

The background of the entire page is a vertical, close-up image of flames. The flames are bright yellow and orange at the base, transitioning to a darker red and black at the top. They appear to be rising and flickering, creating a sense of intense heat and urgency.

EVERYTHING IS ON FIRE

**An Emergency Dementia
Care Startup
Guide for Family Caregivers**

Angie Ward, 2022

Disclaimer

I am not a doctor.

I am just a person who had to learn everything "on the fly" when it came to caring for my Dad in an emergency Dementia care situation.

The tips, tricks, and information provided in this guide are my own experience and not meant as medical advice.

You should seek the help of qualified medical personnel for specific help.

Quick Facts



More than **6 million** Americans are living with Alzheimer's. By 2050, this number is projected to rise to nearly 13 million.



1 in 3 seniors dies with Alzheimer's or another dementia. It kills more than breast cancer and prostate cancer combined.



In 2020, COVID-19 contributed to a **17% increase** in Alzheimer's and dementia deaths.

Table of Contents

<i>Disclaimer</i>	<i>Page</i>
<i>Why I Wrote This Guide (a personal story)</i>	3
<i>The Effects of Dementia</i>	4
<i>Get Familiar Fast!</i>	5
<i>Preparing for Dementia Care at Home (things you should know)</i>	6 - 7
<i>A Day in Dad's Life (a snapshot of Dementia care)</i>	8 - 9
<i>Securing the Home</i>	10 - 11
<i>Hygiene and Care Issues</i>	12
<i>Self Care for the Caregiver</i>	13 - 14
<i>Support Links</i>	15
<i>References</i>	16

My Story

Back in 2020 during the height of the Covid-19 pandemic, my wife and I were plunged headlong into caring for my Father-in-Law, who was living with *very advanced Dementia*.

We had no experience, no expertise, and no time to educate ourselves on the intricacies of Dementia care. Mom had always been Dad's primary caregiver, and when she suddenly died, we found ourselves navigating not only the medical system but meals, hygiene, and self-care on our own with no outside help.

I searched frantically for resources online and called dozens of places, desperately looking for help but caring for someone with active, late-stage Dementia is a full-time, hands on job and you do not have the luxury of stopping to educate yourself AND there were no resources to quickly tell us the basics or give us a plan of how to make it through the first couple of weeks of caring for Dad.

We felt like **EVERYTHING WAS ON FIRE** and absolutely **helpless**.

I never want another family to go through what we went through so I have compiled this quick setup guide to help you navigate an emergency care situation for people living with Dementia. I hope this easy-to-read, quick guide will take some of the stress out of your planning.

Thank you!

The Effects of Dementia

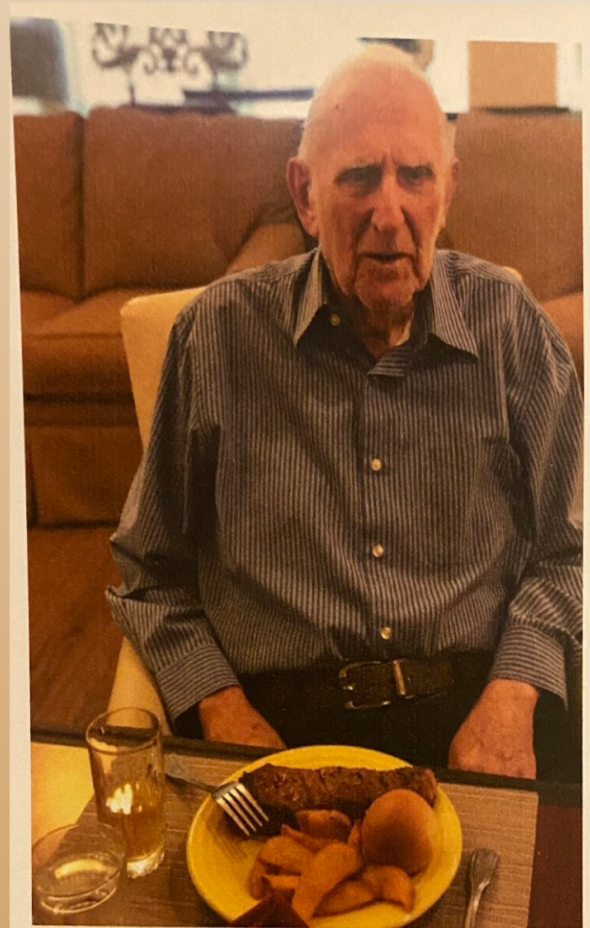
Before Dementia:

- * Dad worked in finance for decades and had a law degree.
- * He attended Church regularly and never swore or made off-color jokes.
- * He was well-groomed and neat.
- * He managed the household finances.
- * He enjoyed working in the yard.
- * He enjoyed listening to audiobooks and watching tv.
- * He loved being with family.
- * Dad was always a pleasant, funny, thoughtful man.



After Dementia:

- * Dad forgot he had been retired for over 20 years.
- * He was no longer able to attend church or social functions.
- * He forgot to shower and sometimes lost his hearing aids.
- * Dad forgot the names of his wife and only child.
- * He was confused, combative, and often had high anxiety.
- * Dad often left the house in the middle of the night and wandered the neighborhood, thinking he was late for work.
- * Dad constantly thought that someone stole his car, his lawnmower, or that people were robbing his home.
- * He sometimes cursed at family and raised his voice.



Memory Care Issues- Getting familiar FAST.

If you find yourself suddenly caring for a family member with Dementia, there are several important things to consider and prepare quickly. I learned from experience that having these things in place can make it much easier to give care and get help quickly:

1. Locate their medications.

Organize them for easy dispensing.



2. Call their doctor.

Find out if the doctor can offer a resource or if there are upcoming appointments they need to attend.



3. Create a schedule.

Keeping a routine is very important for a Dementia sufferer.



4. Secure the home.

*see "Securing the Home" on page 6



5. Remain calm.

It can be very scary to unexpectedly provide care for someone who may not remember your name, or who may be afraid. Your calm mindset will help *you* manage this, as well as keep the Dementia sufferer from feeding off of your anxiety.



Preparing for Care

Sundowning

This is a common occurrence with Dementia sufferers. As the sun goes down, they may become more agitated, confused, or combative.

TIP: Turn on extra lights at night and reduce loud noises in the home.

Remind them that they are safe.



Exiting behavior

Many people with Dementia exit their home or go searching for family members outside. This can be very dangerous because they can get lost or injured.

TIP: Prepare to monitor their whereabouts constantly and secure the home to prevent them from leaving.



Looping

Dementia sufferers may ask the same question over and over, or tell the same story over and over. They simply forget that they've told you. They may get focused on certain ideas or concepts.

TIP: Be prepared to calmly answer their questions or repeat instructions if needed.

What's Your Name?



What's Your Name?

More Preparing for Care

Triggers

Certain noises, smells, or clothing texture may cause discomfort for the person with Dementia.

They may be afraid of new things or become combative in stressful situations. Even a simple car ride can be scary for them.

TIP: Remember that their triggers may change from day to day.



Schedule

Keeping a schedule is VERY important when caring for someone with Dementia.

Any change in their routine could cause anxiety or combative behavior.

TIP: Try to have meals and exercise at the same time every day and definitely keep hygiene and sleep schedules consistent.

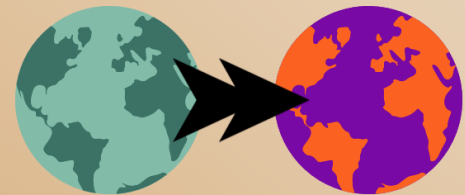


Their world v Our world

Dad would often ask "when his Mother was returning home". Rather than try to convince him that his Mother had been gone for 50 years (which would severely upset him), I would simply say,

"She's at the store and will be home in just a bit...".

TIP: Sometimes allowing the Dementia sufferer to have their own version of the world is kinder and less stressful than constantly reminding them that someone is dead or that they no longer drive.



A Day in Dad's Life

I thought it would help to give you an idea of Dad's daily routine and some of the challenges we encountered:



Morning:

Dad woke up by 8am every day and was generally pleasant. He enjoyed eating a big breakfast and often would take a nap after.

TIP:

I discovered early on that morning was the best time of the day to take Dad to a Dr's appointment or attempt hygiene care because he was generally most amenable to stressful things at that time.



Mid-morning to Lunchtime:

When Dad awoke from his "breakfast nap", he would often be more energetic and liked to take a walk around the neighborhood. He stayed in motion pretty constantly so having an exercise routine was very helpful.

TIP:

If your loved one is able to exercise by themselves or sit outside for some fresh air or even enjoy watching television, take that opportunity to get your own shower, meal, etc. You will quickly find that your own self-care takes a backseat to Dementia care so take the opportunities for self-care where you can.

More "A Day in Dad's Life"



Lunchtime to Dinner:

Dad always took a short nap after lunch (less than 30 minutes) and would often awaken to being more confused and sometimes, more agitated. We observed that he was suffering with "sundowning", which often began at around 5pm.

TIP:

Activities like exercise, sorting items, or even vacuuming can make the Dementia sufferer feel "useful" and help with anxiety.



Dinnertime to Bedtime:

This was the most difficult part of our evening. Dad was often confused, combative, and afraid. He exhibited more "exiting behavior" during this time and would get stuck on concepts like the theft of a car or that someone had broken in to the home.

TIP:

You will need to secure the home to keep the Dementia sufferer from wandering or leaving in the night while you are sleeping. See my tips for securing the home!

Securing the Home

For many Dementia sufferers who exhibit exiting behavior or forget that they no longer drive, it is extremely important to secure your home and surroundings to keep them safe, as well as everyone else.

Door locks

If your loved one exits the home, there are special door-securing devices specifically for Dementia patients! Available on Amazon for about \$12 <https://amzn.to/3hm8NxM>



Door Alarms

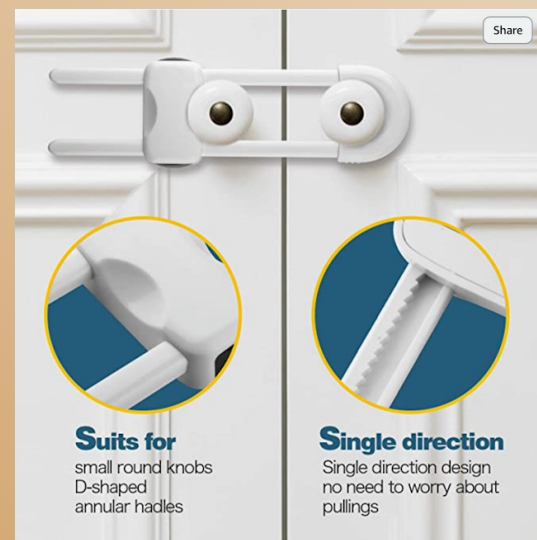
Consider a door alarm if a lock is not convenient. Available on Amazon for about \$20 <https://amzn.to/3FWt4UW>



Cabinet locks

Consider securing medicine, liquor cabinets, and chemicals to avoid a potential life-threatening situation.

Simple cabinet locks are available on Amazon for about \$10 <https://amzn.to/3ff5nFW>



More Securing the Home

Car Keys

Dementia sufferers may forget that they no longer drive and often lack the coordination to drive safely. Consider securing car keys in a location they won't look if they persist on driving. Magnetic key hidiers are available on Amazon for about \$6
<https://amzn.to/3fHXQGm>



Bed Alarms

If your loved one gets out of bed in the night and you are concerned about falls, you may consider a bed alarm from Amazon for about \$100
<https://amzn.to/3DNxwIz>



Weapons

Guns, knives, and anything that an agitated Dementia sufferer might grab in a moment of fear or confusion should be secured.

There are many options for safes on Amazon
<https://amzn.to/3G14iD7>



Hygiene and Care Issues

People suffering with Dementia are often unable to complete their hygiene routine on their own. This can be a delicate situation for both the Dementia sufferer and the caregiver because it is important to maintain dignity while making sure private areas on the body are hygienic.

And let's face it, it can be very awkward helping your Dad with showering or toileting but it is a vital effort for health and general well-being for both them and you!

Bathing/Showering

I found it helpful to have Dad's clothes, soap, towels, etc. laid out next to the shower for easy access when he was done. Also consider talking to them through the door if they prefer to shower alone.

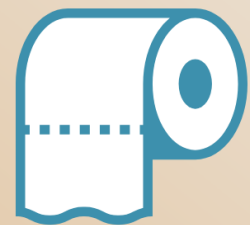
Assistive devices like shower chairs and handrails are very helpful to curtail falls!



Toileting

Dementia sufferers can become constipated due to medications and may not be able to verbalize their discomfort.

Stool softeners are a great option.



Teeth

Do they wear dentures?

Let them be part of their own hygiene routine!

Brush your teeth next to them so you can offer assistance and also model good habits.



Assistive devices

If they use hearing aids or a cane, consider that it may be difficult for them to keep up with these items. If possible, have multiple options for their use.



Haircuts, nails, etc.

It may be stressful to cut their hair or nails so consider doing a little bit at a time in multiple stages to avoid upset.



Self-Care for the Caregiver

Your own self care as a caregiver is **vital**.

The constant vigilance required when caring for a person with Dementia can put **enormous stress** on a caregiver physically, emotionally, and spiritually. Below are some self-care tips:

Sleep

It may be impractical to sleep through the night if the Dementia sufferer is more active at night. Consider hiring a sitter to relieve you.



Hygiene

Believe it or not, carving out time for a hot bath or shower can work wonders for rejuvenating your energy.



Nutrition

If you find yourself not devoting proper time to eating properly, consider asking friends to start a meal train for you. You can also use services like Door Dash! Don't feel guilty!



Asking for help

Reach out to your Church, friends, and support groups if you need someone!



Support groups

Look for local support groups for grief, trauma support, and even elder care.



Exercise

Taking a daily walk or doing light yoga can help ease stress. Fresh air can help clear your mind.



Why is Self-Care so Important?

Caregiver Statistics

According to a recent article on Healthline.com about the worsening health of people providing care in the home to a loved one:

72%



That's the number of caregivers who recently reported that **their own health has declined** while providing care to a loved one.

59%



That's how many caregivers reported **feeling anxiety or depression** during their time of caregiving.

32%



That's how many caregivers **missed their own doctor's appointments** while caregiving.

15%



These are the caregivers who **ended up in the hospital themselves** since becoming a caregiver.

Links to Support for Caregivers

It may be impractical for a caregiver to leave their family member to seek support outside the home so I have provided several links to large, well-known online groups where you can get help from other families going through the same situation:

Dementia Caregivers Facebook Support Group

<https://www.facebook.com/groups/672984902717938>

Caregiver Online Community Support Forum

http://lists.caregiver.org/mailman/listinfo/caregiver-online_lists.caregiver.org

Dementia Mentors

an entire site devoted to helping you navigate care

<https://www.dementiamentors.org>

In-Person Support Groups in your area

https://www.alz.org/norcal/helping_you/support_groups



References and Bibliography

James, John, and Russel Friedman. "The Grief Recovery Method[®] Guide for Loss." Griefrecoveryhouston, 2016, https://www.griefrecoveryhouston.com/wp-content/uploads/grm_ebook_r_new.pdf.

"2020 Alzheimer's Disease Facts and Figures - Wiley Online Library." Alzheimer's Association, <https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/alz.12068>.

Frasier, Laurie, et al. "Dementia Training Manual - Senior Daybreak." Senior Daybreak, Senior Daybreak of Hilltop, June 2015, <https://seniordaybreak.org/wp-content/uploads/sites/103/2016/12/Dementia-Training-Manual.pdf>.

DementiaCareCentral.com. "Stages of Alzheimer's & Dementia: Durations & Scales Used to Measure Progression (GDS, Fast & Cdr)." Dementia Care Central, National Institute on Aging, 24 Apr. 2020, <https://www.dementiacarecentral.com/aboutdementia/facts/stages/>.

Mathews, Susan. "Ideas and Organization Tips." Home Storage Solutions 101, Clear Intentions LLC, 2012, <https://www.home-storage-solutions-101.com/>.

Koskie, Brandi. "The State of Caregiving for Alzheimer's and Related Dementia 2018." Healthline, Healthline Media, 21 Sept. 2018, <https://www.healthline.com/health/state-of-alzheimers#cost-of-alzheimer's---caregiver-health>.