



Holland Home™

# Dementia Care Handbook





Dear Family,

We are honored that you have entrusted your loved one to our care. Holland Home strives to provide excellent, loving, compassionate care to all of our residents, and we recognize the need for specialized care for our residents living with dementia.

Holland Home's Memory Care Services has created the dementia handbook as a tool to assist and educate our families about the disease of dementia. Our goal is that this handbook will provide insight into the challenges we face in caring for our loved ones living with dementia.

Although we may not answer all of your questions, we hope to provide both clinical and practical information that can support us all as we journey through this together.

Our prayer is that you may experience moments of joy along the journey. We are privileged to walk it with you.

God Bless,

A handwritten signature in black ink, reading "Mina Breuker". The script is fluid and cursive, with the first name "Mina" and last name "Breuker" clearly distinguishable.

Mina Breuker

President



## Holland Home's Mission

**In fulfilling God's calling to serve others, we will:**

Serve with love and compassion.

Commit to excellence.

Follow Christ's teachings and example in all we do.

# Table of Contents

## **Dementia: What to Know**

What is Dementia?	4
The Brain and Dementia	5
Dementia-Related Brain	6
Regions of the Brain	7
Memory	8
Vision	9
Hearing	10
Language	11
Sensory-Motor Skills	12
Emotions & Impulse Control	13
What to Expect	14
Dementia Myths	15
Challenging Behaviors	16
Unmet Needs	17
Different Stages of Dementia: The GEMS Model	18

## **Dementia: What to Do**

How to Approach	25
How Do I Communicate?	26
Self-Care	27
Spiritual Practices	28
Psalms 23	29
Common Scenarios and What to Do	30
Help Me Find Joy	33

## **Resources**

Helpful Resources	34
Notes Pages	35

# What is Dementia?

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*Dementia* is a term that describes a wide range of symptoms associated with a decline in memory or other thinking skills.

The mental functions that can be affected are memory, language and communication, ability to focus, reasoning and judgment, and vision.

Dementia is caused by damage to brain cells.

# The Brain and Dementia

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Dementia is *both*

a chemical change in the brain

*and*

a structural change in the brain.

*As a result,*  
**sometimes the brain functions properly,  
and sometimes it doesn't.**

# Dementia-Related Brain

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Used with permission from *Alzheimer's: A Broken Brain*, 1995, University of Alabama Press

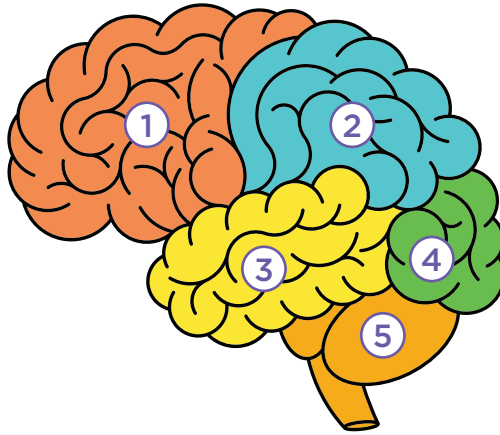
Dementia causes a decrease in the brain's cells, and the brain actually begins to shrink. Dementia can be widespread or occur in specific areas of the brain. As the disease progresses, literal gaps are forming in the brain, which interrupt thought processes and actions.

In Alzheimer's type dementia, many parts of the brain are affected. By the end of the disease, the brain's size has decreased dramatically.



# Regions of the Brain

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- 1. Frontal Lobe:** The control hub of our personalities and communication — managing our problem solving skills, memory, language, emotions, judgment, and sexual behavior.
- 2. Parietal Lobe:** Processes sensory information from all parts of the body — sense of touch, manipulation of objects, and navigation.
- 3. Temporal Lobe:** An auditory data processor analyzing sound information from the ears and translating it into meaningful associations or memories (such as language).
- 4. Occipital Lobe:** Responsible for dealing with visual input from the eyes and assigning meaning to what it sees (such as recognizing letters as words).
- 5. Cerebellum:** Is like a puppet master handling body movement and balance. It also manages attention and is where feelings of fear and pleasure originate.

# Memory

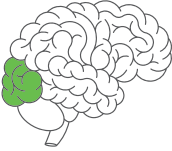
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Dementia causes damage to the ***temporal lobe***, which controls memory storage.

## People May:

- Forget the immediate past
- Use old memories like new
- Misidentify self or others
- Confabulate imaginary experiences to make up for loss of memory
- Get stuck on an old emotional memory track



Dementia also affects the ***occipital lobe***, the part of the brain that is involved with vision, making it difficult to identify objects and people.

## People May:

- Brush teeth with comb (unable to recognize object or its purpose)
- Perceive patterns in carpets to be bugs or dirt
- Lose depth perception
- Lose peripheral vision

# Hearing

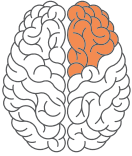
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Dementia affects the ability to listen to and understand speech by attacking the back part of the ***temporal lobe*** and the ***auditory cortex*** of the brain.

## People May:

- Hear what others are saying, but not understand the content of the message
- Nod their head in agreement when they are asked to do something, but then resist care
- Shake their head in response to a question because they don't understand the words
- Perceive a positive message in a negative way (e.g., misinterpret neutral words as a challenge)



Dementia causes language damage by attacking the parts of the brain that process words.

Areas affected include the *left side of the frontal lobe, the temporal lobe, and the auditory cortex.*



## People May:

- Miss one out of four words
- Have problem finding/choosing a word
- Become very vague and repetitive
- Use automatic social responses (such as “fine,” “ok,” “that’s right”)
- Use inappropriate words

# Sensory-Motor Skills

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Dementia attacks the ***motor cortex*** of the brain which is in the back part of the ***frontal lobes***.

This is the part of the brain that plans movements and controls muscles.

## People May:

- Find simple actions such as smiling, swallowing, grasping, or clapping difficult

# Emotions & Impulse Control

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**Dementia affects emotions and impulse control by attacking the limbic system (dealing with emotions) and the frontal lobes (dealing with rational thinking).**



## **People May:**

- Say whatever they are thinking
- Use profanity
- Use sex words or racial slurs
- Act impulsively
- Cry easily
- Lose ability to think through consequences of what they say or do
- Respond quickly and strongly to perceived threat

# What to Expect

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- Everyone experiences dementia differently
- People usually progress through stages of dementia at a slow and steady rate
- This slow progression occurs over an average time period of 8-10 years
- Even though everyone experiences dementia differently, it is predictable in that it:
  - Targets specific parts of the brain
  - Spreads through different parts of the brain in a typical pattern
  - Preserves some parts of the brain



# Dementia Myths

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## **Myth: Dementia is a natural part of getting older.**

**Truth:** *Dementia is a disease, not part of normal aging. In normal aging our brains process information more slowly. It is not normal aging when a person is unable to process information, start or complete a task, distinguish between the past and present, or remember a word.*



## **Myth: My loved one can't remember when I visit, so it isn't worth visiting at all.**

**Truth:** *Everyone has the basic human need to feel love and be relationally connected. Even if your loved one doesn't remember your visits, he/she can experience love and connection that will have a positive impact on his/her well-being.*

## **Myth: Dementia is genetic. Since my mom or dad has it, I'm guaranteed to get it, too.**

**Truth:** *The most important risk factor in dementia is age, not genetics. However, there are some rare causes of dementia that are inherited (for example, Huntington's Disease).*

# Challenging Behaviors

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It is important to remember that dementia is a progressive brain disorder that limits the ability to communicate a need. Often the need is expressed as a troubling behavior.

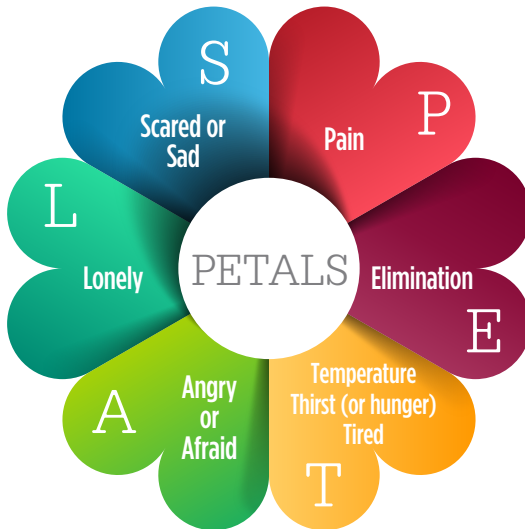
Changing the environment and your own response will often help de-escalate the behavior.

Some challenging behaviors that may occur with dementia are:

- Hitting/Punching
- Yelling/Swearing
- Wandering
- Acting Paranoid
- Asking Repetitive Questions
- Hoarding
- Acting Socially Inappropriate
- Exit Seeking (e.g., the need “to go home” or “go to work”)
- Refusing care
- Crying for long periods of time
- Worrying



# Unmet Needs



Many challenging behaviors exhibited by persons receiving dementia care are actually caused by an unmet physical or emotional need. Help determine the root cause of the behavior by using the acronym PETALS to help ensure you have met the person's physical and emotional needs.

**Pain:** Are they uncomfortable or hurting?

**E**limination: Do they need to use the bathroom or are they soiled?

**T**emperature: Too hot or cold; **T**hirst or hunger; **T**ired or over stimulated?

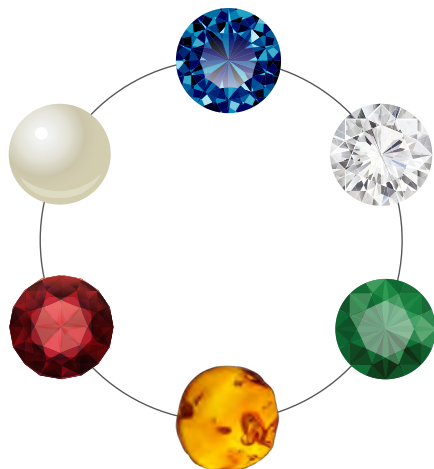
**A**ngry or **A**fraid?

**L**onely or **L**ooking for something?

**S**cared or **S**ad?

# Different Stages of Dementia: The Gems Model

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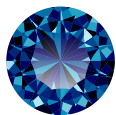


Teepa Snow's GEMS were developed as identifiers to help determine an individual's changing abilities. Understanding the GEMS levels will lead to an adjustment of expectations and hands-on care to better meet the ever-changing needs of individuals living with Alzheimer's and other forms of dementia.

## Here are the two guiding principles:

- Rather than looking at me as a person with a disease, look at me as someone who has value.
- Help me to shine in my journey.

GEMS® classification and POSITIVE APPROACH® techniques, strategies, and overall approach to care were created and developed by Teepa Snow, Positive Approach LLC. GEMS® and POSITIVE APPROACH® are registered trademarks of Positive Approach LLC. *Applies to pages 18–25. Used by permission.*



## Sapphire: True Blue

### *Optimal Cognition, Healthy Brain*

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*My brain is “true blue.” I am aging normally and do not have dementia. It’s hard to find words, but I can describe what I am thinking so you understand. I can learn new things and change habits, but it takes time and effort. Honoring my choices and preferences, when possible, is important. I need more time to make decisions. Give me the details, and let me think about it before you need an answer. I am able to remember plans and information but supports are helpful. I like specific prompts such as notes, calendars, and reminder calls. Health changes in vision, hearing, balance, coordination, depression, anxiety, pain, or medication may impact my behavior, but my cognitive abilities remain the same.*

- Aging normally: intact cognition
- Slowing down: need more time to process
- True to self: likes/dislikes are the same
- Able to learn: takes practice
- Stress, fatigue, or pain may induce Diamond moments
- Time to recharge or heal can restore to Sapphire

# Diamond: Clear & Sharp

## *Routines & Rituals Rule*

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*My brain is clear and sharp. I can be cutting and hard to deal with. I have many facets, so everyone sees me differently. This can cause conflict among my family or care team as it is hard to tell if I am just being stubborn or truly experiencing change in my abilities. I can socially chit-chat and have good cover skills. I want to keep habits and environments as they have always been, even when they are not working. I am often focused on finances or expenses, and will resist most change including new expectations, routines, or environments. I can become accusatory — thinking others are trying to trick or conspire against me. Short brief visits will not expose my true struggles. Even if you are around all the time, you may not notice how much I am changing because instinctively you fill in the gaps for me.*

- Clear and sharp: likes the familiar
- May resist change or won't let things go
- Rigid under pressure: limited perspective
- Becoming protective: may be territorial
- Repeats self: hard to integrate new information
- Can cover mistakes in social interaction
- Symptoms may or may not be dementia related



## Emerald: Green & on the Go

### With a Purpose *Naturally Flawed*

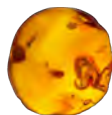
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*I have little awareness of my changing abilities. You assume I can take care of myself, but my personal care is slipping, often resulting in poor nutrition or hygiene. I can chit-chat, but struggle with words, and understand only about three-fourths of what you say. I know you are unhappy with me by your tone of voice or expression. If I am lost in my life, accept the moment I am in, listen and stay calm. Because I am easily frustrated, I often lose control of emotions and may blow up unexpectedly. When I feel afraid or consumed I will want to “go home.” I remember strong feelings, but won’t remember details. My brain sometimes makes up information to fill in the blanks, which makes you think I am lying. If you argue, I may become resentful or suspicious of you. I can’t be rational and will not want your help if you make me feel incompetent.*

- Desire independence: noticeable ability change
- Vocabulary and comprehension diminishing
- Communication becoming vague
- May neglect personal care routines
- On the go: need guidance and structure
- Difficulty finding way to and from places
- May be lost in time
- Misplace things: may become afraid or accusatory
- Insecure about being perceived as incompetent

# Amber: Caught in a Moment of Time *Caution Required*

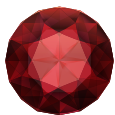
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*I am caught in time and focused on sensation. I know if I like you based on how you look, sound, move, smell and respond to me. It may surprise you when I take, investigate, touch, smell, taste or take apart items, but it is a function of my brain processing information and it soothes me. I need to do things over and over and like simple tasks. I will resist what I can't tolerate and I have limited safety awareness. I have no ability to stop myself and, for safety reasons, you need to respond to me immediately. I am typically incontinent, may not feel hunger or thirst, and can't express my needs. My mouth, hands, feet, and genitalia are highly sensitive due to changes in my nervous system. Therefore, activities like eating, taking medication, mouth care, bathing, and toileting may distress me. Please notice my cues and stop if I am resisting. Wait a few minutes, connect with me, and try a different approach.*

- Focused on sensation: five senses
- Will react to how things look, sound, feel, smell or taste
- Lives in the moment: not socially aware
- No safety awareness: typically very busy
- Difficulty understanding and expressing needs
- No ability to delay needs or wants
- Needs help with tasks: may resist
- Hard to connect with: may exhaust caregivers





## Ruby: Deep & Strong in Color

*Others Stop Seeing What is Possible*

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*My brain is in late stage change. Transition is difficult for me. I like simple instruction and would rather you show me, one step at a time, instead of telling me what to do. My fine motor skills are very limited, and I will need assistance with utensils, zipping, buttoning, or brushing teeth. I tend to hold, pinch, and manipulate items with my thumb rather than using my fingers. Because I can't control the muscles in my mouth, I have difficulty swallowing. My vision has changed, and I have no depth perception. I may misjudge distance, trip over large objects, or get stuck behind doors. I have gross motor reactions and will have either a desire to move or an intense fear of falling. Pulling or pushing me feels like you are trying to hurt me or make me fall. Using Hand-under-Hand assistance helps me to feel safe and secure. I still have automatic verbal and rhythmic response. I enjoy music, your presence, and a willingness to be quiet with me.*

- Retains rhythm: can sing, hum, pray, sway, and dance
- Understands expressions and tone of voice
- Losing ability to understand language
- Limited skill in mouth, eyes, fingers, and feet
- Can mimic big movements: gross motor abilities
- Loss of depth perception: monocular vision
- Falls prevalent: can only move forward
- Care partners will have to anticipate unmet needs

# Pearl: Hidden Within a Shell

## *Beautiful Moments to Behold*



*My brain is losing its ability to control my body, and I am at the end of my journey. Like an oyster, I am hidden in a shell, but will have moments when I become alert and responsive. Use our time to be with me, not just care for me. And please don't talk about me as though I am not still here. I respond best to familiar voices and rhythmic gentle movements. I am ruled by reflexes and will startle easily. I appreciate it when you slowly and gradually shift me. When taking care of me, I am comforted when you place one hand securely on my body while using the other. I have trouble coordinating my swallowing and breathing, and am prone to infection because my brain doesn't organize a response. I may not be able to leave my body without permission from you. Your greatest gift to me is to let me know it is all right to go.*

- Person is still there: hidden in a shell
- Moments of connection take time and will be short
- Knows familiar: unmet needs may cause distress
- Unable to move by themselves: fetal position, still and quiet
- Primitive reflexes have taken over: difficulty swallowing
- Brain failure shuts down body: diminishes need to eat or drink
- Care partners need to give permission to let go

# How to Approach

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- Use a consistent positive physical approach
- Pause at edge of personal space (6 feet)
- Get into visual range
- Announce yourself
- Greet by calling the person by name and smile
- Move slowly, offering hand
- Get at or below the person's eye level
- Move to the side of person to communicate
- Be friendly and give compliments
- Give your message: *simple, short, and friendly!*

## How Do I Communicate?

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- Get your loved one's attention by limiting distractions and noise (radio, TV, etc. ), addressing your loved one by name, stating your name and relationship, using positive touch, and getting down to his/her level.
- Non-verbal communication is powerfully effective. Your facial expressions, tone of voice, and physical touch are often better understood than your words.
- Treat your loved one as an adult.
- Speak slowly using simple words and sentences.
- Offer choices instead of asking open-ended questions. Even better, show the choices when possible.
- Demonstrate what you want your loved one to do.
- If your loved one is distressed, show empathy and then redirect their attention to a different topic.
- Break down activities by going step-by-step through the process, making the task more manageable.
- Don't correct your loved one. Affectionately affirm feelings and reassure instead of trying to convince your loved one he/she is wrong.
- Use humor and laugh with (not at) your loved one.

## Self-Care

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**In order to provide quality time with and sustained care for your loved one, you must also take good care of yourself!**

Here are some healthy practices to consider:

*Be active*

*Eat sensibly*

*Get plenty of rest*

*Make time for friends*

*Enjoy the outdoors*

*Find a support group*

*Start a new hobby*

*Enjoy simple pleasures*

*Practice your faith*

*Ask for help*

*See a therapist or counselor*

*Seek respite care*



# Spiritual Practices

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People of faith who have dementia often experience an improved sense of well-being when engaging in faith practices. Here are some of the practices that you can do together:

- Pray
- Read familiar scripture passages
- Sing favorite hymns
- Attend worship services
- Remember God's promises
- Express gratitude
- Experience God in nature



## Psalm 23

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This beloved passage of scripture provides peace and comfort by assuring us of God's presence and provision.

The Lord is my shepherd, I shall not want.  
He makes me lie down in green pastures,  
He leads me beside quiet waters,  
He restores my soul.  
He guides me along the right paths  
for his name's sake.  
Even though I walk through the valley  
of the shadow of death, I shall fear no evil:  
For you are with me;  
your rod and your staff, they comfort me.  
You prepare a table before me  
in the presence of my enemies.  
You anoint my head with oil; my cup overflows.  
Surely your goodness and love will follow me  
all the days of my life,  
and I will dwell in the house of the Lord forever.

# Some Common Scenarios and What to Do

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## Scenario 1

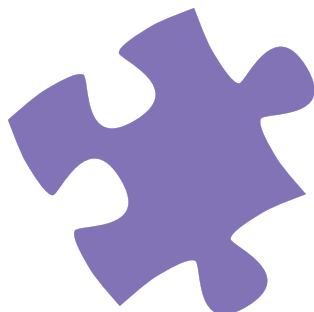
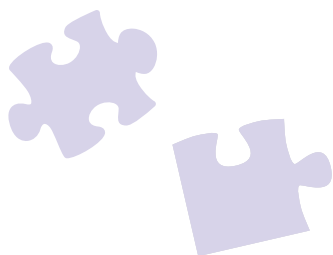
*My mom frequently says she's waiting for dad, but he died years ago.*

It is common for people living with dementia to be confused between the past and present or get stuck in a moment of time. When this happens resist the urge to correct them. Instead, you can redirect your loved one by saying something like, "I'd really like to see dad, too. Tell me about where the two of you loved to go together."

## Scenario 2

*My loved one frequently talks about trying to "bust out of this place."*

Check to see if there are any unmet needs such as using the restroom. Help your loved one engage in a favorite activity that might relieve their anxiety. Don't say, "This is your new home!" as it may increase anxiety and agitation. Offer soothing and validating statements like, "We're going to stay here tonight and have your favorite meal and play a game."





# Some Common Scenarios and What to Do

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## Scenario 3

*My loved one thinks I'm someone else.*

Make sure to introduce yourself by name and relationship when your visit begins. Don't test your loved one by asking, "Do you know who I am?" If your loved one calls you by the wrong name, try chatting about the person for whom you are being mistaken and gently distinguish yourself from that person, e.g., "Oh, I remember Mary. She was our neighbor on Henry Street. She loved working in her flower garden, didn't she?"

Trying to correct your loved one may cause embarrassment, agitation, and reduce self-confidence.

## Scenario 4

*My loved one gets upset and agitated when I try to leave at the end of a visit.*

Reassure your loved one that you'll see them again. If they ask when you'll return, you can tell them that you'll be back as soon as you can; remind them that you love them. If this behavior persists, talk to staff to find out if you can coordinate your leave around a favorite activity or meal time. This might provide enough stimulation and distraction for you to exit without upsetting them.

# Some Common Scenarios and What to Do

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## Scenario 5

*My loved one isn't supposed to stand on his own, but he tries to get up when I say goodbye.*

If your loved one is trying to stand up, don't yell. Yelling is likely to startle and may cause a fall. Instead, calmly offer your hand, and gently help them sit down, saying, "Oh, you don't need to get up. Let me help you sit down. You've had a busy day and should rest. I can let myself out."



# Help Me Find Joy

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A person living with dementia is often living in the moment. We have an opportunity to be with them in their moments, creating a place of joy, peace, comfort, and security. We want to partner with you in discovering things about your loved one: who they are, where they have been, and how to be with them where they are now.

Holland Home strives to help our residents living with dementia find joy in their journey and to care for them with compassion and empathy. The purpose of this handbook is to assist you in traversing this complicated journey.

Holland Home continues to find new and innovative ways to approach and care for our residents living with dementia. Providing ongoing training and education to ensure the best care possible is part of the mission of our Memory Care Services.

In our care we hope to create those positive moments of joy for your loved one. We recognize that they may not remember a specific time or event, but the feeling we leave with them can linger.

Dementia affects not just your loved one, but you as well. We are here to support and be a resource for you. We thank you for this privilege.

God bless you and your loved one,

*Memory Care Services*



# Helpful Resources

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The following resources may help for additional information or questions that may arise. Please also feel free to contact Holland Home Memory Care Services at (616) 235-8683.

## *Support Groups*

Caregiver support groups for adult children and spouses of people living with dementia meet monthly at Holland Home and in the community. Please contact Memory Care Services for more information.

## *Online*

<https://hollandhome.org/memory-care/>

[alz.org](https://www.alz.org) (Alzheimer's Association)

[teepasnow.com](https://www.teepasnow.com)

## *Books*

*Creating Moments of Joy* by Jolene Brackey

*My Journey into Alzheimer's Disease* by Robert Davis

*Learning to Speak Alzheimer's* by Joanne Koenig Coste

*Hiding the Stranger in the Mirror* by Cameron J. Camp

*The 36-Hour Day* by Nancy Mace and Peter Rabins

*Second Forgetting: Remembering the Power of the Gospel During Alzheimer's Disease* by Benjamin T. Mast



## Notes



## Notes





## Notes

The Holland Home Dementia Care Handbook was created by the Dementia Coalition, a group of Holland Home employees whose mission is to honor, serve, and care for those living with dementia.

**Dementia Coalition** (alphabetical by first name)

Audrey Noorman	Jillian England	Rosemay Apol-Hoezee
Cheri LaBeau	Josh Baron	Tim Myers
Comfort Jigo	Laurie Buter	Troy Vugteveen
Gerilyn May	Lynn Bolt	
Heidi Huizinga	Michelle Francisco	

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This handbook was produced with grant funding from the Civil Monetary Penalty Fund under the Michigan Department of Health and Human Services Bureau of Medicaid Policy and Health System Innovation of the Long Term Care Services Division.



**Walking with a friend in the dark is  
better than walking alone in the light.**

- Helen Keller