



Family Conversation Guide for Care Transitions

Talking About the Move from Independence to More Support

Purpose: To help families talk about care transitions with clarity, compassion, and shared responsibility—before crisis forces the conversation.

Before the Conversation: Prepare Yourself

Care transitions are emotional. Preparation helps you lead with steadiness rather than urgency.

Before you begin:

- Choose a calm time (not during a crisis or conflict)
- Clarify *why* you're raising the topic (safety, energy, quality of life)
- Decide what kind of support you are exploring (not final decisions)
- Accept that this may be the *first* of several conversations

Helpful mindset:

This is about **adding support**, not taking control away.

Who Should Be Involved

Involving the right people early prevents misunderstanding later.

Consider including:

- The person with Parkinson's (whenever possible)
- Primary caregiver(s)
- One or two trusted family members
- A neutral support person if helpful (social worker, care coordinator)

Tip: Fewer people often leads to better conversation.

How to Open the Conversation

Start with care, not conclusions.

Gentle opening phrases:

- “I want to talk about how things have been feeling lately—for both of us.”
- “I’ve noticed some changes, and I want to make sure we’re planning together.”
- “This isn’t about making decisions today—it’s about talking things through.”

Avoid opening with:

“You can’t live like this anymore” or “We have to do something now.”

Naming the Changes (Without Blame)

Focus on observations, not judgments.

Use language like:

- “I’ve noticed you seem more tired by the afternoon.”
- “Medications feel harder to manage than they used to.”
- “I’m finding it harder to keep everything safe on my own.”

Avoid:

“You’re declining” or “This is too much for you.”

Addressing the Emotional Side (Out Loud)

Naming emotions reduces defensiveness.

You might say:

- “I know this brings up a lot of feelings.”
- “I’m struggling with guilt even bringing this up.”
- “It’s hard to imagine things changing.”

Important reminder:

Resistance often reflects fear—not refusal.

Framing Support as Protection, Not Loss

How you frame the transition shapes how it's received.

Helpful reframes:

- “This is about conserving energy and staying safe.”
 - “Support can help us keep doing the things that matter.”
 - “This doesn’t mean giving up independence—it means protecting it.”
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Inviting the Person with Parkinson’s Into the Conversation

Preserving dignity is essential.

Ask open questions like:

- “What feels hardest right now?”
- “What worries you most about change?”
- “What kind of help would feel acceptable?”

Listen more than you speak.

Managing Common Reactions

If you hear...

- “*I don’t need help.*” → “I hear that. Can we talk about what help would *not* feel okay?”
- “*I don’t want to be a burden.*” → “You’re not a burden. This is about support, not worth.”
- “*Let’s not talk about this.*” → “That’s okay. Can we revisit it later?”

Do not force agreement.

Planting the seed matters.

Ending the Conversation Well

Conversations should end with clarity—not pressure.

Helpful closing statements:

- “Thank you for talking about this with me.”
- “Let’s sit with this and talk again.”
- “We’ll take this one step at a time.”

If appropriate, identify one next step:

- Gathering information
 - Talking with a professional
 - Trying a small support change
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After the Conversation: What Matters Most

- Expect emotions to resurface later
 - Be patient with repeated questions or resistance
 - Revisit the topic gently
 - Involve support if family tension arises
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When to Bring in a Neutral Guide

Consider professional support if:

- Family members disagree strongly
- Conversations stall or escalate
- Guilt or conflict becomes overwhelming
- Decisions feel too heavy to manage alone

Social workers, care coordinators, ADRCs, or elder care planners can help facilitate these conversations.

A Final Thought

Care transitions are not single decisions—they are shared conversations over time. When approached with respect, honesty, and patience, they can strengthen trust rather than fracture it.

You are not taking something away.
You are building a safer path forward—together.

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