GrandmaLitt
A Caregiver's Guide

Practical support for memory changes, "going home," sundowning, pacing, doctor visits, and caregiver burnout

This e-book is for the caregiver: the person waking up through the night, managing the worry, making decisions, and loving someone through dementia.

Important: This booklet helps you prepare for a health care visit. It is not a diagnosis or a substitute for medical care. Sudden or severe changes in confusion, speech, weakness, chest pain, fever, falls, or immediate safety concerns need urgent medical help.

Contents

Tap or scroll to the section you need. Each part can also be printed and taken to an appointment.

Inside this guide

1. Memory & Thinking Visit Guide
What to bring, what to notice, and what to ask the doctor.

2. Understanding Sundowning
What late-day confusion can look like and gentle ways to respond.

3. Why Is My Loved One Pacing?
Needs to check, redirection ideas, and safety notes.

4. Memory & Thinking Questions to Ask and Write Down
A detailed caregiver observation sheet for orientation, recall, attention, daily living, and safety.

5. “I Want to Go Home”
What it may mean, how to respond, safety checks, and caregiver notes.

6. When the Caregiver Is Overwhelmed
Burnout, sleeplessness, worry, brain fog, and a personal check-in.

Memory & Thinking Visit Guide

A free caregiver worksheet to take to the doctor

You know your loved one best.
Caregivers often notice changes first. Use this guide to organize what you are seeing, so you can clearly share it with a health care provider.

Important: a memory screen is not a diagnosis

At an office visit, a provider may use a brief screen often called the Mini-Cog. It includes remembering three unrelated words and drawing a clock. It is a screening tool - not a home diagnosis.

Results can be affected by illness, medication, hearing or vision problems, language, education, stress, and many other things. Ask the provider to administer and interpret it.

What to write down before the appointment

- When did you first notice a change? Was it gradual or sudden?
- Examples of memory changes: repeating questions, forgetting recent conversations, or misplacing important items.
- Examples of thinking or daily-living changes: trouble paying bills, following a familiar recipe, using the phone, driving, or managing medicines.
- Changes in mood or behavior: anxiety, suspiciousness, agitation, withdrawal, sleep changes, pacing, or wanting to "go home."
- Any recent falls, pain, fever, illness, dehydration, medication changes, alcohol use, vision or hearing changes.
- What helps the person feel calmer or more like themselves?

My notes for the doctor

Use a few clear examples. You can write directly on this page or copy the notes into your phone.

Change I noticed	When it happens / how often	Example or concern

Questions you can ask

- Could this change be related to a medical condition, medication, infection, poor sleep, depression, or hearing/vision loss?
- Would a cognitive screening or a more complete evaluation be appropriate?
- What changes should make me call the office right away?

When to get urgent medical help

Sudden or dramatically worse confusion - especially with weakness, trouble speaking, chest pain, fever, a fall, or safety concerns - needs urgent medical help.

Bring this guide with you. Your notes can help the provider understand what is changing and what support may be needed.

Understanding Sundowning

What it is, what may trigger it, and gentle ways to respond

What sundowning means

Sundowning is a name for increased confusion, anxiety, restlessness, irritability, or agitation that begins or gets worse in the late afternoon, evening, or nighttime. It is not a separate disease, and it does not happen to every person with dementia.

What it can look like

- Pacing, calling out, wanting to leave, or saying "I need to go home."
- More confusion, worry, irritability, shadowing a caregiver, or difficulty settling for sleep.
- Seeing ordinary shadows or noises as something frightening.

Why it may happen

There is not one single cause. Late-day tiredness, a changed body clock, too much activity or noise, hunger or thirst, pain, constipation, a new environment, and reduced lighting can all add to distress.

A gentle evening plan

- Keep the routine predictable: meals, bathing, medicines, and bedtime at familiar times.
- Plan demanding tasks, appointments, and outings earlier in the day when possible.
- Use daylight or time near a window during the day. In the evening, turn on enough lights to reduce shadows.
- Lower the stimulation: softer voices, less TV, fewer visitors, less rushing.
- Offer comfort: a favorite song, familiar photos, a snack or drink if appropriate, folding towels, or sitting together.
- Write down what happened right before an episode. Over time, that can reveal a trigger.

What to say

"You are safe with me." "I hear that you want to go home. Tell me what you miss about home." "Let's sit together for a minute."

Try not to argue, correct, quiz, or say "You are already home" over and over.

When to call the provider

Call the health care provider if the change is new, suddenly worse, or you suspect pain, illness, constipation, a medication issue, poor sleep, or depression. Get urgent help for immediate danger or a medical emergency.

Why Is My Loved One Pacing?

A caregiver guide to needs, redirection, and safer movement

Pacing is communication without words.

The person may be trying to meet a need, release discomfort, find something familiar, or make sense of confusion. Treat it as a clue - not "bad behavior."

First, check for a need

- Bathroom, hunger, thirst, pain, feeling too hot or cold, tiredness, boredom, or loneliness.
- A missing person, item, place, or routine they are looking for.
- A noisy, busy, unfamiliar, or overstimulating space.
- A new medication, illness, constipation, poor sleep, or other physical change.

Ways to respond

- Stay calm and approach from the front. Use a soft, simple sentence: "I am here with you. Let's walk together."
- If it is safe, allow supervised walking instead of blocking or physically restraining the person.
- Offer a purposeful activity: fold towels, hold a familiar object, look through photos, listen to music, have a snack, or help with a simple task.
- Redirect gently. Ask about the place, person, or item they are seeking rather than telling them they are wrong.
- Create a safer walking path: clear trip hazards, secure keys and unsafe items, use comfortable shoes, and consider door alarms if wandering is a risk.
- Notice the pattern: time of day, location, what happened before, and what helped.

Safety comes first

If the person may leave the home unsafely, is falling, becomes aggressive, or cannot be redirected, get help from a health care provider or emergency services when there is immediate danger. Sudden new pacing or agitation deserves a medical check because discomfort or illness can be a cause.

My pacing pattern notes

Time / place	What happened before?	What seemed to help?

Memory & Thinking Questions to Ask and Write Down

A detailed caregiver observation guide to take to the doctor

These are the types of questions a health care provider may use to understand orientation, memory, attention, language, and daily functioning. Ask gently, one question at a time. Write their exact words when you can. Do not correct, quiz repeatedly, or score this at home.

Best way to use this

- Choose a calm time with little noise or distraction.
- If the person becomes upset, tired, or embarrassed, stop and offer comfort.
- Bring the completed pages to the doctor. Your notes are often more helpful than trying to judge a "score."
- Their education, culture, language, hearing, vision, illness, stress, and medication can affect answers.

Part 1: Orientation questions

These questions help show how a person understands the current day, time, and place.

Question to ask	What they said / what you noticed
What is your full name?	
How old are you?	
What is today's date?	
What year is it?	
What month is it?	
What day of the week is it?	
About what time of day is it - morning, afternoon, or evening?	
What season are we in?	
Where are we right now? (home, doctor's office, city, state)	
Who is the current President?	

Part 2: Personal memory and life story

Long-term memories may stay clearer than recent memories. These questions can be comforting as well as informative.

Question to ask	What they said / what you noticed
Where were you born or where did you grow up?	
What was the name of the school you attended?	
What kind of work did you do?	
What are the names of your children, spouse, or close family members?	
Tell me about a favorite holiday, meal, song, or family tradition.	
What is something you liked to do when you were younger?	
Is there someone or somewhere you are looking for today?	

Part 3: Recent memory and recall

A provider may ask the person to remember a few words or details, then ask again a few minutes later. Use this page to write what the provider asked and how your loved one responded.

Words or details the provider asked them to remember:

First word / detail	
Second word / detail	
Third word / detail	
After a few minutes, what did they remember?	
Did they need a hint? What helped?	

Other recent-memory questions you may want the doctor to know about:

- Do they repeat questions or forget a conversation soon after it happened?
- Do they misplace important items or accuse others of taking them?
- Do they remember recent visitors, meals, appointments, or phone calls?

Part 4: Attention, language, and simple problem-solving

These questions are not meant to embarrass anyone. They simply help show what kind of support may be needed.

Question or task	What they said / what you noticed
Can you say the days of the week backward?	
Can you count backward from 20?	
Can you follow a simple 2- or 3-step direction? Example: pick up a paper, fold it, and put it on the table.	
Can you name a common object when you point to it?	
Can you explain what you would do if you were thirsty, cold, or needed help?	

Part 5: Daily living and safety changes

A doctor will want to know what has changed from the person's usual ability - not only whether they can answer a question today.

Daily activity	Doing independently / needs reminders / needs help / no longer able
Taking medicines correctly	
Managing money, bills, or purchases	
Using the phone or remote control	
Preparing a familiar meal or snack	
Bathing, dressing, and toileting	
Finding familiar rooms or items at home	
Driving, using transportation, or walking outside safely	

Part 6: Caregiver concerns to tell the doctor

Bring this page with medication lists, recent changes, and examples. Sudden or dramatically worse confusion needs medical attention right away.

What I have noticed	When it started / how often / what makes it better or worse
Memory or thinking change	
Mood or behavior change	
Sleep, appetite, pain, constipation, falls, illness, or medication change	
Safety concern: wandering, leaving, stove, driving, falls, aggression, or refusing care	
What helps them feel safe, calm, or more like themselves?	

“I Want to Go Home”

What this phrase can mean - and how to respond with comfort

When a person living with dementia says, “I want to go home,” they may already be in the house where they live. The words are real, but the meaning may be deeper than a street address. Dementia can affect a person’s sense of time, place, familiar faces, and what feels safe.

It may mean…

- “I am scared, confused, tired, or overwhelmed.”
- “I miss the people, routines, or responsibilities from an earlier part of my life.”
- “I want my mother, father, spouse, or another person who once made me feel safe.”
- “I am looking for comfort, quiet, privacy, belonging, or something familiar.”
- “Something does not feel right in my body or around me.”

This is not usually a person being difficult. It is often their way of communicating a feeling or an unmet need.

What “home” can be to them

Home may be a place from childhood, a home they shared with a spouse, a neighborhood from long ago, a parent they miss, or simply the feeling of safety and being cared for. Their mind may be visiting an earlier time that feels more familiar than the present.

Listen for the meaning behind the words

- If they say, “I need to go home,” try: “Tell me about home. What do you miss about it?”
- If they mention a person: “You are thinking about your mother. Tell me what you remember about her.”
- If they are upset: “You sound like you need to feel safe. I am right here with you.”
- If they are looking for a task: “What did you need to do when you got home? Let’s do that together.”

Their answer can give you a clue. They may need a snack, the bathroom, rest, quiet, reassurance, a familiar song, a photograph, a short walk, or simply someone to sit beside them.

Words and actions that can help

Keep your voice soft. Approach from the front. Use short sentences and one idea at a time.

You can say:

- “You are safe with me.”
- “I hear you. You want to go home.”
- “Let’s sit together and tell me about home.”
- “Before we go, let’s have a little snack / use the bathroom / look at this picture together.”
- “Can you help me with something first?”

Try to avoid:

- Arguing: “You are already home!”
- Quizzing: “Do you know where you are?”
- Long explanations, scolding, or repeated correction.
- Blocking, cornering, or physically restraining the person unless there is immediate danger.

Gentle redirection ideas

- Move to a quieter, well-lit room.
- Offer a favorite song, familiar photo, drink, snack, blanket, or simple activity.
- Walk together if it is safe. Change the subject after you first acknowledge the feeling.

When to look for a medical or safety concern

Call a health care provider when this is new or suddenly worse, or when you notice pain, fever, illness, constipation, poor sleep, a medication change, dehydration, or a major behavior change. Seek urgent help for immediate danger, a fall, chest pain, trouble speaking, weakness, or a sudden dramatic change in confusion.

If they may leave the home unsafely, prepare a safety plan with their provider and keep current identification and contact information available.

My “going home” pattern notes

What was happening right before they said “I want to go home”?	
Time of day / place / people nearby	
What did they say they missed or needed?	
What did you try?	
What helped, even a little?	

When the Caregiver Is Overwhelmed

You can love them deeply and still be tired, angry, sad, scared, or worn out.

Caregiver burnout is more than “having a hard day.” It is the emotional, mental, and physical exhaustion that can build when you have been carrying responsibility, worry, interrupted sleep, and other people’s needs for too long without enough support or rest.

Burnout can happen when…

- You are always “on,” even while sleeping or trying to rest.
- You have nobody who truly understands the responsibility you carry.
- You are managing behaviors, appointments, money, medication, safety, and your own life at the same time.
- You feel guilty for wanting a break, even when your body and mind are asking for one.

Needing help does not mean you do not love them. It means you are human.

Signs you may be burning out

Burnout is a warning sign - not a character flaw. Notice it early, before you are completely empty.

Signs of caregiver burnout	Pause and check yourself
Feeling exhausted before the day even begins	Am I waking up already dreading the day?
Getting irritated, impatient, numb, or angry more easily	Am I reacting bigger than I want to?
Pulling away from friends, church, family, or things I used to enjoy	When did I last do something just for me?
Feeling hopeless, trapped, lonely, resentful, or like nobody sees me	Who can I honestly talk to today?
Skipping my own showers, meals, medicine, appointments, or basic needs	What have I put off for myself?
Headaches, body pain, stomach problems, appetite changes, or getting sick often	What is my body trying to tell me?

What lack of sleep and constant worry can do

Caregiving often includes listening for movement at night, staying alert for wandering, worrying about falls, or lying awake thinking about tomorrow. Lack of sleep and worry can affect the caregiver’s body and mind.

You may notice:

- Brain fog: forgetting words, losing your train of thought, misplacing things, or feeling mentally slow.
- Poor concentration: forgetting appointments, leaving tasks unfinished, trouble making decisions, or making mistakes in familiar routines.
- Feeling emotional: crying easily, feeling on edge, racing thoughts, dread, fear, or feeling like you cannot turn your mind off.
- Physical effects: headaches, body aches, stomach upset, appetite changes, blurred thinking, or feeling shaky and drained.
- Relationship strain: snapping at people you love, isolating yourself, or feeling unseen and unsupported.

These are signals to slow down and reach out - not proof that you are failing.

Your caregiver check-in and next step

You do not have to solve everything today. Choose one small step: accept help, ask a family member for a shift, call a friend, speak with your doctor, contact a counselor, or rest while someone safe sits with your loved one.

My caregiver check-in	Write it down honestly
Sleep: How many hours did I really sleep last night?	
Stress: What is weighing on me the most right now?	
Body: What symptoms have I noticed in myself?	
Emotions: What am I holding in?	
Support: Who can I ask for one specific thing today?	
One thing I need in the next 24 hours	

Please get immediate help if you feel unable to keep yourself or someone else safe. If stress, sadness, anxiety, sleeplessness, or physical symptoms are ongoing, talk with your own health care provider.