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A FAMILY GUIDE

Things I Wish I Would Have Done Before My Mom Ended Up on a Ventilator

Early Signs of Deconditioning Every Family Should Know

Real lessons.
Helpful guidance.
A stronger tomorrow
for the ones we love.

RECOGNIZE THE SIGNS

TAKE ACTION SOONER

HELP THEM LIVE STRONGER

BECAUSE THEY STILL HAVE MORE GOOD DAYS AHEAD.

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A note before you begin

This guide is educational. It is not a diagnosis or a substitute for medical care. A change in weight, strength, appetite, pain, mobility, breathing, or behavior can have many causes. When something changes, involve the person's healthcare professional and ask questions early.

Home Aide Mississippi
Taking Care Of YOU Right At Home
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A MESSAGE FROM THE FAMILY

I Wish I Knew Then What I Know Now

I wish I would have been more active in my mom's care.

I wish I would have listened more closely when she said she was in pain.

I wish I would have been more proactive when she started getting weak.

I wish I would have been more concerned when she started losing weight.

Those wishes are not written here to create guilt. They are written because families often live in the gray area between “Mom seems okay” and “Something is seriously wrong.” Small changes can be easy to explain away: she is tired, she is eating less, she does not want to get up today, she says she hurts, she is just getting older.

This guide is about learning to pause when those changes appear. Not to panic. Not to diagnose. But to notice, document, ask, and act sooner.

One important distinction

My mom's hospitalization and need for a ventilator are part of my family's story. This book does not claim that weight loss, pain, or weakness caused that outcome. The purpose is to help families recognize changes that deserve attention before a crisis occurs.

CHAPTER 1

The Changes We Call “Just Aging”

Aging is not a diagnosis. When an older adult changes, the question is not simply, “Is this normal?” The better question is, “Is this a meaningful change from their normal?”

The National Institute on Aging lists significant weight change, poor hygiene, confusion, falls, loneliness or social isolation, and trouble walking or getting around among signs that an older adult may need help.

> **Look for patterns, not one isolated moment**
>
> A single skipped meal may mean very little. A pattern of eating less, moving less, sleeping more, struggling to stand, and withdrawing from usual activities deserves a closer look.

Start by knowing MeMaw's baseline:

- ☐ How far could she normally walk?
- ☐ Could she stand from her favorite chair without help?
- ☐ How much did she usually eat and drink?
- ☐ Did she bathe, dress, cook, shop, or attend church independently?
- ☐ What activities made her happy and kept her moving?
- ☐ What did her normal energy and personality look like?

When you know the baseline, you can recognize a change.

CHAPTER 2

When MeMaw Says, “I'm Hurting”

Pain is information. Older adults may minimize pain, adapt to it, or avoid talking about it because they do not want to be a burden. A family member does not need to determine the cause of pain to take it seriously.

Try asking specific questions instead of only asking, “Are you okay?”

- ☐ Where does it hurt?
- ☐ When did it start?
- ☐ Is it constant or does it come and go?
- ☐ What makes it better or worse?
- ☐ Has the pain changed what she can do?
- ☐ Has she stopped eating, sleeping, walking, bathing, or participating because of it?

Bring the change to the healthcare team

Write down what you observe, when it started, and what activities have changed. Ask what needs evaluation and what warning signs should prompt urgent care.

Do not assume that persistent pain is simply a normal part of aging.

CHAPTER 3

When MeMaw Starts Losing Weight

A change worth noticing

Unintentional weight loss in an older adult deserves attention. The National Institute on Aging notes that sudden, unintended weight loss can sometimes signal an underlying medical problem and recommends discussing rapid unintentional weight loss with a healthcare professional.

Weight loss can happen for many reasons, including reduced appetite, difficulty shopping or preparing food, pain with chewing or swallowing, forgetting to eat, medication effects, mood changes, and medical conditions. Finding the reason matters.

The MeMaw Check

Ask: Is she eating less? Is she skipping meals? Is food tasting different? Is chewing or swallowing difficult? Is she too tired to cook? Has she lost interest in foods she used to enjoy? Is she drinking enough?

Don't turn food into a fight.

Instead, make eating easier to notice and support. Keep a simple record of meals, fluids, appetite, and changes. If weight is falling without intent, ask the healthcare team what evaluation is appropriate. A dietitian or other clinician may be part of the plan.

And remember: a home caregiver should not prescribe a diet or diagnose the cause of weight loss. The role is to observe, support the care plan, and communicate changes.

CHAPTER 4

When MeMaw Starts Getting Weak

The early signs of deconditioning

Deconditioning is a decline in strength, endurance, mobility, or functional ability that can occur when a person becomes less active—often during illness, hospitalization, prolonged bed rest, or a period of reduced movement.

The early signs can be ordinary-looking:

- ☐ She gets up less often.
- ☐ She spends more time in bed or in the recliner.
- ☐ Walking across the room takes more effort.
- ☐ She starts using furniture or walls for support.
- ☐ She needs more help getting dressed or bathing.
- ☐ She stops going outside or participating in familiar activities.
- ☐ She becomes afraid of falling.
- ☐ She needs more recovery time after simple activity.

The cycle can feed itself

Less movement can lead to less strength and confidence. Less strength can make movement harder. That can lead to even more inactivity. The goal is to identify the change early and ask the healthcare team what activity is safe.

Never start a new exercise or mobility program for someone with significant illness, pain, recent hospitalization, or fall risk without appropriate clinical guidance.

CHAPTER 5

Don't Wait Until She Can't Get Up

One of the most useful things a family can do is notice functional change before it becomes a crisis.

Instead of asking only, “What diagnosis does she have?” ask:

- ☐ What could she do six weeks ago that she cannot do now?
- ☐ What takes longer now?
- ☐ What requires another person's help now?
- ☐ What activity has she stopped?
- ☐ What is she afraid to do?
- ☐ What changed first—pain, appetite, energy, walking, mood, or something else?

Functional changes can be especially useful to communicate because they describe what is happening in everyday life—not just what a person says they feel.

A simple sentence can open the conversation

“Doctor, six weeks ago Mom could walk from the bedroom to the kitchen by herself. Now she needs help standing and gets exhausted after a few steps. This is a change from her normal.”

CHAPTER 6

Become an Active Care Partner

Being active in a loved one's care does not mean trying to become their nurse or doctor. It means knowing the baseline, noticing changes, asking questions, keeping information organized, and making sure concerns reach the right professional.

Build your family care notebook:

- ☐ Current medication list and allergies
- ☐ Diagnoses and major health history
- ☐ Primary care and specialist contacts
- ☐ Preferred pharmacy
- ☐ Baseline mobility and daily activities
- ☐ Recent weight or appetite changes
- ☐ Falls or near-falls
- ☐ Important equipment used at home
- ☐ Upcoming appointments
- ☐ Questions that need answers

Ask for teach-back

When a clinician gives complicated instructions, ask: “Can you explain what we should watch for at home, and what should make us call you or seek urgent care?” Then repeat the plan back in your own words to make sure you understood it.

CHAPTER 7

When MeMaw Goes to the Hospital

A hospital stay can be overwhelming. Families may be trying to understand new diagnoses, tests, medications, equipment, and discharge plans at the same time.

Write down questions as they come. Before discharge, make sure the family understands:

- ☐ Why was she hospitalized?
- ☐ What diagnoses were made?
- ☐ What tests were completed?
- ☐ Are any test results still pending?
- ☐ Which medicines changed?
- ☐ What medicines should she stop, start, or continue?
- ☐ What symptoms should make us call the doctor?
- ☐ Who do we call after hours?
- ☐ When are the follow-up appointments?
- ☐ What equipment or assistance is needed at home?
- ☐ What can she safely do physically right now?
- ☐ Who is responsible for follow-up on pending results?

AHRQ's care-transition resources emphasize medication reconciliation, clear written discharge plans, warning signs, follow-up, and communication with patients and families.

CHAPTER 8

The First 72 Hours Back Home

Coming home is not the end of the care transition. It is the beginning of a new routine.

Use the first few days to observe—not to overwhelm.

- ☐ Can she get in and out of bed safely?
- ☐ Can she get to the bathroom?
- ☐ Is she eating and drinking according to the care plan?
- ☐ Are medications available and understood?
- ☐ Is she unusually sleepy, confused, weak, or short of breath?
- ☐ Does she have the equipment that was ordered?
- ☐ Does the family know who to call with questions?
- ☐ Are follow-up appointments scheduled?

Know the urgent warning signs

Severe trouble breathing, chest pain or pressure, fainting, new severe confusion, blue/gray lips or skin, new one-sided weakness or trouble speaking, inability to wake normally, or another symptom that feels like a medical emergency requires urgent medical attention. When in doubt about a serious or rapidly worsening emergency, call 911.

This is not an exhaustive emergency list. Follow the person's discharge instructions and clinician-specific guidance.

CHAPTER 9

How Home Support Can Help

Sometimes a family does not need someone to take over. They need another set of eyes, hands, and ears to help the older adult remain as independent as safely possible.

Depending on the agency, plan of care, and applicable rules, non-medical home care may include:

- ☐ Companionship and social engagement
- ☐ Assistance with activities of daily living
- ☐ Meal preparation and routine support
- ☐ Light housekeeping related to the client's needs
- ☐ Errands or transportation when offered and appropriate
- ☐ Respite support for family caregivers
- ☐ Observation and communication of changes to the appropriate person

Know the boundary

Non-medical home care does not replace a physician, nurse, therapist, dietitian, emergency service, or other licensed clinician. A caregiver's job is to follow the approved service plan, stay within scope, document appropriately, and report changes.

When families understand the difference between medical and non-medical support, they can build a stronger care team.

CHAPTER 10

The MeMaw Check

A one-page family observation tool

Use this page to notice changes. It is not a diagnostic tool. Bring meaningful changes to the appropriate healthcare professional.

Observation	Noticed?	When / Notes
Unintentional weight loss	■ Yes ■ No	_____
Eating less than usual	■ Yes ■ No	_____
Difficulty chewing or swallowing	■ Yes ■ No	_____
More pain or new pain	■ Yes ■ No	_____
Less walking or movement	■ Yes ■ No	_____
New difficulty standing from a chair	■ Yes ■ No	_____
More help needed with bathing or dressing	■ Yes ■ No	_____
New fall or near-fall	■ Yes ■ No	_____
More time in bed or recliner	■ Yes ■ No	_____
New or worsening shortness of breath	■ Yes ■ No	_____
New confusion or major behavior change	■ Yes ■ No	_____
Less interest in people or activities	■ Yes ■ No	_____
Poor hygiene or difficulty maintaining routines	■ Yes ■ No	_____
Trouble getting to appointments, shopping, or preparing meals	■ Yes ■ No	_____
Family caregiver feels overwhelmed or unable to meet needs	■ Yes ■ No	_____

CHAPTER 11

The 7-Day Change Log

Small changes are easier to communicate when you write them down. Use one row each day and bring the completed page to appointments when useful.

Day	Food / Fluids	Movement	Pain / Symptoms	Notes
1	_____	_____	_____	_____
2	_____	_____	_____	_____
3	_____	_____	_____	_____
4	_____	_____	_____	_____
5	_____	_____	_____	_____
6	_____	_____	_____	_____
7	_____	_____	_____	_____

What changed most this week?

_____
_____
_____

CHAPTER 12

Questions to Take to the Healthcare Team

- ☐ What do you think could be causing the weight loss or weakness?
- ☐ What changes should we track at home?
- ☐ What symptoms mean we should call you the same day?
- ☐ What symptoms mean we should seek emergency care?
- ☐ Is it safe for her to walk or exercise? What level is appropriate?
- ☐ Does she need a physical or occupational therapy evaluation?
- ☐ Does she need a nutrition or swallowing evaluation?
- ☐ Could any medications be affecting appetite, energy, balance, or alertness?
- ☐ What follow-up testing or appointments are needed?
- ☐ What is the safest plan for returning to normal activities?

Bring the right information

Bring the medication list, allergies, recent changes, weight trend if available, fall history, symptom notes, and the questions you wrote down. A concise timeline can make a complicated story easier to understand.

CHAPTER 13

Our Family Care Plan

Loved one's name	_____
Primary doctor	_____
Important specialists	_____
Preferred pharmacy	_____
Emergency contact	_____
Primary family caregiver	_____
Other helpers	_____
Important equipment	_____
Next appointment	_____
Biggest current concern	_____

Three things we will pay closer attention to:

_____

_____

_____

CHAPTER 14

If Your Family Needs More Help

When a family considers home care, ask questions before choosing an agency. You are not just hiring a person—you are inviting an organization into your loved one's home.

- ☐ What services do you provide, and what is outside your scope?
- ☐ How do you screen and train caregivers?
- ☐ How do you handle call-offs and last-minute coverage?
- ☐ Who supervises the caregiver?
- ☐ How do you communicate changes to the family?
- ☐ How are care plans created and updated?
- ☐ What happens if there is an incident or complaint?
- ☐ How do you protect client privacy?
- ☐ What are your rates, minimums, and payment policies?
- ☐ Who do I call after hours?

A good fit is personal

The right support should fit the person's needs, preferences, routines, culture, and goals. Ask whether the agency listens to the family and respects the older adult's independence.

You Don't Have To Wait For The Crisis

You don't have to be a nurse.
You don't have to know everything.

You just have to notice.
You have to ask.
You have to listen.
And when something changes, you have to speak up.

Sometimes the biggest warning signs don't look like emergencies. They're small changes that happen one day at a time.

For the families who are watching

If this guide helps you notice one change sooner, ask one important question, or have one conversation you might otherwise have avoided, then it has done what it was created to do.

BECAUSE THEY STILL HAVE MORE GOOD DAYS AHEAD.

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IMPORTANT INFORMATION

Medical Disclaimer & Sources

This guide is for general education only. It is not medical advice, does not diagnose or treat any condition, and does not replace the instructions of a physician, nurse, therapist, dietitian, pharmacist, or other qualified healthcare professional. Individual needs vary. Follow the care plan and seek professional advice for changes in symptoms, nutrition, mobility, medications, or breathing.

Emergency symptoms can require immediate medical attention. When a situation appears life-threatening or rapidly worsening, call 911.

Sources & further reading

National Institute on Aging (NIA): Maintaining a Healthy Weight; Does an Older Adult in Your Life Need Help?; Healthy Eating As You Age.

Centers for Disease Control and Prevention (CDC): Older Adult Activity: An Overview; Physical Activity Benefits for Adults 65 or Older.

Agency for Healthcare Research and Quality (AHRQ): Care Transitions / IDEAL Discharge Planning; Re-Engineered Discharge resources.

Prepared as a Home Aide Mississippi family education resource.

Version: September 2026