



Caregiver's journey map

Supporting those with Alzheimer's
and other dementias

**AgingWell Hub, co-founded with Philips, is a cross sector collaborative of the Global Social Enterprise Initiative (GSEI) at Georgetown University's McDonough School of Business*

Proprietary content dated Oct. 17, 2017

Foundational journey map

A journey map is a type of alignment diagram that illustrates the dimensions of a persona's life as he/she goes through an experience. The map typically shows the interactions, activities, pain points, and thoughts of a persona as he/she tries to accomplish a goal during a defined period of time. The goal of a journey map is to illustrate the various facets of an experience simultaneously in order to create a realistic snapshot of the persona's life during this period.

Six phases

The caregiving journey is divided into six phases. Phases from a Philips Design research document were used as the starting point and then were further refined by the working group. The final phases include the following:

- 1 Noticing changes
- 2 Making adjustments
- 3 Shifting priorities
- 4 Increasing demands
- 5 Full-time care
- 6 End of life

In order to keep the map a manageable size and prevent information overload, an information layering approach has been used. This allows the map to be printed at a range of sizes and to easily transition into a digital format in the future. The map is divided into the foundation area — which remains stable — and the focus area where information can be layered in to provide additional detail.

Journey map foundation

The foundation for the caregiver journey map includes the following three parts:

- **Phases of disease** The duration of each of the six phases for Karen is listed.
- **Karen thinks...** The thoughts and questions of Karen are described for each phase of the map.
- **Karen's experience** The experience is the centerpiece of the map. It includes a timeline of key events in Karen's caregiving experience. Around the key events timeline, the caregiving interactions, and consequences that Karen has with her mother, brother, husband, and children are displayed.

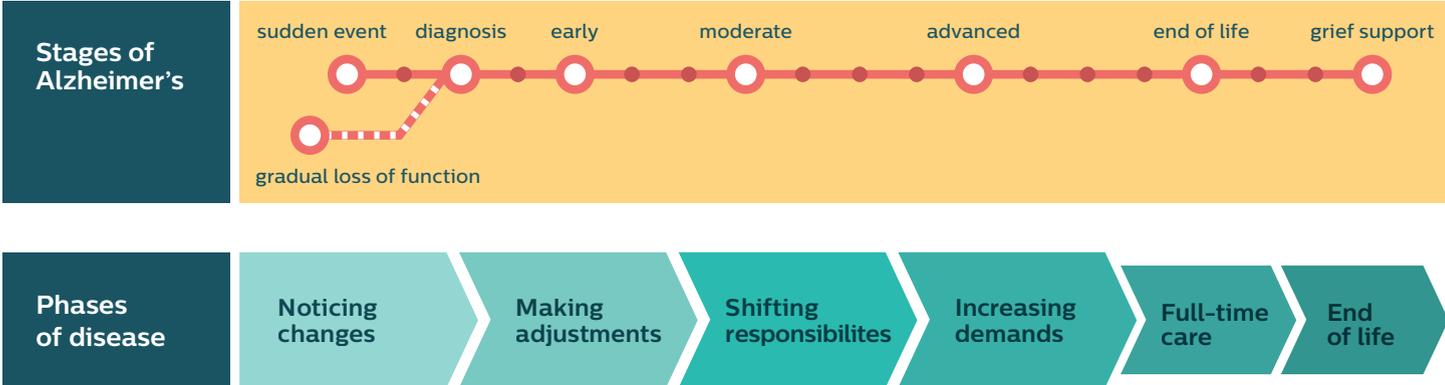
Focus areas

Supporting information is introduced in the bottom third of the map. This information can be interchanged in order to layer additional insights and highlight relationships between data.

- **Karen does...** The repetitive caregiving activities are listed along with a pie chart showing how Karen's time is divided among the elements in her life. Over time, the caregiving activities increase substantially, taking time from her personal life, career, and family.
- **Karen needs...** The pain points within Karen's caregiving experience are highlighted with colored bullets that map back to lists of unmet needs for each phase. The unmet needs are categorized into five opportunity areas, which were adapted from AARP's *Caregiving Innovation Frontiers*.

Caregiving through all stages

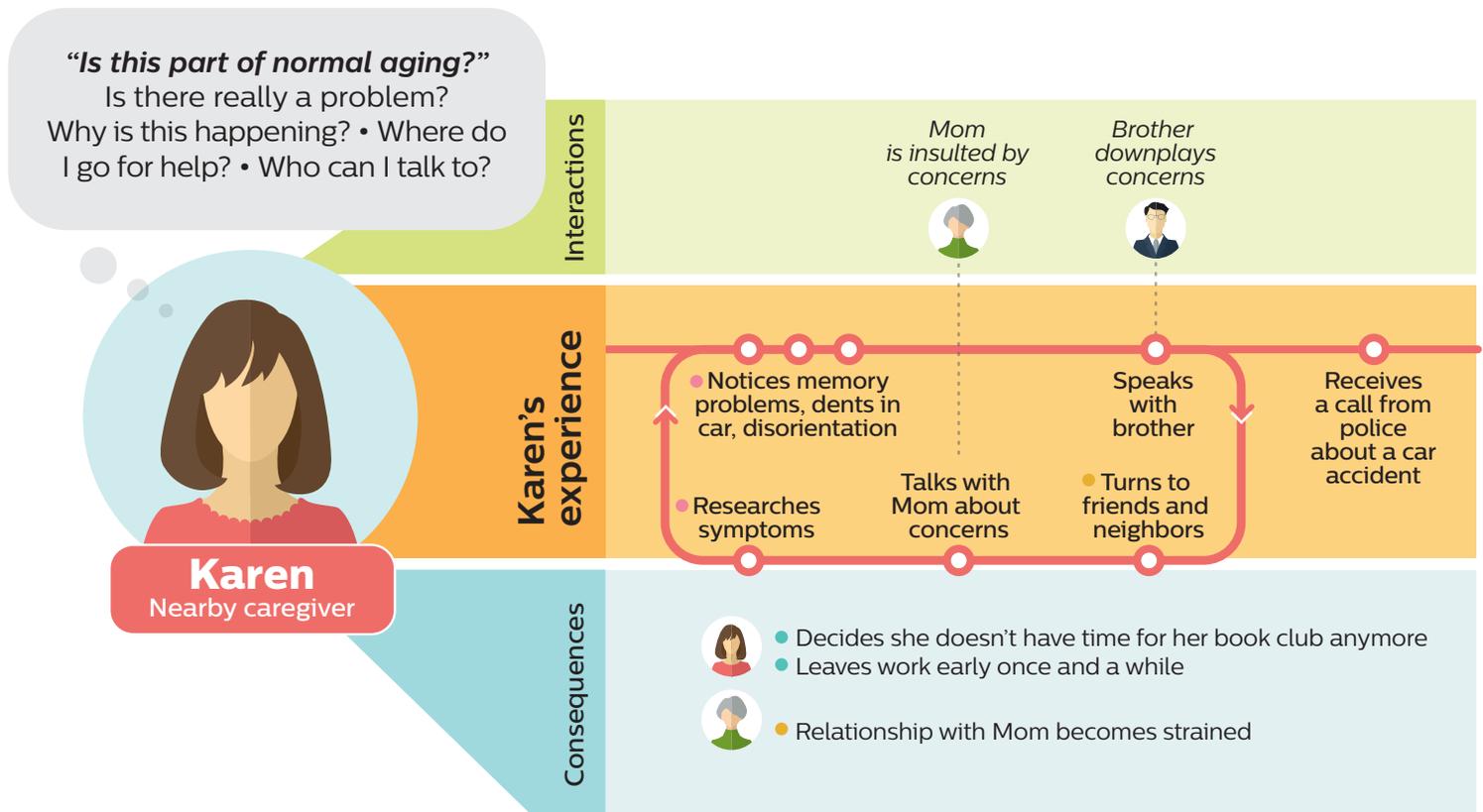
The working team mapped the stages of caregiving to match the stages of Alzheimer's disease.



Caregiver journey — a project of [agingwellhub](#)*

Phases of disease

Phase 1 Noticing changes (2 years)



Karen does...



Karen needs...

Health and safety

- An understanding of warning signs for dementia
- A reputable source for info on symptoms

Social wellbeing

- A way to align her family and gain support
- Someone knowledgeable to talk to about her concerns

Care coordination

- A way to monitor Mom's symptoms

Financial/legal

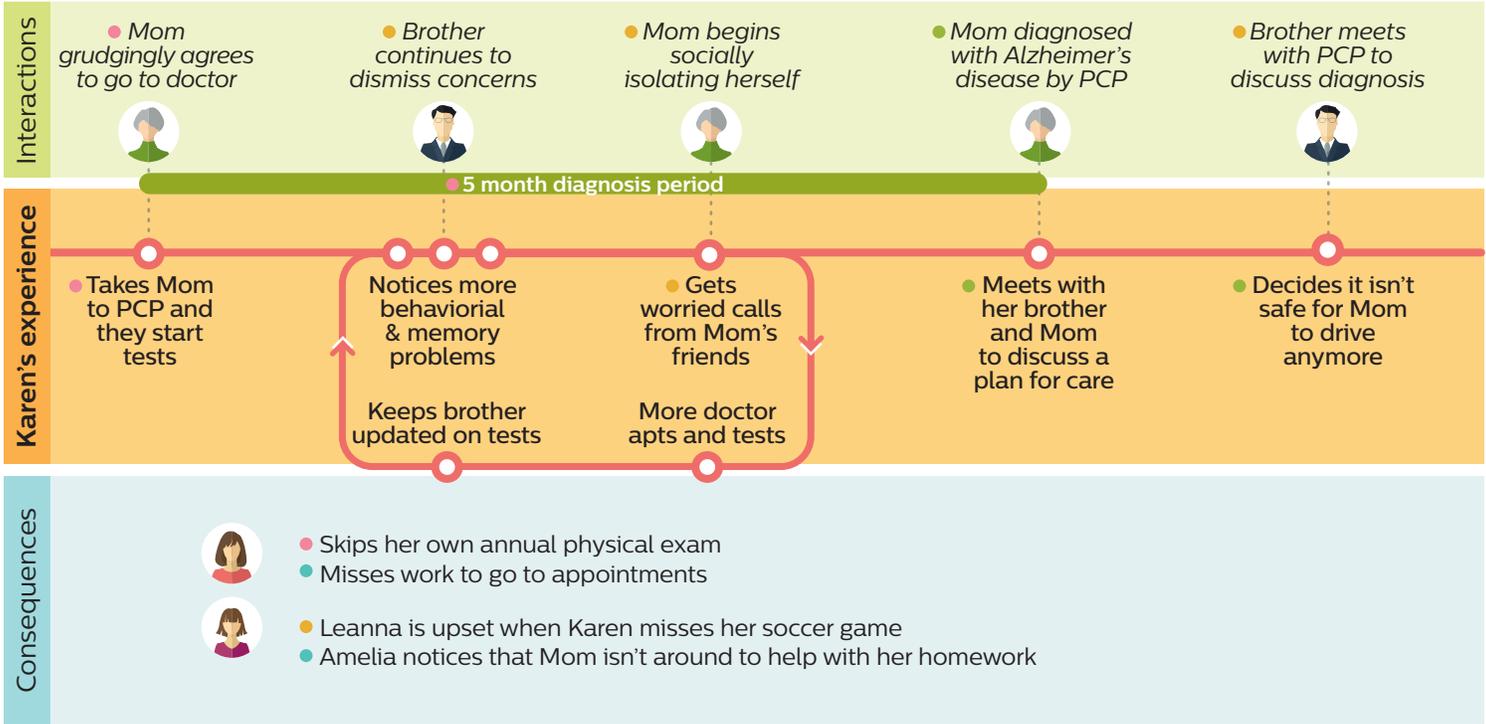
Caregiver quality of life

- Flexible schedule at her work

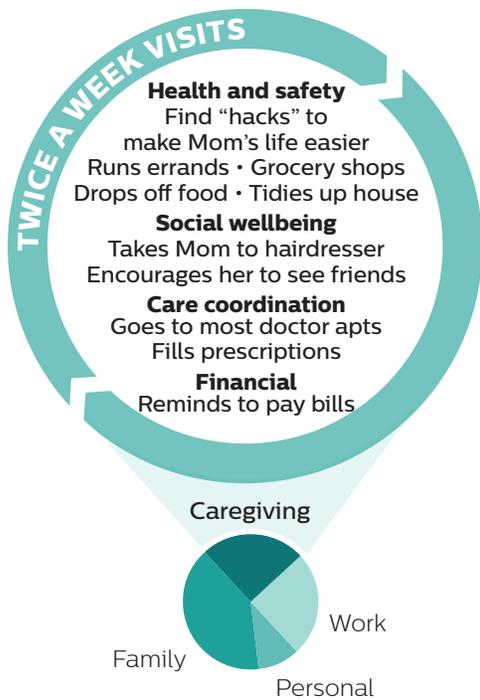
Phase 2 Making adjustments (1 year)



“This is not normal aging, but what is it?”
 Will it get better? • What help is available to me? • What do I do next?
 How do I make sure Mom is safe?



Karen does...



Karen needs...

Health and safety

- A straightforward, quicker path to diagnosis
- Time to focus on her own physical and mental health
- Methods for getting Mom to agree to go to the doctor

Social wellbeing

- Ways to keep Mom's spirits up
- Help balancing caregiving with other activities in her life
- Help keeping her brother informed about diagnosis process

Care coordination

- Help with Mom's home and running errands
- Info on what to expect with the disease to aid in planning
- A shared understanding of the disease and the caregiving needed

Financial/legal

- Guidance on what legal documents she needs and when to do them
- Guidance to do advance directives early enough that Mom can communicate her wishes and help make decisions

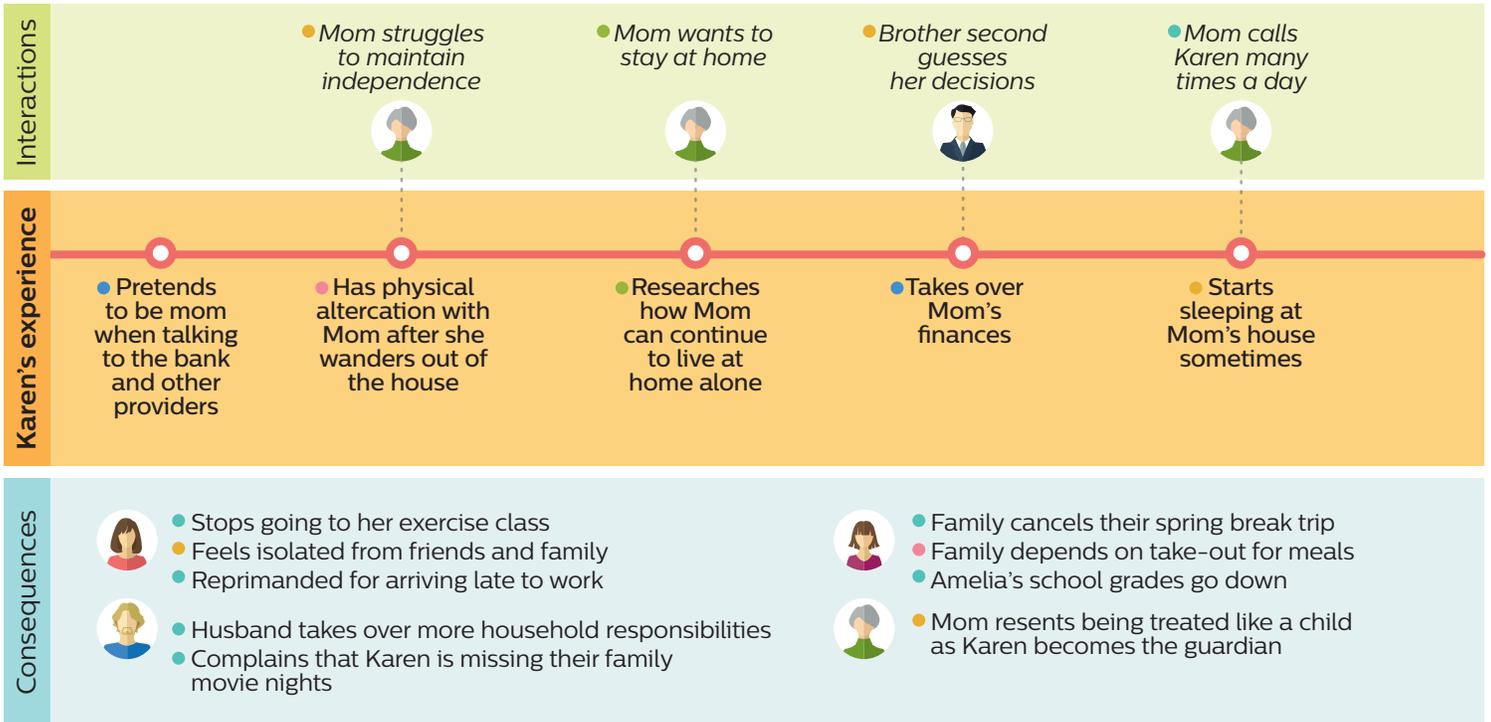
Caregiver quality of life

- Time to focus on her work, with less distractions

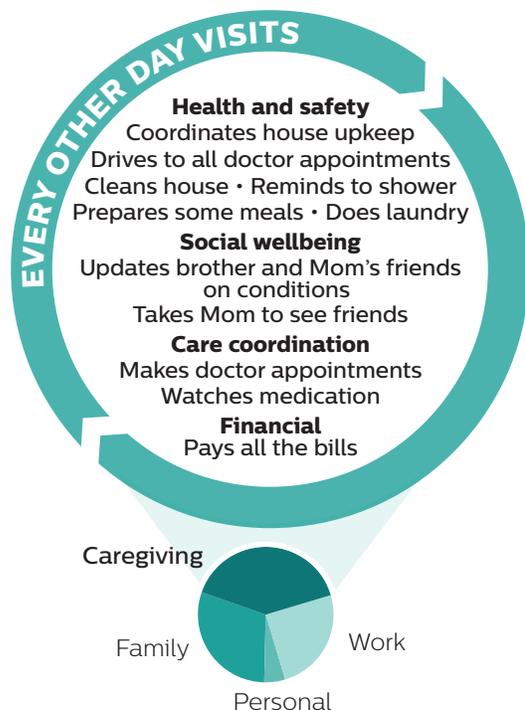
Phase 3 Shifting priorities (2 years)



“I know it’s Alzheimer’s. What do I do now?”
 What is the treatment? • How do I fit this into my life?
 This is more than I thought. Where can I get help?
 How do I keep Mom independent in her home?



Karen does...



Karen needs...

Health and safety

- Help with Mom's difficult and abusive behavior
- Info on how to have a healthy lifestyle while caregiving
- Quick options for meals at both homes
- Help with Mom's wandering

Social wellbeing

- Ways to communicate Mom's status to friends and family
- Guidance for dealing with her changing relationship with Mom
- Ideas for safe ways to make Mom feel independent

Care coordination

- Information on alternative care options
- Guidance on how Mom can continue to live at home alone
- Alternative transportation options for getting Mom to appointments

Financial/legal

- Financial info to help plan for full-time care needs
- Guidance on taking care of Mom's finances

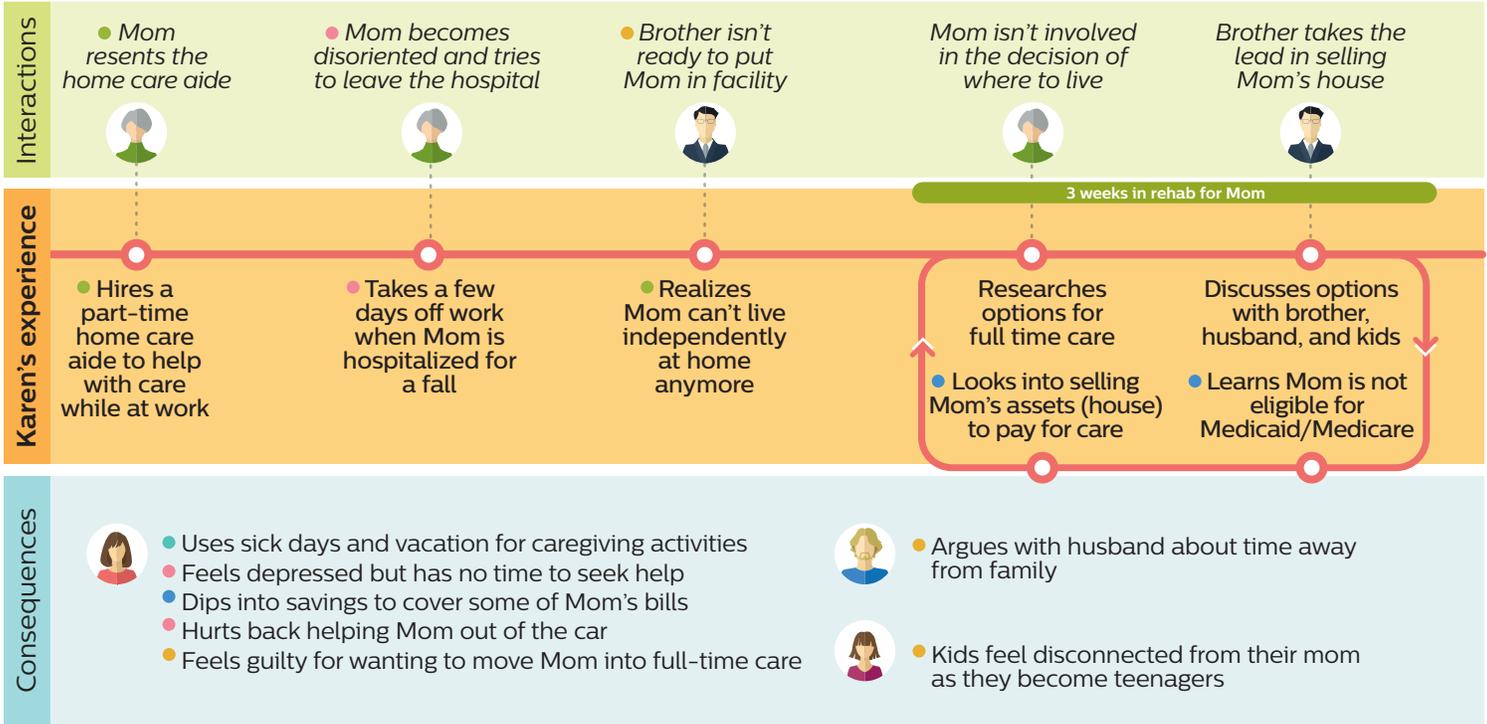
Caregiver quality of life

- A private environment at work to discuss her caregiving situation
- A break from caregiving
- Time to take care of herself

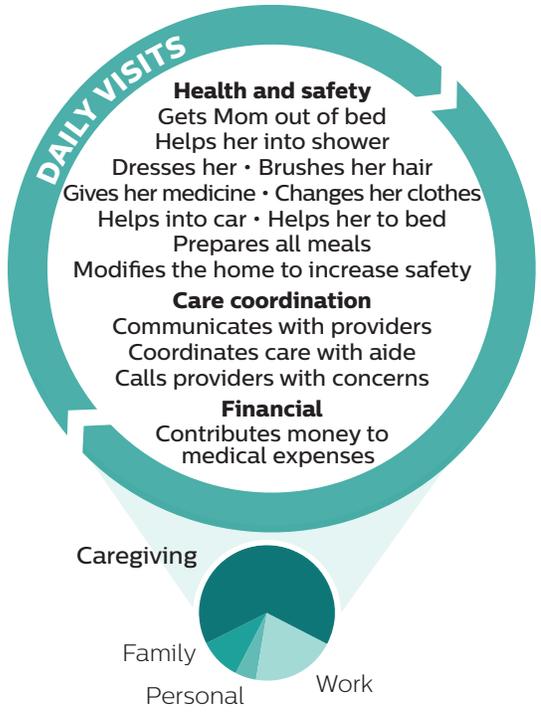
Phase 4 Increasing demands (2 years)



“How much longer can I take care of Mom?”
 When will Mom need full time care? • How will we afford it?
 Where is the best place for Mom to live?
 How do I tell Mom she can't go home again?



Karen does...



Karen needs...

- Health and safety**
 - Training on how to safely do basic care and increasing medical tasks
 - Emotional support to deal with grief and depression
 - Information on how to increase the safety in Mom's home
 - Information on avoiding hospital readmittance
- Social wellbeing**
 - Ways to get family on the same page regarding Mom's deteriorating condition
 - Breaks in caregiving so she can spend time with family and friends
- Care coordination**
 - Training in patient advocacy
 - Information and support on when is the right time to move to full-time care
 - Support for integrating caregiving help into the household
 - Information on the various types of full time care
- Financial/legal**
 - Options for how to afford full-time care
 - A better understanding of Mom's eligibility for Medicare/Medicaid
 - Financial advice and support for spending down Mom's assets to be eligible for Medicaid
- Caregiver quality of life**
 - Ability to take a leave of absence from her work without hurting her career
 - Less intrusive way to stay in touch with Mom

Caregiver journey summary

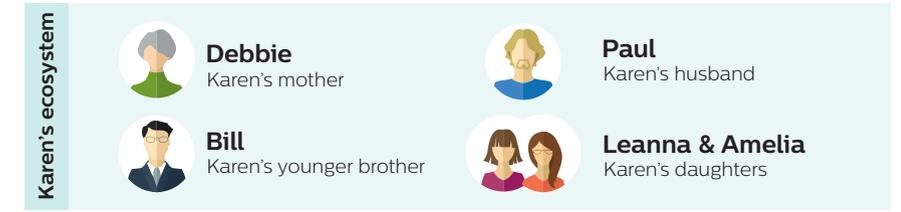
A project of [agingwellhub](#)*

*AgingWell Hub, co-founded with Philips, is a cross sector collaborative of the Global Social Enterprise Initiative (GSEI) at Georgetown University's McDonough School of Business



“What will be next? How do I manage this?”

Age 43 when caregiving begins
Care recipient Her mother, Debbie
Diseases Alzheimer's disease, hypertension
Living situation Lives separately, 20 minutes away
Career Full-time office manager



Phases of disease

Noticing changes (2 years)

Making adjustments (1 year)

Shifting priorities (2 years)

Increasing demands (2 years)

Full-time care (1.5 years)

End of life (6 months)



“Is this part of normal aging?”

“This is not normal aging, but what is it?”

“I know it's Alzheimer's. What do I do now?”

“How much longer can I take care of Mom?”

“How do I make sure Mom is safe 24 hours a day?”

“Mom is in a facility. Why is this still so hard?”

Karen's experience

- Karen notices issues with her mom: memory problems, dents in car, and disorientation
- She discusses her concerns with her mom and brother, who are dismissive
- She turns to friends and the Web for information

- After Mom has a car accident, Karen takes her to the PCP and the 5 month diagnosis process begins
- She keeps her brother updated on all the tests and appointments she takes Mom to
- After an Alzheimer's Disease diagnosis, Karen meets with her brother and Mom to discuss a plan for care

- Karen realizes Mom can't drive or take care of her finances anymore, but Mom wants to stay in her own home
- Mom begins wandering and becomes more violent
- Karen starts sleeping at Mom's house sometimes to make sure she is safe

- Karen hires a part-time home care aide that Mom dislikes
- She takes a few days off work when Mom is hospitalized for a fall
- While Mom is in 3 weeks of rehab, Karen researches full-time care options and Medicaid/Medicare
- After discussing the options with her family and brother, they decide Mom will move in with Karen

- After Mom moves in with Karen's family, the whole family helps with caregiving (sometimes reluctantly)
- Karen moves to part-time work and struggles to find good dependable care workers
- Karen and her brother sell Mom's house to pay for her care
- Karen sleeps very little and her family reaches their breaking point

- Karen visits full time facilities and select a local nursing home they can afford
- She returns to full-time work but is constantly pulled away for caregiving responsibilities
- As Mom stops eating and drinking, Karen takes time off work to be with her until her death
- Karen continues to deal with issues of debt, grief, and family discord



Karen's key needs

- An understanding of warning signs for dementia
- A reputable source for info on symptoms
- A way to align her family and gain support
- Someone knowledgeable to talk to about her concerns
- Flexible schedule at her work

- A straightforward, quicker path to diagnosis
- Time to focus on her own physical and mental health
- Ways to keep Mom's spirits up
- Help keeping her brother informed about diagnosis process
- Info on what to expect with the disease to aid in planning
- Guidance on what legal documents she needs and when to do them
- Guidance to do advance directives early enough that Mom can communicate her wishes

- Help with Mom's difficult and abusive behavior
- Info on how to have a healthy lifestyle while caregiving
- Help with Mom's wandering
- Ways to communicate Mom's status to friends and family
- Guidance for dealing with her changing relationship with Mom
- Guidance on how Mom can continue to live at home alone
- Guidance on taking care of Mom's finances

- Training on how to safely do basic care and increasing medical tasks
- Information on how to increase the safety in Mom's home
- Ways to get family on the same page regarding Mom's deteriorating condition
- Breaks in caregiving
- A better understanding of Mom's eligibility for Medicare/Medicaid
- Ability to take a leave of absence from her work without hurting her career

- Home modifications for the health and safety of Mom
- Education about behavioral issues
- A way to educate care workers about Mom and her needs in the home
- Expanded family leave options
- Debt management counseling
- An understanding of worker rights and options for protecting her job while caregiving
- Respite options on a regular basis
- Emotional support and validation

- Advice on taking care of herself in stressful situation
- Information on what to look for in a facility
- A way to monitor Mom and her care when she is at work
- An understanding of hospice and when to transition to it
- A way to make care providers aware of power of attorney
- Advice for how to stretch Mom's money for the duration of her life

Spotlight: Journey summary

The caregiver journey summary provides an at-a-glance view of Karen's experience, life balance, key needs, and persona ecosystem.

agingwellhub.org



AgingWell Hub, co-founded with Philips, is a cross sector collaborative of the Global Social Enterprise Initiative (GSEI) at Georgetown University's McDonough School of Business
Proprietary content dated Oct. 17, 2017

© 2017 AgingWell Hub. All rights reserved. This book or any portion thereof may not be reproduced or used in any manner whatsoever without the express written permission of the publisher.