The Crisis Deck

100+ Scripts For The Moments That Break You

Sarah Mitchell

The Crisis Deck

100+ Scripts For The Moments That Break You

(US Edition)

Sarah Mitchell

My Helpful Books
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How to Use This Guide

Read This First

You're probably reading this at night after a terrible day. That's okay. This guide is designed for exactly that moment.

Emotional Readiness Check

Before you use a script, ask yourself:

Can I handle the blowback?

- They may get angry, cry, or guilt-trip you
- They may not want to speak to you
- They may recruit other family members against you
- Are you prepared for this?

Is this the right level?

- Have I tried gentler approaches first?
- Am I escalating because I'm angry, or because gentler approaches failed?
- Would I regret this tomorrow?

What to Expect After You Set a Boundary

The Extinction Burst

When you change the rules, especially with siblings, expect pushback to **intensify before it improves**.

Timeline:

- **Hours 1-24:** Shock, denial, testing ("You don't really mean that")
- **Days 1-3:** Peak escalation—guilt trips, anger, threats, recruiting allies
- **Days 4-7:** Testing continues but intensity decreases
- **Weeks 2-4:** Gradual acceptance (or disengagement)

What's normal:

- Guilt trips getting more intense
- Anger, including yelling
- "After everything I've done for you"
- Silent treatment
- Recruiting other family members
- Threatening to cut you off/out of the will

What's not normal (and requires different response):

- Threats of violence → Call police
- Credible threats of self-harm → Call emergency services
- Showing up at your home uninvited → Don't answer door; call police if needed

Managing Your Own Guilt

The Crisis Deck contains many boundary-setting scripts for various situations and escalation levels.

Always remember: the guilt spike after setting a boundary is **not evidence you did something wrong**.

It's evidence you challenged a system that was exploiting you.

The guilt will peak in the first 48-72 hours and gradually decrease **if you hold the boundary**.

If you cave during the guilt spike, you've taught everyone that sufficient guilt pressure = you back down.

Next time, they'll apply guilt faster and harder.

Getting Support

Talk to someone **outside the family system**:

- Therapist or counselor
- Support group (in-person or online)
- Friend who isn't involved
- Crisis hotline if needed

If possible, avoid seeking validation from people inside the family system. They may be invested in you staying compliant.

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COGNITIVE DECLINE

DISCLAIMER: These scripts provide communication language for caregivers navigating cognitive decline. They do not provide clinical guidance, behavioral intervention protocols, or capacity assessments. Every situation involving cognitive decline should involve the person's physician. When in doubt, consult a licensed professional.

This is a special category of scripts. Most scripts rely on the other person's ability to remember, reason, and follow through. A person with dementia often cannot do these things.

Boundary-setting scripts (Levels 0-5) do NOT apply to a person with cognitive decline. Logic, evidence, past agreements, consequences, deadlines, and ultimatums will probably not work.

These scripts will give you words for the moment, but do not expect long-term behavior change. Use the emotional reframes for the unique grief of dementia caregiving.

WHEN TO CONSULT PROFESSIONALS:

- Physician: Any new or worsening behavioral change, aggression, paranoia, wandering, refusal to eat, or sudden confusion
- Neurologist/Geriatric Specialist: For diagnosis, staging, medication management
- Elder law attorney: For guardianship, POA activation, capacity evaluations
- Therapist: For your own grief, burnout, and emotional processing

TALKING TO THE PERSON WITH COGNITIVE DECLINE

Remember:

- Keep sentences short and simple, introduce one idea at a time
- Use a warm, calm, unhurried tone
- Don't argue, correct, or say "Don't you remember?"
- Respond to the feeling behind the words, not the words themselves
- Remember it's okay to say what works even if it technically isn't true
- What works today may not work tomorrow. That's the disease, not you!

If They Don't Recognize You

What NOT to do:

- Don't say: "It's me! Your daughter! How can you not recognize me?"
- Don't quiz them.
- Don't show visible hurt or cry in front of them – it will cause them distress without understanding why

WHAT TO SAY:

Hi, it's **[your name]**. I'm so glad to see you.

If they ask who you are:

I'm **[Name]**. I'm someone who loves you very much. I'm here to visit.

If they think you're someone else (their mother, sister, etc.):

Go with it. Enter their world. Be that person **for a few minutes.** Ask about a shared memory: "Tell me about when we used to **[something from their past]**."

You are not lying. You are meeting them where their brain lives right now.

If they suddenly recognize you:

Respond warmly and naturally.
Do NOT say: "See? You DO know me!"
Do Say: "It's so good to be here with you."

What to expect after:

- This will happen more frequently as the disease progresses
- Some days they'll know you. Some days they won't. Some days they'll shift mid-conversation.

- The pain of this is real. Process it later with someone you trust, not in the moment with them.
- They are not choosing to forget you. The disease is just erasing the pathways in their brain. Your relationship still exists. Their inability to name it doesn't erase what you've been to each other.

If They Ask for a Deceased Loved One

Moderate-to-advanced decline – Gentle Redirect

[Deceased person] isn't here right now. Tell me about **[him/her]**. What do you like the most?

OR:

[He/She] couldn't be here today. But I'm here. Let's **[look at photos / listen to music / have a cup of tea]**.

If they press:

I'm not sure where **[he/she]** is right now. But you know what I was just thinking about?
[Redirect to a happy memory involving that person]

Early-stage or mild decline – Honest Approach

[Name] died **[timeframe]** ago. I know that's hard to hear. I'm right here with you.

Then sit with them. Hold their hand. Let them grieve. Don't try to "fix" the sadness.

What to expect after:

- If using the redirect approach: they will likely move on within a few minutes. This is not callous. This is the disease allowing them peace.
- If using the honest approach: they may grieve intensely for minutes or hours, then forget and ask again. You will need to decide how many times per day you can do this.
- There is no perfect answer here. Consult their physician about what approach is best for their stage.

They Accuse You of Stealing — De-Escalation Response

Note: They've misplaced something and cannot retrace their steps. The brain fills in the gap with a story: someone must have taken it. This is paranoia caused by the disease. This is not a reflection of your character. Many people with cognitive decline experience delusions like this.

What NOT to do:

- Don't get defensive
- Don't argue or present evidence

WHAT TO SAY

Oh no, your **[item]** is missing? I can see why that would upset you. Let me help you look.

Search with them. Check the usual hiding spots (under the mattress, in coat pockets, in the freezer).

If you can't find it:

I'll keep looking. I know how important that is to you. While I look, would you like **[a cup of tea / to sit outside / to look at your photo album]**?

If they accuse you directly:

I can see you're really upset. I would never take your **[item]**. I want to help you find it. Let's check **[location]** together.

Environmental tip:

- Buy duplicates of frequently "lost" items (glasses, wallet)
- Create a designated "safe spot" and consistently return items there
- Keep a small amount of cash in their wallet so they can see and count it when anxious
- Lock away actual valuables

What to expect after:

- They will likely forget the accusation within minutes to hours
- This will happen repeatedly.
- It still hurts. Talk to your support system about that.

IMPORTANT: If accusations are new, sudden, or escalating in intensity, and especially if accompanied by other new symptoms (confusion, agitation, fever), make sure to contact their physician. New paranoia can indicate a urinary tract infection (UTI), medication side effect, or disease progression that needs medical attention.

They Say "I Want to Go Home" (While at Home) – Comfort & Redirect Script

Note: "Home" doesn't mean a building. It means safety, familiarity, comfort… a feeling. They may be thinking of a childhood home. They may just feel lost and afraid and are using the word "home" to express that.

What NOT to do:

- Don't say: "You ARE home. Look around!"
- Don't show them evidence

WHAT TO SAY

Oh, you need to get home. Do you need to do something there, or do you just want to be there?

This diagnostic question reveals the actual unmet need – are they hungry, bored, scared, need the bathroom?

If they persist:

Tell me about home. What do you love most about it?

Let them talk. Listen. Ask follow-up questions about the home they're describing.

That sounds like a wonderful place. What would we do if we were there right now?

Then gently transition:

I want you to feel comfortable. Let's **[make a cup of your favorite tea / sit in your chair / put on some music you love].** I'm right here with you.

If they're insistent and distressed:

Alright I hear you. Let's get ready to go.

Then begin a slow "getting ready" process—finding a coat, looking for keys, etc.—which often naturally redirects into another activity. They may forget the request within minutes.

What to expect after:

- This request often comes during sundowning or transitions
- Their feeling of wanting "home" may never fully resolve. What you can resolve is only the distress in the moment

- If they are in a facility and this is happening daily, discuss it with the staff. They may have strategies that work for your loved one's specific pattern.

DECODER: What "home" often actually means:

- They're cold, hungry, need the bathroom, or in pain → solve the physical need and the request often stops
- They're bored or understimulated → activity, not reassurance, is the fix
- They're overwhelmed by noise, people, or unfamiliar surroundings → reduce stimulation, move to a quieter space
- They feel like the "workday" never ended → explicitly mark the transition: "The day's all done. Time to relax now."
- They're lonely or scared → presence, touch, familiar music

LAST RESORT: The Drive-Home Trick

If nothing else works and they're escalating:

Actually take them out. Put them in the car, drive around the block or to a nearby store, buy something small, then drive back. As you approach the house, say:

"I think it's this way… does this look right?"

Let THEM "find" home. When they recognize the house, they often walk in and settle immediately, because they arrived, rather than being told they were already there.

This won't work every time or for every person. But when it works, it works because they needed the experience of going home, not the fact of being there.

They Ask the Same Question on Repeat — Patient Re-Answer Script

Note: This is a symptom. They are not trying to annoy you. They genuinely do not know they've asked before

What NOT to do:

- Don't say: "I JUST told you that"
- Don't sigh, roll your eyes, or show frustration (they'll pick up the emotional cue even if they can't understand why you're frustrated)

WHAT TO DO

Answer their question calmly the same way each time. Same words, same warm tone.

For example, if they ask: "What time is dinner?"

Say, “Dinner is at 6. We're having **[specific food]**.”

Environmental tip:

Write the answer on a whiteboard or notepad and place it where they can see it: "Dinner is at 6 PM."

Point to it when they ask: "Let's check the board—looks like dinner is at 6."

If it's driven by anxiety (you can usually tell by the tone):

Respond to the FEELING, not the words:

You seem a little worried. Everything's okay. I'm right here and I've got it handled. You don't need to worry about a thing.

What to expect after:

- This is one of the most draining aspects of dementia caregiving. You are not alone
- Build breaks into your day. Even 15 minutes in another room helps

They Refuse to Eat or Drink — Calm Encouragement Script

Note: They may have lost the ability to recognize hunger or thirst. They may not recognize the food. They may have difficulty with the mechanics of eating (forgetting how to use utensils, trouble swallowing). They may have lost the sense of taste or smell.

What NOT to do:

- Don't force feed
- Don't argue about whether they already ate
- Don't say: "You HAVE to eat" (this creates a power struggle they cannot comprehend)

WHAT TO SAY

I made your favorite – **[specific food]**. Will you try just a little bite? I want to make sure I got the recipe right.

OR:

I'm having some **[food/drink]**. Will you keep me company and have some too?

If they say they already ate:

Oh, that's great. Well, I made a little extra – would you just taste it for me? Tell me if it needs more salt.

If they won't eat at all:

That's okay. How about some **[juice/milkshake/soup]** – something easy? I'll leave it right here for you.

What to expect:

- Offer food in small portions, frequently throughout the day rather than three big meals
- Finger foods may work better than meals requiring utensils
- Bright-colored plates with good contrast to the food can help them see what's on the plate

IMPORTANT: If refusal to eat or drink persists beyond 24-48 hours, or if they are losing weight noticeably, contact their physician. This may indicate pain, difficulty swallowing (dysphagia), medication side effects, depression, or disease progression. Dehydration is a medical concern that requires professional assessment.

They Become Verbally Aggressive — Disengagement & Safety Script

Note: They are overwhelmed, frightened, or in pain and they've lost the ability to express that appropriately. The verbal filter is gone. They are not choosing to be cruel.

What NOT to do:

- Don't yell back
- Don't try to reason
- Don't cry in front of them (it escalates their distress)

WHAT TO SAY

Step 1: *Lower your voice, slow your words, soften your body language.*

I can see you're upset. I'm sorry this is happening. I'm going to give you a few minutes.

Step 2: *Create physical space. Leave the room if safe to do so.*

I'm going to step out for a moment. I'll be right nearby if you need me.

Step 3: *After 10-15 minutes, return with a calm reset:*

Hi **[Name]**. I brought you some **[tea/water/a snack]**. How are you feeling?

Do not reference the outburst. They may not remember it. Start fresh.

What to expect after:

- They will likely not remember the verbal aggression
- YOU will remember. The words hurt even when you know it's the disease
- Debrief with your support system afterward. It is important to process this

IMPORTANT: If verbal aggression is new or escalating in frequency or intensity, contact their physician immediately. This can indicate pain they can't verbalize, a UTI or other infection, a medication reaction, or a change in disease stage. New aggression is a medical symptom, not just a behavior problem.

They Insist on Doing Something Unsafe — In-the-Moment Redirect Script

Note: Don't lecture about why it's unsafe. Don't physically grab or forcefully prevent (unless imminent danger)

WHAT TO SAY

That's a great idea. Before you do that, can you help me with something first?

Redirect them to a safe version of the activity or a different activity entirely.

For example, if they want to cook:

I was actually about to start on dinner. Would you help me with the salad? **[Hand them a safe task, i.e. tearing lettuce, stirring something cold]**

If they want to leave the house:

Let's go together. But first, let me **[find my coat / grab my shoes – use the delay to redirect to another activity or go for a supervised walk]**

If they want to drive:

Oh, the car's in the shop today. I can take us. Where do you want to go?

What to expect after:

- Environmental controls (removing car keys, stove knob covers, locked doors with alarms) are more reliable than conversation
- Discuss any safety modifications with their physician and an occupational therapist

DISCLAIMER: If unsafe behavior is recurring or escalating – especially attempts to leave the house, access to dangerous equipment, or falls – contact their physician. A home safety assessment and possible increase in supervision may be needed.

They Are Confused About Time of Day — Gentle Reorientation Script

Note: The internal clock is disrupted. Sundowning is common and their brain may no longer accurately distinguish day from night.

WHAT TO SAY

If they get up at 2 AM wanting breakfast:

It's still nighttime, but I know you're hungry. How about a small snack, and then let's rest a little more? We'll have a big breakfast when the sun comes up.

If they think it's time to leave for an appointment that doesn't exist:

I checked the calendar and that appointment is actually tomorrow. We have the whole day free today. What sounds good to you?

What to expect:

- Maintaining a consistent daily routine helps anchor their sense of time
- Bright light exposure during the day and dimmer lights in the evening can help regulate their sleep-wake cycle
- Sundowning tends to worsen over time

They Refuse to Bathe or Change Clothes — Dignity-Preserving Scripts

Note: Bathing involves multiple complex steps they can no longer sequence. They may fear the water. Being undressed in front of someone feels vulnerable and humiliating. They may have depth perception issues that make the tub look terrifying. They may genuinely not perceive that they need to bathe.

What NOT to do:

- Don't say: "You smell" or "You haven't bathed in a week"
- Don't argue about when they last bathed
- Don't force them to undress
- Don't make THEM the problem that needs fixing

The core principle: Every script below follows the same rule – **you are the problem, they are the helper.** This flips the power dynamic. Instead of a caregiver telling a resistant person what to do, a clumsy/forgetful caregiver is asking for help fixing THEIR mistake. It removes the shame of being dirty or needing to be managed.

The Hygiene Pivots

THE CLOTHING CHANGE

The Coffee Spill

Oh gosh, I'm so clumsy – I just spilled coffee all over the back of your shirt. I am so sorry! Let's get that off you quickly before it stains.

Why it works: It makes YOU the problem (clumsy) and HER the helper (letting you fix your mistake). It removes the shame of "being dirty."

The Laundry Emergency

Oh no – I need that shirt! I promised **[someone]** I'd show them where I got it, and I need to take a photo of the tag. Can you take it off for a sec? Here, wear this one while I grab a picture.

Hand them a clean shirt. They'll likely forget about the "photo" within minutes.

Why it works: You're asking for a favor, not issuing an order. They feel helpful, not managed.

The Temperature Play

I don't know what's going on with the heat in here – is it hot to you? I'm burning up. Let's both change into something lighter. I'll grab us some fresh clothes.

Change your own shirt too. Make it a shared activity, not a directive.

Why it works: You're doing it WITH them, not TO them. There's no implication that something is wrong with them specifically.

The Gift Setup

Look what I found! **[Sibling/grandchild/friend]** sent this over for you. They really want to see you in it – can we try it on?

Works especially well with something soft and comfortable. Have a few "gifts" pre-staged.

Why it works: Putting on new clothes is exciting. Taking off dirty clothes is shameful. Same outcome, completely different emotional experience.

THE BATH OR SHOWER

The Plumbing Test

The plumber said he fixed the hot water, but I don't trust it. Can you help me test the shower? Just tell me if the temperature feels right. I don't want to get my clothes wet – would you mind stepping in and checking it for me?

Warm the bathroom first. Have towels ready. Once they're in the water, hand them soap casually: "While you're in there, might as well."

Why it works: They're doing YOU a favor. They're the expert testing the plumbing, not the patient being bathed.

The Spa Appointment

I booked us both spa time today! I set up the bathroom – warm towels, that soap you like, the works. You go first since you're the guest of honor.

"Spa" reframes the entire experience. It's a luxury, not a chore.

Why it works: Nobody refuses a spa day. Nobody refuses a shower — they refuse what "shower" represents: being told they're dirty, being undressed, being vulnerable. Change the frame, change the response.

The Doctor's Orders (for you)

The doctor told ME I need to start doing warm soaks for my **[back/knees/feet]**. I ran a bath – but honestly, I don't want to do it alone. Will you sit with me? Or better yet, you go first and tell me if the water's good.

Why it works: You're the patient. They're supporting you. The bath is incidental.

The Before-the-Visit

[Name they like — grandchild, friend, neighbor] is coming over this afternoon! Let's both get freshened up so we look nice. I'm going to change my shirt – want to pick out something to wear? And I set up the bathroom so it's nice and warm for you.

Why it works: There's a social reason – looking nice for a visitor – that has nothing to do with hygiene. It's purpose-driven, not hygiene-driven.

The Oops, My Fault Again

Oh no – I think I got **[sunscreen / lotion / cooking oil]** on your arm earlier when I bumped into you. I'm sorry! Let me get a warm washcloth... actually, it might be easier to just rinse off. The bathroom's all set up – I'll help you, it'll take two minutes.

Start with a warm washcloth on one arm. Gradually expand. If they're comfortable, transition to a full wash.

Why it works: It starts small and non-threatening. You caused the problem. The "bath" is just a practical cleanup, not a judgment.

THE INCREMENTAL APPROACH

When full resistance is entrenched, don't aim for a shower. Aim for one step closer to clean.

Level 1 — Face and Hands:

Here, I warmed up this washcloth for you. Doesn't that feel nice on your face? So refreshing.

If this is all you get today, that's fine. You succeeded.

Level 2 — Sponge Bath:

I got these amazing warm wipes – they're like the ones they use at fancy spas. Want to try them? You can do it yourself – I'll just hand them to you.

No-rinse cleansing cloths are a real product. They're effective and far less threatening than a shower.

Level 3 — Partial Wash:

Let's just do your hair today – I'll do it right at the kitchen sink so you don't even have to get undressed. Sit right here, lean back, I'll do all the work. Just like a salon.

Kitchen sink hair wash = no bathroom, no undressing, no vulnerability.

Level 4 — Full Wash (when they're ready):

Use whichever Hygiene Pivot script above works best for them that day. Warm bathroom. Calm voice. No rush.

Bottom line: A sponge bath with no-rinse wipes while fully clothed is infinitely better than no washing at all. Don't let "proper shower" be the enemy of "any cleaning whatsoever."

Environmental Tips:

- **Buy multiples of their favorite outfit.** If they want to wear the same blue shirt every day, get five identical blue shirts and rotate them. They won't notice.
- **Remove mirrors** if their reflection causes confusion or distress in the bathroom.
- **Warm the bathroom** before they enter – cold tile and cold air are the fastest way to trigger refusal.
- **Use the word "freshen up"** or "spa time" instead of "bath" or "shower" if those words are triggers.
- **Same-gender aide** may reduce embarrassment significantly.
- **Cover them with a large towel** during bathing to reduce vulnerability.
- **Play music they love** in the bathroom. Familiar music can transform the emotional tone of the entire experience.
- **Time it right.** If they're a lifelong morning bather, don't try evenings. If they're calmer after lunch, that's your window.
- **No-rinse products**, shampoo caps, cleansing cloths, rinse-free body wash – are all legitimate alternatives used in hospitals.

They Become Frightened or Paranoid — Reassurance & Grounding Script

Note: Damage to the brain can cause hallucinations (seeing/hearing things) and delusions (false beliefs). Paranoia is common in middle-to-late stage dementia. They are genuinely experiencing these things. It is not "in their head" in the way you might think – it is real to them.

What NOT to do:

- Don't lead with "There's nobody there" or "That's not real"
- Don't try to prove them wrong with evidence or logic
- Don't dismiss their fear
- Don't assume every hallucination needs intervention

Before You React: Is This Actually a Problem?

Not all hallucinations are distressing. Some people with dementia see a deceased loved one sitting in a chair, or a child playing in the corner, and feel comforted by it. Others see animals or familiar faces and aren't bothered at all.

Ask yourself:

- Are they upset, frightened, or agitated by what they're experiencing?
- Is it leading them to do something unsafe?
- Or are they calm – even happy?

If they're not distressed: You don't need to do anything. Sit with them. If they mention seeing someone and seem content, you can say:

That sounds nice. Tell me about them.

A benign hallucination that brings comfort is not a problem to solve. Leave it alone.

If they ARE distressed: Try the scripts below.

When They See Someone Who Isn't There

Step 1 — Acknowledge THEIR experience first.

I can see you're really scared. That must be frightening. I'm right here with you. You're safe.

Lead with what THEY are feeling, not with what YOU see or don't see. The first words out of your mouth should validate their emotional state, not correct their perception.

Step 2 — If they ask you directly: "Do you see him?"

I know you're seeing something. I don't see it myself — but I can tell it's really upsetting you. Let me check.

This is different from "There's nobody there." You're acknowledging their experience as real TO THEM while being honest that you don't share it. You're not arguing. You're not dismissing. You're standing next to them in it.

Step 3 — Take action they can see.

Let me check the whole room for you. I'll look everywhere.

Walk around. Check behind doors, look out windows, open closets. Do it thoroughly and visibly. Then:

I've checked everywhere. It's just us. I'm going to stay right here with you.

Step 4 — Change the environment.

Hallucinations are often tied to something in the space. Try physically changing something:

- **Turn on more lights.** Shadows and dim lighting are the #1 trigger for visual hallucinations. A dark corner becomes a figure. A shadow on the wall becomes a face.
- **Turn off the TV.** People with dementia can lose the ability to distinguish between what's on screen and what's in the room. A crime show isn't entertainment — it's someone breaking into their house.
- **Cover or remove mirrors.** Their own reflection can become a stranger staring at them.
- **Move to a different room.** Sometimes the fastest fix is simply: "Come sit with me in the kitchen. I just made tea."

Changing the environment often breaks the loop faster than any words can.

When They Believe Someone Is Plotting Against Them

Don't say: "Nobody is out to get you. That's ridiculous."

Say This Instead:

That sounds really stressful. I can see why you'd be worried about that. Tell me what's going on.

Let them talk. Listen. Don't argue with the content — respond to the emotion underneath it.

Then:

I'm going to make sure you're safe. Nothing is going to happen to you while I'm here. Let's **[move to a different room / go for a walk / put on some music]**.

Why it works: You haven't agreed that people are plotting. You haven't argued that they're not. You've responded to the feeling and addressed THAT directly. Then you've changed the environment, which breaks the cognitive loop.

When They Accuse YOU of Being the Threat

Don't say: "It's ME! How can you not recognize me?!"

Say This Instead:

Step 1: Increase physical distance. Don't approach. Don't reach for them.

I'm sorry I startled you. I don't want to scare you. I'm going to step back.

Step 2: Reintroduce yourself as if for the first time.

My name is **[Name]**. I'm here to help. You're safe.

Step 3: If they remain frightened, leave the room entirely.

I'm going to give you some space. I'll be right in the other room if you need anything.

Return in 10-15 minutes. When you come back, enter slowly, speak softly, and bring something, such as tea, a snack or a blanket. Don't reference what just happened.

They may not remember the episode at all. Start fresh.

Environmental Tips:

- **Lighting is everything.** Keep rooms well-lit, especially in the late afternoon and evening when sundowning intensifies symptoms. Shadows are not ambiance — they're trigger factories.
- **Remove or cover mirrors.** If they don't recognize their own reflection, a mirror is a window with a stranger staring through it.
- **Monitor TV content.** News, crime shows, loud commercials, and anything with conflict can be perceived as real events happening in the room. If they watch TV, stick to calm content — nature shows, old musicals, cooking programs.
- **Reduce visual clutter.** Busy patterns on wallpaper, curtains, or tablecloths can be misinterpreted. A pattern of flowers becomes faces. Stripes become bars.
- **Check for sounds.** A furnace clicking, a pipe rattling, wind outside — sounds they can't identify become "someone in the house." Identify and address recurring noises.
- **Avoid dark-colored clothing.** Some people with dementia associate dark clothing (especially black) with threatening figures.
- **Consistent faces.** Rotating caregivers or unfamiliar visitors can trigger paranoia. Keep the circle of people they see regularly as consistent as possible.
- **Keep a "comfort kit" ready.** Favorite music, a familiar blanket, photos, a simple snack, and a warm drink. When an episode starts, you grab the kit instead of scrambling.

The Sundowning Pattern

Paranoia and hallucinations often peak in late afternoon & evening. If you’re noticing a pattern:

- Increase lighting before the sun goes down. Don't wait for it to get dark.
- Start calming activities (music, gentle movement, a snack) around 3-4 PM.
- Close curtains before dark so they don't see their own reflection in windows at night.
- Keep the evening routine predictable and quiet.

If sundowning is severe, discuss with a physician. Melatonin, light therapy, or medication timing adjustments may help.

IMPORTANT: Contact a physician **immediately** if:

- Paranoia or hallucinations are **new** — they haven't had them before and suddenly start
- Symptoms are **sudden** in onset (hours to days, not gradual)
- Accompanied by **fever, pain, reduced appetite, or changes in urination** (hallmark signs of a UTI, which is the most common medical cause of sudden psychiatric symptoms in dementia)
- They've **started a new medication** or had a **dose change** in the last 1-2 weeks

- They become **physically dangerous** — to themselves or others
- They are **inconsolable** for extended periods despite all de-escalation attempts

New-onset hallucinations or paranoia in a person with dementia is a medical symptom until proven otherwise. Don't assume it's "just the disease progressing." Rule out: UTI, delirium, medication reaction, pain they can't verbalize, stroke or TIA, or dehydration.

If you can't reach the physician and the person is in danger, call 911.

A note on Lewy body dementia specifically:

If they have been diagnosed with Lewy body dementia or Parkinson's disease dementia, hallucinations are **expected and frequent**, more so than in Alzheimer's. Visual hallucinations are a core feature of the disease, not a complication. This doesn't make them less distressing, but it does mean:

- They may happen daily
- The person may have some awareness that what they're seeing isn't real (especially earlier in the disease)
- **Certain antipsychotic medications can be extremely dangerous** for people with Lewy body dementia and can cause severe, life-threatening reactions. If a doctor prescribes antipsychotics, confirm they know the specific dementia type.

They Wander or Try to Leave — Calm Return Script

Note: They may be living in a past time when they had somewhere to be. They may feel restless and want to walk. They may be looking for something or someone. They may simply not recognize their surroundings as "home".

WHAT TO SAY

If you catch them before they leave:

Where are you headed? That sounds nice. Before we go, let me grab my coat and come with you. **[Use the delay to redirect]** Actually while I'm getting ready could you help me with **[task]**?

If they've already left and you've found them:

There you are! I was looking for you. I'm so glad I found you. Let's walk together. **[Walk WITH them rather than confrontationally turning them around. Gently redirect the path back]**

If they insist they need to go to work/pick up kids:

Oh, **[Boss/school]** called – they said you have the day off today. Lucky us! Let's enjoy it.

What to expect after:

- Wandering is a safety issue, not just a communication issue
- Door alarms, GPS trackers, ID bracelets, and secured locks are essential
- Register with your local police department's vulnerable persons program
- MedicAlert + Alzheimer's Association Safe Return program: 1-888-572-8566

DISCLAIMER: Any new wandering behavior, especially if it's a sudden change, should be reported to their physician. Also discuss with their doctor if wandering is becoming frequent or if they've gotten lost.

They Mistake a Caregiver / Family Member for Someone Else

When this happens: They call you by a sibling's name, think the aide is their old neighbor, or treats your spouse like a stranger.

WHAT TO DO

Go with it. If they call you "Margaret" and Margaret was their sister, be Margaret for a few minutes.

Tell me about Margaret. What did you two used to do together?

Only correct if it's causing a safety issue (e.g., they think the aide is an intruder and become aggressive). Otherwise, let it be.

Remember: This is not about you. Their brain is filing faces into old categories. The fact that your face triggers "someone safe and loved" is actually a good sign, even if the name is wrong.

They Become Upset During Personal Care — Pause & Retry Script

Note: Personal care is intimate. Being undressed, touched, or positioned by another person can feel threatening to someone who doesn't understand what's happening or why.

WHAT TO DO

Step 1: *Stop the task.*

Step 2: *Give them space and a moment to calm down.*

Step 3: *Come back to the task later – or try a different approach.*

What to expect:

- Break the task into smaller steps with breaks in between
- Narrate what you're doing before you do it: "I'm going to help you put your arm through the sleeve now"
- A different caregiver may get a different response – sometimes a professional aide or same-gender helper is less threatening
- Some days will just be harder than others

They Refuse to Leave a Public Place or Get in the Car – Public De-Escalation Script

Note: Public environments are sensory overload for a declining brain – noise, movement, strangers, bright lighting, unfamiliar layouts. When they scream "Go away!" or refuse to move, they are not being defiant. They are in fight-or-flight. Their brain has registered a threat it can't process, and you (the person trying to move them) may be registering as part of that threat. They may not even recognize you in this moment

What NOT to do:

- Don't grab their arm or physically force them toward the car
- Don't raise your voice or match their volume
- Don't say: "You're making a scene" / "People are staring" / "We HAVE to go NOW"
- Don't crowd them – moving closer when they're saying "go away" escalates the fight-or-flight response
- Don't try to reason or explain: "The car is right there, it'll only take a minute" registers as confrontation, not logic
- Don't let your embarrassment drive your next move – your panic is the second crisis

What TO do:

Manage the audience first (2 seconds):

If bystanders are gathering, one calm sentence handles it:

We're okay, thank you. He/she has a memory condition.

This does two things: it stops well-meaning strangers from intervening (which adds more sensory chaos), and it releases YOU from the pressure of being watched.

If you find yourself in public regularly, consider carrying a small card that reads: "My loved one has a cognitive condition. Thank you for your patience." You can hand it to staff, bystanders, or anyone nearby without having to explain out loud – which could agitate your loved one even more.

HOW TO ACT

Step 1: *Stop. Step back. Drop everything in your body language.*

Do the opposite of what your instincts are telling you. Do not move toward them. Take one visible step back. Lower your shoulders. Unclench your hands. Breathe. Your body language is the first message they receive – and right now it needs to say "I am not a threat."

Step 2: *Get low and soft.*

If they're sitting or have backed against something, lower yourself closer to their eye level. Speak slowly, quietly, and with warmth. Use their name.

[Name]. I'm here. You're safe. I'm not going to rush you.

Pause. Let silence do the work. Do not fill the gap with more words.

Step 3: *Respond to the feeling, not the words.*

"Go away" means "I'm scared." Address the fear, not the instruction.

You seem really uncomfortable right now. That makes total sense – it's **[noisy/busy/bright]** here. I don't like it much either.

You are standing beside them in their experience, not correcting it.

Step 4: *Offer comfort, not a plan.*

*Do not mention **[the car / leaving / going home]** yet. Any reference to the thing they're refusing will re-trigger the refusal.*

Would you like to sit down for a minute? Can I get you some water?

If they accept – let them sit. Let the environment recede. This is not wasted time. This is how the de-escalation works.

Step 5: *When the peak passes (and it will), redirect as if the idea is new.*

You'll know the peak has passed when their volume drops, their body softens, or they make eye contact. This may take 2 minutes. Or 15. Wait for it.

I'm getting a bit tired. Want to head to the car and sit down where it's quiet?

or

It's getting **[cold/hot/late]** out here. Let's go sit somewhere more comfortable.

Frame leaving as YOUR need or a shared comfort decision – not as something they must comply with. Offer your arm or hand, palm up, rather than reaching for them.

If they refuse again after the peak has passed:

That's alright. We don't have to go yet. I'll wait with you.

Then wait. Repeat Step 5 in a few minutes with a different framing. Patience here prevents a second escalation.

If they let you approach but won't walk:

Walk beside them, not in front pulling or behind pushing. Match their pace. If they stop, you stop. Physical momentum matters – if they take one step, gently keep that momentum going with a calm, continuous flow of movement and quiet conversation.

You're doing great. Almost there. I can see the car from here.

What to expect after:

- Once in the car, the episode may resolve quickly. The car is enclosed, quiet, familiar – the opposite of the environment that triggered the crisis
- They will likely not remember the outburst. YOU will
- You may feel shaky, embarrassed, or want to cry. That is a normal adrenaline response. Sit in the car for a few minutes before you drive
- This will almost certainly happen again. It's not a failure of your caregiving – it's a symptom of the disease in overstimulating environments

PREVENTION TIPS:

- **Time your outings.** Avoid peak-crowd times. Early morning shops, mid-afternoon restaurants, weekday appointments
- **Park close to the entrance.** Less distance = less exposure = faster exit if needed
- **Keep outings short.** One task per outing. Get in, do the thing, leave before the battery runs out

- **Watch for early warning signs:** fidgeting, scanning the room, going quiet, gripping your arm, facial tension. These often precede the outburst by several minutes. If you see them, leave THEN, before the cascade starts
- **Have a familiar comfort object in the car** – a blanket, a favourite hat, a specific sweet. Something that says "safe" before you even pull out of the car park
- **Know your exits.** Before you enter any public space, note where you came in. If you need to leave fast, you don't want to be searching for the door while managing a crisis

IMPORTANT: If public meltdowns are new, sudden in onset, or dramatically worse than previous episodes, contact their physician. As with all behavioural changes in dementia, new or escalating agitation can indicate pain, infection (especially UTI), medication changes, or disease progression. Don't assume it's "just what happens now" without ruling out a treatable cause.

Soiling, Denial, Hiding, and Fecal Smearing (Scatolia) – Hygiene Crisis Management Script

DISCLAIMER: This script provides communication language and practical guidance for managing incontinence-related behaviours in cognitive decline. It does NOT provide clinical guidance, continence assessment, or behavioural intervention protocols. Bowel incontinence, fecal smearing, and sudden changes in toileting behaviour should always be discussed with the person's physician. Constipation, urinary tract infections, medication side effects, pain, and disease progression can all cause or worsen these behaviours — and many of these causes are treatable. Do not assume anything without proper medical evaluation.

Fecal smearing (scatolia) is a recognised dementia behaviour. Research links it strongly to constipation, sensory changes, discomfort, loss of executive function, insomnia, and understimulation. It is not spite. It is not laziness. It is not something they are choosing to do to you. Their brain can no longer connect the sensation of soiling with the appropriate response. They may not know they are soiled. They may feel the discomfort but not understand what it is. They may try to "fix it" themselves and thus make it worse.

This script covers four scenarios:

1. They have soiled themselves and deny it
2. They are hiding soiled clothing or incontinence products
3. They are smearing feces
4. What to do with yourself after cleanup

SCENARIO 1: They Have Soiled Themselves and Deny It

What's happening: They may genuinely not know. Dementia can eliminate the ability to smell their own body, feel wetness, or connect the sensation of discomfort with its cause. In earlier stages, they may know but be deeply ashamed and use denial as the only dignity they have left. Either way, confrontation makes it worse.

What NOT to do:

- Don't say: "You've had an accident" / "You've soiled yourself" / "Can't you smell that?"
- Don't point at the evidence
- Don't argue when they deny it
- Don't show disgust on your face — they read your expression even when they can't process your words
- Don't take soiled clothing from their hands or body without warning

WHAT TO SAY

Step 1: *Create a reason to change that has nothing to do with soiling.*

I just put fresh clothes out for you. They're really comfortable. Let's swap into those.

or

The doctor said we should change clothes more often to protect your skin. Let's get you into something fresh.

or

I spilled something on your trousers earlier – that was my fault. Let me grab you clean ones.

Accept the blame. Invent a reason. Protect their dignity. This is not lying – it is redirecting a person whose brain cannot process the truth without shame-spiraling.

Step 2: *If they resist:*

That's fine. No rush. How about we just wash your hands and face for now? I'll set the clean clothes right here for when you're ready.

Don't push. The change will happen. Often, once you've stepped away, they'll change on their own or forget why they were resisting.

Step 3: *During the change, be matter-of-fact.*

Warm water. Gentle wipes. Clean clothes laid out in order. Talk about anything OTHER than what you're doing – the weather, a memory, what's for dinner. Your tone is the intervention. If your voice says "this is normal," their brain accepts it as normal.

Let's get you comfortable. There we go. That feels better, doesn't it?

SCENARIO 2: They Are Hiding Soiled Clothing or Incontinence Products

What's happening: This is almost always shame-driven. They know (or knew in the moment) that something was wrong. They tried to manage it. Hiding the evidence is the only problem-solving strategy their brain could generate. In earlier stages, this may be deliberate concealment out of embarrassment. In later stages, they may have simply put the soiled item "away" the way they'd put away anything – in a drawer, under a pillow, in a cupboard.

What NOT to do:

- Don't confront them with the hidden item
- Don't say: "Why did you put this here?" / "This is disgusting" / "You need to tell me when this happens"
- Don't react with visible disgust when you find it
- Don't leave them unsupervised while you process your revulsion – handle your reaction later

WHAT TO DO

Step 1: *Remove the soiled items without comment.*

If they see you find it, do not react. Pick it up as if it were a normal piece of laundry.

Oh, I was looking for things to put in the wash. I'll take this.

Step 2: *Make the hiding unnecessary.*

The goal is not to stop them from soiling, since that may be beyond their control. The goal is to create a system where they don't need to hide it.

Environmental tips:

- Place a lidded bin in every room they spend time in – bedroom, bathroom, living room. Line it with a bag. If they have somewhere obvious to put a soiled item, they're less likely to hide it in a drawer
- Replace regular underwear with pull-up incontinence underwear as part of the daily dressing routine. Don't ask permission – just have them ready as the only option in the drawer. Never call them "nappies" or "diapers." They're just "underwear" or "fresh pants"
- Put dark-coloured washable covers or pads on chairs, beds, and car seats. This reduces visible evidence, which reduces shame, which reduces hiding
- Check known hiding spots discreetly during your daily routine – under pillows, in drawers, behind furniture, inside bags, in pockets of hanging clothes

Step 3: *If the hiding is frequent, talk to their physician.*

Frequent soiling may indicate constipation with overflow, a medication side effect, infection, or a need for prompted toileting on a schedule. This is a medical conversation, not just a behavioural one.

SCENARIO 3: Fecal Smearing (Scatolia)

What's happening: Research consistently links scatolia to constipation, discomfort, sensory-seeking due to understimulation, insomnia, and loss of the brain's ability to understand what feces is or what to do with it. They may be trying to remove something that feels wrong on their skin. They may be responding to a sensory need. They may not understand what they are touching. Reacting with anger or horror may increase frequency and severity.

What NOT to do:

- Don't scream, gag visibly, or express disgust in front of them
- Don't punish, scold, or say "No!" – this registers as a threat and escalates agitation
- Don't try to clean them and the environment at the same time – person first, then environment

WHAT TO DO

Step 1: *Breathe. Put on gloves.*

You have time. Nothing about this moment requires you to move fast. Moving fast creates urgency in your body language, which they will mirror with agitation. Slow is fast here.

Step 2: *Approach calmly. Address the person, not the mess.*

Hey **[Name]**. Let's get you cleaned up. Come with me.

Extend your hand. Lead them to the bathroom. Do not reference the feces, the wall, the bedding, or anything they've touched. Your only job right now is getting them clean.

Step 3: *Clean them with warm water, gentle wipes, and calm narration.*

We're just going to wash your hands. That's it. Nice warm water. There we go.

Talk them through it the way you'd narrate for a child – not condescendingly, but soothingly. "Now your arms. Good. Now let's do a fresh change. You're doing great."

Step 4: *Once they are clean and settled in a safe space, then deal with the environment.*

Dispose of soiled items in sealed bags. Clean hard surfaces with soap and vinegar solution (half tablespoon dish soap, one tablespoon white vinegar, two cups water). Use enzyme-based cleaners on soft furnishings. Open windows. Use an odour-neutralising spray – not air freshener (that just masks it).

Step 5: *Contact their physician.*

Report the behaviour. Ask specifically about:

- Constipation (the most common treatable cause)
- Medication side effects
- Sleep disturbance (scatolia is strongly correlated with insomnia)
- Whether a prompted toileting schedule might help
- Whether a bowel management regime is appropriate

PREVENTION STRATEGIES:

- **Address constipation aggressively.** Adequate fibre, hydration, and movement. Discuss a bowel regime with their physician. Studies show that when constipation is resolved, scatolia frequently stops
- **Prompted toileting.** Take them to the bathroom at regular intervals – every 2-3 hours during waking hours, and immediately after meals. Don't ask "Do you need the toilet?" (they'll say no). Instead, say: "Let's go to the bathroom before we **[next activity]**"
- **Manage access.** Clothing that is harder to remove independently – onesie-style undergarments, back-zip jumpsuits, overalls – buys you time to respond before they can reach a soiled area. This is not about restricting them. It is about creating a window for intervention
- **Provide sensory alternatives.** If smearing appears to be sensory-driven, offer things to hold, squeeze, and manipulate – soft cloths, stress balls, putty, textured blankets. Meet the sensory need with a non-harmful substitute
- **Check for insomnia.** Night-time smearing is frequently linked to disordered sleep. If they are awake and under-stimulated at 3 AM with a soiled incontinence product, their brain will "solve" the discomfort with the only tool it thinks is available. Treating the sleep problem can reduce the smearing

SCENARIO 4: What to Do With Yourself After Cleanup

What just happened to you is not normal caregiving. Cleaning human feces off a wall, out of a carpet, or off another adult's body is biohazard management. The fact that it happened in your home, by someone you love, does not make it less traumatic.

What you may feel:

- Nausea — physical, lasting, sometimes triggered hours later by an unrelated smell
- Rage — at them, at the disease, at every sibling who isn't here
- Disgust — followed immediately by guilt for feeling disgusted by someone you love
- Grief — for the person your loved one used to be
- Numbness — because you can't afford to feel any of it
- The urge to cry, scream, or walk out the front door and keep walking

All of these are normal. None of them mean you are failing.

WHAT TO DO:

- **Wash yourself.** Not a quick hand rinse. A proper wash. Hot water, soap, clean clothes. This is decontamination and it is also a psychological reset. The smell lingers on skin and clothing and can keep retriggering the stress response until you remove it
- **Open every window.** The odour in the house can be a constant sensory reminder of the trauma, so get it out
- **Eat something.** Your body just ran a stress response. Your blood sugar is likely crashed
- **Call someone.** Not to ask for help (though do that too). Call someone who will listen to you say: "I just spent forty-five minutes cleaning feces off the bedroom wall, and I need to say that out loud to another human being." You need a witness. The isolation of this experience is what makes it psychologically damaging
- **Do not make permanent decisions in this moment.** This is not the moment to decide about facility placement, about ending the caregiving arrangement, about anything. Those may be the right decisions, but make them on a day when you haven't been through a biohazard event. Give yourself 48 hours

WHAT TO SAY TO YOURSELF:

- I didn't sign up for this. I'm doing it anyway, and I'm allowed to hate it while I do it.
- This is the disease. This is not who they are. My disgust is not disloyalty. It is biology.
- I can love them and be revolted by what this disease does, both at the same time.
- Asking for help is not giving up. It's the only way I survive to keep doing this.

IMPORTANT: If scatolia or severe incontinence behaviours are occurring regularly, this is a medical issue requiring professional assessment. Do not try to manage this alone indefinitely. Speak with their physician about:

- A bowel management regime
- Medication review
- Sleep assessment
- Whether the current level of home care is sustainable
- Whether increased professional support or facility placement should be discussed

Scatolia is one of the most commonly cited reasons for caregiver breakdown and transition to residential care. If you are approaching that point, you are not abandoning anyone. You are recognising the limits of what one human being can safely manage. Know the difference between giving up and reaching the end of what home care can provide.

Inappropriate Sexual Behaviour (ISB) – De-Escalation, Boundary, and Caregiver Survival Script

DISCLAIMER: This script provides communication language and practical guidance for caregivers managing sexually inappropriate behaviour in a person with cognitive decline. It does NOT provide clinical assessment, behavioural intervention protocols, or legal advice. Inappropriate sexual behaviour in dementia is a recognised medical symptom requiring professional evaluation. Always report new or escalating ISB to the person's physician. Any physical intervention or environmental restriction must comply with local laws and care regulations, particularly in professional or facility settings. If your loved one's behaviour involves unwanted sexual contact with another person (i.e. another resident in a care facility, a paid caregiver, a visitor, a stranger, or a child) this may have legal implications regardless of their cognitive status. Consult with their physician and, if necessary, a lawyer specialising in elder care and capacity matters. Protecting other people from harm is not optional, even when the person causing harm is a loved one. If ISB includes physical aggression, forceful grabbing, or any situation where you or another person feels physically unsafe, leave the room or create distance immediately. Your safety comes first. Address the behaviour after you are safe, not during.

This is the section nobody wants to read, and nobody wants to admit they need. If you're here, you are likely dealing with one of the most humiliating, confusing, and isolating aspects of dementia caregiving – watching someone you love say things, do things, or touch people in ways that are completely out of character.

This is not who they are. It's what the disease does to the parts of the brain that control impulse, social awareness, and the filter between thought and action. The frontal and temporal lobes (the parts for "this is not the time or place") are damaged. The resulting behaviour looks deliberate but isn't. They are not choosing this any more than they are choosing to forget your name.

That said, understanding why it happens does not mean you have to tolerate it in silence, accept it without boundaries, or manage it alone.

ISB in dementia can include:

- Sexual comments, propositions, or explicit language directed at caregivers, family members, visitors, or strangers
- Grabbing, groping, or touching others' bodies inappropriately
- Public masturbation or genital exposure
- Undressing in inappropriate settings
- Mistaking a caregiver or family member for a romantic/sexual partner
- Persistent sexual advances toward a spouse who does not want them
- Sexual behaviour directed at other residents in a care facility

What ISB is often actually about (the hidden causes):

Not all ISB is sexual. Before you respond, consider whether it might actually be:

- **Discomfort or a toileting need** – They may be touching themselves because they need the bathroom, have a skin irritation, a urinary tract infection, or clothing that's bothering them. This is the most commonly missed cause
- **Undressing because they're hot, confused, or can't manage their clothing** — Not exhibitionism; simply executive function failure
- **Loneliness and the need for physical comfort** – Touch, closeness, and warmth. The sexual expression may be the only language their brain can still produce for "I need to feel connected"
- **Boredom and understimulation** – Idle hands and an under-engaged brain will find something to do
- **Misidentification** – They may genuinely believe you or a caregiver is their spouse, a past partner, or someone from an earlier time in their life
- **Medication side effects** – Benzodiazepines, dopamine agonists, and certain other medications can worsen disinhibition. Review their medication list with their physician
- **Frontotemporal dementia** – ISB is significantly more common in FTD than in other dementias, because FTD specifically attacks the brain's impulse-control systems

This script covers four scenarios:

1. Sexual comments or propositions
2. Inappropriate touching of others
3. Public masturbation or exposure
4. Unwanted sexual advances toward a spouse/partner

SCENARIO 1: Sexual Comments or Propositions

What's happening: The social filter is gone. The thought-to-mouth pathway has no checkpoint. They may say things to you, to paid carers, to strangers, to medical staff – things they would have been mortified by before the disease.

What NOT to do:

- Don't laugh or play along – this can reinforce the behaviour
- Don't react with shock or visible disgust – strong emotional reactions can either escalate or reinforce
- Don't lecture or explain why it's inappropriate – they may not retain it, and shame does not teach a damaged brain
- Don't take it personally – even when it's directed at you

WHAT TO SAY

If directed at you:

Calm, neutral tone. Brief. Then redirect.

That's not something we say to each other. Let's go and **[activity]** – I could use your help.

Do not dwell. Do not explain further. Move the moment forward.

If directed at a paid caregiver:

Intervene immediately. Address the caregiver first, then your loved one.

To the caregiver: I'm sorry. This is the disease – it's not personal, and it's not acceptable. I'll handle it.

To your loved one: [Name], that's not okay. Come with me.

Redirect to another room, another activity. A physical change of space breaks the loop.

If directed at a stranger or in public:

We're okay, thank you – **[he/she]** has a memory condition. I apologise for what was said.

To your loved one, quietly:

Let's go this way. I want to show you something.

Redirect. Leave the environment if possible. Do not scold in public – it can escalate agitation without achieving anything.

PREVENTION

If sexual comments are a recurring pattern, identify when they happen most. During personal care? When a specific person is present? At a certain time of day? Patterns reveal triggers. A care journal helps.

SCENARIO 2: Inappropriate Touching of Others

What's happening: This is the behaviour that most commonly causes paid caregivers to quit, other residents to be at risk, and families to be asked to find alternative care arrangements. It must be addressed – not tolerated, not ignored, not excused with "they don't know what they're doing." While it may be true, the other person's safety and comfort still matter.

What NOT to do:

- Don't ignore it because you're embarrassed
- Don't hit or slap their hand away – this can provoke aggression
- Don't physically restrain unless there is an immediate safety threat
- Don't assume the person being touched is okay with it – check in with them

WHAT TO DO

Step 1: *Interrupt calmly and physically reposition.*

[Name], let's move your hands here.

Gently take their hand and redirect it – to their own lap, to an object, to a different activity. Do not grab. Guide.

Step 2: *Create physical distance.*

Come sit with me over here. I want to talk to you about something.

Move them away from the person they were touching. A change of location often resets the behaviour.

Step 3: *Give their hands something to do.*

This is one of the most effective non-drug interventions. Provide something to hold, squeeze, fold, or manipulate: a stress ball, a soft cloth, a fidget object, a piece of clothing to fold. Occupied hands cannot grab.

Step 4: *Check in with the other person.*

I'm sorry that happened. Are you alright? That behaviour is caused by the disease, and I take it very seriously.

If touching is directed at paid caregivers during personal care:

- Professional attire (scrubs) can reduce the perception of intimacy during care tasks
- Two carers present during bathing, dressing, or toileting can reduce risk
- Same-gender caregivers may (or may not) reduce the behaviour – worth testing
- Clear, task-focused narration during care ("I'm going to wash your left arm now") keeps the interaction clinical rather than ambiguous

SCENARIO 3: Public Masturbation or Exposure

What's happening: They may not know they are in public. They may not recognise that what they are doing is visible to others. They may be responding to discomfort, a toileting need, a skin irritation, or a medication side effect. Or the frontal lobe damage may have simply removed the understanding that this is a private act.

What NOT to do:

- Don't shout – this draws more attention and can cause a reaction
- Don't grab their hands or physically force them
- Don't assume it's sexual – check for physical causes first

WHAT TO DO

Step 1: *Shield first, redirect second.*

Step between them and any audience. Use a blanket, a coat – anything to create a visual barrier. This protects their dignity and buys you time.

Step 2: *Offer a calm redirect.*

Let's go to the bathroom – I think you might be more comfortable in there.

or

Here, put this on – you look cold.

Hand them a blanket, a jacket, or clothing. Covering the exposed area often stops the behaviour because the stimulus changes.

Step 3: *Check for physical causes.*

Once in private, check:

- Is there a rash, irritation, or skin issue in the genital area?
- Do they need the toilet? Are their clothes uncomfortable, too tight, or wet?
- Have they had a recent medication change?

If no physical cause is found and the behaviour recurs, report to their physician.

PREVENTION:

- **Clothing modifications.** Back-fastening clothes, belts that are harder to undo, onesie-style undergarments – these all create a physical barrier that buys time and reduces access
- **Provide private time and space.** If the behaviour is genuinely sexual and not discomfort-driven, some professionals recommend allowing private time in their own room where the behaviour can occur without causing harm to others. This is a complex decision and should be discussed with their physician
- **Reduce boredom.** Understimulation is a consistent trigger. More activity and more engagement = more things for their hands and mind to do

SCENARIO 4: Unwanted Sexual Advances From a Spouse/Partner

What's happening: Your spouse is making sexual demands or advances that you do not want, that feel aggressive, that may come from a person who no longer fully recognises who you are or what your relationship is. They may believe you are someone else. They may be insistent, agitated, or angry when refused.

What NOT to do:

- Don't comply out of obligation, guilt, or fear – you have the right to say no, always, regardless of their condition
- Don't feel guilty for finding their advances distressing – your feelings are valid
- Don't engage when they are agitated – an agitated advance can escalate to aggression

WHAT TO SAY

If the advance is gentle and you want to redirect:

I love you. But not right now. How about we **[sit together / hold hands / watch something together]**?

Offer an alternative form of closeness that meets the need for intimacy without sexual contact.

If the advance is insistent or you feel uncomfortable:
I need to step out for a minute. I'll be right back.

Leave the room. You do not have to explain, justify, or negotiate. Remove yourself. The behaviour will often reset in your absence.

If the advance becomes aggressive or frightening:

[Name], stop. I need you to stop.

Firm, clear, low voice. Then leave the room immediately. Lock the door behind you if necessary. Call someone – a family member, their physician, or emergency services if you feel physically at risk.

WHAT TO DO WITH YOURSELF AFTER ANY ISB EPISODE

What you may feel:

- Revulsion — at the behaviour, at the person, at the disease
- Shame — that this is happening in your family, that your loved one is "that person"
- Guilt — for feeling disgusted by someone you love
- Grief — because the person who said that, did that, grabbed that — is not the person you knew
- Fear — especially if the behaviour was aggressive, especially if you are their spouse
- Isolation — because this is the one thing you cannot tell anyone at the support group, at the dinner table, at the school gates

All of these are normal. None of them are your fault.

WHAT TO DO:

- **Tell their physician. Every time.** ISB is a medical symptom. It needs to be documented, assessed for treatable causes (medication review, infection, pain, depression), and managed with a professional care plan
- **Tell the truth to someone.** A therapist, a specialist support line, a trusted friend. Say the words out loud. The power of the shame diminishes when you say it to a person who doesn't flinch
- **Protect yourself and others.** If the behaviour puts anyone at risk it must be addressed even if the person cannot understand why. Their dignity matters, but so does everyone else's safety
- **Know that this is one of the top reasons caregivers reach their limit.** ISB is one of the most commonly cited reasons for transition to residential care. If you are approaching that decision, you are not abandoning your loved one. You are recognising a situation that has exceeded what one person can safely manage at home

SELF-TALK FOR THE DEMENTIA CAREGIVER

The emotional landscape of dementia caregiving is different. These reframes address the specific grief, guilt, and exhaustion of watching cognitive decline.

MENTAL HEALTH DISCLAIMER

This section provides reframing language for common dementia caregiver thought patterns. It is NOT therapy, clinical treatment, or a substitute for professional mental health care.

Dementia caregivers are at significantly elevated risk for depression, anxiety, and physical health deterioration. If you are experiencing symptoms beyond normal caregiver stress, such as persistent hopelessness, inability to function, thoughts of self-harm, or substance use to cope, please contact:

- **988 Suicide & Crisis Lifeline:** Call or text 988
- **SAMHSA National Helpline:** 1-800-662-4357
- **Alzheimer's Association 24/7 Helpline:** 1-800-272-3900
- **Your own physician or therapist**

These reframes are for the daily emotional weight of dementia caregiving. They are not a substitute for professional help.

THE AMBIGUOUS GRIEF: "I've Lost Them But They're Still Here"

Thought pattern: My loved one is sitting in front of me, alive — but they're not the person I knew. I'm grieving someone who isn't dead. I don't know if I'm allowed to feel this.

What this is: Researchers call this "ambiguous loss." The person is physically present but psychologically absent — or increasingly so. There is no funeral, no closure, no casseroles from neighbors. You are mourning in slow motion, alone, while continuing to provide care to the person you're mourning.

Reframe Script (To Yourself)

Old thought: "I can't grieve — they're not dead. I should be grateful they're still here."

New thought: "I am grieving. And that grief is valid even though they are still alive.

I'm grieving the conversations we can no longer have. The relationship that used to go both ways. The person who knew my name, my history, my life.

That person is disappearing — and I am allowed to mourn that disappearance even while I show up every day for the person who remains.

I can hold two truths at once: I love the person in front of me AND I grieve the person they used to be. Both are real. Both deserve space."

Daily practice: Name one thing you lost today — even small: "Today, she didn't remember my kids' names." Sit with it for 60 seconds. Don't fix it, don't justify it, don't push it away. Then continue your day.

Permission statement: "I am allowed to grieve someone who is still alive. This is not disloyal. This is honest."

THE REPETITION BURNOUT: "I Can't Answer This Question One More Time"

Thought pattern: They've asked me the same question 30 times today. I know I should be patient. I know they can't help it. But I want to scream. Then I hate myself for wanting to scream at someone with a brain disease.

Reframe Script (To Yourself)

Old thought: "If I were a better person, this wouldn't bother me. I'm terrible for being frustrated with a sick person."

New thought: "Hearing the same question 30 times is genuinely maddening. That's not a character defect – that's a normal human nervous system responding to repetitive stimulation.

[Name] asks because they can't remember. I'm frustrated because I CAN remember – every single time.

My frustration does not make me cruel. It makes me human. And humans need breaks from repetitive stress.

What I need: A break. Not permission. Not to be a better person. A break."

Daily practice: When the repetition anger spikes:

1. Breathe once.
2. Answer one more time in the same calm voice.
3. Then create a break: "I'll be right back." Walk to another room for 2 minutes.
4. Return.

That's it. Two minutes. It's enough to reset your nervous system.

Permission statement: "I'm allowed to walk away for 2 minutes without being a bad person."

THE ROLE REVERSAL: "I'm Parenting My Parent"

Thought pattern: I'm bathing them, feeding them, dressing them, managing their medications, making their decisions. This is not how it's supposed to be. I was their child. Now I'm their everything.

Reframe Script (To Yourself)

Old thought: "This isn't fair. I shouldn't have to parent my own parent. I still need a parent."

New thought: "This IS unfair. It's a profound loss – the loss of the person who was supposed to take care of me, or at least stand beside me as an equal.

I'm doing something extraordinary: providing care for the person who once provided care for me. That doesn't erase my grief at losing the parent-child relationship. Both exist at the same time.

I can mourn the parent I lost while caring for the person they've become. Those aren't contradictory. They're the truth of this disease."

Daily practice: Find one moment each day where you connect with who they WERE, not just who they are now. A song they loved. A phrase they used to say. A food they always made. Hold it briefly. Then return to the present.

Permission statement: "I'm allowed to miss my parent while caring for my parent. Those aren't the same person anymore – and pretending otherwise doesn't help either of us."

THE GUILT OF RELIEF: "Part of Me Wishes This Were Over"

Thought pattern: Sometimes I catch myself thinking "I wish this were over." And then I'm horrified — because "over" means they're dead. What kind of person wishes their loved one were dead?

Reframe Script (To Yourself)

Old thought: "I'm a monster for wishing this were over. Something is deeply wrong with me."

New thought: "I'm not wishing for **[Name]**'s death. I'm wishing for the end of suffering — theirs AND mine.

I'm exhausted. I've been grieving for **[months/years]**. I've watched the person I love disappear piece by piece. I'm allowed to want the pain to stop.

Wishing for relief is not the same as wishing for death. And even if the thought crosses my mind in a dark moment — a thought is not an action. It's a signal that I've reached my limit.

What I actually need: more support, more rest, more help. Not more guilt."

Daily practice: When the relief-guilt hits:

1. Name it: "I'm having the relief thought again."
2. Don't judge it: "This thought exists because I'm exhausted."
3. Redirect: "What do I need right now? A break? A call to a friend? To cry?"

Permission statement: "I'm allowed to be tired of this without being a bad person. Exhaustion is not cruelty."

THE ISOLATION: "Nobody Understands What This Is Like"

Thought pattern: My friends don't get it. My siblings don't see it. My spouse is sympathetic but doesn't really understand. I am completely alone in this.

Reframe Script (To Yourself)

Old thought: "No one gets it. I'm totally alone."

New thought: "The people around me may not understand the specific weight of dementia caregiving. That's true.

But I am NOT the only person going through this. Right now, millions of people are answering the same question for the 30th time, cleaning up the same mess, lying awake listening for the same footsteps down the hall.

I am not alone in this experience. I'm alone in my house.

What I need is not for my current circle to magically understand. What I need is to find people who already do."

Daily practice:

- Find one dementia-specific support group — online or in-person. The Alzheimer's Association (alz.org) has options in every state. So does the Family Caregiver Alliance.
- Connect with one person who is also in this. You don't need a crowd. You need one person who says "I know" and means it.

Permission statement: "I'm allowed to seek out people who understand, even if my current circle doesn't. That's not disloyal. That's survival."

THE PERFECTION TRAP: "If I Were Better at This, They'd Be Better"

Thought pattern: If I were more patient, more creative, more present — maybe they'd decline slower. Maybe they'd be less agitated. Maybe I'm making this worse.

Reframe Script (To Yourself)

Old thought: "If I were a better caregiver, **[Name]** would be doing better."

New thought: "**[Name]**'s decline is caused by a progressive, incurable brain disease. Not by me.

I did not cause the disease. I cannot slow the disease. I cannot cure the disease. No amount of patience, love, or perfect caregiving changes the trajectory.

My job is not to stop the decline. My job is to keep **[Name]** as safe and comfortable as possible while it happens.

Some days I do that well. Some days I fall short. Both are true — and neither one changes the course of the disease.

The agitation, the confusion, the aggression — those are symptoms. Not grades on my performance."

Daily practice: When the "I'm not good enough" thought hits:

Write down: "Things I did for **[Name]** today."

Then write down: "Things that happened because of the disease today."

Notice which list is longer. Notice which list you have control over. Focus on that one.

Permission statement: "I am not the cause and I am not the cure. I am a person doing an impossibly hard job with the resources I have."

BONUS REFRAME: Permission List for the Dementia Caregiver

When to use: When dementia-specific guilt is overwhelming. Read this list out loud when you need to hear it.

I give myself permission to:

✓ Not correct them when they're wrong about reality
✓ Walk away for 2 minutes when I've answered the same question 30 times
✓ Grieve my loved one while they're still alive
✓ Feel relieved when they're sleeping peacefully
✓ Hate the disease without hating the person
✓ Acknowledge that this is harder than anyone who hasn't done it can imagine
✓ Choose facility placement without choosing failure
✓ Have a life outside of caregiving, even a small one
✓ Laugh on the days when something absurd happens
✓ Cry on the days when the person I knew briefly reappears and then vanishes again
✓ Accept help from imperfect sources
✓ Stop explaining myself to people who don't understand
✓ Put my own health appointments on the calendar and keep them
✓ Be angry at siblings who won't help, even if their avoidance is driven by fear
✓ Love this person AND be unable to do this anymore at the same time

These permissions are not conditional on:

- Doing "enough" first
- Others being comfortable with your choices
- Other family members agreeing
- Being at the end of your rope (you don't have to hit bottom to deserve a break)

They are yours by virtue of being a human doing work that most people can't even imagine.

Situational Scripts

SIBLING WON'T HELP

> **Before you start:** Have you had a calm, direct conversation about what you need? If not, start at Level 0. Escalate only after gentler approaches have failed.

Level 0: Gentle First Ask

When to use: First time raising the issue. You want to preserve the relationship. Your sibling may not realize how much you're carrying.

Emotional prep: This may feel awkward. That's normal. You're not being demanding—you're being honest.

Opening the Conversation — Collaborative Invitation Script

Hey, I wanted to talk about **[Name]**'s care. Not a crisis—just want to get on the same page.

I've been handling most of **[the daily stuff / medical appointments / coordination]**, and I'm starting to feel the weight of it.

I'm not asking you to match what I'm doing. But I could really use some help with **[specific task]**.

Would you be able to **[specific ask]**? Even once a month would make a difference.

Let me know what works for you.

What to expect after:

- Best case: They say yes and follow through
- Likely case: They agree vaguely but don't follow through
- Possible case: They get defensive or make excuses

If they agree: Great. Give it 2-4 weeks to see if they follow through.

If they get defensive: Don't argue. Say: "I hear you. Think about it and let me know." Then wait.

If nothing changes in 2-4 weeks: Move to Level 1.

Acknowledging Their Life — Adjusted Ask Script

I know you've got a lot going on with **[their situation]**.

I'm not asking you to drop everything.

But **[Name]** needs **[X]**, and I can't do all of it myself.

What's one thing you could take on that would fit your schedule?

Even **[small specific task]** would help.

What to expect after:

- This gives them agency to choose, which increases buy-in
- If they choose something, hold them to it
- If they can't think of anything, suggest 2-3 options

Level 1: Clear Request

When to use: You've had one casual conversation. They agreed vaguely or made excuses. Nothing changed. Time to be more specific.

Emotional prep: This is harder. You're moving from "would be nice" to "I need this." That's allowed.

Specific Need with Timeline — Direct Request Script

I want to follow up on our conversation about **[Name]**'s care.

Right now, I'm covering **[specific responsibilities]**. It's been **[duration]** like this.

I need help with **[specific task]**.

Can you commit to **[specific task + frequency]** starting **[date]**?

If that doesn't work, let me know what would work and when.

I need to know by **[deadline — give them 3-7 days]** so I can plan.

What to expect after:

- They may agree (test whether they follow through)
- They may counteroffer (consider it if reasonable)
- They may say no outright (at least you have clarity)
- They may ignore the deadline (that's information too)

If they follow through: Express genuine appreciation. Reinforce the behavior.

If they don't: Move to Level 2.

Level 2: Firm Boundary

When to use: You've asked clearly at least twice. They've agreed and flaked, or they've ignored you. Pattern is established. Time for explicit boundary with consequences.

Emotional prep: This will feel confrontational. It's not. It's clarity. You're entitled to clarity.

Pattern Acknowledgment — Accountability Script

I've asked you **[number]** times to help with **[Name]**'s care.

[Date]: I asked for **[X]**. You said **[their response]**. **[What happened]**.

[Date]: I asked again. You said **[their response]**. **[What happened]**.

I can't keep having the same conversation.

Here's what I need going forward:

Option A: You commit to **[specific task + frequency]**, starting **[date]**. I need this in writing (text or email is fine).

Option B: You contribute $**[amount]** per month toward paid help. First payment due **[date]**.

If you can't do either, I need you to tell me directly so I can stop expecting help from you and plan accordingly.

I need your answer by **[deadline]**.

What to expect after:

- Guilt trips ("I have my own life")
- Defensiveness ("You're keeping score")
- Counter-accusations ("You chose to be the one who does everything")
- Silence

How to respond:

- Guilt trips: "I understand. I still need to know which option you're choosing."
- Defensiveness: "I'm not keeping score. I'm telling you what I need."
- Counter-accusations: "That's not what this conversation is about. Which option works for you?"
- Silence past deadline: Treat as "no" and proceed accordingly.

After the deadline: If no response, move to Level 3.

Level 3: Binary Choice

When to use: All gentler approaches have failed. You need to force a decision. You are ready and willing to enforce the consequences.

Emotional prep: This will likely damage the relationship in the short term. That's the price of protecting yourself. If you're not ready for that, wait until you are.

Do not send this script if you won't follow through.

Binary Choice — Time or Money Script

[Authority] reviewed **[Name]**'s **[care log/medical status/safety assessment]**.

[He/She] said **[specific medical/safety risk]**.

We need **[specific change]** starting **[day of week + date]**.

I've **[concrete preparation action]**.

If you can't **[specific time commitment]**, here's the alternative: **[service name] —** $**[amount]**/**[hour/day/week]**, we split the **[invoice/bill/monthly cost]**.

Let me know by **[deadline — day + time]**: your time or your money?

What to expect after:

- Peak resistance in first 24-48 hours
- Possible explosion, guilt trip, or silent treatment
- They may test whether you'll actually enforce this
- Some siblings capitulate; some disengage entirely

How to respond to pushback:

- "You're being unreasonable" → "I understand you feel that way. I still need an answer by [deadline]."
- "I can't believe you're doing this" → "I'm doing what I need to do to keep caring for [Name]. Which option works for you?"
- Silence → Treat as "no" after deadline. Proceed with paid help and split the bill.

If they don't pay their share: You may need to decide whether to pursue it (see Escalation scripts) or let it go.

Non-Negotiable Boundary Statement

Use this when they challenge your boundary after you've stated it.

I understand this is hard to hear.

I'm not asking for permission—I'm telling you what I need to keep showing up for **[Name]** long-term.

This isn't negotiable.

Level 3 Variants by Situation

All variants follow the same structure. Use Level 0-2 first when possible.

Sibling Promises But Doesn't Follow Through — Accountability Script

When to use: They've said yes multiple times but never show up. Level 2 didn't work.

You agreed to **[specific commitment]** on **[date]**.

When you didn't show, **[concrete consequence]**.

From now on, I need a different system.

Either you commit to **[specific time contribution]** and I verify it with **[verification method]**, or you contribute $**[amount]**/**[month]** for hired help.

If you commit to time and don't show twice, we switch to the financial option automatically.

Which one?

Sibling Criticizes How You Provide Care — Deflection Script

When to use: They won't help but have opinions about how you should help.

You're welcome to have opinions about **[Name]**'s care.

If you want input on decisions, here's what that looks like: **[specific time contribution]** so you're working with the same information I have.

Or, contribute $**[amount]**/**[month]** toward hired help, and we'll both step back from daily decisions.

If you're not willing to do either, I'm not debating care choices with you.

Let me know by **[deadline]** if you want to contribute.

Sibling Wants Input But Won't Do Work — Forced Trade Script

When to use: They want to make decisions without doing any of the work.

I'm managing **[number]** hours of care per week.

Decision-making authority goes to people doing the work.

If you want equal voice in **[Name]**'s care decisions, commit to equal time: **[number]** hours/**[week/month]** of direct care, starting **[date]**.

If you can't do the time, you can contribute $**[amount]**/**[month]** for hired help—but that's financial support, not decision-making input.

I'll update you on major medical changes either way, but day-to-day care decisions are mine unless you're doing equivalent work.

Which are you choosing?

Multiple Siblings All Avoiding — Group Allocation Script

When to use: You have multiple siblings and none are contributing.

[Name] requires **[number]** hours of care per week.

Right now I'm covering all of it.

There are **[number]** of us.

That's **[hours per person]** hours/**[week/month]** per person, or $**[amount per person]**/**[month]** if you can't do time.

[Sibling 1 name]: Will you commit to **[hours]** hours/**[time period]** or $**[amount]**/**[month]**?

[Sibling 2 name]: Will you commit to **[hours]** hours/**[time period]** or $**[amount]**/**[month]**?

[Continue for each sibling]

I need responses from everyone by **[date + time]**.

If I don't hear from you, I'm proceeding as if your answer is "no" and adjusting my own availability to match what I can sustain, which is **[reduced hours]** hours/**[week/month]**.

That means **[Name]** will need **[specify consequence]**.

Weekend Respite — Binary Choice Script

[Therapist/Doctor name] reviewed my burnout assessment.

[He/She] said continuous care without breaks creates health risks for me and unsafe care for **[Name]**.

I need **[frequency]** off, starting **[specific date]**.

I've contacted **[respite care service]**.

If you can't cover **[specific days/hours]**, here's the alternative: **[Service name]** — $**[amount]**/**[weekend/day]**, we split the cost.

Let me know by **[day + time]**: your time or your money?

Medical Appointment Transport — Binary Choice Script

[Name] has **[number]** medical appointments in **[time period]**: **[list dates if possible]**.

I can cover **[number]** of them.

For the remaining **[number]** appointments, I need you to either:

Transport **[Name]** yourself (includes: driving there, waiting during appointment, driving home — approximately **[hours]** total per appointment),

OR

Pay for **[medical transport service]** — $**[amount]**/**[trip]** roundtrip, total $**[total cost for remaining appointments]**, we split it.

Let me know by **[day + time]**: your time or your money?

Equipment Purchase — Binary Choice Script

LEGAL NOTE: Family members generally have no legal obligation to contribute to another adult's care costs unless they have signed a written agreement, are designated as financially responsible by court order, or are subject to filial responsibility laws (which exist in some states but are rarely enforced). This script describes how some caregivers communicate boundaries about their own participation—it does not create legal obligations for others. Only request financial contributions you are legally entitled to request, and never represent an obligation that has not been legally established. Consult an attorney if you need to pursue actual debt collection.

[Doctor/PT/OT name] prescribed **[equipment]** for **[Name]**.

Insurance covers $**[amount if applicable, or "nothing"]**.

Out-of-pocket cost: $**[amount]**.

This isn't optional—**[Name]** needs this for **[safety reason / mobility / medical necessity]**.

We're **[number]** siblings.

Your share: $**[amount divided by number of contributing siblings]**.

If you can't contribute by **[specific date]**, I'm proceeding with the purchase and you'll owe me $**[amount]** within **[payment deadline]**.

Venmo/Zelle: **[payment handle]**. Let me know by **[date]** if you're contributing.

Ongoing Service — Monthly Recurring Binary Choice Script

[Name] needs **[service]**.

[Authority] recommended **[service]** because **[reason]**.

Monthly cost: $**[amount]**.

I can cover **[your portion]**. Your share: $**[amount]**.

This is **ongoing monthly**, not one-time.

If you can't commit to $**[amount]**/**[month]** starting **[date]**, you need to provide **[equivalent time commitment]**.

Let me know by **[day + time]**: your time or your money?

Household Management — Daily Task Binary Choice Script

I'm managing **[X hours]** of hands-on medical care for **[Name]** per week.

I can't also do **[specific household tasks]**.

Starting **[date]**, you either:

Take over [specific tasks] — this means **[frequency]**,

OR

Pay for **[cleaning service / meal delivery / laundry service]** — $**[amount]**/**[week/month]**, we split the cost.

I've contacted **[service name]** — they start **[date]** if you choose the paid option.

Let me know by **[day + time]**: your time or your money?

Medication Management — Daily Supervision Binary Choice Script

[Doctor name] reviewed **[Name]**'s medication errors log.

[He/She] said **[Name]** requires supervised medication administration **[frequency]** to prevent **[consequence]**.

I can cover **[which doses you can cover]**.

For **[remaining doses]**, you either:

Administer medications yourself at **[specific times] [specific days]**,

OR

Pay for **[home health nurse / medication management service]** — $**[amount]**/**[visit or week]**, we split the cost.

Let me know by **[day + time]**: your time or your money?

Overnight Coverage — Sleep Safety Binary Choice Script

[Doctor/Care team] assessed **[Name]**'s overnight needs.

[He/She] said **[Name]** requires supervision overnight due to **[fall risk / wandering / medical monitoring / toileting needs]**.

I've been doing **[number]** nights per week for **[duration]**. I'm not sleeping enough to function safely.

Starting **[date]**, I need you to cover **[specific nights]**,

OR

Pay for overnight aide: **[Service name]** — $**[amount]**/**[night]**, we split weekly cost of $**[weekly amount]**.

Let me know by **[day + time]**: your time or your money?

Emergency Response — On-Call Rotation Binary Choice Script

[Name] has had **[number]** emergency situations in the past **[time period]**: **[briefly list]**.

I've responded to **all of them**.

Going forward, we need a rotation.

Starting **[date]**, you're on-call for emergencies **[specific schedule]**. This means your phone stays on and you respond within **[time]**.

OR

Pay for **[emergency monitoring service / on-call nursing service]** — $**[amount]**/**[month]**, we split it.

Let me know by **[day + time]**: your time or your money?

Sibling Lives Out of State — Remote Contribution Binary Choice Script

You live **[distance/location]** away. I understand you can't provide hands-on care.

That doesn't eliminate your responsibility to contribute.

[Name] needs **[X hours/week]** of care. I'm providing **[your hours]**.

You can contribute in these ways:

1. **Financial:** $**[amount]**/**[month]** toward paid care
2. **Remote tasks:** Medical billing, insurance appeals, scheduling, research (approximately **[hours/week]**)
3. **Periodic visits:** Cover **[number]** weekends per year so I can take breaks

If you choose remote tasks, I'll send you a task list by **[date]**.

If you choose financial contribution, payment is due **[frequency]** starting **[date]**.

Let me know by **[day + time]**: how are you contributing?

Sibling With Young Children — Adjusted Contribution Binary Choice Script

I know you have **[young children / childcare obligations]**.

I'm not asking you to provide **[X hours]** per week like I do.

But **[Name]** still needs help, and I can't be the only one contributing.

Adjusted options for your situation:

1. **Financial:** $**[reduced amount considering their situation]**/**[month]** toward care
2. **Kid-friendly tasks:** Bring **[Name]** groceries **[frequency]** — kids can come with you
3. **Scheduled relief:** Cover **[specific limited window]** — bring kids if needed

These are manageable with young children.

If none of these work, you need to explain what **will** work, not just that nothing works.

Let me know by **[day + time]**: which option?

Level 4: Consequence Implementation

When to use: They agreed to something (Level 2 or 3), then violated the agreement. Time to act.

Sibling Agrees Then Ghosts — Contract Enforcement Script

NOTE: The following is an example of how some caregivers choose to communicate boundaries. It is not a recommendation to pursue legal action, and users should consult an attorney before referencing courts, regulators, or legal remedies. Only request financial contributions you are legally entitled to request, and never represent an obligation that has not been legally established.

TO: [Sibling name]
RE: Enforcement of Care Agreement for [Name], Date: [Date]

On **[date]**, you agreed to **[specific commitment]**.

You provided **[what they did]** for **[duration]**, then stopped.

I've attempted to reach you **[number]** times:

- **[Date]**: **[method]** — no response
- **[Date]**: **[method]** — no response
- **[Date]**: **[method]** — no response

FINAL DEADLINE: [Date + time]

If you plan to resume your commitment, respond by **[deadline]** with:

1. **When you're resuming** (specific date)
2. **Confirmation** that you understand you're **[X weeks/months]** behind

IF NO RESPONSE BY DEADLINE:

1. I'm declaring you **in default** of our agreement
2. I'm hiring **[paid care service]** to cover what you committed to
3. **You will be billed** $**[amount]** for the hours/services I'm paying for that you agreed to provide

4. If you don't pay within **[payment deadline]**, I'm considering **small claims court** (*Note: Small claims procedures and limits vary by jurisdiction; research your local requirements*)

Alternative: If you can't do the original commitment, propose a revised contribution by **[deadline]**. But non-response is not an option.

[Your name]

Level 5: Relationship Redefinition

When to use: Repeated violations across multiple boundaries. Escalation levels exhausted. Relationship must fundamentally change.

See Escalation Follow-Up Scripts for Level 5 templates.

LOVED ONE DEMANDING IMMEDIATE RESPONSE

Before you start: Is this actually a crisis, or a pattern of manufactured urgency? If it's the first time, respond and set expectations for next time. If it's a pattern, escalate through levels.

Cognitive decline note: If your loved one has dementia, urgency demands are often anxiety-driven, not manipulative. Use redirection and environmental controls, not boundary scripts.

Level 0: Gentle First Ask

When to use: First time establishing communication boundaries. Loved one may not realize the impact of their calls.

Establishing Healthy Communication — Collaborative Script

I love staying connected with you.

I want to make sure I can be there when you really need me.

Can we figure out a rhythm that works for both of us? Maybe regular calls at **[suggested times]** so you know when we'll definitely talk, and I can be focused and present?

For real emergencies—like chest pain, a fall, or something urgent—call me anytime. I'll always pick up for those.

For other things, can you text me and I'll call you back when I can?

Let's try it for a week and see how it goes.

Level 1: Clear Request

When to use: You've established expectations but they're not being followed.

Communication Boundaries — Direct Request Script

I want to be here for you, and I also need to be able to **[work/be present with my family]**.

When you call multiple times for non-emergencies, I can't do either well.

Here's what I need:

For emergencies (chest pain, fall, can't breathe, severe pain): Call me immediately. I'll answer.

For everything else: Text me or call once, and I'll get back to you within **[timeframe]**.

Can we try this? It'll help me be more present when we do talk.

Level 2: Firm Boundary

When to use: Pattern is established despite clear requests. Need explicit rules.

Communication Boundaries — Formal Schedule Script

Going forward, here's our communication schedule:

Scheduled calls: [Specific times — e.g., "Tuesday and Saturday at 7 PM"]

Emergency calls: Anytime, but only for **[define emergency: chest pain, fall with injury, difficulty breathing, sudden severe symptoms]**

Non-emergency questions: Text me and I'll respond within **[24 hours / our next scheduled call]**

If you call outside scheduled times for non-emergencies, I won't answer. I'll call you back at our next scheduled time.

This isn't rejection. This is how I stay available to you long-term.

Level 3: Binary Choice

When to use: Gentle and clear approaches haven't worked. Ready to enforce consequences.

3 AM Crisis Call — Boundary Enforcement Script

I hear that you're **[upset/worried/uncomfortable]**.

If this is a medical emergency—**[specify emergency criteria: chest pain, difficulty breathing, fall with injury, severe bleeding]**—call 911 now. If it's not an emergency, I can help you between **[available hours]**.

For non-emergency needs overnight, **[alternative resource: e.g., "call the nurse hotline on your insurance card"]**. I'm going back to sleep now. I'll call you at **[specific morning time]**.

What to expect after:

- Guilt trip: "What if I die and you didn't come?"
- Anger: "I can't believe you're doing this to me"
- Testing: Calling back immediately

How to respond:

- Don't answer non-emergency calls during your off-hours
- Follow through with the morning call you promised

- If they claim emergency but it wasn't, address it in the morning

Loved one Demanding You Drop Everything — Forced Prioritization Script

I'm **[current obligation]** until **[specific end time]**.

If this is an emergency—**[specify emergency criteria]**—call 911.

If not, I'll call you back at **[specific time]**.

I can't leave what I'm doing right now for a non-emergency.

Loved one Refusing Paid Help — Ultimatum Script

When to use: Loved one wants only you, refuses professional help, and you cannot sustain current level of care.

I can provide **[number]** hours of care per **[week/month]**.

Beyond that, you need paid help or **[specific reduced service]**.

[Home care agency name] can cover **[days/hours]** for $**[amount]**/**[time period]**.

Or, I reduce my availability to what I can sustain: **[specific hours/days]**, and we find a different solution for the remaining time.

Which one?

Loved one Guilt Trip About "Abandonment" — Reframing Script

I know you feel abandoned when I **[set boundary]**.

Abandonment is leaving and not coming back. I'm **[specific ongoing commitment]**.

If I don't **[self-care action]**, I won't be able to keep showing up.

This isn't abandonment. This is how I stay.

Loved one Showing Up Unannounced — Drop-In Boundary Script

I love seeing you, but I can't accommodate unannounced visits.

When you show up without notice, **[specific impact]**.

New policy:

To visit my home: Call or text **[advance notice period]** ahead to check if I'm available.

I'll let you know if that time works. If it doesn't, we'll find an alternative time.

If you show up without notice: I may not answer the door, or I'll ask you to leave and reschedule.

This isn't punishment. This is respecting that I have a household to manage.

Loved one Demanding to Move In — Co-Residence Refusal Script

You're asking to move in with me.

That's not possible.

[Brief reason: "My home isn't set up for your care needs" / "It would put too much strain on my family" / "I need my own space to be able to keep showing up for you"].

Alternatives:

1. **You stay in your current home** with **[paid home care / modifications for safety]**
2. **Assisted living facility** closer to me — I can visit **[frequency]**
3. **Senior apartment or independent living** with services available

I will help you research and transition to one of these options.

But moving in with me is not an option I'm offering.

Loved one Demanding Daily Phone Calls — Communication Boundary Script

(Level 3 version of earlier script)

I want to stay connected with you.

I can't be on the phone **[multiple times per day / for hours each day]** while **[working / managing my household / caring for my children]**.

Here's our communication schedule going forward:

Scheduled calls: [Specific times]

Emergency calls: Anytime, but only for **[define emergency]**

Non-emergency questions: [Text me and I'll respond within 24 hours / Save them for our scheduled calls]

If you call outside scheduled times for non-emergencies, I won't answer. I'll call you back at our next scheduled time.

This isn't rejection. This is how I stay available to you long-term.

Loved one Manipulating Children — Triangulation Boundary Script

You're telling **[children names]** that **[specific things loved one is saying]**.

That stops now.

[Children] should not be in the middle of adult boundary issues.

If you have problems with my decisions, you talk to **me**, not to my children.

If this continues, **[consequence: reduced contact with children]**.

I'm protecting my children from emotional manipulation, even if it's coming from you.

Loved one Refusing Safety Modifications — Safety Ultimatum Script

WARNING: If your loved one is fully dependent on you for food, water, or hygiene, unilaterally reducing care may be considered "abandonment" or "neglect" under state law. If the home is unsafe but you cannot safely leave them alone, you may need to contact Adult Protective Services to report an "unsafe living environment" so the state can intervene/force placement.

You've fallen **[number]** times in the past **[time period]**.

[Doctor/PT name] recommended **[specific modifications]**.

You're refusing these modifications because **[loved one's stated reason]**.

Here's reality:

If you won't make your home safe, I can't provide care there. The liability and the likelihood of serious injury are too high.

Option 1: Install the recommended safety modifications by **[deadline]**. I've gotten quotes: $**[total cost]**. **[We split cost / You pay from your savings / Insurance may cover portion]**.

Option 2: Move to **[assisted living / safer housing]** where the environment is already modified for safety.

I will not keep showing up to a home where you're likely to get seriously hurt.

Which option do you choose?

Loved one Hoarding — Clutter Safety Intervention Script

WARNING: If your loved one is fully dependent on you for food, water, or hygiene, unilaterally reducing care may be considered "abandonment" or "neglect" under state law. If the home is unsafe but you cannot safely leave them alone, you may need to contact Adult Protective Services to report an "unsafe living environment" so the state can intervene/force placement.

Your home has **[specific hazards: blocked exits, fall risks, fire hazards]**.

I can't provide safe care in this environment.

If you fell, paramedics couldn't get to you quickly.

If there's a fire, you couldn't get out.

I can't navigate your home without injury risk.

Options:

Option 1: We declutter starting **[date]**. I'll help, or we hire **[junk removal service / professional organizer]** — cost approximately $**[amount]**. We focus only on **[specific areas]** to create safe pathways.

Option 2: You move to **[alternative housing]** where the environment is manageable.

Option 3: I reduce my visits to **[minimal frequency]** until the home is safe.

I understand this is hard. But I can't provide care in an unsafe environment.

Let me know by **[deadline]**: which option?

HOUSING AND LIVING SITUATIONS

> **Note:** These conversations are among the hardest. They involve loss of independence, identity, and often the family home. Gentler approaches first; escalate only when safety requires it.
>
> **Cognitive decline note:** If your loved one lacks capacity to understand risk, you may need guardianship to make these decisions. Consult an elder law attorney.

Level 0-1: Opening the Conversation

Starting the Housing Conversation — Collaborative Exploration Script

I've been thinking about the future—not because anything's wrong right now, but because I want to understand what matters to you.

If there ever came a time when this house became too much to manage, what would you want?

I'm not suggesting anything. I just want to know your preferences so we can plan together.

Level 2-3: When Safety Is at Risk

Loved one Refusing to Move from Unsafe Home — Facility Discussion Script

Your home has **[specific safety issues: stairs you can't manage, bathroom without grab bars, isolation from emergency services]**.

I understand you love this house. You've lived here **[duration]**.

But it's no longer safe for you to live here alone, even with my help.

We need to discuss options:

Option 1: Assisted Living Facility

- 24/7 support available
- No stairs/maintenance
- Social activities
- Cost: $**[amount]**/**[month]** (*Note: Costs vary significantly by location and level of care*)

Option 2: Senior Apartment (Independent Living)

- Your own apartment
- Services available if needed
- Typically one floor
- Cost: $**[amount]**/**[month]**

Option 3: Moving in with [Sibling Name] (if that's an option)

Option 4: Staying here with 24/7 paid care

- Cost: $**[amount]**/**[month]**
- Only if you can afford it

I can't keep you safe in this house with the level of care I can provide.

Let's visit **[number]** facilities this week. **[Day + time]** — I'll pick you up.

Loved one Wants to Drive Despite Unsafe — Car Key Boundary Script

You've had **[number]** accidents in the past **[time period]**.

[And/Or] You got lost driving to **[familiar location]**.

[And/Or] Your medications list **[driving impairment side effects]**.

[And/Or] [Doctor name] said you shouldn't be driving.

I understand this feels like losing independence.
But if you hurt yourself or someone else, I can't live with that.

Your options:

1. **Surrender keys voluntarily.** I'll arrange transportation: **[senior transport service / ride schedule / I drive you to planned appointments]**.
2. **I take the keys and disable the car.** Same transportation arrangements.
3. **I report to DMV** that you're unsafe to drive (I don't want to do this, but I will). (*Note: Procedures for reporting unsafe drivers vary by state/jurisdiction*)

You're angry. I understand. But I'm not letting you hurt yourself or someone else.

Which transportation option do you want?

(Note: Taking someone's property without their consent or legal authority may have legal consequences. Consult with an elder law attorney about proper procedures in your jurisdiction, which may include capacity assessments, guardianship, or DMV reporting procedures.)

Loved one Refusing Home Health Services — Service Acceptance Ultimatum

[Doctor name] ordered **[home health services]**.

Insurance is covering it.

You're refusing to let them in your home because **[loved one's stated reason]**.

Here's what I can't do:

- I can't provide **[skilled nursing care / proper PT / wound care to medical standards]**
- I'm not trained
- If something goes wrong, I'm liable

Your options:

Option 1: Accept the home health services. They come **[schedule]**. You let them in.

Option 2: You move to **[skilled nursing facility / rehab facility]** where these services are provided as part of the environment.

There is no Option 3 where you refuse medical services and stay home with me trying to substitute.

Let me know by **[deadline]**: which option?

FINANCIAL GUILT/PRESSURE

> **Note:** Financial conversations within families are loaded with history and emotion. Start gentle when possible.

Level 0-1: Opening Financial Conversations

Understanding the Financial Picture — Collaborative Script

I want to make sure we're planning well for your care.

Can we sit down together and look at your income, expenses, and what resources are available?

I'm not trying to take over—I just want to understand what we're working with so we can make good decisions together.

Would **[day/time]** work to go through things?

Level 2-3: Setting Financial Boundaries

Loved one Demanding Money — Financial Boundary Script

My monthly budget allows for $**[amount]** toward your expenses.

Beyond that, I don't have money to give.

If you need more than $**[amount]**/**[month]**, we need to:

1. **Review your expenses** to identify cuts
2. **Apply for assistance programs** (Medicaid, SNAP, utility assistance)
3. **Sell assets** if available
4. **Find additional income sources** (renting room, reverse mortgage if you own home)

I can help you navigate these options, but I can't give you money I don't have.

What I can cover: $**[amount]**/**[month]**. What's your highest priority expense?

Sibling Accusing You of "Stealing" — Financial Transparency Script

You're accusing me of misusing **[Name]**'s money.

Here's what happens now:

1. I'll provide you **complete financial records** for the past **[time period]**: bank statements, receipts, care expenses.
2. You review them and **identify specific transactions** you believe are inappropriate.
3. If you find actual misuse, we involve **[attorney/financial advisor/adult protective services]**.
4. If you don't find misuse, you **publicly retract** your accusation to anyone you told.

If you're not willing to actually review the records and identify specific issues, stop making accusations.

If you keep making accusations without evidence, I'll consult an attorney about slander.

Do you want the financial records, or are you done accusing me?

Expected to Quit Job for Care — Economic Reality Script

I earn $**[amount]**/**[year/month]** from my job.

My expenses: $**[amount]**/**[month]** (housing, utilities, food, insurance, debt).

If I quit, I lose **[income + benefits]** and have no way to cover **[expenses]**.

[Name] needs **[X hours/week]** of care.

Options that don't require me to quit:

1. **Paid home care** for hours I'm at work — $**[amount]**/**[month]**
2. **Adult day program** during work hours — $**[amount]**/**[month]**
3. **Sibling coverage** during work hours
4. **Facility placement** — $**[amount]**/**[month]**

I'm not quitting my job. We need to choose from the options above.

Which one makes sense for **[Name]**'s situation?

Being Asked to Sign Financial Documents — Legal Protection Script

I'm not signing **[document type]** without an attorney reviewing it first.

Financial documents have legal consequences.

If I sign, I could be responsible for **[debt/obligation/liability]** that I didn't agree to.

Here's what happens:

1. I take this document to an attorney
2. Attorney explains what I'm signing and what risks I'm taking
3. If attorney says it's safe, I'll consider signing
4. If attorney says it's risky, I'm not signing

If you need someone to sign **[document]** immediately, **you sign it** or **[other sibling] signs it**.

I'm not signing anything without legal review, regardless of how urgent you say it is.

Loved one Spending Beyond Means — Budget Enforcement Script

Your income: $**[amount]**/**[month]**

Your essential expenses: $**[amount]**/**[month]** (housing, utilities, food, medical, insurance)

What's left: $**[amount]**/**[month]** for everything else.

You're spending $**[amount]**/**[month]** on **[non-essential items]**.

That's **[amount over budget]** more than you have.

I'm not covering the difference.

Either:

1. Cut spending to stay within $**[amount]**/**[month]** budget, OR
2. Accept reduced services (example: **[specific service to cut]**)

I'll help you make a budget, but I won't supplement your income so you can spend beyond your means.

Which expenses are you cutting?

Sibling Demanding Equal Inheritance While Doing No Care — Future Asset Script

NOTE: Only request financial contributions you are legally entitled to request, and never represent an obligation that has not been legally established.

I'm providing **[X hours/week]** of care for **[Name]**.

At market rate ($**[amount]**/**[hour]** for this level of care), that's $**[amount]**/**[month]** or $**[amount]**/**[year]** in unpaid labor.

You're contributing **[zero hours / $0]**.

If **[Name]** passes with assets remaining, I'm consulting an attorney about **caregiver compensation from the estate** for the work I've done.

In many states, caregivers can claim compensation for care provided. (*Note: Laws vary significantly by jurisdiction; consult an elder law attorney*)

If I pursue this, the estate would be reduced by my compensation before inheritance distribution.

Your choice:

1. **Start contributing** now (time or money), so we're both investing in **[Name]**'s care, OR
2. **Accept** that when **[Name]** passes, I may claim compensation for years of unpaid labor, reducing your inheritance

I'm not providing years of free labor while you wait for an equal payout.

Loved one Refusing to Disclose Financial Information — Financial Access Ultimatum

You're asking me to **[pay for / contribute to] [expense]**.

Before I contribute anything, I need complete financial information:

1. Your monthly income (Social Security, pension, investments)
2. Your assets (savings, home equity, investments)
3. Your debts (credit cards, loans, mortgages)
4. Your monthly expenses (documented, not estimated)

If you have assets or income that could cover **[expense]**, I need to know that before I contribute.

If you won't disclose your finances, I can't make informed decisions about helping financially.

Binary choice:

Option 1: Provide complete financial information (bank statements, tax returns, bills), and we'll determine if you need help and how much I can provide.

Option 2: Don't disclose, and handle your expenses yourself.

I'm not contributing money when I don't know if you actually need it.

END-OF-LIFE AND ADVANCE DIRECTIVES

> **Note:** These conversations are uncomfortable but essential. Approach with gentleness when possible.

Level 0: Opening the Conversation

Starting the Advance Directives Conversation — Gentle Opener Script

I've been thinking about something that's hard to talk about, but important.

None of us knows what the future holds. If something happened and you couldn't speak for yourself, I want to make sure your wishes are followed.

Have you ever thought about what you'd want? Like, if you were really sick and couldn't make decisions—who would you want to make them for you? What would you want them to know about your preferences?

I'm not trying to be morbid. I just want to be prepared to honor what you'd want.

Can we talk about it?

Level 2-3: When Documents Are Needed

Getting Advance Directives Completed — Legal Document Urgency Script

We need to complete your advance directives.

These documents tell us what you want if you can't speak for yourself:

1. **Healthcare Power of Attorney** (who makes medical decisions if you can't)
2. **Living Will** (what treatments you do/don't want)
3. **DNR order** (your wishes about resuscitation)

Why this is urgent:

If something happens and you can't communicate, **I** won't be able to make medical decisions for you without legal authority.

Doctors will either:

- Do everything possible (whether you'd want it or not), OR

- Not let me participate in decisions

This isn't about "giving up" or thinking you're dying soon.

This is about making sure your wishes are followed **if** something happens.

Next steps:

Option 1: I'll schedule appointment with **[elder law attorney]** for **[this week/next week]** to complete documents properly. (*Note: Requirements and procedures vary by state*)

Option 2: We use **[state-specific form / hospital social worker]** to complete basic forms today.

We're doing this by **[deadline]**.

Which option works for you?

Loved one Wants "Everything Done" Without Understanding — Realistic Expectations Script

You're saying you want "everything done" if your heart stops.

I need to make sure you understand what that means.

CPR (Chest Compressions):

- Someone pushes hard on your chest, often breaking ribs (this is normal and necessary)
- They do this for minutes or longer
- Your chest will be bruised and painful afterward (if you survive)

Intubation (Breathing Tube):

- Tube goes down your throat into your lungs
- Machine breathes for you
- You can't talk
- You may be sedated/restrained so you don't pull it out
- May be on this for days, weeks, or permanently

Realistic Outcomes:

For someone your age with **[condition]**, statistics show:

- **[X%]** survive CPR to leave the hospital
- Many survivors have brain damage from oxygen deprivation
- Many end up on long-term ventilator support
- Recovery is long and difficult

I'm not telling you what to choose.

But I need you to know what you're choosing.

Given this information, what are your wishes?

Do you still want full CPR and ventilator support?

Or would you prefer comfort care if your heart stops?

I'll support whatever you decide.

FAMILY DYNAMICS AND CONFLICT

Level 0-1: Preventing Triangulation

When Family Member Wants to Vent About Another — Neutral Ground Script

I hear that you're frustrated with **[other family member]**.

I'm not in a position to fix things between you two, and I don't want to be in the middle.

If you need to vent, I can listen for a few minutes. But I'm not going to relay messages or take sides.

If there's a real issue that affects **[Name]**'s care, let's talk about that specifically.

Level 2-3: Addressing Undermining

Family Member Undermining Medical Decisions — Authority Clarification Script

TO MEDICAL TEAM:

Important Note: State law regarding next-of-kin medical decision-making authority varies.

I'm **[Your Name]**, **[Name]**'s **[Healthcare Power of Attorney / legal guardian / closest next-of-kin]**.

[Interfering person's name and relationship] has been **[contacting staff / contradicting my decisions / trying to override my instructions]**.

[Interfering person] does **NOT** have medical decision-making authority for **[Name]**.

Legal authority:[If you have POA:] I have Healthcare Power of Attorney, executed **[date]**. Copy attached to chart.

[If you are legal guardian:] I'm legal guardian, court-appointed **[date]**. Guardianship papers attached.

[If you are default next-of-kin:] I'm **[Name]**'s **[relationship]** and closest next-of-kin. **[Interfering person]** is **[their relationship]** with no legal authority.

Please:

1. **Contact only me** for medical decisions
2. **Do not accept instructions** from **[interfering person]**

3. **Document in chart** who has legal authority
4. **Inform all staff** of proper contact

My phone: **[number]**

TO INTERFERING FAMILY MEMBER:

You've been **[calling the hospital / telling staff different instructions / contradicting my decisions]** about **[Name]**'s medical care.

You do not have medical decision-making authority.

[I have Healthcare POA / I'm legal guardian / I'm next-of-kin].

If you disagree with decisions I'm making, you can:

1. **Talk to me directly**, OR
2. **Consult an attorney** about challenging my authority (*Note: Procedures vary by jurisdiction*)

What you can't do is confuse medical staff about who's in charge or override my decisions.

I've informed the medical team that you do not have authority.

Extended Family Offering Unhelpful Advice — Advice Boundary Script

I know you're trying to help.

I'm not looking for advice right now about **[Name]**'s care.

[Name] has a medical team making treatment decisions based on **[his/her]** specific situation.

If you want to help, here's what would be useful:

[Choose what you actually need:]

- **"Bring a meal"** on **[day/time]**
- **"Send a grocery gift card"**
- **"Call [Name] to chat"** (takes pressure off me to entertain **[him/her]**)
- **"Pray/send good thoughts"** (if you believe in that)

What I don't need:

- Articles about treatments
- Stories about what worked for someone else
- Criticism of decisions already made
- Suggestions to try **[alternative treatments / different doctors / miracle cures]**

If you want to help practically, let me know which of the above you can do.

Otherwise, I appreciate your concern, but I can't engage with medical advice right now.

Loved One Manipulating Against Sibling — Refusing Triangulation Script

You're telling me **[what loved one is saying about sibling]**.

I'm not getting in the middle of this.

If you have an issue with **[Sibling]**, talk to **[Sibling]** directly.

I'm not relaying messages, and I'm not taking sides.

My relationship with **[Sibling]** is separate from yours.

If there's something that affects **[Name]**'s care, we can discuss that specifically. But I won't be a messenger or a referee.

SELF-CARE AND CAREGIVER BURNOUT

Saying No to Non-Essential Requests — Priority Boundary Script

I'm managing **[X hours]** of essential care for you per week: **[list essentials]**.

I'm at capacity.

[Request] is not essential for your **health or safety**.

I can't take on non-essential tasks right now.

For **[request]**, your options are:

1. **Do it yourself** (if you're capable)
2. **Ask [other person]** to help
3. **Hire someone** to do it
4. **Let it go** — it's not urgent

I'm prioritizing what keeps you healthy and safe.

Everything else is on hold until I have more capacity.

Caregiver Needs Day Off — Mandatory Break Announcement

I'm taking **[time off]** off from caregiving.

This is not negotiable. I need this for my health.

Here's the plan:

[Option 1: Coverage arranged] [Sibling/paid caregiver/respite service] will cover. They'll be here **[schedule]**. I've briefed them on your routine and needs.

[Option 2: No coverage available] I won't be available **[dates/times]**. For non-emergencies, **[alternative]**. For emergencies, call 911.

I'll be back **[return date/time]**.

My phone will be **[on for emergencies only / off entirely]**.

Caregiver Setting Office Hours — Availability Schedule Script

Going forward, my caregiving availability is:

ON-DUTY:[List specific days and hours]

During these hours:

- I'm available for **[appointments, errands, calls, care tasks]**
- Call/text anytime

OFF-DUTY:[List off-duty hours]

During these hours:

- I'm **not available** for non-emergencies
- **For emergencies** (medical crisis, fall, immediate safety issue): Call me
- **For non-emergencies**: **[Text me and I'll respond during next on-duty period / Save it for tomorrow / Handle it yourself or call someone else]**

This schedule is how I stay sustainable as your caregiver long-term.

LEGAL AND FINANCIAL DOCUMENTS

Loved one Resisting Estate Planning — Legacy Protection Script

You don't have a will or estate plan.

If something happens to you, here's what happens:

Without a will:

- The state decides who gets your **[assets]**
- We go through probate court (6-18 months, costs thousands)
- Family members may fight over assets
- Your wishes won't be honored because we don't know what they are

With estate planning:

- **YOU** decide who gets what
- You decide who's in charge of carrying out your wishes
- We avoid probate (or make it much simpler)
- Your family doesn't have to guess or argue

Documents you need:

1. **Will** (who gets your assets)
2. **Trust** (if you have significant assets — avoids probate)
3. **Healthcare POA** (who makes medical decisions if you can't)
4. **Financial POA** (who handles money if you can't)

Next step:

I'm scheduling you with **[elder law attorney]** for **[date and time]**.

This appointment takes 1-2 hours.

It costs approximately $**[amount]**.

This protects your family from conflict and protects your wishes.

We're doing this by **[deadline]**.

Accessing Loved one's Financial Accounts — POA Activation Script

NOTE: Many banks require Power of Attorney to be on their own specific internal forms and may reject general statutory forms. Threatening regulatory complaints immediately can sometimes cause a bank's fraud department to freeze the account "for protection." Start with a cooperative approach. Use the threat of a complaint only as a last resort after escalating to a branch manager.

TO: [Bank/Financial Institution Name]
RE: Power of Attorney Activation for [Name], Account #: [Number]

I'm **[Your Name]**, Financial Power of Attorney for **[Name]**.

[Name] is no longer able to manage **[his/her]** finances due to **[cognitive decline / physical incapacity / medical condition]**.

I'm activating my POA authority as of **[date]**.

Attached:

1. **Original POA document** (or certified copy) executed **[date]**
2. **ID for [Name]**
3. **My ID**

Actions Requested:

1. **Add me to account** with full authority per POA
2. **Provide online access**
3. **Send statements to my address**: **[address]**
4. **Transfer phone contact** to me for account matters

POA is valid under **[state]** law. It does **not** require **[Name]**'s current signature or consent to activate — **[Name]** granted me this authority when **[he/she]** signed the POA while having capacity.

If you require additional documentation, specify what you need.

If you deny activation of this valid POA, I'll file a complaint with **[state banking regulator / Consumer Financial Protection Bureau]**.

Contact me at **[phone/email]** to confirm activation.

[Your Name]
Financial Power of Attorney for [Name]
[Date]

RESPITE AND RELIEF

Requesting Respite from Sibling — Specific Respite Ask Script

I need a break.

I'm asking you to cover **[Name]**'s care for **[specific time period]**.

Here's what that means:

You'll need to:

- **[List specific tasks]**
- **Be at [Name]'s home / Have [Name] at your home** (specify which)
- **Be reachable by phone** if I need to contact you about something

I need your answer by [deadline].

If you can't do it, I need to know now so I can hire respite care (cost: $**[amount]** — we'd split it).

This isn't optional for me. I need this break to keep doing this long-term.

Arranging Emergency Backup — Backup Coverage Establishment Script

TO: [Backup Person — Sibling/Friend/Neighbor]

I'm primary caregiver for **[Name]**.

I need an emergency backup plan for situations where I can't provide care:

- If **I** have medical emergency
- If **I** have family emergency (my kids, spouse, etc.)
- If **I** am unavoidably prevented from covering care

I'm asking you to be my emergency backup.

What that means:

Advance preparation:

- I'll give you a **care information packet** (medications, routines, emergency contacts)
- We'll do a **trial run** where you shadow me for **[X hours]** to learn **[Name]**'s routine
- You'll have keys/access codes to **[Name]**'s home

When activated:

- I'll call/text: "Emergency backup needed. Can you cover **[Name]** starting **[time]**?"
- You come within **[timeframe]**
- You stay until I can resume or we arrange alternative

Frequency: Hopefully never, realistically maybe **[once or twice per year]**.

Are you willing to be my emergency backup?

If yes, let's schedule the training visit for **[date/time]**.

If no, I need to know now so I can ask someone else or hire a service.

The Workplace (Protecting Your Income)

DISCLAIMER: This chapter provides communication language only. It is NOT legal advice, employment law guidance, or a substitute for an employment attorney.

Employment laws vary significantly by:

- State/jurisdiction
- Company size
- Union status
- Employment contract terms
- Industry regulations
- FMLA eligibility requirements
- ADA accommodation procedures

WHAT THIS CHAPTER IS NOT:

- NOT legal advice about your employment rights
- NOT a guarantee of job protection
- NOT authorization to violate employment contracts or policies
- NOT a substitute for HR guidance or employment attorney consultation

YOUR RESPONSIBILITIES:

- Verify your rights under FMLA (Family and Medical Leave Act) if applicable
- Review your employee handbook and company policies
- Document all caregiving-related work absences and accommodations
- Consult an employment attorney before taking action that could affect your job
- Understand that employers may have legitimate business reasons for denying requests

WHEN TO CONSULT PROFESSIONALS:

- Employment attorney: Before requesting major accommodations, filing complaints, or if facing termination
- HR department: To understand company-specific policies and your eligibility for FMLA/accommodations
- Union representative: If you are in a unionized workplace

By using these scripts, you acknowledge that employment protections and outcomes vary widely, and you accept responsibility for understanding your specific employment situation.

Before You Start: Know Your Employment Rights (Overview Only)

This is general information only. Consult an employment attorney for advice specific to your situation.

Potentially relevant laws (if you qualify):

- **FMLA (Family and Medical Leave Act):** May provide up to 12 weeks unpaid leave for caregiving (eligibility requirements apply)
- **ADA (Americans with Disabilities Act):** May require reasonable accommodations (applies to some caregiving situations)
- **State-specific family leave laws:** Some states have additional protections

You may NOT be protected if:

- You work for small employer (FMLA requires 50+ employees)
- You haven't worked there long enough (FMLA requires 1,250 hours in past 12 months)
- Your caregiving situation doesn't meet legal definitions
- Requested accommodation creates "undue hardship" for employer

These scripts assume you have verified your rights. If unsure, consult an attorney BEFORE using.

EMPLOYER REQUESTING EXCESSIVE CAREGIVING DISCLOSURE

Level 0-1: Professional Information Boundary

When to use: Employer asking intrusive questions about loved one's condition, prognosis, or care details beyond what's needed for accommodation request.

Emotional prep: You do not owe your employer a detailed medical history of your loved one. Provide minimum necessary information.

Privacy Protection Script

I'm managing care responsibilities for my **[loved one/family member]**, which is why I'm requesting **[specific accommodation: flexible schedule/time off/remote work]**.

For privacy reasons, I'm not comfortable sharing detailed medical information.

What I can share: **[Name]** requires regular care and medical oversight. This creates scheduling conflicts with my current work arrangement.

I'm happy to provide documentation from **[his/her]** physician confirming care needs if required for FMLA or accommodation approval.

Is there specific information you need for the accommodation process, or is this sufficient?

REQUESTING FLEXIBLE WORK ARRANGEMENT

Level 1: Professional Accommodation Request

When to use: You need schedule flexibility to manage caregiving but can still perform your job fully.

Emotional prep: This is a negotiation. Come prepared with a specific proposal and be ready to compromise.

Flexible Schedule Request Script — Option Proposal Format

I'd like to discuss a flexible work arrangement to accommodate care responsibilities.

Current challenge: I'm managing care for my **[loved one]**, which requires **[specific time commitment: medical appointments twice monthly, emergency availability during business hours, morning care routine]**.

Proposed solution:

- **Option 1:** Shift my hours to **[proposed schedule: 7am-3pm instead of 9-5, or 10-6 instead of 9-5]**
- **Option 2:** Work remotely **[X days per week]**
- **Option 3:** Compressed schedule **[4 ten-hour days]**

How work gets done:

- All deadlines met
- Available for **[meetings/calls]** during **[core hours]**
- Reachable by **[phone/email/Slack]** during business hours

I'm open to a trial period of **[30/60/90 days]** to demonstrate this works.

Can we discuss which option might work for the team?

What to expect after:

- Employer may counteroffer different arrangement
- May require documentation or FMLA paperwork
- May approve trial period with checkpoints

BOSS PRESSURING YOU TO SKIP MEDICAL APPOINTMENTS

Level 2: Firm Boundary — Non-Negotiable Appointment

When to use: Manager implying you should cancel your loved one's medical appointment to attend a work meeting or deadline.

Emotional prep: Your loved one's health appointment is not optional. Stand firm.

Medical Appointment Boundary Script

I have a medical appointment with my **[loved one]** on **[date/time]** that cannot be rescheduled.

This is with **[his/her] [specialist type: cardiologist/oncologist/surgeon]** and the next available appointment is **[timeframe: 6 weeks out/after critical procedure date/when symptoms may worsen]**.

I will **[complete deliverable before I leave / delegate to [colleague] / complete when I return on date]**.

My work will be covered. The appointment is not negotiable.

If boss continues to pressure:

I understand this is inconvenient timing. The appointment was scheduled **[timeframe]** ago and involves a **[serious condition/post-surgical follow-up/diagnostic test]** that cannot wait.

If there's a conflict with my using **[PTO/sick time/FMLA]**, please let me know what documentation you need. Otherwise, I'll see you on **[return date]**.

COWORKERS MAKING COMMENTS ABOUT YOUR ABSENCES

Level 1-2: Professional Deflection

When to use: Colleagues making passive-aggressive comments about your caregiving absences or flexible schedule.

Emotional prep: You don't owe coworkers explanations. Keep it professional and brief.

Coworker Boundary Script — Polite Shutdown

If coworker says: "Must be nice to leave early all the time"

Response: I have an approved flexible arrangement with **[manager name]**. If you're interested in flexible scheduling, you should talk to **[manager/HR]**.

If coworker says: "We're picking up your slack"

Response: I'm meeting all my deadlines and deliverables. If you're feeling overloaded, let's talk to **[manager]** about workload distribution. That's not a caregiving issue, that's a team capacity issue.

If coworker says: "How long is this going on?"

Response: I'm managing care responsibilities. I don't have a timeline. My arrangement is approved by management, and my work is getting done.

EMPLOYER DENYING FMLA / REASONABLE ACCOMMODATION

Level 3: Formal Documentation Request

LEGAL WARNING: *This script involves formal legal processes. Consult an employment attorney before using if you are concerned about consequences, retaliation or termination.*

When to use: Employer denied your FMLA request or reasonable accommodation request, and you believe you qualify.

Emotional prep: This escalates the situation. Be prepared for potential relationship damage with your employer. Only use it if you've verified your legal eligibility.

FMLA Denial Appeal Script — Written Format

TO: **[HR Department / Manager Name]**
RE: Appeal of FMLA Denial for **[Your Name]**, DATE: Date

I am writing to formally appeal the denial of my FMLA request dated **[date of request]**.

Basis for Appeal:

I meet FMLA eligibility requirements:

- I have worked for **[Company]** for **[length of time: over 12 months]**
- I have worked **[1,250+ hours]** in the past 12 months
- **[Company]** employs **[50+ employees within 75 miles]**

My request is for a qualifying reason under FMLA: care for my **[loved one]** with a serious health condition.

Documentation:

Attached is medical certification from **[Name]**'s physician, **[Dr. Name]**, dated date, confirming **[he/she]** requires care for **[condition]** and that I am needed to provide care.

Requested Action:

I request that **[Company]** approve my FMLA leave for **[dates]** and provide written confirmation of approval.

If this appeal is denied, please provide:

1. Specific reason for denial
2. Documentation of which FMLA requirement I do not meet
3. Information about my right to file a complaint with the U.S. Department of Labor

I am available to discuss this matter at **[phone]** or **[email]**.

Thank you for reconsidering this request.

Sincerely,
[Your Name], **[Date]**

Boundary Conditions:

- **DO consult attorney before sending** if you fear retaliation
- **DO keep copies of all documentation**
- **DO NOT threaten lawsuit** unless attorney advises
- **DO follow up in writing** if no response within 5 business days

NEEDING TO REDUCE HOURS / GO PART-TIME

Level 2-3: Formal Hour Reduction Proposal

When to use: Current full-time schedule is unsustainable with caregiving; you need to reduce hours to stay in the workforce.

Emotional prep: This may result in reduced income and benefits. Be financially prepared for potential consequences.

Part-Time Proposal Script

I need to discuss reducing my hours due to caregiving responsibilities.

Current situation: I'm managing care for my **[loved one]**, which requires **[X hours per week]**. My current full-time schedule is no longer sustainable.

Proposal: Reduce to **[X hours per week / X days per week]** starting **[date]**.

How this works:

- I'll maintain responsibility for **[core duties]**
- **[Colleague/hire]** can cover **[tasks being handed off]**
- I'll be available **[specific days/times]**

I understand:

- This may affect my benefits **[health insurance, PTO, retirement]**
- My salary will be prorated to **[X%]** of current
- My role may be restructured

I'd like to explore whether this is feasible before I need to [resign/take unpaid leave].

Can we discuss options?

What to expect after:

- Employer may deny request (no legal obligation to approve part-time)
- May require formal transition plan
- Benefits may be reduced or eliminated
- May result in role change or eventual termination

CONSIDERING RESIGNATION

Level 4: Exit Strategy

When to use: No accommodation is sufficient; you need to leave the workforce temporarily or permanently to provide care.

FINANCIAL WARNING: Resigning has significant financial consequences. Consult a financial advisor and explore all alternatives first (FMLA, unpaid leave, part-time, accommodations).

Emotional prep: This is a major life decision. Grieve the loss if this was not your choice.

Professional Resignation Script

I am resigning from my position as **[title]**, effective **[date: typically 2 weeks from submission]**.

This decision is due to caregiving responsibilities that require full-time attention.

I have valued my time at **[Company]** and appreciate **[specific positives: mentorship, opportunities, team]**.

Transition plan:

- I will complete **[current projects / deliverables]** by date
- I have documented **[processes / handoff information]** for my successor
- I am available for questions through **[last day]**

Please let me know the process for **[final paycheck, benefits transition, exit interview, return of company property]**.

Thank you for the opportunities I've had here.

Sincerely,
[Your Name]

After Resignation:

- Explore COBRA for health insurance (expensive but may be only option)
- File for unemployment if eligible in your state (caregiving may not qualify)
- Update resume to explain gap ("Family care responsibilities")
- Plan for re-entry to workforce when caregiving role ends or reduces

COWORKERS OFFERING UNSOLICITED ADVICE

Level 0-1: Polite Shutdown

When to use: Well-meaning colleagues suggesting you're handling caregiving "wrong" or offering solutions you didn't ask for.

Advice Boundary Script — Gentle

I appreciate you thinking of me.

Right now, I'm working with **[loved one]**'s medical team on the care plan, and we have a system that's working.

If I need input, I'll definitely reach out. For now, I'd love to just **[focus on work / talk about non-caregiving topics]**.

Thank you for understanding.

If colleague persists:

I hear that worked for your situation. Every caregiving situation is different.

I'm not looking for advice right now, just trying to keep my head above water at work.

Let's talk about **[work topic / anything else]**.

The Marriage & Kids

RELATIONSHIP & FAMILY DISCLAIMER

This chapter provides communication language only. It is NOT marriage counseling, therapy, parenting advice, or a substitute for professional mental health services.

WHAT THIS CHAPTER IS NOT:

- NOT a substitute for couples therapy or family counseling
- NOT legal advice about custody, divorce, or family law
- NOT parenting guidance for complex behavioral or psychological issues
- NOT a guarantee that your relationship will survive caregiving stress

REALITY CHECK:

Caregiving stress is a **leading cause of marital conflict and divorce.** Research shows:

- Caregiver burnout affects intimate relationships
- Partners often feel neglected or resentful
- Children may act out or become parentified
- Family units can fracture under sustained stress

Your responsibilities:

- Seek couples therapy if marital conflict is escalating
- Seek family therapy if children are showing behavioral changes
- Do not use these scripts as substitute for addressing underlying relationship problems
- Understand that sometimes protecting your marriage means reducing caregiving, not increasing communication skills

When to consult professionals:

- Couples therapist: If partner is threatening separation or you're having recurring fights about caregiving
- Family therapist: If children are regressing, acting out, or showing signs of anxiety/depression
- Individual therapist: If you are burned out to the point of emotional numbness or rage

These scripts assume both parties want to preserve the relationship. If your partner has checked out, scripts will not fix structural problems.

PARTNER FEELING NEGLECTED

Level 0: Reconnection Acknowledgment

When to use: Partner has expressed (directly or indirectly) feeling like you're not present, intimate, or connected because of caregiving demands.

Emotional prep: They're not wrong. Caregiving is consuming you. This is acknowledging reality, not defending yourself.

Reconnection Script — Vulnerability

You're right. I've been absent.

Caregiving is taking everything I have right now, and you're getting the scraps. That's not fair to you.

I don't want us to become roommates who coordinate logistics.

Can we block **[specific recurring time: Saturday mornings, Tuesday evenings]** as *us time*—no loved one calls, no caregiver brain, just us?

I can't promise I'll be perfect at it, but I want to try.

What do you need from me that you're not getting?

What to expect after:

- Partner may unload pent-up resentment (let them)
- Partner may test whether you follow through (you must)
- Reconnection takes time; one conversation is not enough

If partner says "it's fine" but clearly isn't:

It's not fine. I can see it in **[how you've been distant / your tone / the fact that we haven't had a real conversation in weeks]**.

I need you to tell me what's wrong so I can actually address it instead of guessing.

PARTNER UNDERMINING CAREGIVING DECISIONS

Level 1-2: Unified Front Request

When to use: Partner is contradicting your caregiving decisions in front of your loved one or criticizing how you're handling care.

Emotional prep: You're a team. Disagreements happen in private, not in front of others.

Unified Front Script

I need us to be on the same page about [Name]'s care.

When you **[specific behavior: told Mom she didn't need the aide / contradicted my decision in front of Dad / said I was overreacting about the fall risk]**, it undermined my authority and confused **[Name]**.

What I need:

- If you disagree with a decision, tell me privately first
- We discuss, decide together, then present unified front
- In the moment, back me up publicly even if you have concerns

Can we agree:

- Disagreements happen behind closed doors?
- We support each other's care decisions in front of **[Name]**?

I'll do the same for you.

CHILDREN ACTING OUT DUE TO CAREGIVER STRESS

Level 1: Age-Appropriate Conversation

When to use: Children showing behavioral changes (clingy, acting out, regressing, grades dropping) that coincide with your increased caregiving role.

Emotional prep: Your children didn't choose this. They're losing access to you and don't have adult coping skills.

Child Reassurance Script (Ages 6-12)

Adapted for child's developmental level

Hey, I want to talk to you about something.

I know I've been spending a lot of time with **[Name]** lately. I know it feels like I'm not around as much.

Here's what's happening: **[Name]** is sick and needs help. I'm helping take care of **[him/her]**, kind of like how I take care of you when you're sick, but it takes longer.

This is NOT because:

- You did something wrong
- I don't want to be with you
- **[Name]** is more important than you

What I need you to know:

- I love you just as much as always
- This won't last forever
- You can tell me when you're feeling sad or mad about this

What we can do:

- **[Specific scheduled time: Every Saturday morning, just you and me]**
- If you need me, **[specific signal: text me this emoji and I'll call you as soon as I can]**

Does that help? Do you have questions?

Teen Script (Ages 13+)

I want to talk about what's happening with **[Name]** and how it's affecting our family.

I know I've been preoccupied and stressed. I know you're getting less of my time and attention. That sucks, and I'm sorry.

Here's the reality: **[Name]** needs a lot of help right now, and I'm trying to balance that with being present for you. I'm not doing it perfectly.

What I won't do:

- Pretend this isn't hard
- Ask you to take care of me emotionally (that's not your job)
- Expect you to "help with **[Name]**" if that's not what you want

What I will do:

- Keep showing up for you, even if I'm distracted
- Make sure you know you can talk to me
- Protect **[specific boundary: your activities, your college plans, your social life]** from caregiving demands

What I need from you:

- Tell me if you're struggling
- Don't bottle it up and explode later
- *(If age-appropriate)* Maybe cut me a little slack when I'm maxed out

Questions? Feelings?

PARTNER DEMANDING YOU QUIT CAREGIVING

Level 2-3: Relationship Boundary Negotiation

When to use: Partner has issued an ultimatum: "It's me or your loved one" or "I can't do this anymore."

Emotional prep: This is a crisis. Your partner has reached their limit. You need couples therapy, not just a script.

CRITICAL: This script is crisis triage, not solution. **Get into couples therapy immediately.**

Crisis De-Escalation Script

I hear that you're at your breaking point.

I don't want to lose you. I also can't abandon my **[loved one]**.

This feels like an impossible choice, and I need help figuring out how we get through this without destroying us.

Here's what I'm willing to do right now:

- **[Reduce caregiving hours from X to Y]**
- **[Hire more help so I'm less consumed]**
- **[Set specific boundaries: no calls after 8pm, no weekend visits, etc.]**
- **[Start couples therapy this week]**

What I can't do:

- Walk away from **[Name]** entirely
- Pretend this isn't hard for both of us

Can we agree to work with a therapist to find a path forward before either of us makes permanent decisions?

I love you. I want to fix this. But I need you to help me figure out how.

If partner refuses couples therapy or gives ultimatum anyway:

I hear that you've made a decision.

I hope we can work through this, but I understand if you can't.

I'll **[reduce caregiving as much as possible / we can separate temporarily / other compromise]**, but I need time to figure out sustainable care for **[Name]** before I can make permanent decisions about us.

Can we agree to **[separation timeline / therapy trial / specific boundary trial]** before deciding it's over?

CHILDREN ASKING WHY LOVED ONE IS "DIFFERENT"

Level 0: Age-Appropriate Honesty

When to use: Child notices loved one's cognitive decline, personality changes, or physical limitations.

Emotional prep: Honesty is kind. Lies create confusion and fear.

Dementia Explanation Script (Ages 6-12)

You've noticed **[Name]** is acting different, haven't you?

Here's what's happening: **[Name]** has something called **[dementia/Alzheimer's/illness]**. It makes **[his/her]** brain not work as well as it used to.

What that means:

- Sometimes **[he/she]** forgets things (even important things like your name)
- Sometimes **[he/she]** gets confused or says things that don't make sense
- Sometimes **[he/she]** acts grumpy or different from how **[he/she]** used to be

What that does NOT mean:

- It's not your fault
- **[He/she]** still loves you (the love is still there even if **[he/she]** can't show it the same way)
- It's not contagious (you can't catch it)

How you can help:

- Be patient when **[Name]** forgets things
- Tell me if something **[he/she]** does scares or upsets you
- Remember the **[Name]** **[he/she]** used to be—those memories are real

Does that make sense? Questions?

PARENTIFYING YOUR CHILDREN

When to use: You've been leaning on your children for emotional support, asking them to help with caregiving, or treating them like peers instead of kids.

Emotional prep: This is hard to admit. You've been putting adult burdens on children because you're drowning. Stop.

Parentification Correction Script

I need to apologize.

I've been treating you like you need to help me manage **[Name]** or support me through this. That's not fair.

You're **[age]**. You're supposed to be **[doing age-appropriate things: focused on school, friends, being a kid]**. You're not supposed to be taking care of me or worrying about adult problems.

What changes now:

- I'm not going to vent to you about **[Name]** anymore
- I'm not going to ask you to **[specific caregiving task: sit with loved one, give loved one his/her pills, help me decide about nursing homes]**
- I'm going to handle my stress with **[therapist / other adults]**

Your job is to be **[age].** My job is to protect you from having to be an adult before you're ready.

I'm sorry I put that on you. It stops now.

PARTNER WANTS TO MOVE LOVED ONE INTO YOUR HOME

Level 3: Non-Negotiable Boundary

When to use: Partner is suggesting or insisting loved one move in with your family; you know this will destroy your household.

Emotional prep: This may create significant marital conflict. Stand firm.

Co-Residence Refusal Script (To Partner)

I know you think having **[Name]** move in would solve the care problem.

I understand the impulse. But I need to be very clear: I am not willing to have [Name] live with us.

Here's why:

- Our home is not set up for **[Name's care needs: mobility issues, dementia supervision, medical equipment]**
- It would consume our family life—no privacy, no separation, constant vigilance
- Our kids need a home that's theirs, not a nursing home
- I need a space where I can stop being a caregiver and just be **[your partner / the kids' loved one]**

Alternative solutions:

- Assisted living near us
- In-home care at **[Name's]** current residence
- Adult day program + evening aide

I know this feels harsh. But moving **[Name]** in could end **[our marriage / my sanity / any quality of life for the kids]**. I can't do it.

If partner insists anyway:

I hear that you disagree.

This is a non-negotiable boundary for me. If you move **[Name]** in, **[consequence: I will move out temporarily / I will not participate in [his/her] care / this will damage us beyond repair]**.

I need you to respect this boundary. We can find other solutions, but co-residence is off the table.

SEX LIFE DESTROYED BY CAREGIVER EXHAUSTION

Level 0-1: Honest Conversation

When to use: Physical intimacy has disappeared because you're too exhausted, touched-out, or emotionally numb.

Emotional prep: This is vulnerable. Your partner needs to hear the truth, not excuses.

Intimacy Conversation Script

I know we haven't been physical in **[timeframe]**.

I'm not avoiding you because I don't love you or don't find you attractive. I'm avoiding you because I am **touched out.**

I spend **[hours per week]** doing physical caregiving—bathing, toileting, dressing, lifting. By the time I get home, the idea of anyone touching me makes me want to crawl out of my skin.

I don't have a solution yet. But I need you to know it's not about you.

What might help:

- **[Specific time frame: Saturday morning after I've had space]**
- **[Non-sexual physical connection first: cuddling, massage]**
- **[Professional help: couples therapy, sex therapist]**

I miss you. I miss us. I'm just completely depleted right now.

Can we figure this out together?

KIDS COMPETING WITH LOVED ONE FOR ATTENTION

Level 1: Reassurance + Boundary Reinforcement

When to use: Children acting out, regressing, or explicitly saying "You care more about **[Name]** than me."

Attention Redistribution Script

I need to tell you something important.

You are noticing that I spend a lot of time with **[Name]**. You might be thinking I care more about **[him/her]** than you.

That is not true.

Here's the difference: **[Name]** is sick and needs help. You are healthy and capable. I give **[Name]** time because **[he/she]** can't take care of **[himself/herself]** anymore.

But **you are my priority.** Always.

To prove it:

- Every **[specific time/day]**, you get me 100%. No phone, no caregiver mode.
- If you say "I need you," I will **[specific action: call you back within an hour, come home, give you attention]**

You are not in competition with **[Name]**. You both matter to me.

If you're feeling like I'm not there for you, tell me. Don't bottle it up.

Deal?

Managing Paid Help (The Manager Role)

EMPLOYMENT & CONTRACTOR DISCLAIMER

This chapter provides communication language for managing paid caregivers. It is NOT legal advice about employment law, contractor classification, or labor regulations.

CRITICAL EMPLOYMENT CLASSIFICATION WARNING:

If you hire a caregiver directly (not through agency), you may be an **employer** with legal obligations:

- Payroll taxes (Social Security, Medicare, unemployment)
- Workers' compensation insurance (required in most states)
- Minimum wage and overtime compliance
- W-2 reporting
- Potential liability for on-the-job injuries

"Paying under the table" is illegal and exposes you to:

- Back taxes and penalties from IRS
- State labor violations
- Personal liability if worker is injured
- Lawsuit for unpaid wages or benefits

WHAT THIS CHAPTER IS NOT:

- NOT legal advice about hiring practices or employment law
- NOT guidance on contractor vs. employee classification (consult attorney or accountant)
- NOT a substitute for proper background checks, contracts, or insurance
- NOT a guarantee that caregiver will perform adequately or that relationship will work out

YOUR RESPONSIBILITIES:

- Verify caregiver's background, references, and credentials
- Understand tax obligations if hiring directly (consult accountant or use payroll service)
- Have written agreement outlining duties, schedule, pay, and termination terms
- Obtain workers' compensation insurance if required in your state
- Comply with all labor laws regarding wages, breaks, and hours

When to consult professionals:

- Employment attorney: Before hiring directly, if facing dispute, or if worker claims injury
- Accountant/payroll service: To properly handle payroll taxes and reporting
- Insurance agent: To obtain appropriate liability and workers' comp coverage
- Home care agency: To avoid direct employment complications (agency is employer, not you)

By using these scripts, you acknowledge that hiring and managing caregivers involves legal and financial risks, and you accept responsibility for complying with applicable laws.

HIRING THROUGH AGENCY VS. DIRECT HIRE

Decision Framework:

Agency (Recommended for Most Caregivers):

- **Pros:** Agency handles employment taxes, insurance, background checks, backup coverage
- **Cons:** More expensive ($25-50/hour vs. $15-25/hour for direct hire)
- **Best for:** Caregivers who don't want employer responsibilities

Direct Hire:

- **Pros:** Less expensive, more control
- **Cons:** You are the employer with all legal obligations
- **Best for:** Caregivers comfortable with payroll taxes and risk, or have accountant/lawyer support

These scripts assume you've made hiring decisions and set up legal/financial structure properly.

CAREGIVER NOT FOLLOWING CARE PLAN

Level 1: Direct Feedback

When to use: Paid caregiver is not doing tasks as instructed (skipping medications, not assisting with hygiene, watching TV instead of engaging patient).

Emotional prep: This is an employee performance issue. You're the boss. Be direct.

Care Plan Enforcement Script

I need to talk to you about **[specific issue: medication schedule / personal care / the activity plan]**.

What I observed:

- **[Date/Time]**: **[Specific observation: 2pm medication wasn't given, loved one was in the same clothes two days in a row, etc.]**

What needs to happen:

- **[Specific corrective action: Medications must be given on schedule, loved one needs to be bathed and dressed daily, etc.]**

Going forward:

- I'll be **[checking medication log daily / doing spot checks / asking loved one questions about activities]**
- If this happens again, **[consequence: written warning, shift reduction, termination]**

Is there something preventing you from following the care plan? Do you need more training or clarification?

What to expect after:

- Good caregiver: Apologizes, corrects immediately
- Problem caregiver: Makes excuses, gets defensive, problem continues

If problem continues after this conversation: Move to Level 2.

CAREGIVER CALLING IN SICK FREQUENTLY

Level 2: Pattern Accountability

When to use: Caregiver has called in sick or no-showed multiple times, leaving you scrambling for coverage.

Emotional prep: Chronic unreliability is fireable offense. You need a backup plan.

Attendance Accountability Script

I need to address your attendance.

Pattern I'm seeing:

- Date: Called in sick **[X hours]** before shift
- Date: Called in sick

This has happened **[X times]** in **[timeframe: past month]**.

Impact:

- I have to scramble for last-minute coverage
- **[Name]** doesn't get consistent care
- I can't rely on your schedule

What needs to change:

- If you're sick, I need **[minimum notice: 24 hours]** except true emergencies
- I need you to show up for confirmed shifts
- If you can't commit to this schedule, I need to find someone who can

Going forward:

- One more unexcused absence = **[consequence: termination, shift reduction, probation]**

Is there something I should know about why you're frequently unavailable? Health issue? Schedule conflict?

If pattern continues: Consider termination and hiring a replacement.

PARENT DOESN'T LIKE NEW CAREGIVER

Level 1-2: Distinguish Valid from Invalid Concerns

When to use: your loved one is complaining about a paid caregiver (too bossy, doesn't do things right, wants someone else).

Emotional prep: Distinguish between:

- **Valid concern:** Caregiver is rough, dismissive, not doing job
- **Invalid concern:** Loved one doesn't like being told what to do, resisting care

Validation Assessment Script (To Loved one)

I hear that you're not happy with **[caregiver name]**.

Tell me specifically what's happening.

Questions to ask:

- Is **[caregiver]** being unkind or rough with you?
- Is **[caregiver]** not doing what **[he/she]** is supposed to do?
- Or do you not like being told when to shower/take meds/eat?

If concern is valid (caregiver being inappropriate):

Thank you for telling me. I'm going to **[observe during the next shift / talk to the caregiver / request a different caregiver from the agency]**.

If concern is invalid (patient resistance to care):

I understand you don't like having help. But **[caregiver]** is here to keep you safe.

[He/she] is doing **[his/her]** job—making sure you **[take medications / stay clean / eat meals]**. That's not going to change.

You don't have to be best friends with **[caregiver]**. But I need you to cooperate with basic care.

If **[caregiver]** is unkind or disrespectful, tell me immediately. But if **[he/she]** is just doing **[his/her]** job and you don't like it, that's different.

CAREGIVER BOUNDARY VIOLATIONS

Level 2-3: Immediate Correction or Termination

When to use: Caregiver has violated clear boundaries (using phone excessively, bringing guests, taking food/items from home, being inappropriate).

Emotional prep: Depending on severity, this may be immediate termination offense.

Boundary Violation Script

I need to address **[specific violation: using your phone during work hours, bringing your friend to a shift, taking food from the house without asking]**.

This is a violation of **[our agreement / basic professional boundaries]**.

Severity Level:

Minor (correctable): Excessive phone use, minor task avoidance **Major (fireable):** Theft, bringing unauthorized people, neglect, abuse

If MINOR:

This cannot happen again. Going forward:

- **[Clear expectation: Phone only during breaks, no guests ever, ask before taking anything]**
- If this happens again, **[consequence: written warning, immediate termination]**

Do you understand?

If MAJOR:

This is a serious violation. **[Your employment is terminated immediately / I'm reporting this to [agency/authorities]]**.

Your final paycheck will be **[per legal requirements: mailed/available on X date]**.

[If theft/abuse/neglect:] I am documenting this incident and **[reporting to agency / filing police report / contacting adult protective services]**.

Boundary Conditions:

- **DO terminate immediately** for theft, abuse, neglect, endangerment

- **DO report to agency** if caregiver is agency employee
- **DO document** everything for potential legal/insurance claims
- **DO NOT give second chances** for serious violations

CAREGIVER ASKING FOR RAISE / MORE HOURS

Level 1: Professional Negotiation

When to use: Caregiver requests pay increase or schedule expansion.

Emotional prep: This is a business negotiation. Consider fairly; don't guilt-agree to unsustainable terms.

Raise/Hours Negotiation Script

I appreciate you bringing this to me directly.

Let me think about **[raise request / additional hours]** and get back to you by **[specific date]**.

Questions I need to consider:

- What's the market rate for **[your experience level / certification]** in this area?
- Can I afford **[requested amount / additional hours]**?
- Has your performance earned an increase?

If you're saying yes:

I can **[approve raise of $X/hour starting date / add X hours per week to your schedule]**.

If you're saying no:

I've considered your request. I'm not able to **[increase pay / add hours]** right now because **[reason: budget constraints, current rate is already at market, performance concerns]**.

I value your work, but this is what I can afford.

If caregiver threatens to quit over denial:

I understand if you need to find a position that pays more / offers more hours. I'd be sad to lose you, but I respect your decision.

Let me know if you decide to give notice so I can plan for transition.

Boundary Conditions:

- **DO NOT guilt-agree** to unsustainable pay/hours
- **DO research market rates** before responding
- **DO give clear answer** within reasonable timeframe (don't string caregiver along)

CAREGIVER OVERSTEPPING INTO FAMILY DECISIONS

Level 2: Role Clarification

When to use: Caregiver offering opinions on medical decisions, family dynamics, or care choices beyond their scope.

Emotional prep: They work FOR you, not WITH you as equal decision-maker.

Role Boundary Script

I appreciate that you care about **[Name]**.

I need to clarify boundaries around decision-making.

Your role is to **[provide personal care / administer medications / assist with daily activities / follow care plan]**.

Your role is NOT to **[make medical recommendations / give input on family decisions / tell me how to handle [Name's] care / comment on family dynamics]**.

When you **[specific behavior: suggested I should put Dad in a nursing home, told me I was handling Mom's medication wrong, gave unsolicited advice about family conflict]**, that crossed a line.

Going forward:

- If you observe something concerning about **[Name's]** health, tell me factually (not opinion)
- Medical and care decisions are made by me and **[Name's]** doctors
- Do not offer opinions on family matters

Is this clear?

PARENT BEING ABUSIVE TO CAREGIVER

Level 1-2: Intervene to Protect Caregiver

When to use: Loved one is verbally abusive, demeaning, or hostile to paid caregiver (racist comments, insults, inappropriate demands).
Emotional prep: You are responsible for maintaining respectful environment. Your loved one's behavior may drive away good caregivers.

Caregiver Protection Script (To Loved one)

I need to talk to you about how you're treating **[caregiver name]**.

[He/she] told me that you **[specific behavior: called [him/her] names, made [racist/sexist] comments, yelled at [him/her] for doing [his/her] job]**.

This is not acceptable.

Here's the reality:

- **[Caregiver]** is here to help you
- **[He/she]** is treating you with respect
- If you continue to be **[verbally abusive / demeaning]**, **[caregiver]** will quit
- No one else will want to work here if you treat them like this

What needs to change:

- You speak to **[caregiver]** politely
- You follow **[his/her]** care instructions
- No insults, no demeaning comments

If you can't do this, we'll have to **[find facility placement where staff is trained to handle difficult behavior / accept that you won't have consistent care]**.

To Caregiver (privately):

I'm sorry my **[loved one]** is treating you this way. It's not okay. I've spoken to **[him/her]** about it. If it continues, please tell me immediately.

If you decide this isn't workable for you, I understand. I'll provide a good reference if you leave.

SETTING UP CAREGIVER FOR SUCCESS (ORIENTATION)

Level 0: Proactive Training

When to use: New caregiver's first day/week—preventing problems through clear expectations.

Caregiver Orientation Checklist

On Day 1, provide written:

Care Plan Overview:

- **[Name]**'s diagnoses and conditions
- Mobility status (walker, wheelchair, transfer needs)
- Cognitive status (alert, confused, dementia stage)
- Medication schedule (provide written list with times/doses)
- Dietary restrictions/preferences
- Bathroom/toileting needs
- Skin care/wound care needs (if applicable)

Daily Schedule:

- Morning routine (wake time, breakfast, hygiene)
- Activity expectations (walk, engage in conversation, TV okay but not default)
- Meal prep responsibilities
- Afternoon routine
- Evening routine (dinner, medications, bedtime)

Boundaries:

- Phone use: **[Only during breaks / emergency calls only]**
- Food: **[Help yourself to X, ask before taking Y]**
- Visitors: **[No guests allowed]**

- Smoking: **[Not on property / outside only during breaks]**

Emergency Protocols:

- If **[Name]** falls: **[Call 911, then call me]**
- If **[Name]** refuses care: **[Call me, don't force]**
- If medical emergency: **[Call 911 first, then me]**
- My contact: **[Phone]** (I answer or call back within X time)

Household Rules:

- Shoes on/off?
- Pets (if applicable): **[Do not feed, let in/out, etc.]**
- Cleaning duties: **[Wash dishes you use, tidy common areas, laundry if needed]**

Questions?

Let's do the first shift together so I can show you where everything is and how **[Name]** likes things done.

The Public & Extended Circle

SOCIAL BOUNDARIES DISCLAIMER

This chapter provides communication language for managing extended family, friends, neighbors, and community members. It is NOT a guarantee that relationships will be preserved or that social consequences can be avoided.

Setting boundaries with extended circle may result in:

- Relationship damage or loss
- Being labeled "difficult," "ungrateful," or "cold"
- Social isolation (people may avoid you to avoid discomfort)
- Family members siding against you
- Loss of informal support network

These scripts prioritize your capacity and your immediate family unit over extended circle expectations. This is a valid choice, but it has social costs.

What this chapter is NOT:

- NOT a guarantee that extended family will respect boundaries
- NOT advice for managing complex family estrangements or abuse (seek therapist)
- NOT legal advice about defamation, harassment, or restraining orders

When to consult professionals:

- Therapist: If extended family conflict is severe or you're being scapegoated
- Attorney: If family member is engaging in harassment, stalking, or making false accusations

EXTENDED FAMILY OFFERING UNSOLICITED ADVICE

Level 0-1: Polite Deflection

When to use: Aunt, cousin, family friend, or distant relative giving you unwanted medical/care advice.

Emotional prep: They mean well (usually). Keep it light.

Advice Deflection Script

Thank you for thinking of us.

Right now, **[Name]** has a medical team managing **[his/her]** care, and we have a plan that's working.

I appreciate you sharing what worked for **[your family member]**, but every situation is different.

If I need additional input, I'll definitely reach out.

If they persist:

I hear that you have strong feelings about this.

I'm not looking for advice right now—I'm working with **[Name's]** doctors on the care plan.

Let's talk about something else. How are you doing?

CHURCH/COMMUNITY GROUP EXPECTING YOU TO PARTICIPATE

Level 1-2: Capacity Boundary

When to use: Community members (church, volunteer group, social organization) expecting continued participation despite caregiving demands.

Emotional prep: You cannot be everything to everyone. Give yourself permission to step back.

Community Participation Boundary Script

I appreciate **[organization]**'s support and community.

I need to let you know that I'm stepping back from **[specific role/commitment: weekly volunteer shift, committee position, regular attendance]** for now.

I'm managing caregiving responsibilities for my **[loved one]**, and I don't have the capacity to **[show up consistently / take on responsibilities / be reliable]**.

What I can do: (Choose realistic option)

- Nothing right now (and that's okay)
- Attend occasionally when I have capacity
- Contribute **[specific limited way: financially, one-time help, etc.]**

What I cannot do:

- Commit to regular attendance
- Take on roles that require reliability
- Feel guilty for prioritizing my family's needs right now

I hope to be more involved again when things stabilize. For now, I need to focus on what's in front of me.

Thank you for understanding.

NEIGHBORS COMPLAINING ABOUT CAREGIVING IMPACT

Level 2: Factual Response

When to use: Neighbors complaining about:

- Increased traffic (aides, medical equipment, family visitors)
- Noise (yelling, confusion, night disturbances)
- Property appearance (medical equipment visible, less maintenance)

Emotional prep: You may be violating HOA rules or creating legitimate nuisance. Address factually.

Neighbor Complaint Response Script

I understand you're concerned about **[specific issue: increased cars, noise, etc.]**.

Here's what's happening: I'm managing care for my **[loved one]** who has **[condition]**. This requires **[specific situation: home health aides during the day, medical equipment, occasional emergency situations]**.

What I can do:

- **[Specific mitigation: park in driveway, add soundproofing, maintain yard, etc.]**

What I cannot do:

- Eliminate all impact (this is medical necessity)
- Hide the fact that **[Name]** lives here and requires care

I'm doing my best to be considerate while managing a difficult situation.

If there's a specific, reasonable accommodation I can make, I'm open to discussing it.

If neighbor threatens HOA complaint or legal action:

I understand you're frustrated.

If you need to **[file complaint / contact HOA]**, that's your right.

I'm complying with **[applicable laws: fair housing, disability accommodations]** and doing what's necessary to care for a family member.

EXTENDED FAMILY DEMANDING VISITATION

Level 2: Visiting Protocol

When to use: Extended family members wanting to visit loved one frequently, without regard for their capacity or your schedule.

Emotional prep: You control access. You are the gatekeeper.

Visitation Boundary Script

I know you want to visit **[Name]**.

Right now, visits need to be coordinated in advance because:

- **[Name]** tires easily and can only handle **[X length]** visits
- **[Name's]** medical schedule (appointments, therapy, rest periods) is complex
- I'm managing care and can't accommodate drop-in visits

New visiting protocol:

- Call/text me at least **[24/48 hours]** in advance to request visit time
- I'll let you know if that works with **[Name's]** schedule
- Visits are **[X duration: 30 min, 1 hour]** max
- **[Specific rules: No perfume/cologne, no bringing food, must stay if loved one has an outburst, etc.]**

This isn't about keeping you away—it's about protecting **[Name's]** health and managing the household.

If family member shows up unannounced:

I appreciate you wanting to see **[Name]**, but I asked you to call first.

Now is not a good time. **[Name]** is **[resting / having medical care / not feeling well]**.

Please call me tomorrow and we'll schedule a visit.

If they insist: I'm going to have to ask you to leave. This is my home, and I need you to respect my boundaries about visits.

EXTENDED FAMILY CRITICIZING CARE CHOICES

Level 2-3: Authority Clarification

When to use: Extended family member (sibling of loved one, distant relative, in-law) publicly criticizing your caregiving decisions.

Emotional prep: You do not answer to extended family. Shut this down.

Care Decision Authority Script

I understand you have opinions about **[Name’s]** care.

Let me be clear about who makes care decisions:

Decision-makers:

- **[Name]** (when capable)
- **[Name’s]** healthcare power of attorney: me *(if true)*
- **[Name’s]** medical team

Not decision-makers:

- Extended family who are not involved in daily care
- People who visit occasionally and have opinions

You are welcome to:

- Visit **[Name]** (when coordinated with me)
- Offer emotional support
- Share your concerns privately with me

You are NOT welcome to:

- Publicly criticize care decisions
- Undermine medical team's recommendations
- Tell me how to care for **[Name]** when you're not here daily

If you continue to **[specific behavior: post on Facebook about how I'm handling things, tell other family members I'm making wrong decisions, confront me at family events]**, I will **[consequence: limit your access to information, reduce your visiting privileges, stop engaging with you about [Name’s] care]**.

FRIENDS DISAPPEARING BECAUSE CAREGIVING IS "TOO MUCH"

Level 0: Acceptance + Self-Protection

When to use: Friends who used to be present have stopped calling, inviting you out, or engaging because they "don't know what to say" or your situation is uncomfortable.

Emotional prep: This hurts. Grieve the loss. Recognize who shows up and who doesn't.

Friend Loss Acknowledgment (To Self)

This is not a script for them. This is internal processing for you.

What's happening:

- **[Friend name]** has stopped reaching out
- **[Friend name]** declined last 3 invitations with vague excuses
- **[Friend name]** avoids asking how I'm doing

Reality check:

- Some friendships are "good times only" friendships
- Some people cannot handle discomfort or neediness
- This is information about who they are, not about your worth

What you can do:

- Stop initiating with people who consistently don't reciprocate
- Invest energy in relationships that ARE showing up
- Accept that your circle may get smaller right now (that's okay)

What you cannot do:

- Force people to care
- Make them comfortable with your hard reality

- Pretend everything is fine to keep them around

If you want to address it directly (optional):

Hey, I've noticed we haven't connected in a while.

I'm not sure if it's because you're busy or because my caregiving situation is uncomfortable to be around.

If it's the latter, I get it. I'm hard to be friends with right now—I'm stressed, I can't do fun things easily, and I talk about hard stuff.

I miss you, but I also need friends who can handle where I'm at.

If that's not you, no hard feelings. If it is, I'd love to **[specific small ask: text sometimes, grab coffee when I have a break]**.

SOCIAL MEDIA BOUNDARY (People Commenting on Your Caregiving Posts)

Level 1: Digital Boundary

When to use: You posted about caregiving on social media; people are commenting with unsolicited advice, judgment, or unwanted input.

Emotional prep: You control your digital space. Delete, block, or limit as needed.

Social Media Boundary Script (Comment/DM Response)

Thank you for your concern.

I'm sharing to process, not to solicit advice.

If I need input, I'll ask directly.

If comments continue or become hostile:

I'm turning off comments on this post / limiting who can see my posts going forward.

My social media is for connection with people who support me, not debate about my choices.

LOVED ONE'S FRIENDS/COMMUNITY BYPASSING YOU

Level 2: Information Gatekeeper

When to use: your loved one's friends, church members, or community calling/visiting them directly, getting them upset or confused, making promises they can't keep.

Emotional prep: You filter communication for your loved one's wellbeing. This is protective, not controlling.

Communication Gatekeeper Script

I appreciate that you care about **[Name]**.

I need to ask that future contact go through me first.

Here's why:

- **[Name]** gets confused/overwhelmed by unexpected calls or visits
- **[Name]** sometimes agrees to things **[he/she]** can't follow through on
- I'm managing **[his/her]** schedule and need to coordinate

Going forward:

- Text or call ME to arrange visit/call with **[Name]**
- I'll coordinate time that works
- If **[Name]** calls you directly and seems confused, please let me know

This isn't about cutting you off—it's about protecting **[Name]** from stress and confusion.

Thank you for understanding.

Self-Talk (Inner Boundaries)

MENTAL HEALTH DISCLAIMER

This chapter provides reframing language for common negative thought patterns. It is NOT therapy, clinical treatment, or a substitute for professional mental health care.

WHEN SELF-TALK SCRIPTS ARE NOT ENOUGH:

If you are experiencing:

- Suicidal thoughts
- Severe depression (inability to get out of bed, loss of interest in everything, hopelessness lasting weeks)
- Panic attacks
- Rage that feels uncontrollable
- Emotional numbness (can't feel anything)
- Self-harm urges
- Substance abuse to cope

STOP. CALL:

- **988 Suicide & Crisis Lifeline:** Call or text 988
- **SAMHSA National Helpline:** 1-800-662-4357
- **Your doctor or therapist immediately**
- **911 if in immediate danger**

These scripts are for normal caregiver guilt and burnout thoughts. They are NOT treatment for clinical mental health conditions.

If you've been using these reframes for weeks and still feel terrible, **see a therapist.** Caregivers are at high risk for depression and anxiety. Medication and professional therapy may be necessary.

THE GUILT LOOP: "I'm Not Doing Enough"

Thought pattern: No matter how much I do, it feels like I should be doing more. I feel guilty when I rest, guilty when I set boundaries, guilty when I feel resentful.

Reframe Script (To Yourself)

Old thought: "I'm not doing enough. A good daughter/son would do more."

New thought: "I am doing **[specific amount: 15 hours a week, daily visits, managing all medical appointments]**. That IS enough.

'Enough' is not defined by **[Name's]** infinite needs. It's defined by my actual capacity.

I can meet **[X specific responsibilities]** sustainably. Beyond that breaks me, which helps no one.

Guilt is not evidence I'm failing. Guilt is evidence I was raised in a culture that tells me self-preservation is selfish.

It's not."

Daily practice: When guilt spike hits, list 3 specific things you DID today:

1. **[Specific task]**
2. **[Specific task]**
3. **[Specific task]**

Say out loud: "I did **[X]**. That is enough."

THE RESENTMENT SPIRAL: "I Hate Them For Needing Me"

Thought pattern: I'm angry at my loved one for being sick/needy. Then I feel guilty for being angry. Then I feel like a terrible person.

Reframe Script (To Yourself)

Old thought: "I'm a terrible person for resenting my own loved one. What's wrong with me?"

New thought: "Resentment is a normal human response to having my life consumed by someone else's needs.

It doesn't mean I don't love **[Name]**. It means I'm exhausted and grieving my own life.

I can feel two things at once: Love AND resentment. Compassion AND anger. Duty AND desire to run away.

All of these are normal.

I'm not a terrible person. I'm a burned-out person having predictable emotional responses to an impossibly hard situation.

The thought 'I hate them' doesn't make me a monster. Acting on it would. I'm not acting on it. I'm showing up anyway."

Daily practice: When resentment hits:

1. Name it: "I'm feeling resentful right now."
2. Validate it: "That's understandable given **[specific situation]**."
3. Separate feeling from action: "I can feel this AND still **[do the next necessary thing]**."

Permission statement: "I give myself permission to feel resentment without shame."

THE COMPARISON TRAP: "Other People Do This Better"

Thought pattern: Everyone else seems to handle caregiving gracefully. I'm falling apart. What's wrong with me?

Reframe Script (To Yourself)

Old thought: "My sister is handling this so much better than me. She's not falling apart."

New thought: "I have no idea how my sister (or anyone else) is actually doing. I see their outsides, not their insides.

They might be:

- On antidepressants
- In therapy twice a week
- Crying every night
- About to crack

Or they might genuinely be fine because:

- Their situation is different (less hours, more help, more money)
- Their personality is different (less anxious, more detached)
- Their relationship with **[Name]** is different

Either way, it doesn't matter.

I am not them. My capacity is mine.

Comparing my inside experience to someone else's outside performance is self-torture with no benefit.

The only question that matters: Am I doing what I can sustain? If yes, I'm doing it right."

Daily practice: When comparison thought hits: "Their path is not mine. I'm doing this MY way, and that's valid."

THE MARTYR SCRIPT: "If I Don't Do It, No One Will"

Thought pattern: I have to do this alone because no one else will step up. I'm the only one who cares. I have no choice.

Reframe Script (To Yourself)

Old thought: "If I don't do this, **[Name]** will suffer. I have no choice."

New thought: "**I always have choices.** They might all be hard choices, but I'm choosing.

Right now, I'm choosing to provide **[X level of care]**.

If I stopped, **[Name]** would not die alone in a gutter. **[Name]** would:

- Have to accept paid help
- Have to move to facility
- Have siblings step up (or face consequences of not stepping up)
- Have to accept reduced care

None of those are ideal. But they're also not my responsibility to prevent by destroying myself.

I am not the only person who can care for [Name]. I am the only person currently WILLING to do it at this level.

Those are different things.

If I set a boundary and **[Name]** suffers because no one else steps up, that is THEIR failure, not mine."

Daily practice: Write down: "Things that would happen if I stopped caregiving completely today."

Reality-check the catastrophic fantasies. Most are not true.

Permission statement: "I am allowed to let other people face consequences of their choices (or lack of action)."

THE FUTURE PANIC: "This Will Never End"

Thought pattern: I can't do this for 5 more years / 10 more years / indefinitely. I'm trapped forever.

Reframe Script (To Yourself)

Old thought: "I'm going to be doing this until **[Name]** dies. I can't survive that long."

New thought: "I don't have to do this for 5 years. I have to do this TODAY.

Tomorrow is not here yet. I cannot survive the imagined future—I can only survive right now.

Right now, I am surviving.

Also, reality check:

- [Name]'s condition will change (progression, decline, crisis that forces facility placement)
- My capacity might increase (kids grow up, job changes, I get help)
- I might choose differently in 6 months (and that's allowed)

I am not signing a lifetime contract. I'm making a choice for today.

If this becomes unsustainable, I will make different choices WHEN THAT HAPPENS. Not now.

Right now, I put one foot in front of the other.

That's all I have to do."

Daily practice: When future panic hits:

- Bring attention back to the present: "What is my next task in the next hour?"
- Do only that task
- Repeat

Permission statement: "I'm allowed to change my mind about what I can handle."

BONUS REFRAME: The Permission List

When to use: When you need explicit permission to do something caregiving culture says is "selfish."

Read this list out loud when guilt is overwhelming:

I give myself permission to:

✓ **Take a day off without guilt**

✓ **Say no to requests I cannot fulfill**

✓ **Feel angry at [Name] for being sick**

✓ **Resent my siblings for not helping**

✓ **Put my marriage before [Name]'s preferences**

✓ **Protect my children from caregiver stress**

✓ **Choose facility placement if home care is destroying me**

✓ **Let [Name] be unhappy with my decisions**

✓ **Prioritize my own health appointments**

✓ **Spend money on respite care instead of saving it**

✓ **Tell people "I can't" without justifying why**

✓ **Cry, rage, fall apart, and still be doing a good job**

✓ **Survive this however I need to survive this**

✓ **Be imperfect, inconsistent, and still be enough**

These permissions are not conditional on:

- Doing "enough" first
- Earning them through suffering
- Other people agreeing with them
- [Name] being okay with them

They are yours by virtue of being a human with limits.

Escalation Follow-Up Scripts

Escalation Level 1 — Boundary Restatement (When Initial Script Challenged)

I understand you're **[family member reaction]**.

The boundary I stated is not changing.

[Restate core boundary from original script in 1 sentence]

If you test this again, **[consequence]**.

Escalation Level 2 — Consequence Implementation Notice (When Boundary Violated After Restatement)

You **[specific violation]**.

I said **[consequence]** would happen if you did this.

As of **[date/now]**, **[consequence implementation]**.

We can revisit this in **[timeframe]** if **[condition]**.

Escalation Level 3 — Final Boundary / Relationship Redefinition (When Consequence Also Violated)

[PATTERN SUMMARY]

Over **[timeframe]**, you've:

- **[Violation 1]**
- **[Violation 2]**
- **[Violation 3]**

I set boundaries. You ignored them.

I implemented consequences. You kept pushing.

[RELATIONSHIP REDEFINITION]

Going forward:

[Option A: Restricted Re-engagement] Our relationship is now limited to **[specific restricted interaction]**.

I will not **[list what caregiver is no longer doing]**.

If you can demonstrate **[specific behavioral change]** for **[timeframe]**, we can discuss expanding contact.

[Option B: Complete Disengagement] I'm done.

I can't provide care for **[Name]** while managing your **[pattern]**.

From now on, all communication about **[Name]**'s care goes through **[third party]**.

Do not contact me directly.

Sibling-Specific Escalation — Paid Caregiver Substitution Notice

NOTE: Only request financial contributions you are legally entitled to request, and never represent an obligation that has not been legally established. Consult an attorney about whether you have legal grounds to pursue compensation (such as through caregiver contracts, unjust enrichment claims, or estate claims). Small claims procedures and substantive law vary significantly by jurisdiction.

TO: [Sibling Name]
RE: Paid Caregiver Billing — [Name]'s Care

You committed to **[specific help promised]** on **[dates of commitment]**.

You failed to show **[number]** times: **[list dates]**.

I can't provide **[Name]**'s care without reliable help.

Effective [date], I'm hiring **[service provider]** for **[hours/services]** at $**[amount]**/**[time period]**.

Your share: $**[amount]**/**[time period]**.

Payment due: [date] via [payment method]

If payment not received by **[deadline]**, I will:

1. **Reduce my own care hours** to match what I can sustain without your help
2. **Notify [Name]** that **[he/she]** will need **[alternative care arrangement]** for hours I can no longer cover
3. **Consider small claims court** for unpaid care expenses if you continue refusing

You had the option to contribute time. You chose not to show up. This is the financial alternative.

[Caregiver Name], [Date]

Loved one-Specific Escalation — Caregiver Availability Reduction Notice

I'm currently providing **[number]** hours of care per week.

That's not sustainable.

Starting [date], my availability is **[reduced hours/days/specific schedule]**.

For the remaining **[hours/days]** you need coverage, you have these options:

Option 1: [Paid home care service] — $**[amount]**/**[time period]Option 2: [Adult day program]** — $**[amount]**/**[time period] Option 3: [Facility placement]**

If you don't choose by **[deadline]**, I'll arrange **[default option]**.

This isn't negotiable. I'm telling you what I can sustain, not asking for permission to have limits.

Medical Provider Escalation — Formal Complaint Notification

WARNING: Filing false complaints with regulatory agencies may constitute filing a false report, fraud, or abuse of process under state and federal law, which can result in criminal prosecution, civil liability, and fines. Only file complaints if every statement you make is truthful and based on facts you can prove with documentation. If unsure whether your concerns meet reporting standards, consult with an attorney or patient advocate before filing.

TO: [Provider/Facility Name] — [Administrator/Compliance Officer]
CC: [Relevant Department Heads]
RE: Formal Complaint Notification — Patient [Name]

This letter notifies you that I am filing formal complaints with the following regulatory bodies regarding care provided to **[Name]**:

[Select applicable:]

- **State Medical Board** — [License # of provider if applicable]
- **State Department of Health** — Facility Inspection Division
- **Centers for Medicare & Medicaid Services (CMS)** — Quality Improvement
- **Joint Commission** — Patient Safety Concerns
- **U.S. Department of Health & Human Services, Office for Civil Rights** — HIPAA violations
- **State Insurance Commissioner** — Insurance complaints

Pattern of Violations:

1. **[Date]**: **[Specific incident]**
2. **[Date]**: **[Specific incident]**
3. **[Date]**: **[Specific incident]**

Attached:

- Copies of all communications
- Documentation of reported symptoms/concerns
- Medical records (if obtained)
- Billing statements showing services (if relevant)

Remedies Sought:

- **[Specific request]**
- **Provider review by [relevant authority]**
- **Compensation for [financial harm if applicable]**

I am providing **[5 business days]** for you to remedy the above violations before I finalize formal complaints.
Contact me at **[phone/email]** if you wish to discuss resolution.

[Caregiver Name], [Date]

Bonus Resources

Extinction Burst Survival Guide

IMPORTANT: The "extinction burst" concept applies to boundary-testing behavior by people who are generally rational but resistant to change. This guide does NOT apply to situations involving: active domestic violence, untreated severe mental illness, active substance abuse, or anyone who has been physically violent in the past. If you feel unsafe, the advice to "hold the boundary" does not apply—prioritize your physical safety and contact domestic violence resources or law enforcement. This is behavioral psychology education, not safety planning for dangerous relationships.

What's Happening Right Now

You set a boundary.

Your **[sibling/parent/family member]** is **[escalating/guilt-tripping harder/threatening/angry]**.

You're wondering: *"Did I do this wrong? Should I back down?"*

No.

This reaction is called an **extinction burst**, and it means your boundary is working.

Why Boundaries Make Things Worse First

When you've always said yes, family members learn: "If I push hard enough, **[Caregiver Name]** will cave."

When you suddenly say no, their first response is: *"I just need to push HARDER."*

This is not conscious manipulation. It's learned behavior.

The pattern that worked before (pushing until you give in) is suddenly not working, so they escalate to force the old pattern back.

Expected escalations:

- Guilt trips intensify
- Threats
- Recruiting allies

- Accusations

How Long This Lasts

Peak escalation: 48-72 hours after boundary set

Most extinction bursts resolve within **3-7 days** if you hold the boundary.

If you back down during the escalation, you've taught them: *"I just have to escalate MORE next time."*

What You're Feeling (And Why It's Normal)

Guilt spike: You feel MORE guilty after setting the boundary than before.

This is paradoxical but normal.

Before the boundary, guilt was diffuse background noise.

After the boundary, guilt is acute and specific: *"I'm causing this pain right now."*

The guilt spike indicates the boundary is working.

If you felt no guilt, the boundary probably didn't threaten the exploitative pattern.

Why this is actually good:

Setting boundaries activates this guilt because you're asserting self-preservation in a culture that frames that as "selfish."

The guilt is not evidence you did something wrong. It's evidence you challenged a system that was exploiting you.

What To Do During Extinction Burst

1. Hold the boundary verbatim

Do not soften it.Do not negotiate.Do not explain more.Do not apologize for having limits.

Repeat the exact boundary language from your script if challenged.

2. Use Escalation Script if pushed

If family member violates boundary, move to **Escalation Level 1** script.

If they violate again, move to **Escalation Level 2**.

3. Document escalation behaviors

If a family member threatens self-harm: Call emergency services (911). If a family member threatens you: Document, consider restraining order. If a family member recruits flying monkeys: Send identical boundary statements to anyone who contacts you.

4. Get external support (NOT from family system)

Talk to: therapist, friend outside family, support group, crisis hotline.

Do NOT seek validation from people in the family system, they may be invested in you staying compliant.

5. Remind yourself of the alternative

If you back down now, you're teaching them that escalation works.

Next time you set a boundary, they'll escalate faster and harder.

The only way to stop extinction bursts is to survive one without backing down.

When to Retreat (Safety Exceptions)

Retreat if:

- Family member becomes physically violent or threatens imminent violence
- Your physical safety is at risk
- You're in active danger

In these cases:

- Remove yourself from situation immediately
- Call 911 if necessary
- Contact domestic violence resources
- Boundary enforcement requires safety first

Distinguish between:

- **Emotional escalation** (guilt trips, anger, threats to cut off contact) → Hold boundary

- **Physical danger** (violence, credible threats of harm) → Prioritize safety, retreat, involve authorities

After the Extinction Burst

If you hold the boundary for **7-10 days** without backing down, family members will typically:

1. **Test once or twice more** (lighter testing)
2. **Accept the boundary** (grudgingly)
3. **Adjust behavior** (may take weeks/months for full adjustment)

Or:

1. **Disengage entirely** (cut off contact rather than respect boundary)

Outcome 4 is not your failure. It means the relationship only worked when you had no limits.

That's not a relationship—that's exploitation.

The Capacity Calculation Worksheet

Purpose

This worksheet calculates your **actual sustainable caregiving capacity**.

Not what you "should" be able to handle.Not what **[Name]** needs.Not what your family expects.

Your capacity. Based on math.

Step 1: Calculate Total Available Hours

168 hours in a week

Subtract REQUIRED time (non-negotiable):

Category	Hours / Week	Your Number
Sleep (minimum 6 hrs/night × 7)	42	
Work (including commute)		
Childcare (if applicable)		
Basic self-maintenance (eating, hygiene, medical appointments)	14	
TOTAL REQUIRED TIME		

REMAINING AVAILABLE HOURS = 168 - [Total Required] = ____

This is your **absolute maximum discretionary time per week.**

Step 2: Allocate Discretionary Time

Of your remaining ____ **hours**, allocate to:

Category	Hours / Week	Your Number
Relationship maintenance (partner, kids, friends)		
Essential life management (bills, grocery, home maintenance)		
Physical health needs (exercise, preventive care)		
Mental health minimum (therapy, decompression, hobbies)		
TOTAL OTHER COMMITMENTS		

REMAINING FOR CAREGIVING = [Remaining Available] - [Total Other Commitments] = ____

Step 3: Calculate Current Caregiving Load

Caregiving Task	Hours / Week	Your Number
Direct hands-on care (bathing, dressing, feeding, medication)		
Medical appointment accompaniment (including travel)		
Medical coordination (calling doctors, insurance, pharmacy)		
Household tasks for **[Name]** (cleaning, laundry, shopping)		
Financial management for **[Name]** (bills, paperwork)		
Crisis response time (ER visits, urgent calls)		
TOTAL CURRENT CAREGIVING LOAD		

Step 4: Identify the Gap

Your sustainable caregiving capacity: ____ hours/week (from Step 2)

Your current caregiving load: ____ hours/week (from Step 3)

GAP = [Current Load] - [Sustainable Capacity] = ____ hours/week

Step 5: Interpret Your Gap

If gap is 0 or negative: You're operating within capacity (rare). Boundaries are still valid for specific situations but capacity isn't exceeded.

If gap is 1-10 hours/week: Manageable with minor adjustments. Specific task boundaries or schedule modifications may be sufficient.

If gap is 11-30 hours/week: Significant unsustainable overload. Requires help (family or paid) for 11-30 hours/week worth of tasks.

If gap is 31+ hours/week: Crisis-level exploitation. Requires major intervention: paid help, facility placement, or family distribution of 31+ hours/week of work.

Step 6: Create Your Boundary Data

Use these numbers in your boundary scripts:

"I'm currently providing ____ hours of care per week. My sustainable capacity is ____ hours per week. That's a gap of ____ hours that need to be covered by [paid help/sibling help/reduced services]."

"I can provide ____ hours per week ongoing. Beyond that, you need [paid help/facility care]."

Step 7: Identify Specific Tasks to Offload

From Step 3 (Current Caregiving Load), identify **____ hours** worth of tasks that MUST be offloaded to close the gap.

Tasks to offload (specific enough to delegate or hire out):

1. ____ (____ hrs/week)
2. ____ (____ hrs/week)
3. ____ (____ hrs/week)
4. ____ (____ hrs/week)
5. ____ (____ hrs/week)

Use this list in scripts:

*"I need **[Sibling]** to cover **[Task 1]** and **[Task 2]**, or contribute $**[amount]**/month for paid help."*

*"I can no longer provide **[Task 3]** and **[Task 4]**. Here are three agencies that provide that service."*

Why This Math Matters

Caregivers are socialized to ignore capacity limits.

Family, medical system, culture all act as if caregiving demand should automatically create caregiving capacity.

It doesn't.

Your body still needs sleep.Your employer still requires work hours.Your other relationships still need maintenance.

This worksheet gives you factual data to replace emotional manipulation:

Manipulation: *"If you loved me, you'd make time."***Data:** *"I'm already providing 35 hours/week. There are only 168 hours in a week. The math doesn't work."*

Manipulation: *"Other people manage."***Data:** *"Other people have paid help, or they're not working 40 hours/week, or they've sacrificed their health. Here's my actual capacity: X hours. What's yours?"*

Manipulation: *"You're being selfish."***Data:** *"I'm providing X hours/week. You're providing Y hours/week. Selfishness isn't asking for help—it's demanding I exceed physical capacity while you do nothing."*

Script Customization Guide

The Structural Integrity Problem

The scripts in The Crisis Deck work because of **specific structural elements**.

If you remove or soften these elements, the script loses its force.

This guide teaches you what you CAN change vs. what you CANNOT change.

What You CANNOT Change (Structural Elements)

1. Binary Choices

Why it exists: Eliminates avoidance; forces decision.

Examples in scripts:

- *"your time or your money"*
- *"Do physical therapy OR we arrange for full-time aide"*
- *"Accept paid help OR accept reduced coverage"*

DO NOT soften to:

- ~~"Would you be willing to help OR maybe contribute financially if that works better for you?"~~
- ~~"Let me know what you think about these options"~~
- ~~"Whatever you can do would be appreciated"~~

Customization allowed: Change the SPECIFIC choices, but maintain binary structure.

Example:

- Original: *"your time or your money"*
- Customized: *"cover weekends OR pay for weekend aide"* ✓

2. Specific Deadlines

Why it exists: Prevents indefinite delay; creates accountability.

Examples in scripts:

- *"Let me know by **[day + time]**"*
- *"Starting **[date]**"*
- *"I need responses from everyone by **[date + time]**"*

DO NOT soften to:

- ~~"Let me know when you get a chance"~~
- ~~"Soon"~~
- ~~"As soon as possible"~~

Customization allowed: Change the DATE, but always include specific date + time.

Example:

- Original: *"Let me know by Friday at 5 PM"*
- Customized: *"Let me know by Tuesday at noon"* ✓

3. Dollar Amounts

Why it exists: Makes financial alternatives concrete and actionable; prevents vague promises.

Examples in scripts:

- *"$25/hour"*
- *"$800/month"*
- *"we split the $1,200 invoice"*

DO NOT soften to:

- ~~"help with costs"~~
- ~~"contribute what you can"~~
- ~~"a reasonable amount"~~

Customization allowed: Change the AMOUNT to match your actual costs, but always include exact numbers.

Example:

- Original: *"$25/hour, we split the invoice"*
- Customized: *"$30/hour, we split the weekly bill"* ✓

4. Authority References

Why it exists: Transfers legitimacy from caregiver to external expert; reduces "you're just being difficult" accusations.

Examples in scripts:

- *"Dr. Chen reviewed..."*
- *"The social worker said..."*
- *"According to the discharge planner..."*

DO NOT soften to:

- ~~"I think..."~~
- ~~"It seems like..."~~
- ~~"In my opinion..."~~

Customization allowed: Change the SPECIFIC authority figure, but always attribute it to external experts.

Example:

- Original: *"Dr. Chen reviewed Dad's care log"*
- Customized: *"The physical therapist evaluated Mom's mobility"* ✓

5. Non-Negotiability Statements

Why it exists: Prevents re-opening debate; establishes finality.

Examples in scripts:

- *"This isn't negotiable"*
- *"I'm not asking for permission"*
- *"This is what I need"*

DO NOT soften to:

- ~~"I really hope you can understand"~~
- ~~"Please consider this"~~
- ~~"I'd appreciate it if..."~~

Customization allowed: NONE. Use verbatim.

What You CAN Change (Content Variables)

Variables You SHOULD Customize:

All **[bracketed variables]** are meant to be replaced with your specific details:

- **[Name]** → Your loved one's name or "Mom"/"Dad"
- **[Sibling]** → Sibling's name
- **[Doctor Name]** → Actual doctor name
- **[Specific time commitment]** → Actual hours/days needed
- **[Deadline]** → Actual date + time
- **[Amount]** → Actual dollar amount from quotes you've received
- **[Service name]** → Actual agency/service you've researched
- **[Symptoms]** → Actual symptoms you're observing
- **[Care log/medical assessment]** → Actual document being referenced

Common Softening Mistakes to Avoid

Mistake 1: Adding Qualifiers

DON'T:

- ~~"I *kind of* need..."~~
- ~~"I *think* I need..."~~
- ~~"If *possible*, could you..."~~

DO:

- "I need..."

Mistake 2: Seeking Permission

DON'T:

- ~~"Would it be okay if..."~~
- ~~"Do you think you could..."~~
- ~~"Is there any chance..."~~

DO:

- "I need..." or "You need to..."

Mistake 3: Apologizing for Boundaries

DON'T:

- ~~"I'm sorry, but..."~~
- ~~"I hate to do this, but..."~~
- ~~"I feel terrible about this, but..."~~

DO:

- "I understand this is hard to hear." (acknowledgment, not apology)

Mistake 4: Offering Too Many Options

DON'T:

- ~~"You could do Option A, or Option B, or maybe Option C, or if none of those work, we could brainstorm other ideas..."~~

DO:

- "Option A or Option B. Which one?" (binary only)

Mistake 5: Using Vague Language

DON'T:

- ~~"soon"~~
- ~~"when you can"~~
- ~~"a reasonable amount"~~
- ~~"if you're able"~~

DO:

- "by **[specific date + time]**"
- "now" or "starting **[date]**"
- "$**[exact amount]**"
- "commit to **[specific action]**"

When You Should NOT Customize

Don't customize if:

1. **You're softening because you feel guilty** → Use the Extinction Burst guide instead; hold the script as written
2. **Family member asked you to soften it** → That's them testing the boundary; hold firm
3. **You think it sounds "too mean"** → Force level is intentional; it works because it's firm
4. **You want to add explanations** → Scripts are deliberately short; don't dilute

The scripts work because they're structurally sound, not because they're polite.

Hiring Paid Help — Resource Navigator

When to Use This Guide

You need this if:

- Your capacity calculations show a gap you can't close
- Siblings refuse to help (time or money)
- Your loved one needs care you can't/shouldn't provide
- You're approaching burnout and need coverage

This guide walks you through finding and hiring paid caregiving help.

STEP 1: Determine What Help You Need

Go back to your **Capacity Calculation Worksheet**.

Look at **Step 7: Tasks to Offload.**

Categorize tasks by skill level required:

Skill Level	Tasks	Examples
Companion Care (non-medical)	Supervision, meal prep, light housekeeping, transportation, companionship	Sitting with a loved one while you work; driving to appointments; cooking meals
Personal Care (ADL assistance)	Bathing, dressing, toileting, mobility assistance, feeding	Help getting in/out of the shower; assistance with dressing
Skilled Nursing (medical)	Medication administration, wound care, catheter care, IV therapy, injections	Post-surgical wound care; managing complex medication schedules
Specialized Care	Dementia care, hospice care, physical therapy, occupational therapy	Behavioral management for Alzheimer's; end-of-life care

Write down which level(s) you need: ____________________________

STEP 2: Understand Your Options

Option A: Home Care Agency

What it is: Company that employs/contracts caregivers; sends them to your home.

Pros:

- Agency handles hiring, background checks, insurance, backup coverage
- You call agency if caregiver doesn't show; they send replacement
- Caregivers trained by agency
- Agency licensed/insured

Cons:

- More expensive ($25-50/hour typically)
- Less control over which caregiver assigned
- Caregiver may rotate

Best for: People who need reliability/accountability; don't want to manage hiring/payroll.

Option B: Independent Caregiver

What it is: You hire a caregiver directly; act as employer.

Pros:

- Less expensive ($15-25/hour typically)
- More control over who you hire
- Consistent caregiver (if relationship works)

Cons:

- YOU responsible for: background checks, payroll taxes, worker's comp insurance
- No backup if caregiver doesn't show
- Legal employer responsibilities

- More risk (liability if caregiver injured in your home)

Best for: People comfortable with employment responsibilities; tight budgets.

Option C: Adult Day Programs

What it is: Loved one goes to a facility during the day (typically 8 AM - 5 PM) for supervision, activities, and meals.

Pros:

- Social interaction for loved one
- Structured activities
- Respite for caregiver during day
- Less expensive than in-home care ($50-100/day typically)

Cons:

- Loved one must be mobile enough to attend
- Doesn't cover overnight or weekend typically
- Loved one may resist "going to daycare"

Best for: Loved ones who can benefit from socialization; caregivers who need daytime relief.

Option D: Facility Placement

What it is: Assisted living, memory care, or skilled nursing facility (loved one lives there full-time).

Pros:

- 24/7 professional care
- Caregiver no longer primary provider
- Social activities and medical oversight
- Appropriate for higher-level care needs

Cons:

- Expensive ($3,000-10,000+/month depending on level of care)
- Loved one may resist or feel "abandoned"
- Quality varies significantly by facility

Best for: When home care is no longer safe/sustainable even with paid help.

STEP 3: Find Services in Your Area

For Home Care Agencies:

Resources:

1. **Eldercare Locator** — eldercare.acl.gov — Free referral service (call 1-800-677-1116)
2. **Caring.com** — caring.com/senior-care — Reviews of local agencies
3. **A Place for Mom** — aplaceformom.com — Free referral service
4. **AARP Caregiving Resources** — aarp.org/caregiving
5. **Local Area Agency on Aging** — Google "[Your County] Area Agency on Aging"

Get at least 3 agencies to compare:

Agency 1: __________________ Phone: ______________ Rate: $***/hourAgency 2:***
__________________ Phone: ______________ Rate: $/hourAgency 3: __________________
Phone: ______________ Rate: $_____/hour

For Independent Caregivers:

Resources:

1. **Care.com** — care.com (background checks available)
2. **CareLinx** — carelinx.com
3. **Local Facebook groups** — "[Your City] Caregivers" or "[Your City] Senior Care"
4. **Craigslist** — Under "Healthcare" jobs (post what you need)
5. **Personal referrals** — Ask friends, church, support groups

WARNING: If hiring independent caregiver, YOU are responsible for:

- Background check (run through care.com or checkr.com)
- Payroll taxes (hire payroll service or use gusto.com)
- Worker's compensation insurance (required in most states)
- W-2 at end of year
- Employment liability

For Adult Day Programs:

Resources:

1. **National Adult Day Services Association** — nadsa.org — Find programs
2. **Eldercare Locator** — eldercare.acl.gov
3. **Local senior centers** — Often run or know of day programs

STEP 4: Screen Agencies/Caregivers

Questions to Ask Home Care Agencies:

1. **"Are you licensed in [state]?"** (Most states require license)
2. **"Are your caregivers employees or contractors?"** (Employees = better insurance/training)
3. **"What background checks do you run?"** (Should include criminal, abuse registry)
4. **"What training do caregivers receive?"** (CPR, dementia care, specific conditions)
5. **"What happens if our assigned caregiver doesn't show?"** (Should have backup plan)
6. **"Can we request a specific caregiver?"** (Some agencies allow)
7. **"What's your cancellation policy?"** (If you don't need them one day)
8. **"What's included in your hourly rate?"** (Companion care vs. personal care vs. skilled)
9. **"Is there a minimum number of hours per visit?"** (Some require 2-4 hour minimum)
10. **"How do you handle rate increases?"** (Get this in writing)

Questions to Ask Independent Caregivers (If Hiring Directly):

1. **"What's your experience with [loved one's condition]?"** (Dementia, mobility issues, etc.)
2. **"Are you certified as CNA/HHA/PCA?"** (Certified = more training)
3. **"Can you provide 3 references?"** (ALWAYS check references)
4. **"Are you CPR certified?"**
5. **"What tasks are you comfortable doing?"** (Bathing? Medication reminders? Hoyer lift?)
6. **"What's your availability?"** (Weekends? Overnight? Short notice?)
7. **"What's your rate?"** (Clarify if negotiable, overtime, holiday rates)
8. **"Do you have reliable transportation?"**
9. **"How do you handle emergencies?"** (Loved one falls, medical crisis)
10. **"Are you comfortable with pets?"** (If applicable)

BACKGROUND CHECK: Use care.com or checkr.com — costs $30-50. ALWAYS DO THIS.

STEP 5: Understand Costs & Payment Options

Typical Costs (2026 estimates — vary by region):

Service Type	Cost Range	What It Includes
Companion care (agency)	$25–35/hour	Non-medical support: supervision, companionship, light tasks
Personal care (agency)	$30–45/hour	ADL help: bathing, dressing, toileting
Skilled nursing (agency)	$40–75/hour	Medical care: wound care, medication administration
Independent caregiver	$15–25/hour	Varies by caregiver's training and experience

Adult day program	$50–100/day	Daytime supervision, meals, activities
Assisted living facility	$3,000–6,000/month	Room, meals, supervision, activities
Memory care facility	$5,000–8,000/month	Specialized dementia care
Skilled nursing facility	$8,000–15,000/month	24/7 medical care

Calculate your need:

If you need **____ hours/week** of **[service type]** at **$____/hour**:

Weekly cost: $____ x ____ hours = $_____**Monthly cost:** $_____ x 4.3 weeks = $_____

Payment Options:

Option 1: Out-of-Pocket

Pros: Most control; can start immediately**Cons:** Expensive for most families

Option 2: Long-Term Care Insurance

If loved one has LTC insurance:

- Check policy for home care coverage
- Contact insurance company for pre-approval process
- May cover 50-100% of costs depending on policy

How to use:

1. Call insurance company listed on policy
2. Request home care benefit information
3. Ask: "What agencies are in-network?" or "Do you reimburse for independent caregivers?"
4. File claims according to policy requirements

Option 3: Medicaid (for low-income seniors)

Eligibility: Income below $2,000-2,500/month (varies by state); assets below $2,000-10,000 (varies)

What it covers: May cover home care, adult day programs, or facility care

How to apply:

1. Contact your state Medicaid office
2. Ask about "Home and Community-Based Services (HCBS) waiver"
3. May have waiting list (apply early)

Find your state Medicaid: medicaid.gov

Option 4: Veterans Benefits (if loved one is veteran or spouse of veteran)

Aid & Attendance Benefit:

- Up to $2,300/month (veteran) or $1,200/month (spouse) toward care costs
- Eligibility: Wartime veteran + need help with daily activities

How to apply:

1. Contact VA at 1-800-827-1000
2. Request "Aid & Attendance" benefit application
3. Need: DD-214, medical documentation of need

More info: va.gov/pension/aid-attendance-housebound

Option 5: Sibling Cost-Sharing

Use the "Pay or Play" approach:

From your boundary scripts, calculate your sibling's fair share.

Example:

- You need 20 hours/week of help
- Cost: $30/hour x 20 hours = $600/week

- 2 siblings = $600 ÷ 2 = $300/week per sibling

Set up payment:

- Venmo/Zelle: Direct transfer
- Joint account: Both contribute monthly
- Invoice: Send monthly invoice with receipts

Option 6: Hybrid (Multiple Sources)

Many families combine:

- Caregiver covers X hours (unpaid)
- Medicaid covers Y hours (if eligible)
- Siblings split cost of remaining Z hours
- Loved one's income pays part

STEP 6: Start Service

For Agency:

1. **Schedule intake assessment** (agency evaluates loved one's needs)
2. **Sign contract** (read carefully: cancellation terms, rate increases, minimums)
3. **Meet caregiver before first shift** (if agency allows)
4. **Create care plan** (written list of tasks for caregiver)
5. **Give caregiver house tour** (where things are, routines)

For Independent Caregiver:

1. **Trial shift** (have them work one shift while you're present to observe)
2. **Written agreement** (schedule, tasks, rate, payment method, termination terms)
3. **Set up payroll** (use gusto.com or hire payroll service — DO NOT pay under the table; tax/legal risks)
4. **Create care instructions** (written guide to loved one's routine, preferences, medications)

5. **Emergency contacts** (give caregiver your number, doctor's number, 911)

CARE INSTRUCTIONS TEMPLATE:

Loved one's Name:Caregiver Name:Date:

Daily Routine:

- Morning: [e.g., "Up by 8 AM, medications at 8:30 AM, breakfast by 9 AM"]
- Afternoon: [e.g., "Lunch at noon, nap 1-3 PM"]
- Evening: [e.g., "Dinner at 6 PM, medications at 7 PM, bedtime 9 PM"]

Medications: [List with times and doses]

Allergies: [Food, medications]

Medical Conditions: [Diabetes, dementia, mobility issues, etc.]

Tasks to Complete:☐ [e.g., "Prepare meals"]☐ [e.g., "Assist with bathing"]☐ [e.g., "Light housekeeping"]☐ [e.g., "Medication reminders"]

Safety Concerns: [Fall risk, wandering, etc.]

Emergency Contacts:

- Caregiver (you): [Phone]
- Doctor: [Name, Phone]
- 911 for emergencies

STEP 7: Address Loved one's Refusal (If Applicable)

Common Loved one Objections:

"I don't need help."→ Script: *"Dr. [Name] says you need supervision for [safety issue]. I can't provide 24/7 coverage. Either we hire help or we discuss facility placement."*

"I don't want a stranger in my house."→ Script: *"I understand. The alternative is I reduce my availability to [X hours/week] and you go without coverage the rest of the time. Which do you prefer?"*

"I only want YOU to help me."→ Script: *"I can provide [X hours]. Beyond that, you need professional help or we discuss facility placement. This isn't negotiable."*

"We can't afford it."→ Script: *"We can afford [X hours/week] if we use your income + [sibling contribution / Medicaid / VA benefits]. The alternative is facility placement, which costs more."*

Loved one Refusal Strategy:

1. **Start with trial** — "Let's try 2 hours, 3 days/week for one month"
2. **Find good personality match** — Request different caregiver if first one doesn't click
3. **Let loved one direct** — Caregiver takes instructions from loved one where possible
4. **Frame as "helper for caregiver"** — "This person helps ME so I can keep helping you"
5. **If loved one refuses entirely** — Use boundary scripts; reduce your availability to force acceptance

CLOSING NOTE

These scripts are tools, not magic.

They work when:

- You're dealing with people who have some capacity for reason
- The relationship is worth preserving
- You have minimal leverage and need language to create it

They DON'T work when:

- You're dealing with someone in active addiction or untreated severe mental illness
- The relationship is already destroyed
- Safety is at risk (yours or your loved one's)

If scripts repeatedly fail, the problem is not the script. The problem is the situation requires a different intervention:

- Therapy (for you, for them, for the relationship)
- Legal action (legal authority over decision-making, protection order, employment lawyer)
- Facility placement (because home care is no longer safe or feasible)
- Relationship termination (because some relationships cannot be saved)

You are not failing if scripts don't work. You're facing a situation that requires more than words.

Know the difference.

My Helpful Books

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To speak freely and honestly about the difficult realities of family caregiving, the author has chosen to write under the pen name Sarah Mitchell. While the strategies and coping mechanisms in this book are based on real-world scenarios, names, identifying details, and personal circumstances have been altered or constructed to protect the privacy of individuals and to present a cohesive guide. The advice contained herein is based on research and general principles, not the specific personal history of the author.

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