

THE CAREGIVER BRIEF

# The Caregiver's *Doctor Visit* Playbook

50 scripts for talking to any doctor,  
at any stage of dementia caregiving.

Free Resource — [caregiverbrief.com](https://caregiverbrief.com)

These scripts are communication tools. They help you report what you observe and ask the right questions. They are not medical advice. Always work with qualified healthcare professionals for decisions about your loved one's care.

[caregiverbrief.com/scripts](https://caregiverbrief.com/scripts)

# How to use this playbook

Dementia caregivers are the most important people in any medical appointment — but no one teaches them how to be heard. You know things about your loved one that the doctor will never observe in a 15-minute visit. These scripts give you the exact words to make sure that information reaches the people who need it.

Each script includes: the situation it's designed for, the exact words to say, a follow-up response for common pushback, and a practical tip. You don't have to memorize them. Print the ones that apply to your next visit and bring them in.

**A note on the showtime effect:** People with dementia often perform significantly better in clinical settings than at home. This is real, documented, and extremely common. Scripts 9, 10, and 11 address this directly — worth reading first.

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# Before the Appointment

## SCRIPT 1

### How to Write a Symptom Summary the Doctor Will Actually Read

*When to use:* Before any appointment, when you want to make sure the most important information gets through instead of getting lost in a rushed 15-minute visit.

#### SAY THIS:

*"I've put together a one-page summary of the changes I've been observing since our last visit. It covers three things: new behaviors, changes in daily function, and my top two questions. I'll hand it to the nurse at check-in so it goes in the chart."*

If they respond with "We'll have time to go over everything during the visit":

*"I appreciate that — I just find it helpful to have it written down so nothing gets missed. It's one page, front only."*

**Tip:** Keep it to one page, three sections max: (1) New or worsening behaviors with dates and frequency, (2) Changes in daily function — eating, sleeping, bathing, dressing, (3) Your top two questions. Lead with the most alarming change, not the longest list. Bullet points, not paragraphs. Doctors read bullets.

## SCRIPT 2

### How to Send a Note to the Doctor Before the Visit

*When to use:* When your loved one will be present at the appointment and you need the doctor to know things they can't hear you say — incontinence, aggression, sexual behavior, or safety concerns.

#### SAY THIS:

*"I'm calling ahead of [Name]'s appointment on [date]. I'd like to send a brief note through the patient portal — or by fax if that's easier — with some observations the doctor needs to know before the visit. My loved one will be present and I won't be able to bring up some of these things in front of them. Can you tell me the best way to send that?"*

If they respond with "Just bring it up at the appointment":

*"I understand, but some of what I need to share would be upsetting for [Name] to hear in the room. A quick note in advance would help the doctor be prepared. What's the best way to get it to them?"*

**Tip:** Most practices accept faxes, patient portal messages, or a note left with the front desk on arrival — marked "for physician eyes only, before the visit." Keep it to half a page: date, behavior description, frequency, your concern. Sign it with your name and relationship.

### SCRIPT 3

## How to Prepare Your Loved One So the Appointment Doesn't Become a Crisis

*When to use:* The morning of the appointment, when you're managing anxiety, confusion, or resistance about going.

### SAY THIS:

*"We're going to see Dr. [Name] today — you know them, they're the one who's been taking good care of you. We'll just be there for a little while, then we'll stop for [something they enjoy — coffee, lunch, a drive]. You don't have to do anything difficult. I'll be right there the whole time."*

If they respond with "I don't need to go to the doctor, there's nothing wrong with me":

*"I know you feel okay, and that's a good sign. This is just a routine check-in so we can keep it that way. It won't take long."*

**Tip:** Schedule appointments for the time of day when your loved one is at their best — usually mid-morning. Handle basic needs first: bathroom, breakfast, comfortable clothes. Don't mention the appointment until 20–30 minutes before you need to leave. Don't argue about whether they "need" to go — just redirect to the plan.

## SCRIPT 4

# How to Request a Longer Appointment Slot

*When to use:* When booking any dementia-related appointment — the standard 15-minute slot is almost never enough.

### SAY THIS:

*"I'm scheduling an appointment for [Name], who has dementia. This is a complex visit — we have several concerns to cover and it takes extra time for [Name] to process and respond. Can we please be scheduled for a longer appointment — 30 or 45 minutes if possible? I want to make sure the doctor has enough time to address everything."*

If they respond with "We only have standard 15-minute slots available":

*"I understand. Is there any way to book two consecutive slots, or to note in the chart that extra time will be needed? I'd hate to have to schedule a follow-up just to finish what we couldn't cover."*

**Tip:** Call the scheduling line at least a week out. If the practice has a patient care coordinator or a nurse navigator, ask for them — they often have more flexibility than front desk staff. Note the dementia diagnosis explicitly when scheduling. Some practices code these as "complex visits" which automatically extends the time.

## SCRIPT 5

# What to Bring to Every Dementia Appointment (Script for the Front Desk)

*When to use:* At check-in, to make sure the staff flags your role and your materials reach the doctor before the exam.

### SAY THIS:

*"I'm [Name]'s [relationship] and primary caregiver. I have a written summary of behavior changes since the last visit — I'd like to make sure it gets to the doctor before they come in, not after. I also have an updated medication list and a list of questions. Can I hand these to you now and have them added to the chart?"*

If they respond with "You can give that to the doctor yourself":

*"I'd prefer it go in the chart now, if possible — that way the doctor has a chance to review it before they walk in. It's just one page."*

**Tip:** Bring four things to every appointment: (1) A written one-page behavior summary, (2) A complete and current medication list — every prescription, supplement, and OTC drug with dosages, (3) Your top 2–3 questions written out, (4) Insurance cards and any referral paperwork. Keep a standing folder in the car so you never leave the house without it.

## SCRIPT 6

# How to Request a Private Moment with the Doctor Before the Patient Enters

*When to use:* When you arrive at the appointment and need to speak with the doctor alone before your loved one is in the room.

### SAY THIS:

*"Before [Name] comes in, I'd like to ask for two minutes with the doctor privately. I have some observations that I can't share in front of [Name] — they involve behaviors that would upset or embarrass them. Is there any way to arrange that, even briefly?"*

If they respond with "The doctor will speak with everyone together":

*"I understand — and I've also sent a note ahead of the visit through [portal/fax]. Can you confirm the doctor has seen it? That note covers the things I'm not able to raise in front of [Name]."*

**Tip:** If a pre-visit private moment isn't possible, ask the nurse or medical assistant when they take vitals — they often relay information to the physician before the exam begins. Alternatively, you can hand the nurse your written summary and ask them to make sure the doctor reads it before entering. Your fallback is the note you sent in advance (Script 2).

## SCRIPT 7

# How to Describe Behavior Changes in Clinical Terms – Not "She's Worse"

*When to use:* Any time you're reporting changes to the doctor and want to make sure your observations land with clinical weight.

### SAY THIS:

*"I want to describe what I'm seeing as specifically as I can. Over the past [timeframe], [Name] has been [behavior — e.g., 'refusing to bathe more than once a week, getting verbally aggressive when I try to help, and asking the same three questions on a loop throughout the day']. This is a change from [what the baseline was — e.g., 'two months ago when they were cooperative with personal care']. It's happening [frequency — e.g., 'daily now, compared to a few times a week before']."*

If they respond with "Some of that is expected at this stage":

*"I understand it may be within the range of the disease — I just want to make sure you have the full picture of what we're managing at home, so we can talk about whether there's anything that should change."*

**Tip:** The clinical language that gets a response: frequency ("three times a day"), duration ("episodes lasting 20–30 minutes"), change from baseline ("this is new in the last six weeks"), and functional impact ("she can no longer dress herself without a full meltdown"). "She's worse" tells the doctor nothing. "She refused to bathe four days this week and became physically aggressive when I tried to help" tells the doctor everything.

## SCRIPT 8

# How to Report the Frequency and Duration of Symptoms Accurately

*When to use:* Before any appointment where you're reporting a new or worsening symptom — to make sure your report is specific enough to act on.

### SAY THIS:

*"I've been tracking this so I can give you accurate information. [Symptom] is happening approximately [X times per day/week]. Each episode lasts roughly [duration]. It started [timeframe — e.g., 'about three weeks ago']. The pattern I've noticed is [trigger or timing — e.g., 'it usually happens in the late afternoon, around 4–6 PM']. Here's what it looks like when it happens: [brief description]."*

If they respond with "That level of detail isn't necessary":

*"I want to make sure I'm giving you what you need. Is there a specific format or timeframe that's most useful to you?"*

**Tip:** Keep a simple log on your phone or a small notebook. You don't need a medical chart — just date, time, what happened, how long it lasted, what preceded it. Even two weeks of data gives a doctor far more to work with than a general impression. Free apps like Dementia Diary or a simple Notes app entry work fine.

# During the Appointment — Getting Heard

## SCRIPT 9

### When Your Loved One Says "I'm Fine" and Contradicts Everything You Say

*When to use:* In the exam room when your loved one is minimizing or actively contradicting your reports — and the doctor might take their word for it.

#### SAY THIS:

*"Doctor, I want to flag something for you. [Name] tends to present much better in a clinical setting than at home — that's actually common with dementia, I've read it's sometimes called the 'showtime effect.' What I'm describing about daily functioning at home is different from what you're seeing right now. May I share a few specifics?"*

If they respond with "Well, [Name] seems to be doing well today":

*"I'm glad they seem well. What I need you to understand is that today is not a typical day. At home, in the last [timeframe], [give two specific examples from your notes]. I'm not exaggerating — I've been keeping a log."*

**Tip:** Don't get into an argument with your loved one in the exam room. Address the doctor directly, calmly, and with specifics. You are not trying to "win" — you're adding clinical information the doctor can't observe in a 15-minute visit. Bring your written notes. A piece of paper with dated observations carries more weight than a verbal debate.

## SCRIPT 10

# How to Ask for Private Time with the Doctor During the Visit

*When to use:* Mid-appointment, when you realize you need to share something the doctor needs to hear but your loved one shouldn't.

### SAY THIS:

*"Dr. [Name], would it be possible to have two or three minutes with you privately at some point during this visit? There are a couple of things I want to make sure I share with you that I haven't been able to bring up."*

If they respond with "We can talk openly here":

*"I appreciate that — but some of what I need to share involves sensitive behaviors that would be upsetting for [Name] to hear discussed. Even a quick conversation in the hallway would be helpful."*

**Tip:** If the doctor can't step out, ask the nurse or medical assistant to stay with your loved one for a few minutes while you speak to the doctor in the hall. Alternatively, use the restroom as your exit — "I'm going to step out for a moment" — and catch the doctor or nurse in the hallway. You have a right to share this information. Don't leave without doing it.

## SCRIPT 11

# How to Report the Showtime Effect — "They're Not Like This at Home"

*When to use:* Whenever your loved one performs better at the appointment than they do at home and you need the doctor to understand the gap.

### SAY THIS:

*"I want to make sure you're getting an accurate picture of [Name]'s daily functioning — because what you see here today is likely their best performance. People with dementia often rally in a clinical setting, especially when someone in authority is paying attention to them. At home, the baseline is very different. Specifically: [give two or three concrete, dated examples]."*

If they respond with "It's encouraging that they can rally like that":

*"I agree it's a good sign. But I want to make sure care decisions are based on the daily reality, not the best-case scenario. The daily reality is [example]. I've been keeping notes — do you want me to leave a copy in the chart?"*

**Tip:** The showtime effect is real and well-documented. You are not wrong, you are not exaggerating, and you are not being disloyal by reporting it. The doctor needs both pictures: what they observe clinically and what you observe daily. Your job at the appointment is to provide the second picture, clearly and specifically.

## How to Report Incontinence Without Embarrassment

*When to use:* When incontinence has started or worsened and the doctor needs to know — even when your loved one is in the room.

### SAY THIS:

*"I want to make sure we address bladder and bowel control today. [Name] has been having accidents — this is new [or 'this has gotten significantly worse'] in the last [timeframe]. It's happening [frequency]. I want to make sure we rule out any treatable causes and talk about how to manage it going forward."*

If they respond with "That's expected at this stage":

*"I want to make sure we're not missing something treatable — like a UTI or a medication side effect — before we assume it's just progression. Can we check for that?"*

**Tip:** Incontinence is one of the most under-reported symptoms because caregivers are embarrassed and don't want to humiliate their loved one. Doctors need to know because: (1) new or sudden incontinence can signal a UTI, which causes rapid cognitive decline in dementia patients, (2) it affects medication choices, (3) it's a major factor in care planning. Say it plainly and quickly — the doctor has heard it thousands of times.

## How to Report Aggression or Violent Behavior

*When to use:* When your loved one has become physically aggressive — hitting, grabbing, throwing objects — and the doctor needs the full picture.

### SAY THIS:

*"I need to talk about physical aggression. [Name] has become physically aggressive in the last [timeframe] — [describe specifically: hitting, grabbing, throwing, biting]. It happens most often when [trigger — e.g., 'during personal care, or when I try to redirect them']. The most recent episode was [timeframe] and [brief description of what happened]. I'm concerned about [Name]'s safety and my own. I want to talk about what's driving this and what our options are."*

If they respond with "Aggression is common in dementia — there are behavioral approaches you can try":

*"I'd like to hear those — and I'm also wondering whether there's a medical or pain component we should rule out first, since [Name] can't reliably tell me when something hurts."*

**Tip:** Be specific: what happened, when, how often, what preceded it. Don't minimize to protect your loved one's image. Aggression is a medical symptom, not a character flaw. Also note whether it's escalating — frequency and severity matter. You are not betraying them by reporting it. You are getting them help.

## How to Report Sexually Inappropriate Behavior

*When to use:* When your loved one has said or done something sexually inappropriate — touching, exposing themselves, making comments — and you need the doctor to know.

### SAY THIS:

*"I need to bring something up that's been very difficult. [Name] has been displaying sexually inappropriate behavior — [brief, clinical description: making sexually explicit comments, touching me or others inappropriately, exposing themselves]. This started [timeframe] and happens [frequency]. I understand this can be a symptom of the disease, but it's affecting our home environment significantly and I need to know what we can do about it."*

If they respond with "This can happen with dementia — it's a known symptom":

*"I know — and I'm glad it's on your radar. I'd like to talk about whether there are behavioral or other approaches that can help reduce these incidents, because it's putting a real strain on our situation."*

**Tip:** This is one of the most under-reported dementia symptoms because caregivers are mortified. You don't need to describe graphic details — keep it brief and clinical. The doctor needs to know it's happening to assess neurological changes, rule out medication side effects, and help you protect everyone involved. You are not embarrassing your loved one. You are getting them proper care.

## How to Report That Your Loved One Is Refusing to Eat

*When to use:* When your loved one has significantly reduced their food or fluid intake, is regularly refusing meals, or has lost noticeable weight.

### SAY THIS:

*"[Name] has been refusing to eat consistently for the last [timeframe]. They're eating roughly [describe — e.g., 'a few bites at each meal, sometimes nothing']. They've lost [weight change if known] and I'm concerned about nutrition and hydration. I want to know whether this is disease progression, a physical issue like swallowing difficulty, or something else — and what I should do about it."*

If they respond with "Reduced appetite is common as the disease progresses":

*"I want to make sure we're not missing a treatable cause first — like dental pain, a swallowing problem, nausea from a medication, or depression. Can we check for those?"*

**Tip:** Note specifics: how many meals they're refusing, what they will and won't eat, whether they seem interested in food but then stop, whether they cough or choke while eating (possible swallowing issue). Weight loss in dementia patients is clinically significant — if you know the number, say it.

## How to Report That Your Loved One Is Sleeping Excessively

*When to use:* When your loved one is sleeping significantly more than before — napping for hours, hard to wake, sleeping through activities.

### SAY THIS:

*"I want to flag a change in [Name]'s sleep. They've been sleeping [describe — e.g., '16–18 hours a day, taking multiple long naps, very hard to wake up'] for the past [timeframe]. This is a significant change from [baseline — e.g., 'a month ago when they were awake most of the day']. I want to understand whether this is disease progression, a medication effect, or something else we should investigate."*

If they respond with "Increased sleep is normal in later stages":

*"I want to make sure we're not missing a reversible cause — like a medication change, depression, infection, or thyroid issue — before accepting it as progression. Is that worth checking?"*

**Tip:** Note when the change started, how many hours they're sleeping total, whether they're difficult to wake, and whether they seem confused or disoriented when they do wake. Also note any recent medication changes — sedation from new or adjusted medications is a common and reversible cause.

## How to Tell the Doctor the Medication Doesn't Seem to Be Working

*When to use:* When a medication was prescribed to manage a specific symptom — cognitive, behavioral, or psychiatric — and you're not seeing any improvement, or things have gotten worse.

**SAY THIS:**

*"I want to talk about [Name]'s current medication. We started it [timeframe] and I've been watching carefully for [what you were told to expect — e.g., 'improvement in agitation']. What I'm actually observing is [what's happening — e.g., 'the agitation has stayed the same' or 'it's actually gotten worse since we started']. I'm not sure if we need more time, a different dose, or whether this approach is working for [Name]. Can we talk through what the next step should be?"*

If they respond with "Give it more time":

*"How much more time should we give it, and what specific changes would tell you it's working? I want to know what I'm watching for."*

**Tip:** Keep notes from the day a new medication starts. What was the target symptom? What have you observed each week? Concrete before-and-after observations carry weight. You are not second-guessing the doctor by raising this — you are providing the clinical data they can't observe. Don't accept "give it more time" without a clear timeline and a measurable goal.

## How to Ask the Doctor to Speak Plainly — Not in Medical Jargon

*When to use:* Any time the doctor uses terminology you don't understand, or gives you information you can tell you're not fully absorbing.

### SAY THIS:

*"I want to make sure I actually understand what you just said — can you tell me what that means in everyday language? I'm going to be making decisions based on this information, and I want to make sure I've got it right."*

If they respond by repeating the same explanation in the same terms:

*"Let me try to repeat back what I understood, and you tell me if I have it right: [your interpretation]. Is that accurate?"*

**Tip:** It is completely okay — and medically important — to stop the doctor mid-explanation and ask for plain language. Bring a notebook and write down what they say. If you're going to forget it five minutes later, say: "Can I record this on my phone so I can review it later?" Most doctors will say yes. You can also bring a second person to the appointment specifically to help absorb and remember what's said.

# Asking the Right Questions

## SCRIPT 19

### What Stage Is My Loved One In — and What Does That Mean Practically?

*When to use:* When you want a clearer picture of where your loved one is in the disease and what that means for what's coming.

#### SAY THIS:

*"Can you tell me where you'd place [Name] on the disease spectrum right now — mild, moderate, or severe? And more importantly, what does that stage mean practically for what we should expect and what we should be planning for at home?"*

If they respond with "Everyone progresses differently, it's hard to say":

*"I understand there's variability — I'm not asking for a timeline. I'm asking what the characteristic features of their current stage look like so I know what's within range and what should concern me."*

**Tip:** Doctors often avoid staging conversations because every person progresses differently. You're not asking for a prediction — you're asking for a practical framework. If they use the three-stage model (mild/moderate/severe), ask what typically comes next in each area: memory, behavior, physical function. Write it down.

## SCRIPT 20

### What Symptoms Should I Expect Next?

*When to use:* When you want to get ahead of changes instead of being blindsided by them.

#### SAY THIS:

*"Based on where [Name] is right now, what are the most likely changes I should expect over the next few months to a year? I'd rather be prepared than caught off guard. What new symptoms or losses should I be watching for?"*

If they respond with "It's really hard to predict":

*"I understand you can't give me a timeline. I'm asking what's typical for this stage and type of dementia — not a guarantee, just the most common trajectory so I can be mentally and practically prepared."*

**Tip:** Ask this question in terms of categories: memory, behavior, physical function (swallowing, mobility, continence), and safety. Getting even a rough picture lets you prepare emotionally, put legal and financial pieces in place, and research care options before you're in crisis mode.

## SCRIPT 21

### When Should I Call You vs. Go to the ER?

*When to use:* At any appointment — you need a clear decision rule so you're not guessing at 2 AM.

#### SAY THIS:

*"I need you to help me draw a clear line. When something changes with [Name], when should I call your office — and when should I go straight to the ER? Can you give me specific situations for each? I want to know exactly what crosses the line."*

If they respond with "Use your judgment":

*"I'd feel a lot better with something more concrete. For example, if [Name] suddenly becomes much more confused than usual — is that a call-you situation or an ER situation? What about a fall with no obvious injury? A fever?"*

**Tip:** Write the answer down during the appointment. The general rule: sudden changes — sudden new confusion, inability to speak or move, difficulty swallowing, high fever, signs of stroke or seizure — are ER situations. Gradual changes, worsening behaviors, new symptoms that aren't emergencies — call the office. Ask for the after-hours number and when it's appropriate to use it.

## Is It Safe to Leave My Loved One Alone?

*When to use:* When you're genuinely uncertain whether your loved one can be safely left alone — even for an hour — and you need a clinical assessment.

### SAY THIS:

*"I need your help assessing something that's become a real concern: is it safe to leave [Name] alone? I'm not sure where the line is. Specifically, I'm worried about [your specific concern — e.g., 'them leaving the stove on, not remembering to take medication, wandering outside']. Can you walk me through what to assess, and is there a formal evaluation we should do?"*

If they respond with "At this stage, it should be fine for short periods":

*"Can you tell me specifically what I should be watching for that would change that assessment? What behaviors or changes would tell me it's no longer safe?"*

**Tip:** The honest answer depends on specific capabilities: Can they use the phone to call for help? Do they recognize dangerous situations (fire, stranger at the door)? Do they wander? Can they manage their own medications? Ask the doctor to address those specific questions. If you're unsure, err toward not leaving them alone and ask about resources for respite care or companion services.

## What Changes Should I Be Watching for Between Appointments?

*When to use:* At the end of every appointment — to walk out with a clear monitoring list instead of vague worry.

### SAY THIS:

*"Before we finish, can you tell me specifically what you'd like me to watch for between now and our next appointment? Not just in general — but what would prompt me to call you before the next scheduled visit? What changes would be important for you to know about?"*

If they respond with "Just call if anything seems wrong":

*"That's helpful — can you give me two or three specific examples of what 'seems wrong' looks like for someone at [Name]'s stage? I want to know what's worth a call and what I should just note for the next visit."*

**Tip:** Write this down before you leave the office. Ask the doctor to prioritize: what are the most clinically significant changes to watch for right now? For most dementia patients this includes: sudden increase in confusion, new falls, changes in eating or swallowing, high fever, significant new behavioral symptoms. Get the specific answer for your loved one.

## How Do I Know If They're in Pain?

*When to use:* When you're concerned your loved one may be experiencing pain but can't reliably tell you.

### SAY THIS:

*"[Name] can't consistently communicate whether they're hurting, and I'm worried I might be missing pain that's driving some of the behavior changes I'm seeing. What behavioral signs should I be watching for that would tell me they're in pain? And how do we assess for pain in someone who can't self-report?"*

If they respond with "We'll monitor it at appointments":

*"I want to be able to catch it between appointments too. Are there specific behaviors — like increased agitation, facial expressions, guarding a body part, changes in movement — that should put me on alert?"*

**Tip:** Common behavioral signs of pain in people with dementia include: increased agitation or crying out especially with movement, facial grimacing, guarding a body part, resistance to touch in a specific area, changes in gait, and new sleep disturbances. Ask the doctor specifically about pain assessment tools designed for non-verbal patients — they exist and your care team should know them.

## Should We See a Specialist — Neurologist, Geriatrician, or Psychiatrist?

*When to use:* When you're not sure if your current care setup is complete — or when specific symptoms make you wonder if a specialist's perspective is needed.

### SAY THIS:

*"I want to ask about your recommendation for specialists. [Name] is currently seeing you as their primary [or neurologist]. Given where things are right now — especially [specific concern: behavioral symptoms, complex medication needs, rapid progression] — do you think we should also be seeing a neurologist, geriatrician, or geriatric psychiatrist? I want to make sure we have the right team."*

If they respond with "I think we're managing this well here":

*"I trust your judgment — I'd also like to understand what would trigger a referral. What would you see that would make you say 'this patient needs a specialist'?"*

**Tip:** Different specialists bring different expertise: neurologists for diagnosis, disease type, and cognitive decline; geriatricians for the whole-person complexity of older patients on many medications; geriatric psychiatrists for behavioral and psychological symptoms. You can request a referral — you don't need to wait to be offered one.

## Are There Clinical Trials We Should Consider?

*When to use:* When you want to explore whether your loved one might be a candidate for research studies or newer treatments.

### SAY THIS:

*"I've been reading about clinical trials for dementia and Alzheimer's. Is [Name] a potential candidate for any trials that are currently enrolling? Are there criteria that would make them eligible or ineligible? And what would participating actually look like for us?"*

If they respond with "I don't know of any right now":

*"Is there a resource you'd recommend for finding trials — like [clinicaltrials.gov](https://clinicaltrials.gov) or a research center you'd refer us to? I'd like to at least understand the landscape."*

**Tip:** ClinicalTrials.gov is the official database. The Alzheimer's Association TrialMatch ([alz.org/trialmatch](https://alz.org/trialmatch)) is a free matching service. Eligibility varies widely by disease stage, diagnosis type, and health history. Ask whether the practice has any academic affiliations or referral relationships with research centers.

## When Should We Think About Hospice?

*When to use:* When you want to understand what the criteria for hospice are and how to recognize when the conversation should start — before you're in a crisis.

### SAY THIS:

*"I want to have a proactive conversation about hospice — not because I think we're there yet, but because I don't want to have this conversation for the first time in a crisis. Can you help me understand: what does hospice for a dementia patient look like, when is it typically appropriate, and what are the signs we're approaching that point?"*

If they respond with "We're not at that stage yet":

*"I know — and I'm glad. I'm asking now, while we have time, so I can understand the criteria and start getting emotionally and practically prepared. What signs would tell you it's time to bring this up seriously?"*

**Tip:** Hospice eligibility for dementia typically involves: minimal verbal ability, inability to walk without assistance, inability to eat without help, recurrent infections, and a physician's judgment that life expectancy is likely six months or less. Hospice is comfort-focused care — it does not mean giving up. It often increases quality of life significantly. Ask now, not later.

## What Does a Good Day vs. a Bad Day Tell Us Medically?

*When to use:* When your loved one has notable fluctuations in cognition and you're trying to understand what the pattern means — and whether good days are masking problems.

### SAY THIS:

*"[Name] has very significant day-to-day variation — some days they're quite sharp and engaged, other days they seem to be in a different world. On the bad days, [describe specifically]. I'm wondering: what does that fluctuation tell you medically? Is it significant, and does the pattern point to anything specific we should investigate?"*

If they respond with "Fluctuation is common in dementia":

*"I understand it's common — but I've read that significant fluctuation can sometimes point to a specific type of dementia, or to other contributing factors like medication, sleep, or infection. Is that worth looking into in [Name]'s case?"*

**Tip:** Significant day-to-day cognitive fluctuation is a hallmark feature of Lewy body dementia — it's worth naming if the variation is dramatic. But it can also be caused by infections (especially UTIs), poor sleep, dehydration, medication timing, or other medical factors. Noting the pattern of good days vs. bad days — with dates and specifics — gives the doctor real diagnostic information.

# Behavioral Challenges — Reporting to the Doctor

## SCRIPT 29

### How to Describe Hallucinations to the Doctor

*When to use:* When your loved one is seeing, hearing, or sensing things that aren't there — and you need to report it accurately.

#### SAY THIS:

*"[Name] has been experiencing what I believe are hallucinations. [Describe specifically: visual, auditory, or tactile — e.g., 'They're seeing people in the room who aren't there' or 'They hear voices or music that I can't hear']. This started [timeframe] and happens [frequency — e.g., 'mostly in the evenings, almost daily']. They [do/do not] seem frightened by it. I need to understand what's causing this and what we should do."*

If they respond with "Hallucinations can occur with dementia — it depends on the type":

*"That's what I wanted to ask about. Does this change how you think about the diagnosis or the type of dementia we're dealing with? And is there anything we should do differently, or anything to avoid?"*

**Tip:** Be specific about the type: visual (seeing things), auditory (hearing things), tactile (feeling things on the skin). Note whether the person is distressed by the hallucination or seems to accept it. Also note timing — hallucinations that are worse in the evening may be related to sundowning; visual hallucinations are strongly associated with Lewy body dementia and are medically significant in that context.

## How to Describe Paranoia and False Accusations

*When to use:* When your loved one is accusing you or others of stealing, cheating, lying, or plotting against them — and you need to report it to the doctor without it sounding like a complaint.

### SAY THIS:

*"[Name] has developed paranoid beliefs over the last [timeframe]. Specifically, they're accusing [me/family members/aides] of [description — e.g., 'stealing their belongings, poisoning their food, having affairs']. I understand this is a symptom of the disease, not something they're doing deliberately. But it's happening [frequency] and it's affecting our ability to provide care. I want to understand whether this is likely to escalate, what might be driving it, and whether there's anything we should do."*

If they respond with "This is a known symptom — try validation and redirection":

*"I'm trying those approaches. Can you help me understand whether there's also a medical component — like a sleep disturbance, a medication side effect, or anxiety — that might be amplifying this? And at what point does the level of paranoia warrant a different approach?"*

**Tip:** Paranoia and false accusations (delusions) are extremely painful for caregivers — they feel like a personal attack from someone they're sacrificing themselves to care for. They are neurological symptoms. Describe them clinically to the doctor: what the accusation is, how often it happens, whether it's escalating, and what effect it has on care delivery. The emotional weight is yours to carry — but the report to the doctor should be factual and specific.

## How to Describe Sundowning

*When to use:* When your loved one becomes significantly more agitated, confused, or distressed in the late afternoon or evening — the classic sundowning pattern.

### SAY THIS:

*"[Name] has a very consistent pattern of increased confusion and agitation in the [late afternoon/evening]. It starts around [time] and usually lasts until [time or 'they fall asleep']. During that window, they [describe behaviors — e.g., 'become very anxious, try to leave the house, don't recognize the environment, repeat certain phrases, become verbally or physically aggressive']. This has been happening [timeframe] and it's [escalating/stable]. I need help managing this because it's one of the most difficult parts of the day."*

If they respond with "Sundowning is very common — here are some environmental strategies":

*"I'd like to hear those. I also want to ask whether there's anything medically contributing to it — like a sleep disorder, pain that's worse by evening, or a medication wearing off — that we should look at."*

**Tip:** Track the timing precisely. Knowing that it reliably starts at 4 PM vs. 7 PM matters for both behavioral management and medical assessment. Note what makes it better or worse. Common triggers include fatigue, hunger, low light, and overstimulation. Ask whether the timing correlates with any medication schedule.

## How to Describe Wandering Behavior

*When to use:* When your loved one leaves home or attempts to leave without awareness of danger — or when they pace and seem unable to settle.

### SAY THIS:

*"[Name] has started wandering — [describe the specific behavior: 'leaving the house without telling me, being found in the yard at night, trying repeatedly to leave for a destination that no longer exists, pacing the house for hours']. This has happened [frequency] in the last [timeframe], most recently [date/brief description]. I'm very concerned about safety. What do I need to put in place, and is there anything medically driving this that we should assess?"*

If they respond with "You'll need to implement safety measures at home":

*"I'm working on that. I also want to know: is there a medical component — like pain, a UTI, a medication side effect, or anxiety — that might be making this worse? And is there a formal assessment you'd recommend to understand the level of risk?"*

**Tip:** Report wandering incidents to the doctor every time they happen — even if you handled it safely. Each incident is clinically significant data. Ask about the Alzheimer's Association Safe Return program, GPS tracking options, and door alarm systems. If wandering is a new behavior or has escalated, it's a major safety signal that should change the care conversation.

## How to Describe Sudden Aggression or Rage Episodes

*When to use:* When your loved one has episodes of sudden, intense aggression — explosive and out of proportion to what triggered it — that feel different from baseline agitation.

### SAY THIS:

*"I want to describe something specific because it feels different from general agitation. [Name] is having what I'd call rage episodes — sudden, explosive aggression that comes on very quickly and is much more intense than their usual behavior. [Describe: hitting, screaming, throwing things, trying to leave]. It happens [frequency] and usually [does/does not] have a clear trigger. The most recent episode was [brief description]. I'm trying to understand if there's a medical component — like pain, a neurological change, or a medication issue — that could be driving this."*

If they respond with "Aggression can be a symptom of dementia":

*"I know — I'm specifically asking about the sudden, explosive quality. It feels different from irritability or resistance. Is sudden-onset severe aggression a signal to look for something specific?"*

**Tip:** Note whether the episodes are truly sudden (zero to explosive in seconds) or build up. Sudden-onset severe aggression can signal pain, a medical event, or a specific neurological change worth investigating. Also note whether there's a post-episode period — do they seem confused afterward, or do they return to baseline immediately? That pattern is clinically relevant.

## How to Describe Rapid Mood Swings

*When to use:* When your loved one shifts between emotional states very quickly — laughing to crying, calm to terrified, warm to hostile — in ways that seem disconnected from what's happening around them.

### SAY THIS:

*"[Name]'s emotional state has become very unpredictable. They shift very quickly between [examples — e.g., 'laughing and engaged to crying and distraught, or calm to terrified, sometimes within minutes']. It's not always connected to what's happening in the environment — it can happen seemingly out of nowhere. This is [a new pattern / getting more frequent] in the last [timeframe]. I want to understand whether this is disease progression, a medication effect, or something else."*

If they respond with "Emotional lability is common in dementia":

*"Can you help me understand whether the pattern or severity warrants any change in approach? And is there a specific type of change — like a sudden worsening — that should prompt me to call?"*

**Tip:** Emotional lability — rapid, involuntary shifts in emotion — is a recognized neurological symptom, not just "moodiness." Describe it to the doctor in those terms. Note whether it's new or worsening, how long episodes last, and whether there's a tearful or laughing component. It can sometimes be treated.

## How to Describe Repetitive Speech or Actions

*When to use:* When your loved one asks the same question repeatedly, tells the same story on a loop, or performs the same physical action over and over — and you need to report it clinically.

### SAY THIS:

*"I want to describe [Name]'s repetitive behaviors because they've increased significantly. Specifically: [describe — e.g., 'they ask where their mother is approximately 30 to 40 times a day' or 'they fold and unfold the same cloth for hours' or 'they repeat the same three-sentence story every 10 minutes']. This has been happening [timeframe] and seems to be increasing in frequency. I want to make sure this is on your radar and ask whether there's any medical significance to the pattern or intensity."*

If they respond with "Repetition is very common in dementia — here's how to respond":

*"I appreciate that — I also want to ask whether the intensity or specific content tells you anything clinically. And is there a level of repetitive behavior that would suggest we look for an anxiety or compulsive component that might respond to treatment?"*

**Tip:** Repetitive behaviors fall into two categories worth distinguishing: repetitive questions (memory-driven — they don't retain the answer) and repetitive physical actions (can be anxiety-driven, self-soothing, or neurologically compulsive). Noting which type — and whether the physical actions have a ritualistic quality — gives the doctor useful information.

## How to Describe Sleep Reversal

*When to use:* When your loved one has flipped their sleep schedule — awake and active at night, sleeping most of the day — and it's becoming a serious caregiving and safety issue.

### SAY THIS:

*"[Name]'s sleep schedule has reversed. They're awake and active — [describe: 'up pacing, trying to leave, agitated, confused'] — through much of the night, and then sleeping for most of the day. This has been the pattern for [timeframe]. It's becoming a safety concern because they're unsupervised at night, and it's affecting my ability to function. I want to understand what's causing this and what we can do about it."*

If they respond with "Sleep disruption is very common in dementia":

*"I understand it's common — I'm asking specifically about a complete reversal of the sleep-wake cycle. Is there a medical cause worth investigating — like a pain issue, a medication effect, or something neurological — before we assume it's just the disease? And are there approaches beyond sleep hygiene that we should consider?"*

**Tip:** Complete sleep reversal (not just insomnia, but a full flip of the day-night schedule) is both medically significant and a major caregiving crisis. It is associated with circadian rhythm disruption that is neurological in origin. Document when they're awake, when they sleep, and how long the pattern has been going on. This is a conversation worth having even if you have to push past "it's common."

# Safety Conversations

## SCRIPT 37

### How to Ask the Doctor to Tell Your Loved One to Stop Driving

*When to use:* When you believe your loved one is no longer safe to drive but they refuse to stop — and you need the doctor's authority to make it real.

#### SAY THIS:

*"I need your help with something I haven't been able to resolve on my own. [Name] is still driving, and I genuinely believe it's no longer safe. They have had [describe — near-misses, getting lost, damage to the car, difficulty with directions]. When I raise it, they dismiss me. I need you to have a direct conversation with them today about whether it's safe to continue driving — and if not, I'd like you to document that recommendation. Your word carries weight that mine doesn't right now."*

If they respond with "I'd need to do a formal evaluation first":

*"I completely support that — can we schedule it today or as soon as possible? And in the meantime, is there anything you can say to [Name] that acknowledges this is on the table?"*

**Tip:** Most states require physicians to report patients with certain medical conditions — including moderate to severe dementia — to the DMV. Ask the doctor about reporting requirements in your state. A written note from the physician — even just a letter saying driving is no longer recommended — can be enormously powerful. You can also request a formal driving evaluation from an occupational therapist.

## How to Report a Fall and What the Doctor Needs to Know

*When to use:* After any fall — whether or not there was an obvious injury — to give the doctor the clinical picture they need.

### SAY THIS:

*"I need to report a fall. [Name] fell on [date]. Here's what I observed: [what they were doing before the fall, how they fell, what surface they landed on, whether they lost consciousness, whether they complained of pain]. Afterward, [describe how they seemed — confused, in pain, returning to normal quickly]. There [was/was not] a visible injury. I want to make sure we assess whether there's a hidden injury, and also talk about what might have caused the fall and what we should do to prevent the next one."*

If they respond with "If there's no obvious injury, we'll monitor":

*"I want to make sure we're not missing something — like a hairline fracture or a subdural bleed — that might not be obvious right away, especially given that [Name] can't reliably report pain. What symptoms should I watch for that would tell me we need imaging?"*

**Tip:** Falls in dementia patients are medically significant even without obvious injury. Subdural hematomas (bleeding in the brain) can develop slowly after a head impact and may not be symptomatic immediately. Report every fall, every time. The doctor needs to know: circumstances, mechanism of fall, any loss of consciousness, current complaints. Ask specifically about whether imaging is warranted.

## How to Ask for an Official "Unsafe to Be Left Alone" Assessment

*When to use:* When you need documentation of your loved one's safety status — for care planning, insurance purposes, family conversations, or your own clarity.

### SAY THIS:

*"I need a formal assessment of [Name]'s ability to be safely left alone. This isn't just my gut feeling — I need something clinical, something I can point to. Specifically, I'm worried about [describe your concerns: fire safety, medication errors, wandering, inability to call for help]. Is there a formal assessment you can do, or can you refer us to someone who can — like an occupational therapist or geriatric care manager? And would you be willing to document your clinical opinion on this?"*

If they respond with "At their stage, they shouldn't be left alone":

*"I need that in writing — for insurance purposes, for conversations with family members who disagree with me, and for my own protection as a caregiver. Can that be documented in the chart and can I get a copy?"*

**Tip:** A written clinical statement that your loved one cannot be safely left alone has real-world consequences — it can support access to home health services, support family members who are in denial, and protect you legally. Don't just accept a verbal opinion. Ask for documentation. An occupational therapist can also conduct a formal home safety assessment that carries clinical weight.

## How to Raise the Topic of Guns in the Home

*When to use:* When there are firearms in the home and your loved one's dementia creates a genuine safety risk — for themselves, for you, or for others.

### SAY THIS:

*"I need to raise something that's difficult but important. There are firearms in the home, and I'm becoming increasingly concerned that [Name]'s dementia creates a safety risk. I'm worried about [your specific concern — e.g., 'them accessing a weapon during a paranoid episode or a moment of confusion, or accidentally discharging a weapon']. I don't know how to handle this on my own. I need your guidance — and I'd also like to know if there's a clinical recommendation you can make that might carry more weight in this conversation than my own concerns."*

If they respond with "That's a family decision":

*"I understand it's sensitive. But from a clinical standpoint, is there a safety recommendation you can make about firearms access for someone at [Name]'s stage of dementia? That recommendation might make a difficult family conversation much easier."*

**Tip:** This is one of the most under-discussed and highest-stakes safety conversations in dementia care. A physician's recommendation that firearms be secured or removed carries real weight. Ask specifically about: transferring custody to another family member, trigger locks, or secure storage options. You are not taking away a right — you are preventing a tragedy.

## How to Report a Wandering Incident

*When to use:* After any incident where your loved one left home or was found somewhere unsafe — to make sure it's properly documented and triggers the right response.

### SAY THIS:

*"I need to report a wandering incident. On [date], [Name] [describe what happened — left the house, was found by a neighbor, was picked up by police, was missing for X amount of time]. Here are the details: [what they were wearing, how far they got, what their mental state was when found, how they explained it]. This [was the first time / has happened before — frequency]. I need this documented in the chart, and I need us to talk about what safety measures need to change immediately."*

If they respond with "We should increase supervision":

*"I agree — and I want to be specific about what that means practically. Can you help me think through: door alarms, GPS tracking, enrollment in a safe return program, and whether the current living situation is still safe? I want to leave today with a concrete plan."*

**Tip:** Every wandering incident should be in the medical chart. The Alzheimer's Association Safe Return program provides ID bracelets and a 24/7 emergency response system — ask the doctor to recommend enrollment if they haven't. GPS tracking devices designed for dementia patients are also available. If this is a repeat occurrence, the conversation about whether the current living situation is still safe must happen now, not later.

## How to Ask About Home Safety Modifications

*When to use:* When you want a professional assessment of what changes to make at home — and want it framed as a medical recommendation, not just a suggestion.

### SAY THIS:

*"I want to make [Name]'s home as safe as possible, but I don't know what I don't know. Is there a formal home safety assessment we should do? Can you refer us to an occupational therapist who specializes in this? I want to know about fall prevention, wandering prevention, kitchen safety, bathroom modifications — all of it. What's the right process to get a professional set of eyes on the home environment?"*

If they respond with "Here are a few general tips":

*"I appreciate that — and I'd also like a formal referral if possible. A professional home assessment would help me prioritize, and it may also help with insurance coverage for some modifications. Is that something you can order?"*

**Tip:** Occupational therapists who specialize in home safety for older adults or dementia patients can assess the full environment and make specific, prioritized recommendations. Many insurance plans, including Medicare, cover this assessment with a physician referral. Common priorities: grab bars in bathroom, stove shut-off devices, door alarms, removing trip hazards, medication lockboxes, and door knob covers to prevent wandering.

# Care Transitions

## SCRIPT 43

### How to Ask the Doctor When It's Time for Memory Care

*When to use:* When you're approaching or past your limits at home and need a clinical perspective on the transition conversation — not just reassurance.

#### SAY THIS:

*"I need to have an honest conversation about memory care. I've been managing at home, but I want to understand clinically: what are the signs that tell you it's time? Not just practically, but medically — what would you be seeing in [Name] that would make you say the home care situation is no longer appropriate? I want your honest assessment, not just reassurance."*

If they respond with "You'll know when you're there":

*"I'm asking because I'm afraid I'll push myself past the point where I can make a good decision. Can you give me two or three specific indicators — either in [Name]'s condition or in my situation as a caregiver — that should trigger this conversation?"*

**Tip:** Common clinical indicators that memory care is warranted: unsafe behaviors that can't be managed at home (wandering, aggression, falls), inability to perform basic daily functions even with help, caregiver health or safety is being compromised, around-the-clock supervision is needed. The decision is never purely medical — it's also personal, financial, and familial. But a doctor's clinical framing can make an impossible conversation more possible.

## How to Ask About Home Health Aides — What Does Insurance Cover?

*When to use:* When you're considering bringing in paid help at home and want to understand what's covered before you make calls and face sticker shock.

### SAY THIS:

*"I'm looking into home health aides for [Name]. Before I start making calls, can you tell me what you can order or recommend that would be covered by Medicare or their insurance? I want to understand the difference between what's covered — like skilled nursing or therapy services — and what I'll likely need to pay out of pocket. And is there a referral or an order that needs to come from you to unlock any coverage?"*

If they respond with "Medicare doesn't cover custodial care":

*"I understand. Can you tell me what Medicare does cover in terms of home health? And do you know what Medicaid or supplemental insurance might cover for [Name]'s situation? Or can you refer me to a social worker who can help navigate this?"*

**Tip:** Medicare covers skilled care (nursing, physical therapy, occupational therapy) ordered by a physician for homebound patients — but does not cover ongoing custodial care (help with bathing, dressing, meals). Medicaid may cover custodial care depending on the state and income eligibility. Ask for a referral to a social worker or care coordinator — navigating insurance coverage is their specialty and it's free.

## How to Tell the ER Staff Your Loved One Has Dementia

*When to use:* In any emergency room situation — this is your entry script from the moment you arrive.

### SAY THIS:

*"I need to tell you something important before anything else: [Name] has dementia. They cannot accurately report their own symptoms or medical history. I am their [relationship] and primary caregiver. I have a current medication list and their medical history with me. Please note in the chart that they have dementia and that clinical information should come from me, not from their self-report. They may appear calm or articulate — that does not reflect their baseline or what's been happening at home."*

If they respond with "We'll get their information from them directly":

*"I understand your protocol — I want to support that process. I also need you to know that any information they give you may be unreliable. I have accurate information about their current condition, medications, and what happened today. Please make sure that reaches the treating physician."*

**Tip:** Carry a one-page medical summary for your loved one in your wallet or phone at all times. It should include: diagnosis, current medications, known allergies, primary care physician and neurologist contact information, advance directives status, and your name and phone number as primary caregiver. Hospitals see dementia patients every day who present better than they function at home. Your job is to make sure the ER team has the accurate picture immediately.

## What to Tell a New Doctor Who Doesn't Know Your Loved One's History

*When to use:* At a first appointment with any new physician — specialist, new PCP, urgent care, anyone who doesn't have the file.

### SAY THIS:

*"Before we start, I want to give you the context you need to treat [Name] effectively. They have [diagnosis] — diagnosed [timeframe]. Here's a quick summary of where they are right now: [current functional level in 2–3 sentences]. Their current medications are on this list. Their primary care physician and neurologist are [names]. The most important things to know today are [your top two or three: e.g., 'they cannot reliably report pain, they become very agitated with unfamiliar environments, and they have a history of adverse reactions to [class of medication — e.g., sedatives]']. I'll hand you this summary page."*

If they respond with "We'll get the records from their regular doctor":

*"That's great — and while you're waiting for those records, I want to make sure you have what you need to treat them today safely, since some of this information affects immediate decisions."*

**Tip:** Keep a two-page summary document updated and ready: diagnosis and date, disease stage, current medications, known allergies and adverse reactions, functional status, communication abilities, behavioral triggers, and your contact information. Print several copies and keep them in your bag. Never assume records have transferred. Never assume the new doctor knows anything. You are the continuity of care.

## How to Communicate a Hospitalization to the Regular Care Team

*When to use:* When your loved one has been hospitalized and you need to make sure their regular doctors are in the loop — and that the hospital team has what they need.

### SAY THIS:

*"I need to make sure [Name]'s regular care team is informed about this hospitalization. Can you tell me: does the hospital have a process for notifying the primary care physician and neurologist? I'd also like to ask: what information from their outpatient care would be most helpful for the hospital team right now? And what should I tell [Name]'s regular doctors when I call them?"*

If they respond with "We'll handle the coordination":

*"I appreciate that. In my experience, direct communication doesn't always happen automatically. I'd like to call [Name]'s PCP and neurologist myself to make sure they know what's happening and to ask if there's anything the hospital team should know about [Name]'s history. Is that okay with you?"*

**Tip:** Don't wait for hospitals and outpatient physicians to coordinate — they often don't, or it happens too slowly. Call your loved one's primary care physician and neurologist yourself, the same day. Give them: the reason for hospitalization, the admitting hospital and unit, the attending physician's name, and your phone number. Ask them: "Is there anything specific to [Name]'s history that the hospital team needs to know?" Hospitalization is a high-risk period for dementia patients — delirium, falls, and medication errors are common.

# Advocating for Yourself as the Caregiver

## SCRIPT 48

### How to Ask the Doctor for a Caregiver Mental Health Referral

*When to use:* When you recognize that you're not okay — anxiety, depression, grief, or all three — and you need a referral or at least a starting point.

#### SAY THIS:

*"I want to ask about support for me. I've been [describe honestly — e.g., 'struggling with anxiety and depression, not sleeping, feeling like I'm losing myself in this role']. I know my wellbeing directly affects the quality of care I can provide, and I'm not okay right now. Can you refer me to a therapist or counselor who has experience with caregiver situations — ideally someone who understands grief, loss, and the specific stressors of this role? I just need somewhere to start."*

If they respond with "It's normal to feel stressed as a caregiver":

*"I know it's normal — and I'm telling you I've moved past normal stress into something that's affecting my daily functioning. I need an actual referral, not just validation. Can you help me find someone?"*

**Tip:** You are allowed to be a patient too. Your mental health is not a footnote to the care visit — it is clinically relevant because caregiver burnout directly affects patient safety. If the doctor doesn't take it seriously, ask the nurse or ask for a referral to a social worker, who will. Many therapists specialize in grief, loss, and caregiver burnout. You deserve actual support, not a pat on the back.

## How to Tell the Doctor You Are Burning Out

*When to use:* When you're at or past your limit — exhausted, resentful, physically unwell — and you need a professional to hear it and respond with something more than sympathy.

### SAY THIS:

*"I need to be honest with you: I am burning out. I'm not sleeping. I've stopped taking care of my own health. I'm experiencing [describe honestly: 'anger, resentment, crying every day, physical symptoms I've been ignoring']. I know this is affecting my ability to care for [Name] safely. I'm not saying this to complain — I'm saying it because I need help figuring out what has to change. I can't keep going the way I'm going. What resources exist that I don't know about?"*

If they respond with "You really need to take some time for yourself":

*"I agree — and I need concrete help doing that. Can you refer me to a social worker? Can you help me understand what respite care options exist and whether insurance covers any of them? I need actual options, not just permission."*

**Tip:** Caregiver burnout is a medical issue — not a character failure, not a sign that you don't love enough. Symptoms include: exhaustion that sleep doesn't fix, withdrawal from your own life, physical illness, inability to feel positive emotions, and resentment toward the person you're caring for. Say all of it. The care team cannot help you if they don't know how bad it is. You naming it is the first step to changing it.

## How to Ask What Support Resources Exist for You — Not Just Your Loved One

*When to use:* At any appointment — especially when you feel invisible in the care equation — to find out what's actually available to help you as the caregiver.

### SAY THIS:

*"I want to ask specifically about resources for me — not just for [Name]. I know there's a focus on the patient, and that makes sense. But I'm the one keeping this whole situation together, and I'm doing it largely alone. What support resources exist for caregivers in our situation? Support groups, respite care, social work services, education programs, financial assistance — what should I know about that I probably don't?"*

If they respond with "There are some Alzheimer's Association resources":

*"Can you be specific? I want a list with actual names, phone numbers, or websites — not just a general direction. Is there a social worker here I can speak with today who can walk me through what's actually available locally?"*

**Tip:** The Alzheimer's Association 24/7 helpline (800-272-3900) is a real resource — trained specialists, not a phone tree. The Eldercare Locator (1-800-677-1116) connects caregivers to local services. Ask specifically about: respite care programs (temporary relief for caregivers), caregiver support groups, AARP caregiver resources, and any hospital or practice-based social work services. You deserve support. Ask for it by name.

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