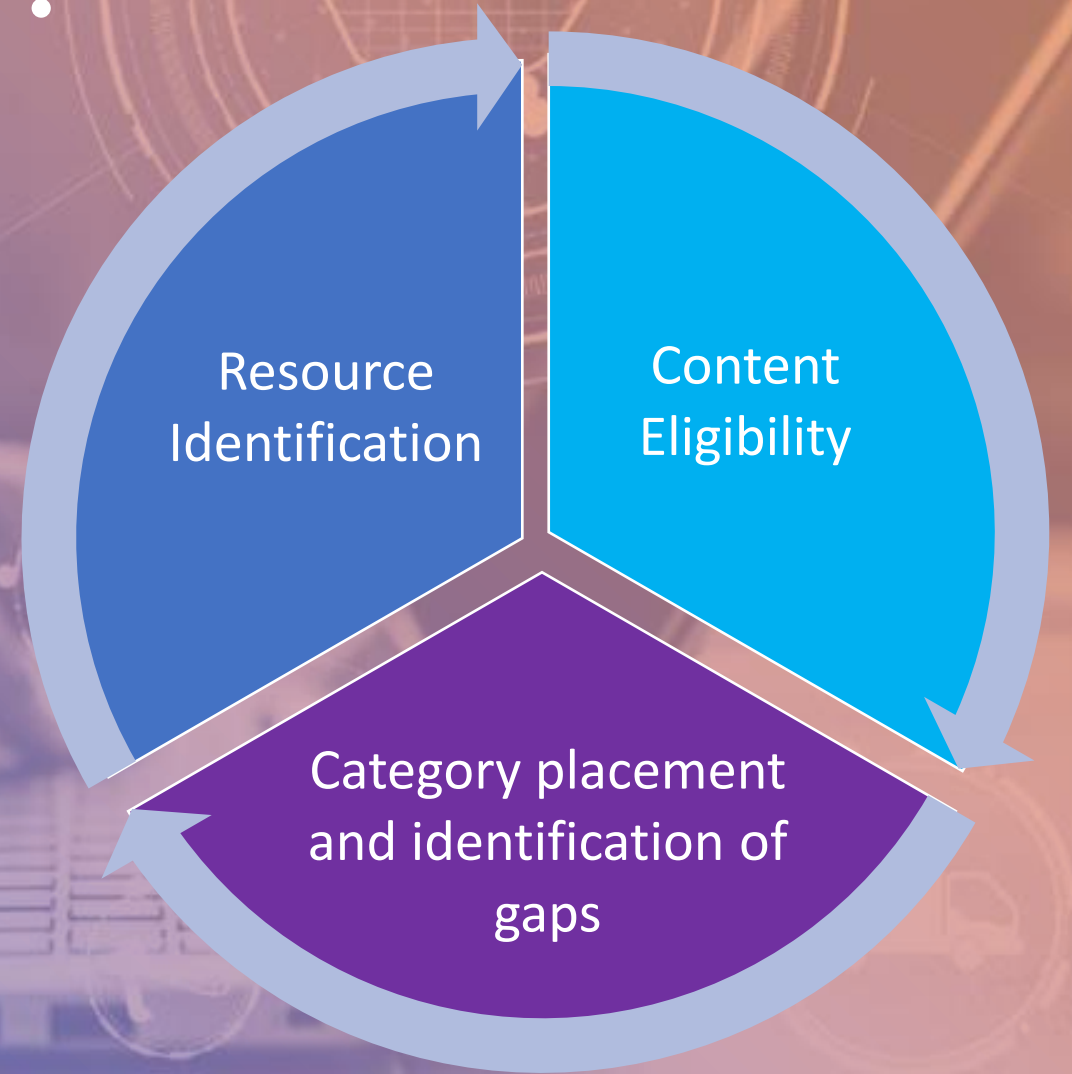
# POLL QUESTION

Where do you go to find information for your patient? Caregivers?

- VA SharePoint
- Google search or other open access search engine
- Refer them to the Caregiver support program or other external caregiver support programs (e.g., Alzheimer's Association)
- Refer to their social worker
- Ask your other colleagues
- I have my own favorite resources
- I don't know



# Choosing the Right Resources





Number	Title of Resource	Patient Population	Author(s)	VA/Non-VA	Type of Resource	# Pages			
1	Management of Dementia-Related Behaviors: a Guide for Caregivers	Dementia	South-Central (specifically Texas per Prasad)	VA	Caregiver Brochure Pocket sized brochure Letter sized brochure	2 2 10	<a href="https://www">https://www</a>		
2	Careblazer Survival Guide	Dementia	Natali Edmonds, Gerontologist: Arizona VA - the careblazer's survival	Non-VA	Workbook/ booklet	(requiring permission)	?	<a href="https://www">https://www</a>	
3	Delerium: What Families Need to Know	Dementia and CogI	South-Central (specifically Texas per Prasad)	VA	Brochure	Printable/Virtual	2	<a href="https://www">https://www</a>	
4	Making the Most of Your Families's Video Visit	All	Howard Gordon, MD and HSRD, VA Chicago	VA	Brochure	Printable/Virtual	2	<a href="Microsoft Wo">Microsoft Wo</a>	
5	Making the Most of Your Patient's Video Visit: 5 Habits for Successful Communication	All	Howard Gordon, MD and HSRD, VA Chicago	VA	Infographic	Printable/Virtual	1	<a href="Office of How">Office of How</a>	
6	Getting Ready for Your Telehealth Visit	All	Howard Gordon, MD and HSRD, VA Chicago	VA	Brochure	Printable/Virtual	2	<a href="Microsoft Wo">Microsoft Wo</a>	
7	How to Get Ready for Your Video Visit: 3steps to a successful video visit	All	Howard Gordon, MD and HSRD, VA Chicago	VA	Infographic	Printable/Virtual	4	<a href="Office of How">Office of How</a>	
8	ORH: Caregiver Video Series	Dementia	ORH and VA Rural Health Center	VA	Video Series	Virtual	N/A	<a href="https://www">https://www</a>	
9	Caregiver Self-Care Activity Workbook	All	Resource Rating			/ booklet	Printable/Virtual	54	<a href="Self-Care Act">Self-Care Act</a>
10	Pleasant Activities List	All				Printable/Virtual	12	<a href="https://www">https://www</a>	
11	Alzheimers Disease in People with Down Syndrome	AD	NIA/NIH	Non-VA but Gov	Factsheet	Printable PDFs (virtual) or free	4	<a href="https://order">https://order</a>	
12	Legal and Financial Planning for People Living with Dementia	AD	NIA/NIH	Non-VA but Gov	Factsheet	Printable PDFs (virtual) or free	6	<a href="https://order">https://order</a>	
13	Caring for a person with Alzheimer's Disease: Your Easy-to-Use Guide	AD	NIA/NIH	Non-VA but Gov	Guide (Eng & Spa)	Printable PDFs (virtual) or free	106	<a href="https://order">https://order</a>	
14	Next Steps After an Alzheimer's Diagnosis	AD	NIA/NIH	Non-VA but Gov	Resource/ Support Handout (Eng &	Printable PDFs (virtual) or free	2	<a href="https://order">https://order</a>	
15	Alzheimer's Disease Fact Sheet	AD	NIA/NIH	Non-VA but Gov	Factsheet	Printable PDFs (virtual) or free	8	<a href="https://www">https://www</a>	
16	The Dementia's: Hope Through Research	AD	NIA/NIH	Non-VA but Gov	Guide (Eng & Spa)	Printable PDFs (virtual) or free	40	<a href="https://order">https://order</a>	
17	Biomarkers for Dementia Detection and Research	AD	NIA/NIH	Non-VA but Gov	Factsheet	Printable PDFs (virtual) or free	8	<a href="https://order">https://order</a>	
18	Understanding Alzheimer's Genes (Easy-to-Read Booklet)	AD	NIA/NIH	Non-VA but Gov	Booklet	Printable PDFs (virtual) or free	24	<a href="https://order">https://order</a>	
19	Participating in Alzheimer's Research	AD	NIA/NIH	Non-VA but Gov	Booklet	Printable PDFs (virtual) or free	24	<a href="https://order">https://order</a>	
20	Lewy Body Dementia: Information for Patients, Families, and Professionals	AD	NIA/NIH	Non-VA but Gov	Booklet	Printable PDFs (virtual) or free	44	<a href="https://order">https://order</a>	

# Resource Ratings

## Eligibility Criteria

- Health Literacy
- Visual Ease for Population (size, font, color, pictures and white space etc.)
- Audience
- Ease of Access Overall
- Nationally Accessible
- PDF or Printable
- Varied Formats

Resource Category	Rating	Rater 1 and 2	Rater 3	Rater 4	Rater 5	Final
		(JM + DHG)	SD	SH	LW	
<b>1 Dementia Overview</b>						
<b>1A Dementia Education and Information</b>		Number	Additional			
	1st	2	60	2	2	60
	2nd	22	90	91	22	22
	3rd	8L	91	60	91	91
<b>1B Related Dementias</b>						
	1st	20		97	20	20/21
	2nd	21		20	21	
	3rd	97		21	97	97
<b>1C Dementia and Down Syndrome</b>						
	1st	11		96	95	96
	2nd	95		95	96	11
	3rd	96		11	11	95
	1st	19		19	19	16
	2nd	17		16	16	17
	3rd	16		17	17	19
						13
						60

# Resource Rating

<b>1 <u>Dementia Overview</u></b>	Dementia Education and Information Related Dementias Dementia and Down Syndrome Dementia Research All Encompassing Guides
<b>2 <u>Daily Care</u></b>	ADLs (grooming/bathing/dress etc). Medication Dementia and Activity Participation Traveling Driving Sex and Intimacy Sleep
<b>3 <u>Behavior Changes</u></b>	Anxiety and Depression Delirium Sundowning Wandering Aggression/Agitation Hallucinations/ Paranoia Repetitive or Inappropriate Behaviors
<b>4 <u>Safety</u></b>	Home Safety Gun Safety Falls Prevention
<b>5 <u>Caregivers</u></b>	Self Care and Support Resources and Programming Legal, Financial, Employment Goals of Care/ End-of-Life Communication Long-Term Placement
<b>6 <u>Current Challenges</u></b>	Technology/Telehealth COVID Related Care

# Common Groups and Organizations

- VA Office of Rural Health (ORH)
- VA Geriatrics and Extended Care
- National Institute on Aging/ National Institutes of Health (NIA/NIH)
- Alzheimer's Association National and Local Chapters (AA)



# Website

[Dementia Resources for Caregivers and Families \(gerischolars.org\)](https://gerischolars.org)



## ☰ TABLE OF CONTENTS ☐☐

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- 6 Brain Health
- 7 Telehealth and Technology
- 8 COVID-19 and Dementia Care
- 9 Comprehensive Dementia Care Guides
- 10 Additional Websites
- 11 Content Experts
- 12 Terms of Use

## Dementia Resources for Caregivers and Families

### Clinician Reviewed VA and Non-VA Resources for Families Caring for Veterans with Dementia



The VA GRECC-Connect team of doctors and nurses reviewed over 100 online dementia resources to assist and support people with dementia.

The GRECC-Connect team took care of these resources in varied formats (booklet, video, etc.) organized by topic and available for direct download from the pdf or the direct link. To learn more about GRECC-Connect, visit the webpage [here](#).

The GRECC-Connect team wishes to thank the individuals who provided support and information during the review process.

★ **NO COURSE REGISTRATION REQUIRED!**

## Website

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for Caregivers and  
Families \(gerischolars.org\)](http://gerischolars.org)



### Daily Activities



The daily activities section provides resources for dementia caregivers targeting challenges with common activities.



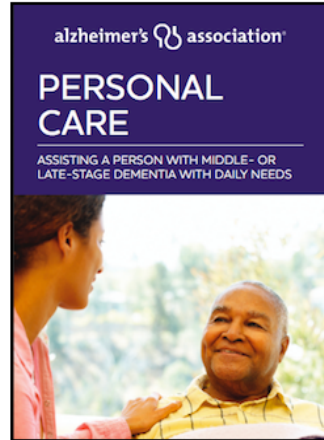
-  Activities of Daily Living (Grooming/Bathing/Dressing etc.)
-  Medication
-  Dementia and Activity Participation
-  Traveling
-  Driving
-  Sex and Intimacy
-  Sleep
-  Nutrition

# Website

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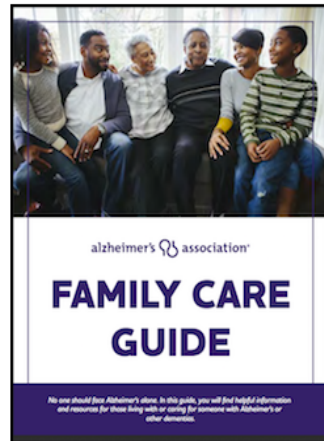


## Activities of Daily Living (Grooming/Bathing/Dressing etc.)



### Personal Care: Assisting a person with middle or late stage dementia with daily needs

Source: Alzheimer's Association, 2016  
12 pages



### Family Care Guide: Daily Living

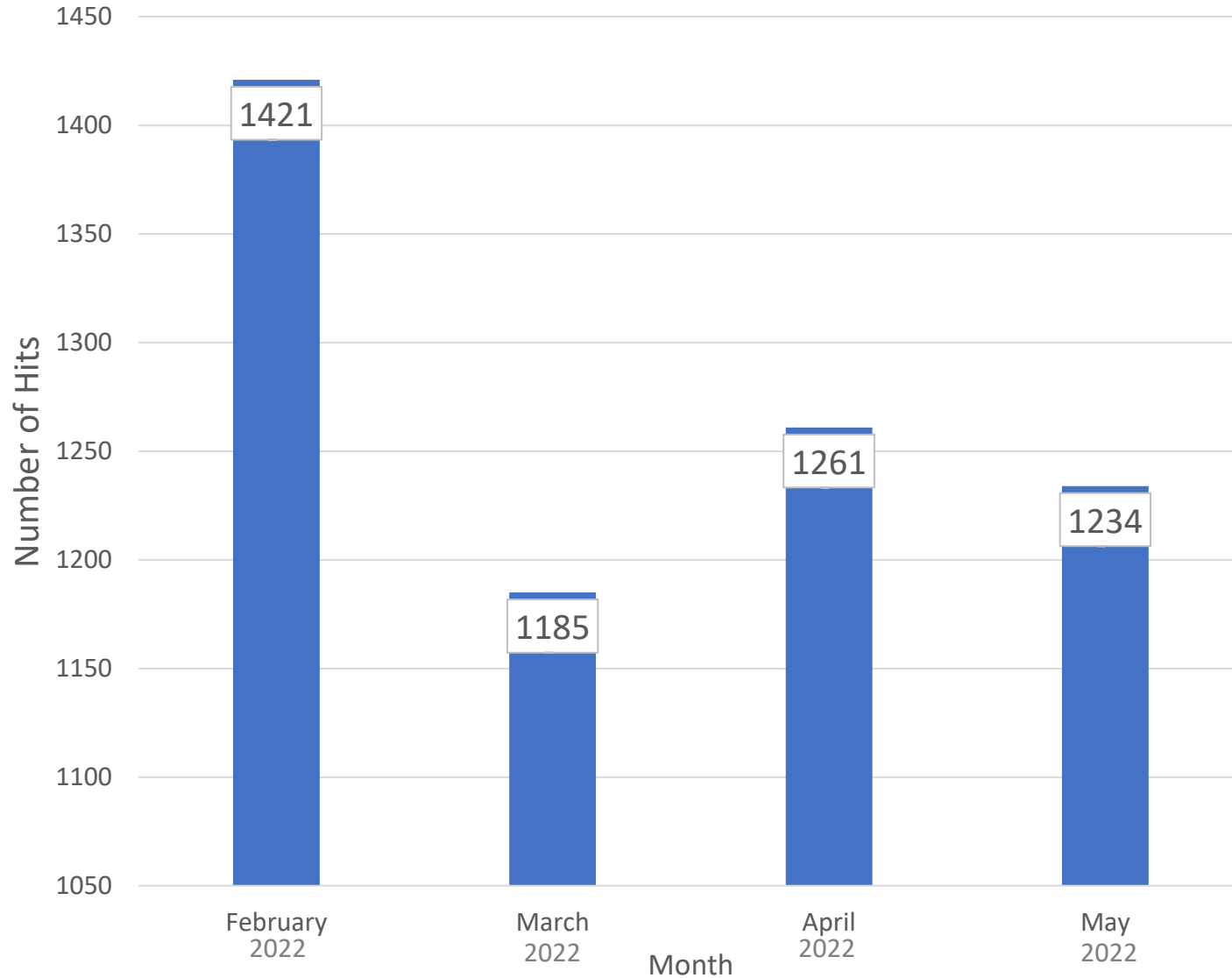
Source: Alzheimer's Association, MA/NH, Accessed 2021  
Chapter 3: Pages 10-18 (43 pages total)



### Refusal to Bathe

Source: UCLA Alzheimer's & Dementia Care Programs, Accessed 2021  
Video, via YouTube, 04:28 minutes

Number of Hits Per Month



# Statistics to Date

## Most Popular Subcategories

**Feb** : Educational Information: 103 Hits

**March**: Educational Information: 82 Hits

**April**: Anxiety and Depression: 92 Hits

**May**: Educational Information: 96 Hits

## Consistently Above 50Hits/Month

Caregiver Self-Care and Support

Educational Information

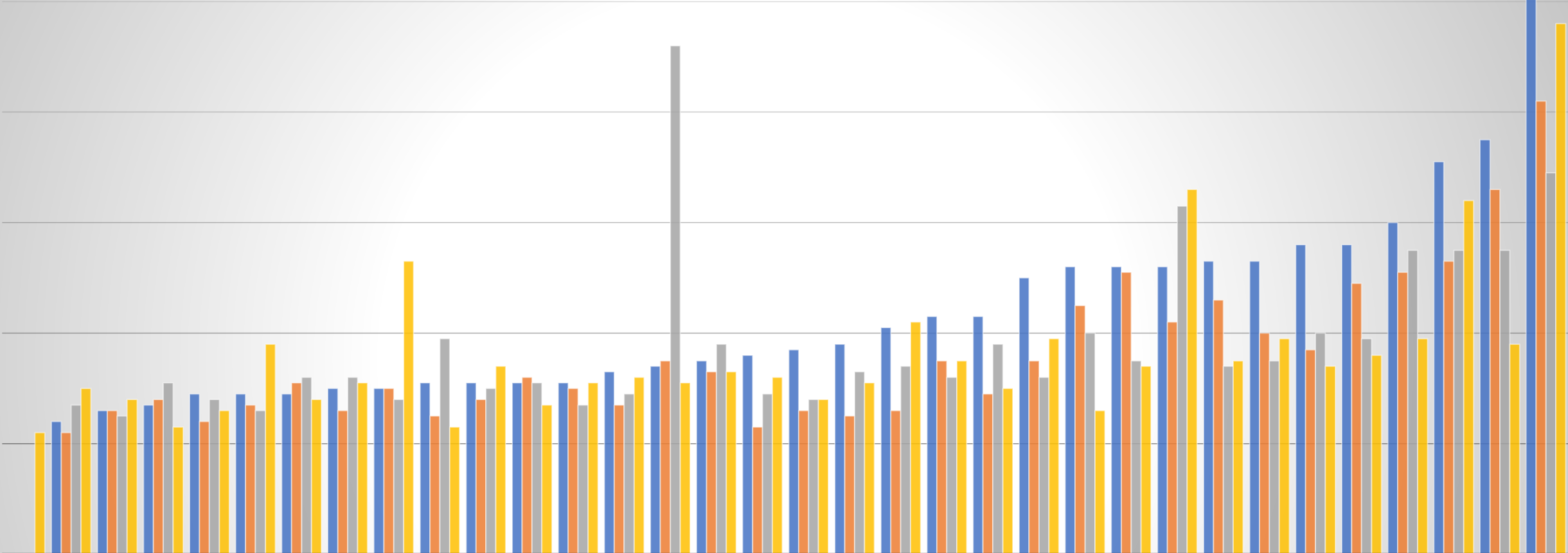
ADLs

***\*\*No category below 22hits/month\*\****



# Overall Number of Hits Per Category Per Month

Number of Hits



	Nutrition	Emergency Preparedness	COVID-19	Websites	Long-term placement	Repetitive	Video Series	Delirium	Legal/finance	Goals/EoL	Sleep	Telehealth	Wandering	Research	Anx/Dep	Hallucination	Falls Prevention	Firearm Safety	Travel	Communication	Meds	Resources/Program	Driving	Activity	Comp Care Guides	Sex	Home Safety	Sundown	Aggression	Non-Alz	Brain Health	Self-Care/Support	ADLs	Education info
Feb	0	24	26	27	29	29	29	30	30	31	31	31	31	33	34	35	36	37	38	41	43	43	50	52	52	52	53	53	56	56	60	71	75	103
March	0	22	26	28	24	27	31	26	30	25	28	32	30	27	35	33	23	26	25	26	35	29	35	45	51	42	46	40	37	49	51	53	66	82
April	0	27	25	31	28	26	32	32	28	39	30	31	27	29	92	38	29	28	33	34	32	38	32	40	35	63	34	35	40	39	55	55	55	69
May	22	30	28	23	26	38	28	31	53	23	34	27	31	32	31	33	32	28	31	42	35	30	39	26	34	66	35	39	34	36	39	64	38	96

■ Feb ■ March ■ April ■ May

2022



Case Example

Mr. Bing



# Get To Know Mr. Bing

Mr. Bing is a 68 y.o. retired air force Veteran who lives in a rural town in Arizona with his wife and dog, Gray. He is a 2-hour drive to the local VA hospital.

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**PMH:** diabetes and hypertension, BP 150's/70's.

**Medications:** Metformin, Lisinopril and Simvastatin.

**Occupation:** Part-time cashier

**Hobbies:** volunteering at a soup kitchen, landscaping his yard, taking care of his dog, and visiting sister that lives 1 hour away.

Mr. Bing has a supportive family with a wife and two daughters. One daughter lives locally and the other lives in California.



# Changes In Memory

Over this past year Mr. Bing started to notice some changes to his memory.

- He is forgetting why he went into a room and misplacing items.
- He takes longer to complete everyday tasks and is has trouble balancing the cash register.
- Mrs. Bing agrees and has noticed additional changes in Mr. Bing's memory over the past 6-8 months as well
- He normally is the planner for their family, managing finances and does most of the grocery shopping however, he is been having more difficulty completing these tasks.

# Recent Incidents

Mr. Bing's financial errors at work were substantial enough that he was terminated from his job

He also recently got lost driving to his sister's house, which is a familiar route. He pulled over at a gas station and had to call his wife for directions.



# Cognitive Evaluation

After hearing about his symptoms, his PCP referred him for a neuropsychological assessment. Mr. Bing was diagnosed with Mild Cognitive Impairment (MCI).

The family does not know much about MCI or dementia.

“ I’ve noticed a big change in his memory. He keeps asking me about my job even though he knows I quit last year. I don’t know what is going on with him”

- Sarah, Daughter

“ He’s just getting old, he used to always be a little absent minded, even grandma used to say that when he was younger. He’s fine.”

- Jane, Daughter

“ What medicine can we give him to get him back to his old self?”

-Mrs. Bing, Wife

# Dementia Caregiver Resources Website

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## Dementia Resources for Caregivers and Families

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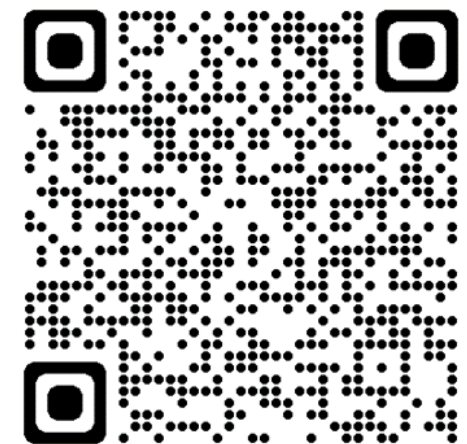
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The GRECC-Connect team wishes to thank the VA and its staff who provided support and information.

### Dementia Overview



The dementia overview section provides resources about the disease process and diagnosis of dementia.



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## POLL QUESTION

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- Using the Caregiver Resources Website, what resources might you give Mr. Bing and his family at this point?





## Dementia Overview



The dementia overview section provides resources that focus on general information about the disease process and diagnosis of dementia.

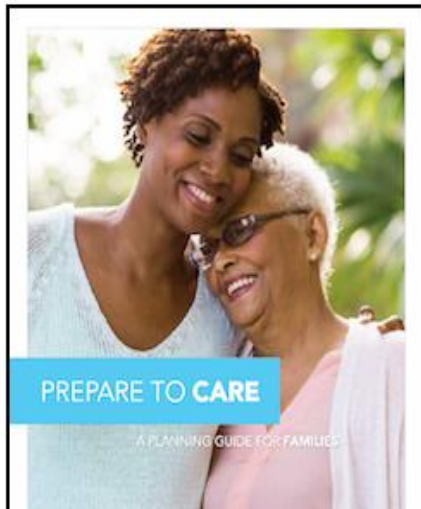
 [Dementia Education and Information](#)

 [Non-Alzheimer's Dementias](#)

 [Dementia Research](#)

## Dementia Education and Information

[Return to: Dementia Overvi... ↗](#)



### Prepare to Care: A Planning Guide for Families

Source: AARP, 2012

36 pages



## Pressing Concern: Driving

Mr. Bing was specifically referred to complete a driving evaluation

"My daughters had a meeting without me and decided that they want me to stop driving, but they are making a big deal out of nothing. I'm very comfortable driving on the road. I've been driving longer than they've been alive."

- Mr. Bing

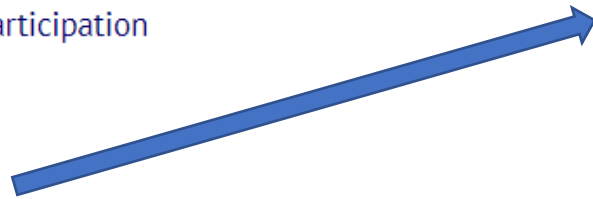
# Pressing Concern: Driving

## Daily Activities



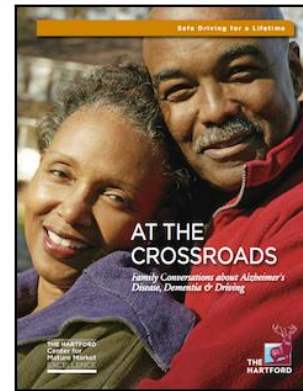
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- Activities of Daily Living (Grooming/Bathing/Dressing etc.)
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- Dementia and Activity Participation
- Traveling
- Driving
- Sex and Intimacy
- Sleep
- Nutrition



## Driving

Return



### At the Crossroads: Family Conversations about AD, Dementia, and Driving

Source: The Hartford Center for Mature Market Excellence®, March 2013  
28 pages



### We Need to Talk - Family Conversations with Older Drivers

Source: The Hartford Center for Mature Market Excellence®, May 2018  
24 pages



### Driving and Dementia

Source: UCLA Alzheimer's and Dementia Care Program, 2018  
Video, via YouTube, 03:14 minutes

# Pressing Concern: Driving



## OT Driving Evaluation

Displayed safe driving behavior

Suggested to drive only short distances, familiar areas, and during the day

Mrs. Bing will now take over the drives to visit his sister and daughter.

The team will continue to monitor this situation closely



Fast Forward  
5 Years...

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## Mr. Bing is now 73 years old, and his MCI has progressed to dementia

- More difficulty managing medications
- Leaves food in the microwave and has left the stove on a few times
- Can't figure out how to make outgoing calls on his smartphone
- More suspicious and paranoid of others. He is quick to anger and often accuses his family of misplacing his wallet and taking his money
- His home is cluttered as he is exhibiting hoarding behavior



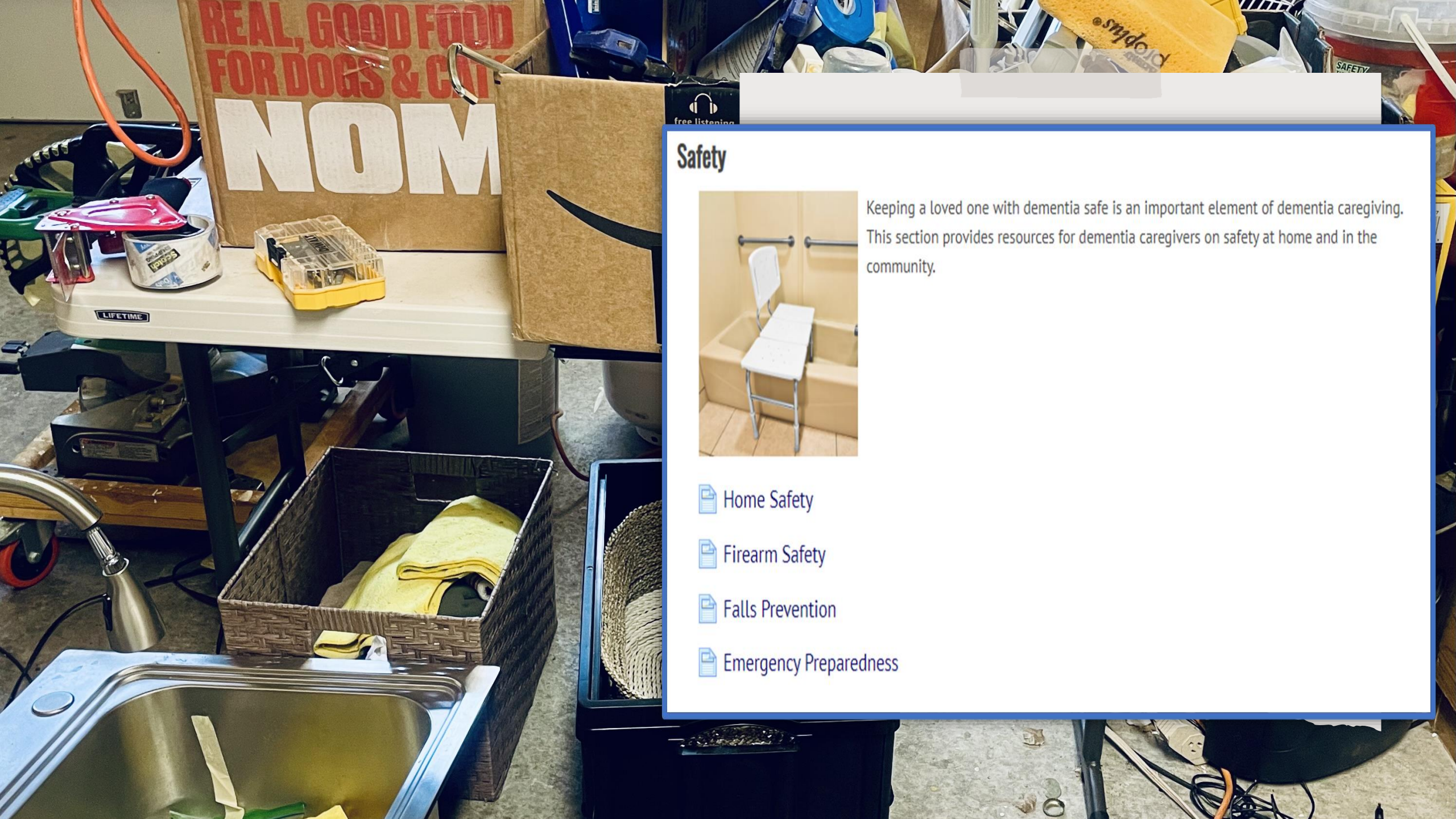
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## POLL QUESTION

---

- What resources might you give Mr. Bing and his family AT THIS STAGE?



## Safety



Keeping a loved one with dementia safe is an important element of dementia caregiving. This section provides resources for dementia caregivers on safety at home and in the community.

-  [Home Safety](#)
-  [Firearm Safety](#)
-  [Falls Prevention](#)
-  [Emergency Preparedness](#)

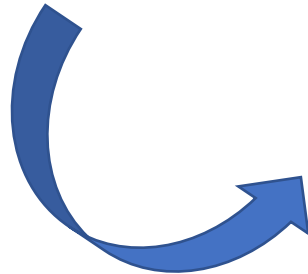


## Safety

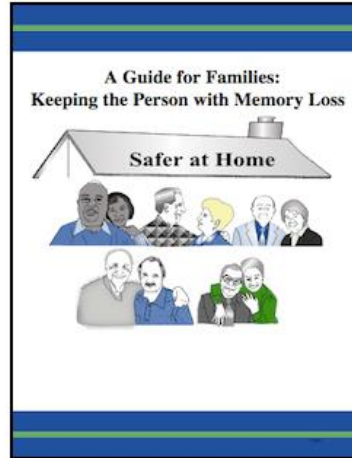


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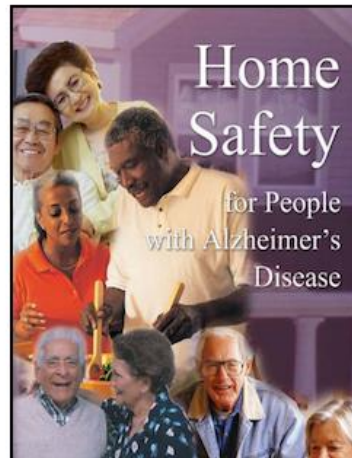


## Home Safety



### Home Safety Booklet

Source: Bedford GRECC, March 2019  
via VA website, 27 pages



### Home Safety for People with Alzheimer's Disease

Source: NIH/NIA, December 2008  
44 pages



Fast Forward  
*1 More Year...*

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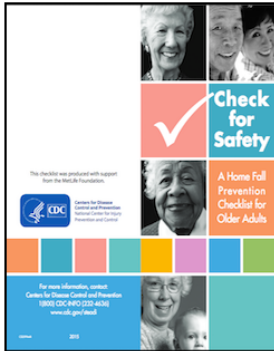
- Mr. Bing is on 7 different medications, but he often refuses to take them
- 

- This past week after taking his blood pressure medications, he felt lightheaded after standing up from the toilet and suffered a fall in the bathroom

- After the fall, he was taken to the ED for further evaluation

# Resource Options

## Falls Prevention



### Check for Safety: A Home Fall Prevention Checklist for Older Adults

Source: CDC, National Center for Injury Prevention and Control, 2015  
8 pages



### Falls Awareness and Prevention Guide

Source: American Academy of Orthopedic Surgeons, Accessed 2021  
6 pages

## Medication



### Refusal to take Medication

Source: UCLA Alzheimer's & Dementia Care Program, Accessed 2021  
Video, via YouTube, 04:03 minutes



### Medication Issues for People with Dementia

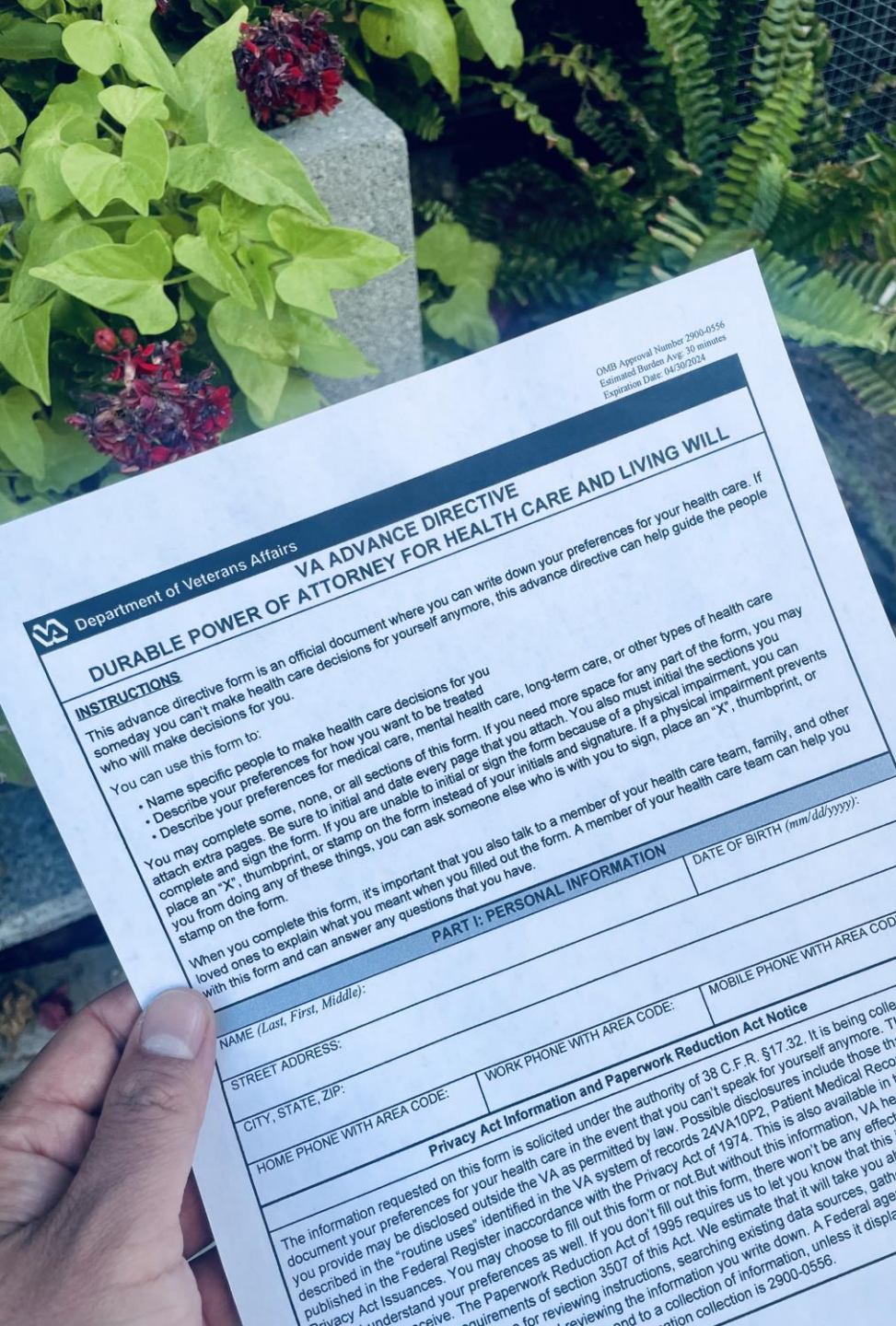
Source: ORH and VA Rural Health Center, Accessed 2021  
Video, via [www.ruralhealth.va.gov](http://www.ruralhealth.va.gov), Caregivers Video Series, 06:09 minutes

# During his emergency department visit...

Mr. Bing's family realized that they have not had a goal of care conversation or completed necessary documents:

- **Healthcare Proxy**
- **Power of Attorney**
- **Living will**

They were given a stack of documents and instructed to complete and bring them into their next doctor's visit



# Resource Options

## Caregivers' Self Care and Support



Being a caregiver for a loved one with dementia can be challenging and overwhelming. This section provides resources that focus on your well-being and support when dealing with challenging aspects of dementia.

- Self Care and Support
- Resources and Programming
- Legal, Financial, and Employment Support
- Goals of Care/End-of-Life
- Communication
- Long-Term Placement

## Legal, Financial, and Employment Support

[Return to: Caregivers' Sel...](#)



### Legal and Financial Planning for People Living with Dementia

Source: NIA/NIH, October 2020  
6 pages, free hard copy available from Source



### Let's talk: Starting the Conversation about Health, Legal, Financial and End-of-Life Issues

Source: ElderCare Locator, Accessed 2021  
9 pages

# Pressing Concern: Caregiver Fatigue

- Mrs. Bing is the sole caretaker for Mr. Bing and she is starting to feel overwhelmed
- Her daughters help every now and then but the every day responsibilities fall to her
- His family is exhausted from arguing with him daily while trying to complete his daily routines, especially bathing
- They can't leave Mr. Bing alone anymore as he is at risk for falls in the home and has been unsafe in the kitchen numerous times.

**She reaches out to his PCP for advice**



## Caregivers' Self Care and Support



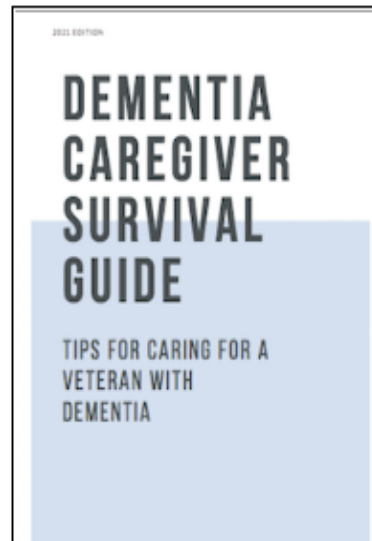
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-  Communication
-  Long-Term Placement



## Self Care and Support

[Return to](#)



### Dementia Caregiver Survival Guide: Tips for Caring for a Veteran with Dementia

Source: Natali N. Edmonds, PsyD, ABPP, in collaboration with GRECC Connect, 2021  
66 pages

# Resource Options



## 2 Years Later



Mr. Bing is eating less, lost ~12lbs of weight

He is frail and spending most of his day in a wheelchair.

No longer recognizes family, doesn't initiate any conversation, and spends his time dozing while watching TV

After seeing a big decline in Mr. Bing's function and quality of life, the family would like to speak to his PCP for another Goals of Care conversation

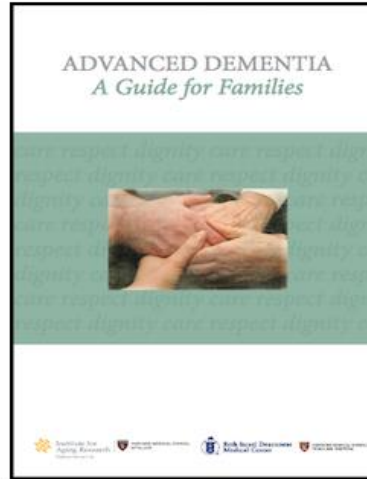
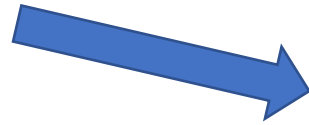
# Resource Options

## Caregivers' Self Care and Support



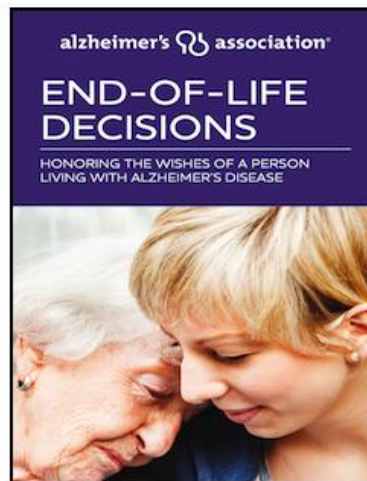
Being a caregiver for a loved one with dementia can be challenging and overwhelming. This section provides resources that focus on your well-being and support when dealing with challenging aspects of dementia.

- Self Care and Support
- Resources and Programming
- Legal, Financial, and Employment Support
- Goals of Care/End-of-Life
- Communication
- Long-Term Placement



### Advanced Dementia: A Guide for Families

Source: Institute for aging Research, Harvard Medical School, Beth Israel Deaconess Medical Center, 2018  
50 pages



### End of Life Decisions

Source: Alzheimer's Association, September 2018  
16 pages



# Mr. Bing Today

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- Mr. Bing's day to day needs became too much for his family to handle on their own
- With assistance from the VA, he successfully transitioned into a CLC
- Mr. Bing's family often visits him at the CLC
- They spend time outside in nature and looking at family photo albums

[Dementia Resources for  
Caregivers and Families  
\(gerischolars.org\)](http://gerischolars.org)

