



EDUCATIONAL RESOURCES

Family Caregiving: Navigating the Challenges

Beth Suereth, Founder and CEO
Caregiving Pathways



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Beth Rooney Suereth



Caregiving
Pathways™

- Caregiver for five years through father's dementia, diabetes, and cancer, then founder of [Caregiving Pathways](#) to teach family caregivers how to manage the hospital stay and the end of life.
- Co-author of publications for [AARP Public Policy Institute](#) and AARP New York (policy); part-time care manager at adult foster care provider [Careforth](#), (practice).
- Health care marketer: Express Scripts (PBM), BioScrip (home infusion provider).
- Volunteer: Overlook Hospital family caregivers center.
- [Certified Caregiving Consultant™, Educator, and Facilitator](#) and end-of-life doula.
- Health Policy and the Affordable Care Act certificate from the University of Pennsylvania and bachelor's degree in English from Boston University

Navigating the Challenges of Family Caregiving

- The Six Stages of Caregiving
- Creating a Care Plan for the Family Caregiver
- Outlining the Family Caregiver's Support Network
- Resources for the Caregiving Journey
- Developing a Family Emergency Plan
- Managing a Hospital Visit
- Four Elements of Family Caregiver Communication
- Managing Family Caregiver Stress
- Arranging Respite and Services
- The Ultimate Goal: Quality of Life through the End of Life

The Six Stages of Caregiving

Challenge #1: Family caregivers are not aware they're on a journey

The Six Stages of Caregiving*

1. Expectant — Adjusting Expectations and Preparing
2. Freshman — Experimenting
3. Entrenched — Developing a Routine
4. Pragmatic — Considering Life after Caregiving
5. Transitioning — Shifting from Curative Care to Comfort Care
6. Godspeed — Living the Lessons Learned

*Based on Denise Brown's Six Caregiving Stages at [The Caregiving Years Training Academy](#)

Care Plan for the Family Caregiver

Challenge #2: Caregiving is overwhelming, part A

The care plan should include an overview

- Take stock of your day-to-day life and how to accommodate caregiving.
- Optimize your physical and mental health.
- Review medications, transportation, health directives, financial resources.
- Take into account cultural considerations, values, goals, emotions, motivations — for you and the person you care for.
- Consider your preferences, willingness, ability, fears, assumptions.
- Realize you will not achieve perfection.
- Recognize the value you're providing.

Care Plan for the Family Caregiver

Challenge #2: Caregiving is overwhelming, part B

The care plan should include crisis management

1. Ask your social network for help with specific tasks, ongoing.
2. Ask health care providers what your focus and priorities should be.
3. Ask health care providers how to you can get and give information — and how COVID affects care.
4. Name your emotions.
5. Talk about your emotions to manage them. AARP Articles:
 - [Avoid Feeling Used and Angry](#)
 - [Overcoming Dread and Negative Feelings](#)
 - [Ambivalent about Caregiving Role](#)
 - [Anger Management Tips](#)

Outlining the Family Caregiver's Support Network

Challenge #3: Caregiving cannot be managed alone

A [CareMap](#) from Atlas of Care helps you see at-a-glance, in a simple diagram, who can help you as you help the person receiving care. You'll outline:

1. Anyone who lives in your home
2. The people you care for and anyone who lives in that home
3. Others who care for the people you care for
4. Others who care for and support you
5. Who lives close by and who lives far away
6. Who is willing and able to provide what type of care

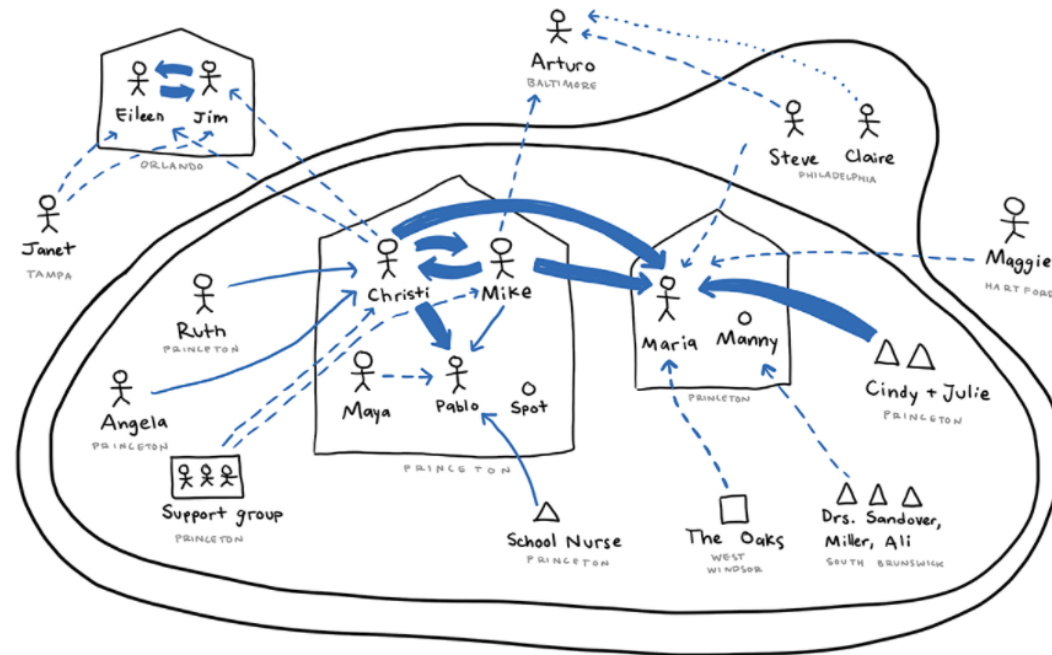
Outlining the Family Caregiver's Support Network

- Atlas CareMap: “Who do you care for — and who cares for you?”

Near: less than 20 minutes away

Middle: 20 min to 2 hours away

Far: more than 2 hours away



Resources for the Caregiving Journey

Challenge #4: Family caregivers don't know about products that help ease pain points

■ Resources

1. [Life in Motion](#) workbook guide and organizer
2. [Atlas of Care](#) support network outline tool (free)
3. [CareTree](#) communication platform (free)
4. [PillMap](#) visual guide to filling the pill organizer, so anyone can do it
5. [Helping Handles](#) harness to help someone get up after a fall
6. [ChuckMates](#) mat with handles to help reposition someone in bed
7. [Gillette TREO](#) razor designed to shave someone else
8. [AARP](#) list of adaptive clothing providers
9. [Aetna](#) list of durable medical equipment (DME) providers

Presenter has no affiliations with any providers.

Resources for the Caregiving Journey

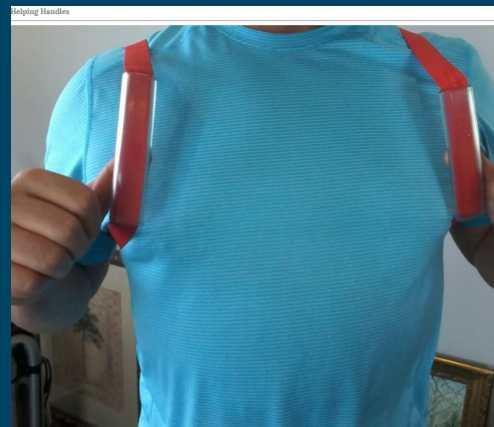
[PillMap](#)



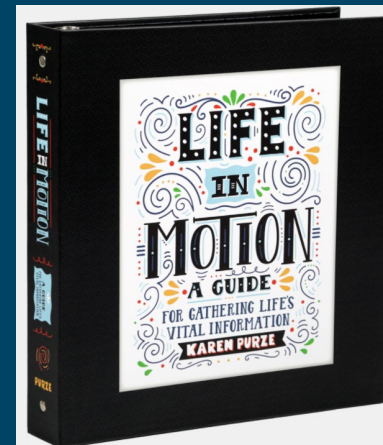
[ChuckMates](#)



[Helping
Handles](#)



[Life in Motion](#)



Family Emergency Plan*

Challenge #5: Family caregivers have family emergencies

- At home
 - Discuss with the person receiving care
 - Gain commitment from those involved
 - Have an ongoing communication strategy
 - Pack a go bag
- At work
 - Determine how to gain buy-in
 - Talk to your manager; provide a plan s/he can share upward
 - Notify colleagues who are involved
- Walk through a faux family emergency. What's the first step?

*See the [Family Emergency Plan](#) at The Caregiving Years Training Academy

Managing a Hospital Visit

Challenge # 6: Many emergencies involve a hospital visit

- The health care system's functionality and perspective
 - Their priorities; weekend vs. weekday; best communication channel; COVID visitor restrictions (and exceptions)
 - Each specialty's approach (pros and cons)
 - Medication management
- Caregiver hospital guide (free) from Caregiving Pathways
 - Write it down
 - Be aware of unconscious biases
 - Help make decisions (give and get information)
 - Update family and friends
 - Learn how to help your loved one recover at home (tasks, supplies, red flags; see [AARP how-to videos](#))

Caregiving
Pathways

How to help
your loved one
in the hospital

You can make a difference



Four Elements of Communicating with Family Caregivers

Challenge # 7: Family caregivers need to be heard and validated

1. Validate the caregiver's feelings.
 - Pre-validating, listening, open-ended questioning, validating.
2. Ask "Why" to uncover the driving motivation.
 - The real issue is often buried.
3. Approach problem solving differently: It's not all practical solutions.
 - The problem to be solved: Caregiver needs to feel understood.
4. Provide key phrases family caregiver can use.
 - I'm new at this. Can you help me understand something?
 - What is the care plan? What has to happen before discharge?

Managing Family Caregiver Stress

Challenge # 8: Family caregivers need techniques specific to caregiving

1. Find things to look forward to
 - Lists of six: List six things you can do in 60 seconds, 6 minutes, 60 minutes
 - Alone: Pet the cat, listen to songs, look at pics or social media, call friends
 - With the person you care for: How the person shaped your life, their music, old photos, ask for stories of favorite memories and people
 - Do nothing; or make it multisensory, physical, emotional, social, spiritual
 - Plan for life after or with caregiving; ask care recipient for advice
2. Use the care recipient's perspective, especially for dementia
 - Bathroom, shower, cook dinner, grocery shop, religious service
 - "It's on the calendar"
 - "According to our schedule..."

Getting Respite and Services

Challenge #9: Family caregivers need respite and support services

1. See National Respite Locator for [respite options](#) by state and how you may be able to [get paid to be a family caregiver](#).
2. Get more information on getting paid for caregiving at [AARP](#).
3. See [Eldercare Locator](#) to search by zip code for Area Agencies on Aging (AAA), State Agency on Aging, support services, housing, elder rights, insurance and benefits, health, and transportation, long-term care planning.
4. Search for support groups, general or specific—live and local or on social media (local via AAA; [AARP](#)).
5. Ask faith and service organizations about volunteers who can stay with the person you care for while you do errands or have fun.
6. Tap family and friends; turn general offers of help into dates to stay with the person you care for.

The Ultimate Goal: Quality of Life through the End of Life

Challenge #10: Focus on quality of life and what still exists

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2. Get more information on getting paid for caregiving at [AARP](#).
3. See [Eldercare Locator](#) to search by zip code for Area Agencies on Aging (AAA), State Agency on Aging, support services, housing, elder rights, insurance and benefits, health, and transportation, long-term care planning.
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Review: Navigating the Challenges of Family Caregiving

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Takeaways for Family Caregivers

- Remember the big picture.
- Have something to look forward to every day.
- Focus on the rewards and satisfaction.



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Thank you

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