



## The In-Between Life of Caregiving at Home

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# The Reality of Home-Based Caregiving

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How caregiving begins

Myths vs. realities

Day-to-day caregiving

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# How caregiving begins

- ❑ Often falls into place suddenly—families don't know where to begin
- ❑ Learning as you go without a clear roadmap
- ❑ Navigating both emotional and practical responsibilities simultaneously
- ❑ Looks easier from the outside than it is
- ❑ “No right way” to care give—every situation looks different
- ❑ It's okay to not know what you're doing at times

# Day-to-day caregiving

- ❖ Balancing care for patient, spouse, parents, and self
- ❖ Managing routines, medical needs, and emotional support
- ❖ Staying focused on immediate needs while juggling long-term uncertainty

**WHATEVER YOU'RE DOING  
TODAY, DO IT WITH THE  
CONFIDENCE OF A 4 YEAR OLD  
IN A BATMAN T-SHIRT.**

# Burnout, Boundaries, and Personal Well-Being

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Recognizing burnout

The importance of personal well-being

Setting boundaries

Letting others in

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# Recognizing burnout

- ❑ Caregivers often minimize their own needs
- ❑ Running on survival mode or staying busy to cope
- ❑ Not recognizing limits until they've already been exceeded

# The importance of personal well-being



- ❑ You cannot help someone else unless you help yourself
- ❑ Filling your own cup—small moments (coffee, shower, rest, nature)
- ❑ Self-compassion: allowing rest without guilt (taking a nap)

# Setting boundaries

- 🌱 Knowing your limits before reaching a breaking point
- 🌱 Planning ahead (recognizing when overnight care is needed)
- 🌱 Trusting others and accepting breaks when offered
- 🌱 Learning to say yes to help and “be a bother”

# Letting others in

- 🌱 Asking for help and acknowledging you need it
- 🌱 Overcoming fear of being a burden
- 🌱 Staying connected vs. pushing people away
- 🌱 Getting creative with outside resources



# Emotional Impact: Grief, Trauma, and Caregiving

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Caregiving and grief side by side

Trauma responses

After caregiving ends

## Caregiving and grief side by side

Grief begins before death  
(anticipatory and ongoing)

Joining a loved one in decline can  
feel traumatic

Holding multiple emotions at once  
(joy, sadness, exhaustion, gratitude)



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# Trauma responses

- ❑ Freezing, hyper-focusing, or staying constantly busy
- ❑ Responding in crisis moments (agitation, emergencies)
- ❑ Not always processing events fully in the moment – not gliding

# After caregiving ends



- Loss can feel disorienting and destabilizing
- Life pauses and requires rebuilding a “new normal”
- Respecting the healing and integration process

# Navigating Support Systems (Before, During, After)

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Building your care team

Family dynamics and communication

Practical communication tools

Support beyond the caregiving period

Managing help in the home

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# Building your care team

- 🍃 Understanding who is involved and what their roles are
- 🍃 Revisiting and clarifying the plan regularly
- 🍃 Encouraging questions and ongoing communication



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# Communication with family and loved ones

- ❑ Different expectations can create strain or conflict
- ❑ Family members on the sidelines vs. primary caregiver experience
- ❑ Importance of group conversations (in person or virtual)

Examples of guided questions or communication for family/support people:

Using “I” statements, “I need...”

What is your biggest concern?

Do you have any questions about what is going on?

Do you understand and agree with our plan?

Creating space for all feelings

# Communication with professional supports

- ✦ Bringing in a second set of ears (friend, support person, healthcare provided chaperone)
- ✦ Writing things down (binders, notebooks, shared logs)
- ✦ Using voice memos or notes to retain information

Examples of guided questions for your clinical team

Express how you need the information “I hear information better this way”

Will you please repeat that?

Will you please slow down?

What can we expect next steps to be?

# Support beyond the caregiving period

- Who remains in your support system after the loss?
- Temporary vs. long-term support (family visiting then leaving)
- Being able to say: “I don’t know what I need yet”

# Managing help in the home

- ❑ Working with private caregivers—varying levels of skill and fit
- ❑ Setting expectations and creating structure
- ❑ Tools: schedules, written plans, communication systems
- ❑ Use of cameras for accountability and clarity
- ❑ Shared communication logs for consistency across caregivers
- ❑ Reducing repetition and confusion with written schedules

# Identity, Relationships, and Life During Caregiving

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Shifts in relationships

Maintaining connection and meaning

Professional caregivers

Providing care to the caregiver

Everyday logistics

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# Shifts in relationships

## Maintaining connection and meaning

- The person receiving care tends to become the priority
- Other parts of life can often take a back seat
- Changes in identity—partner, child, caregiver roles blending
- Enjoying small, meaningful experiences together
- Recognizing the value in simply showing up

## Balancing everyday logistics



- Relying on neighbors/family for short breaks
- Managing evolving to-do lists
- Coordinating care across multiple people and roles
- Showing consideration for private caregivers

# Reflection & Integration

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Open discussion about caregiving experiences

Q&A