



Caregiver 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

agingwell hub

As we age, the majority of us envision staying in our homes and in the communities where we have lived our lives, raised our families and contributed through work and volunteer activities. Surveys consistently reflect that more than 90 percent of older adults prefer to stay in their homes as they age.

In summer 2015, Philips and the Global Social Enterprise Initiative at Georgetown University's McDonough School of Business created the AgingWell Hub to bring together a diverse group of collaborators in order to help older adults achieve this "age-in-place" vision. The AgingWell Hub examines how technology applications, products, and services can help connect older adult residents to community resources such as health care, transportation, groceries, entertainment and government and community services — and vice versa.

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A caregiver's journey

AgingWell Hub has created an integrated journey map for those caring for loved ones with Alzheimer's and other dementias. The map can be used to identify opportunities to provide support and intervention for caregivers, and in turn, to benefit their care recipients. Multiple players in today's health care system — a pharmaceutical company, health care provider, health-related technology provider, university, leading national nonprofits and more — came together to share expert knowledge and proprietary research to develop the map from the perspective of consumers. In this case, the consumer is the unpaid family caregiver of an older adult with Alzheimer's disease.

Tell the whole story

The goal of the caregiver journey map is to capture the 360-degree experience of individuals caring for a loved one with Alzheimer's or other serious cognitive impairment. Creating a common framework and terminology allows us to:

- Identify and prioritize areas where caregivers need support
- Drive alignment and collaboration across various players within the health care and community services ecosystem
- Inform the development of technology-enabled solutions to benefit caregivers as well as their care recipients

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An estimated **5.5 million Americans** have been diagnosed with Alzheimer's disease; 5.3 million of these individuals are age 65 or older.

Cost to society

The direct costs to American society of caring for individuals with Alzheimer's and other dementias in 2017 will total more than \$259 billion.

In 2017, Medicare and Medicaid will spend an estimated \$175 billion — 67 percent of total costs — caring for those with Alzheimer's and other dementias. This is largely a result of the high cost of care in the last five years of life, with the average totaling more than \$287,000 (in 2010 dollars). By comparison, the last five years of life for a person with heart disease or cancer costs on average \$175,000 and \$173,000, respectively.

Alzheimer's is the most expensive disease in America, costing more than cancer and heart disease.

Cost to caregivers and their families

In 2016, 15.9 million family members and friends provided 18.2 billion hours of unpaid care to those with Alzheimer's and other dementias. This contribution of care is valued at \$230 billion.

Caregivers report spending an average of more than \$5,000 per year of their own money to take care of their relative or friend with Alzheimer's. This amount ranged from \$1,000 to more than \$100,000. Spouses spent an average of more than \$12,000 per year, while adult children spent an average of about \$4,800 per year. Indeed, more than 32 percent of individuals caring for patients with Alzheimer's agree or strongly agree that the care has put a financial strain on their family.

It is important to note that none of the cost estimates above include the increasing cost of health care for family caregivers themselves. Many studies have shown that the health of family caregivers can be adversely affected, especially as their caregiving continues and becomes more intense.

Thirty-five percent of caregivers agree or strongly agree that their health has worsened since caring for an Alzheimer's patient. The strain for these family caregivers results in their using health care services at higher rates than non-caregivers of the same age — including rates for emergency room visits, hospital use and doctor visits. An 18-month study examined the health of Alzheimer's

caregivers compared to non-caregivers and captured how the caregiver's health declined steadily and significantly during this time period:

- Emergency room visits and use of hospital-based services doubled from 6.3 to 12.5 total visits per 100 Alzheimer's caregivers
- 25 percent increase in all types of health services

Alzheimer's and dementia caregivers spend on average \$4,766 more per year on their own health care costs. This is largely due to the higher level of stress. Nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress they experience as high or very high and about 40 percent suffer from depression.

Approximately 2/3 of caregivers are women; 34% of them are age 65 or older

Opportunity

Given these challenges, the caregiver journey map can help:

- Create greater understanding of caregiver stress points and areas of need for innovators to address
- Identify opportunities for triggering earlier diagnosis of Alzheimer's so that care and planning can be introduced earlier
- Reveal the cost curve associated with caregiving for Alzheimer's patients — for Medicare/Medicaid, private insurance, and families — to identify innovative solutions to reduce the cost of care and smooth cost spikes in the system and for families
- Provide support for policy recommendations designed to alleviate the care and cost burden to family caregivers

Focus and scope

A core group of corporate, nonprofit and academic leaders (see page 25) came together based on the mutual recognition that overly simplistic and siloed perspectives on caregiving stand in the way of much-needed innovation.

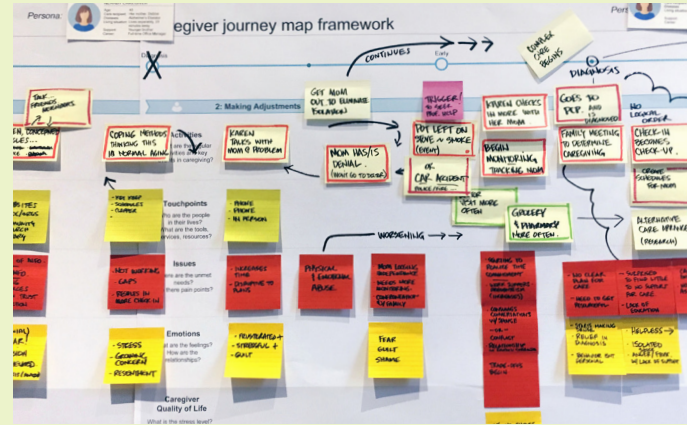
The team felt that capturing the journey of the Alzheimer's family caregiver could have significant positive impact by helping to alleviate the growing societal and personal costs related to the disease.

This initial journey map has been developed from the "persona" or perspective of an adult-aged daughter — the most common caregiving arrangement. It spans the care continuum from the onset of symptoms and pre-diagnosis through the late stages of the disease.

Cocreate workshop approach

The team leaders leveraged design thinking in a collaborative, iterative approach during journey map development sessions with detailed discussion, debate, and interactive mapping.

Sticky notes of various shapes, sizes, and colors were used to capture ideas for the map and the persona story. In this case, Karen (see page 9) is an adult-aged daughter who is working full-time, has two children, and is caring for her mother Debbie. Debbie is 68 years old and has Alzheimer's disease. Notes were moved or anchored with data as design professionals from Philips and Human Spark translated the team exercise into the journey map.



Notes from September workshop



Notes from October workshop

Methodology

The caregiver journey map is a representation of the collective expertise and experience of the core working team supplemented by research studies and interviews with other experts in the fields of health care, financial, and legal services.

As we aim to establish this framework as a standard for health care providers, industry players, and community service providers alike, we have anchored the map with available data and statistics to support the occurrence of key events, concerns, and needs of the caregivers.

Through a series of collaborative design sessions, the core working team followed the process below to develop the framework for the journey map, define personas, populate the map, and append it with key research data.

Phase 1: 3Q 2016 to 2Q 2017

Phase 2: 2017

Possible phase 3

Baseline journey map of adult daughter caring for mother with Alzheimer's (Pre-diagnosis to end-of-life)

Identify pain points and potential innovations; financial model for true cost

Apply methodology to other personas and/or chronic conditions

Personas

A persona is a composite character that represents a segment of people. Based in research, the persona may contain a name, quotes, characteristics, goals, challenges, and motivations in order to create a clear picture of who the character is and what challenges he/she faces.

The caregiver journey map project created four personas to represent a range of caregivers for patients with Alzheimer's disease and other dementias. Existing caregiver personas from the working team were used as a starting point for the first draft of personas. They were adjusted and expanded by the working group, based on their expertise and knowledge in the area of caregiving.

A primary difference between the personas is the relationship to the care recipient as well as the proximity of the caregiver. The working group hypothesized that the distance the caregiver lives from the care recipient and the relationship between the caregiver and care recipient has an important effect on the caregiving experience.

The personas include the following:

- Karen — nearby daughter caregiver
- Peter — distant son caregiver
- Robert — co-residing husband caregiver
- Janet — co-residing daughter caregiver

Karen was selected as the focus of the baseline journey map because she represents the majority of caregivers for patients with Alzheimer's and other dementias (see page 30 for other persona descriptions).

Caregiver ecosystem



Karen
Nearby caregiver

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

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

Core challenges

- Anxiety for the future, worrying constantly “what’s next”
- Balancing attention between Debbie and her own family
- Understanding of the situation when she isn't there
- Figuring out what to expect in the future
- Making sure her mother is safe
- Keeping her relationship in tact with her mother
- Making work a priority
- Remembering to take care of herself

- The eldest daughter in her family
- Feels it is her responsibility to care for her mother
- Married with two pre-teen daughters
- Works full-time as an office manager
- Has always had a close relationship with her mother
- Generally in good health
- Enjoys her book club and exercise classes in her free time
- Has movie night with her family once a week
- Drives 20 minutes to Debbie's house at least once a week to check in and visit
- Her boss doesn't know about her family responsibilities
- Shares household responsibilities with her husband

Karen cares for...



Debbie Karen's mother

- Age 68
- Husband passed away two years ago
- Owns her home
- Has hypertension
- Lives alone and enjoys her independence
- Diagnosed with early stage Alzheimer's disease when she is 70
- Wants to continue living in her own home



Karen Nearby caregiver



Leanna and Amelia Karen's pre-teen daughters

- Age 12 and 10
- See their grandmother less frequently because of her erratic behavior
- Notice Karen's distraction and stress
- Upset when Karen misses their activities and cancels their family vacation
- Know that something is wrong but don't understand exactly what Alzheimer's is

Karen gets support from...



Bill Karen's younger brother

- Age 40
- Lives three hours away and visits twice a year
- Works full time and travels frequently
- Depends on Karen to keep him informed about their mother's condition
- Contributes financially to caregiving
- Has a hard time understanding the severity of the situation
- Very concerned about the financial aspects of caregiving
- Feels guilty for not living closer



Paul Karen's husband

- Age 46
- Works full time as a mechanic
- Picks up the slack in the household while Karen is focused on Debbie's needs
- Wants to support Karen but is overwhelmed by the extra work and the strain on their finances
- Frustrated that Karen is rarely home and is less engaged in their family

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:

- **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.

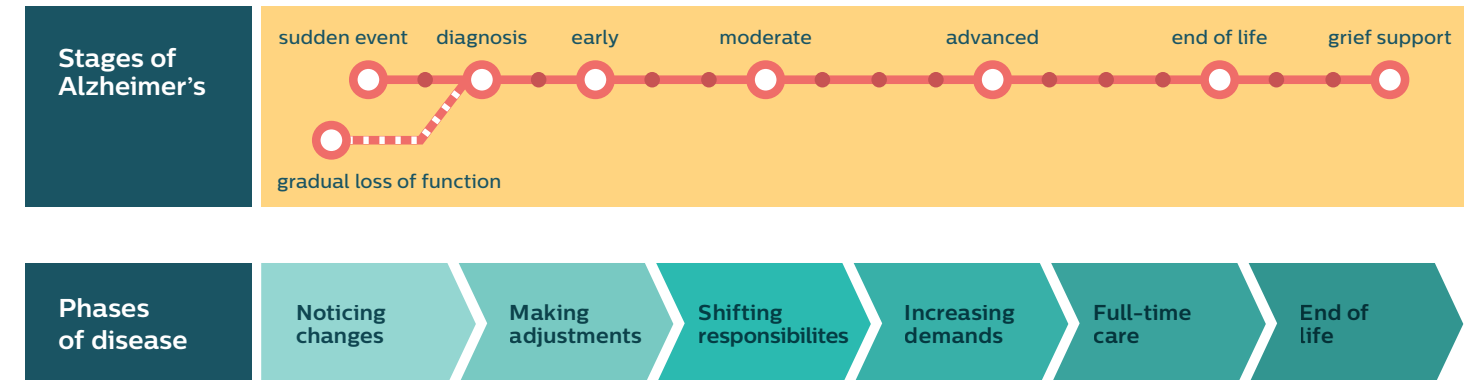
Focus areas

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.

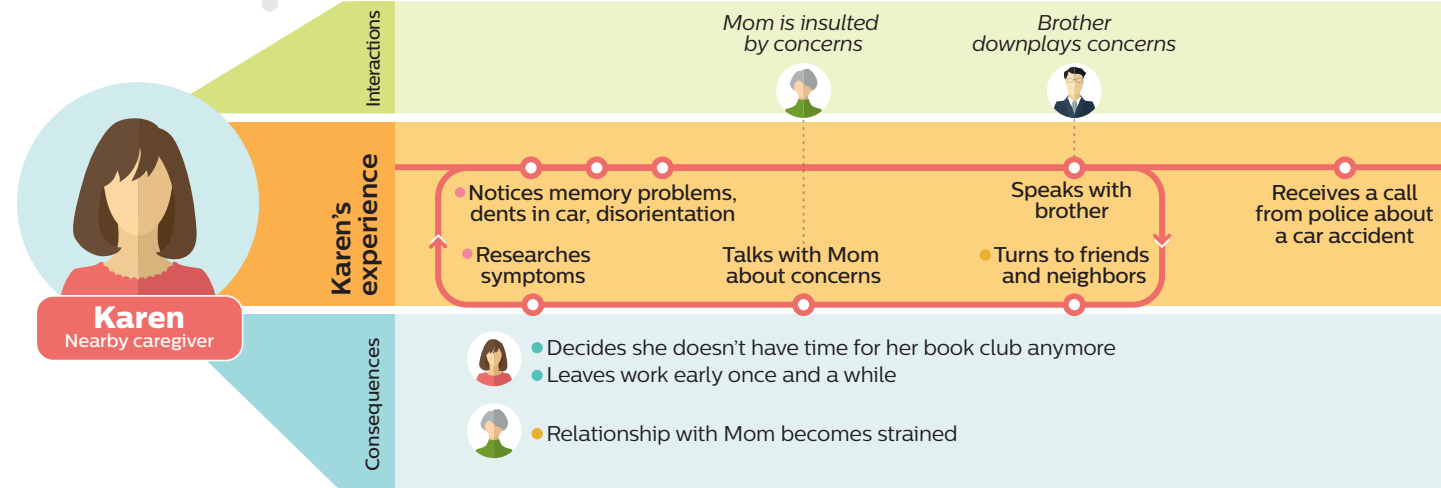


Phases of disease

Phase 1 Noticing changes (2 years)

Karen thinks...

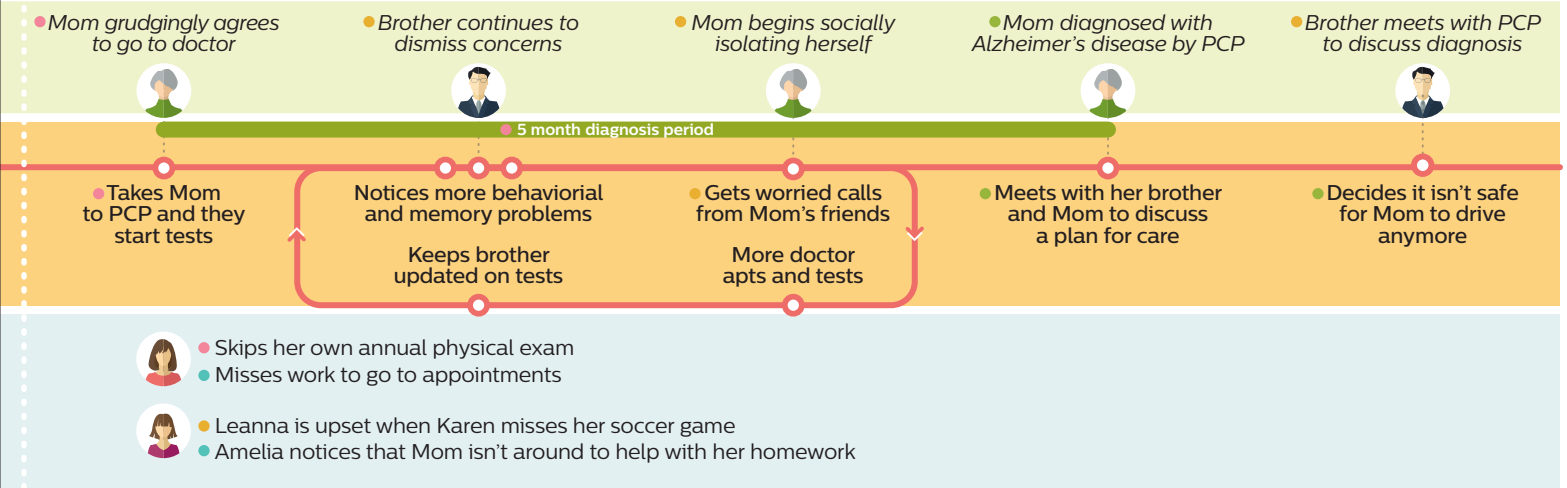
"Is this part of normal aging?"
Is there really a problem? • Why is this happening?
Where do I go for help? • Who can I talk to?



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?



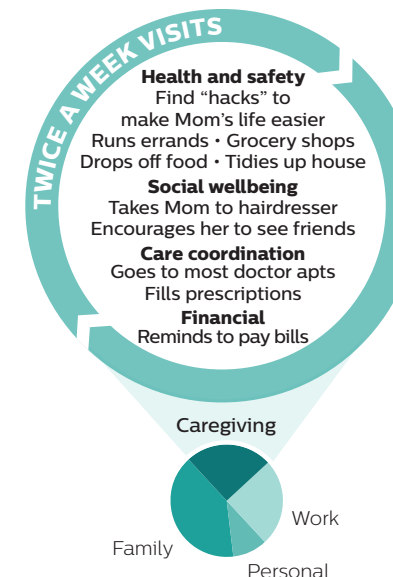
Karen does...



Karen needs...

- Health and safety**
 - 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

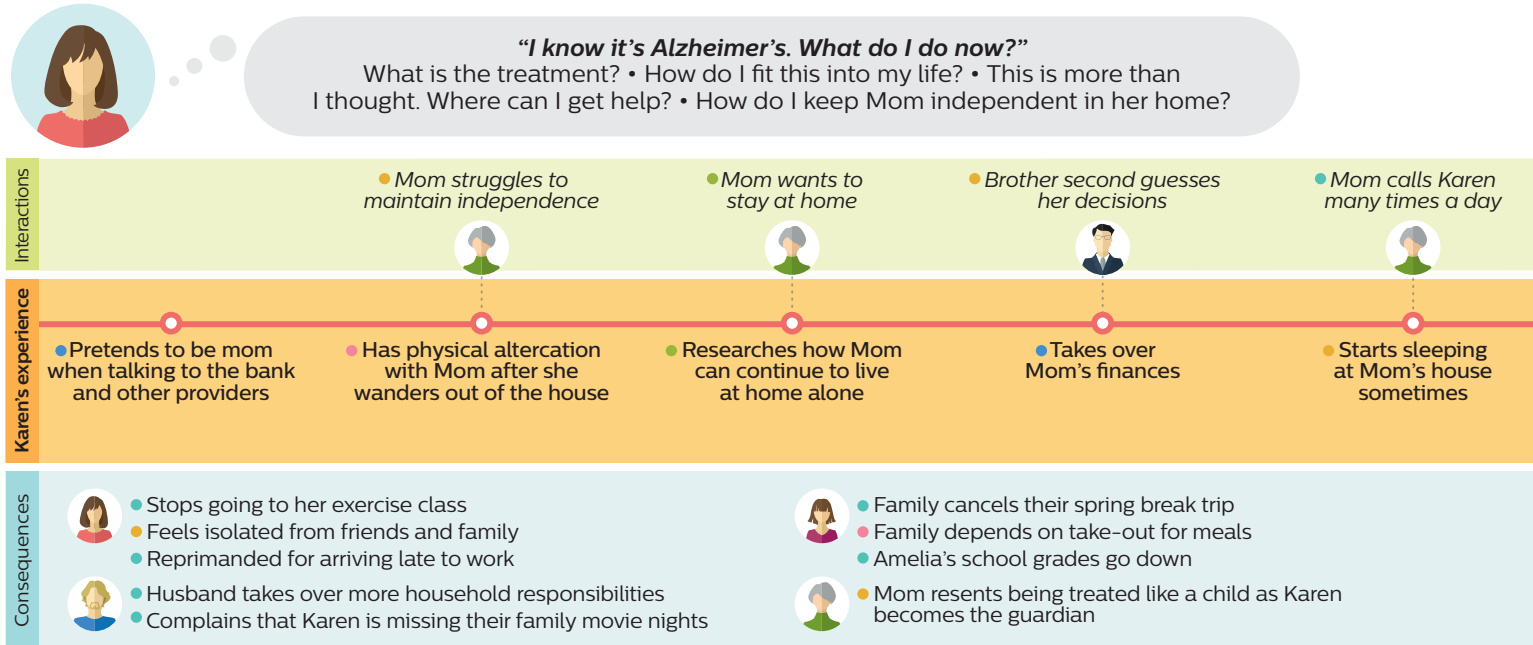
Karen does...



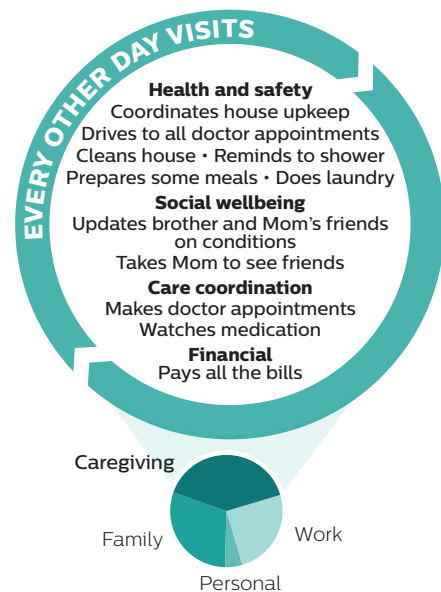
Karen needs...

- 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)



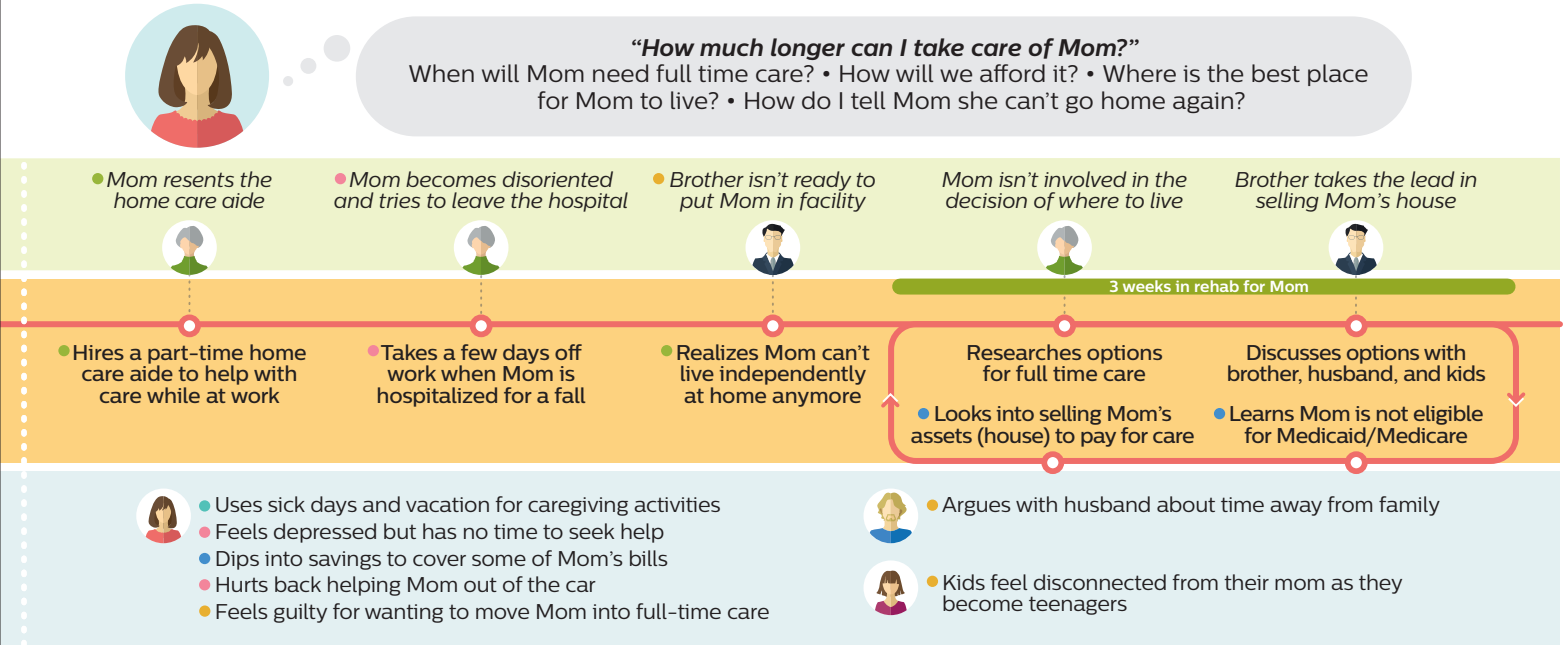
Karen does...



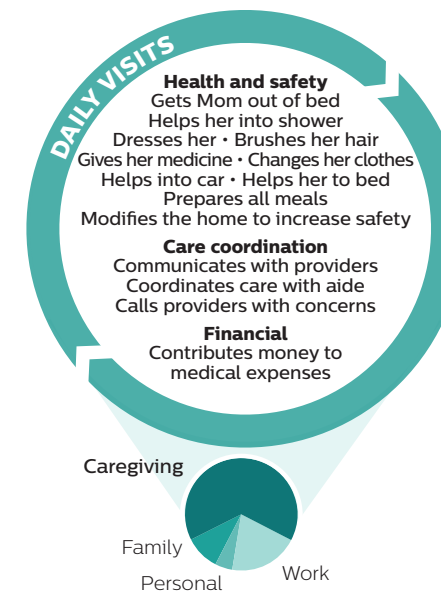
Karen needs...

- 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)



Karen does...



Karen needs...

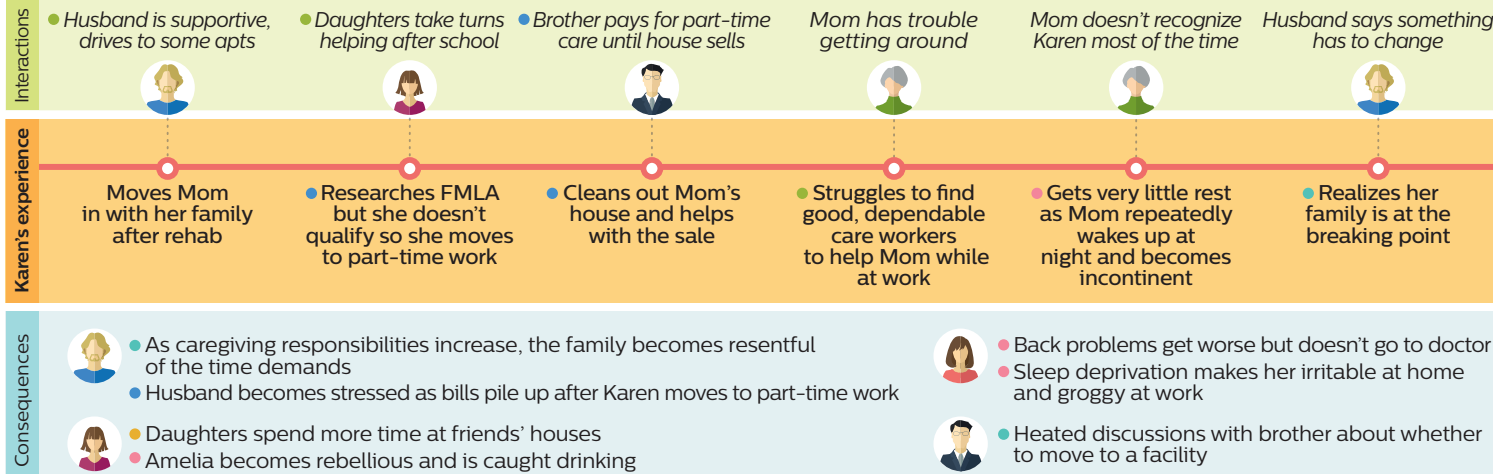
- Health and safety**
 - Training on how to safely do basic care and increasing medical tasks
 - Emotional support to deal with grief and depression
 - Information on how to increase the safety in Mom’s home
 - Information on avoiding hospital readmittance
- Social wellbeing**
 - Ways to get family on 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

Phase 5 Full-time care (1.5 years)

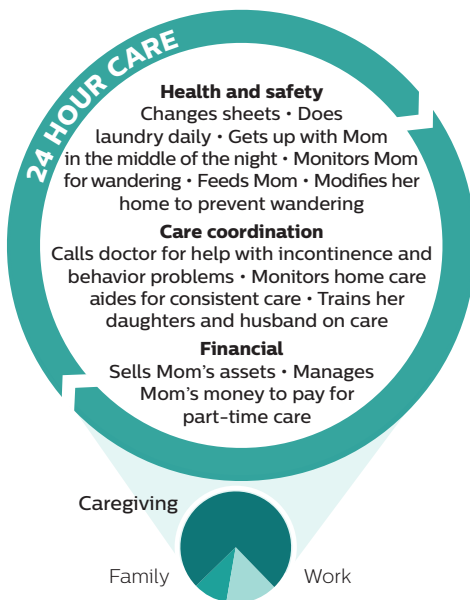


“How do I make sure Mom is safe 24 hours a day?”

I have no medical training. How do I manage this? • Is this the best place for Mom to live? • What is best for my family? • How long can I do this?



Karen does...



Karen needs...

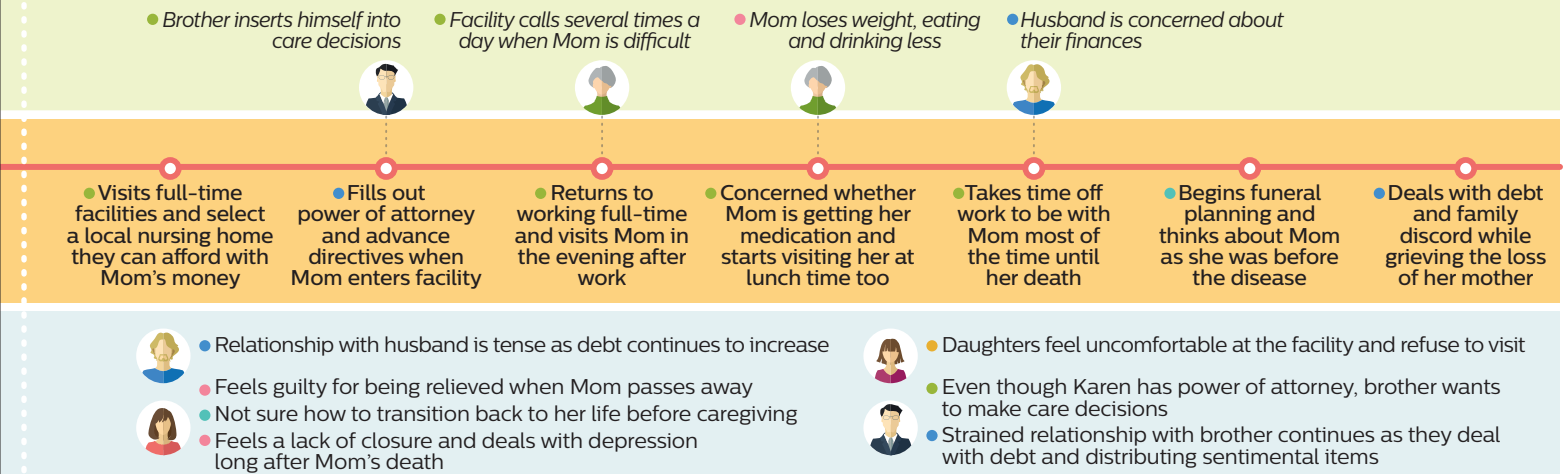
- Health and safety**
 - Quick and healthy way to take care of meals
 - Home modifications for the health and safety of Mom
 - Education about behavioral issues
 - Medication Management
- Social wellbeing**
 - Knowledge of community resources for Mom and Karen
 - Support for parenting responsibilities
- Care coordination**
 - Understanding of caregiver rights
 - A way to educate care workers about Mom and her needs in the home
 - A way to evaluate care workers and select ones that fit Mom's needs
 - Communication coordination with brother
 - Education on dementia for her family, especially her children
- Financial/legal**
 - Expanded family leave options
 - Debt management counseling
- Caregiver quality of life**
 - An understanding of worker rights and options for protecting her job while caregiving
 - Respite options on a regular basis
 - Emotional support and validation
 - Downtime with her family

Phase 6 End of life (6 months)

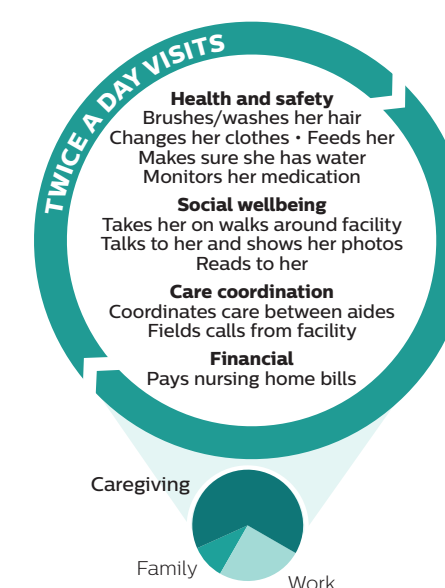


“Mom is in a facility. Why is this still so hard?”

Did I do the right thing? • How do I make sure she is well taken care of? • What if Mom's money runs out? • How will we afford this? • Is this the end? • How do I go back to life before caregiving?



Karen does...



Karen needs...

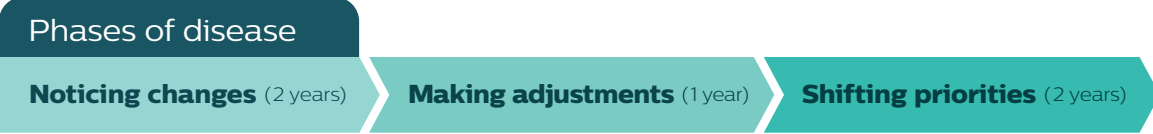
- Health and safety**
 - Healthy coping strategies
 - Advice on taking care of herself in stressful situation
 - An understanding of the end of life symptoms for Alzheimer's patients
- Social wellbeing**
 - Cooperation from her brother and the rest of her family
 - Ways to rebuild relationships with friends and family
 - Advice on how to distribute Mom's personal items without her input
- Care coordination**
 - Information on what to look for in a facility
 - Advice on which type of facility is right for Mom
 - 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
- Financial/legal**
 - Information about full time care options and the associated costs
 - Guidance to fill out power of attorney and advance directive documents earlier
 - Advice for how to stretch Mom's money for the duration of her life
- Caregiver quality of life**
 - Time to focus on her work without caregiving interruptions
 - A way to get general spiritual support (not necessarily religiously oriented)
 - Access and knowledge about support groups
 - Reconnection with hobbies

Spotlight: Journey summary

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

Caregiver journey summary

A project of [agingwellhub](#)*



“Is this part of normal aging?”

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

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

- 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 appts she takes Mom to
- After an Alzheimer's Disease diagnosis, Karen meets with her brother and Mom to discuss a plan for care

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

- 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'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

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

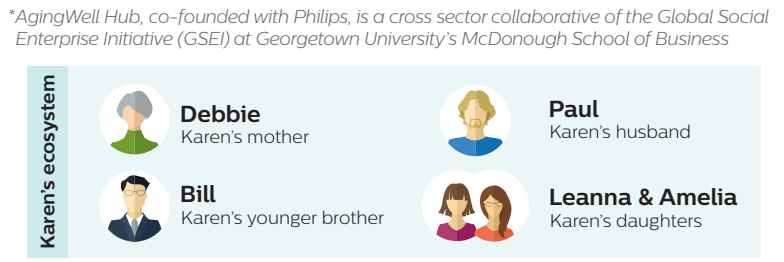
Age 43 when caregiving begins

Care recipient Her mother, Debbie

Diseases Alzheimer's disease, hypertension

Living situation Lives separately, 20 minutes away

Career Full-time office manager



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

- 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

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

- 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

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

- 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



- 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

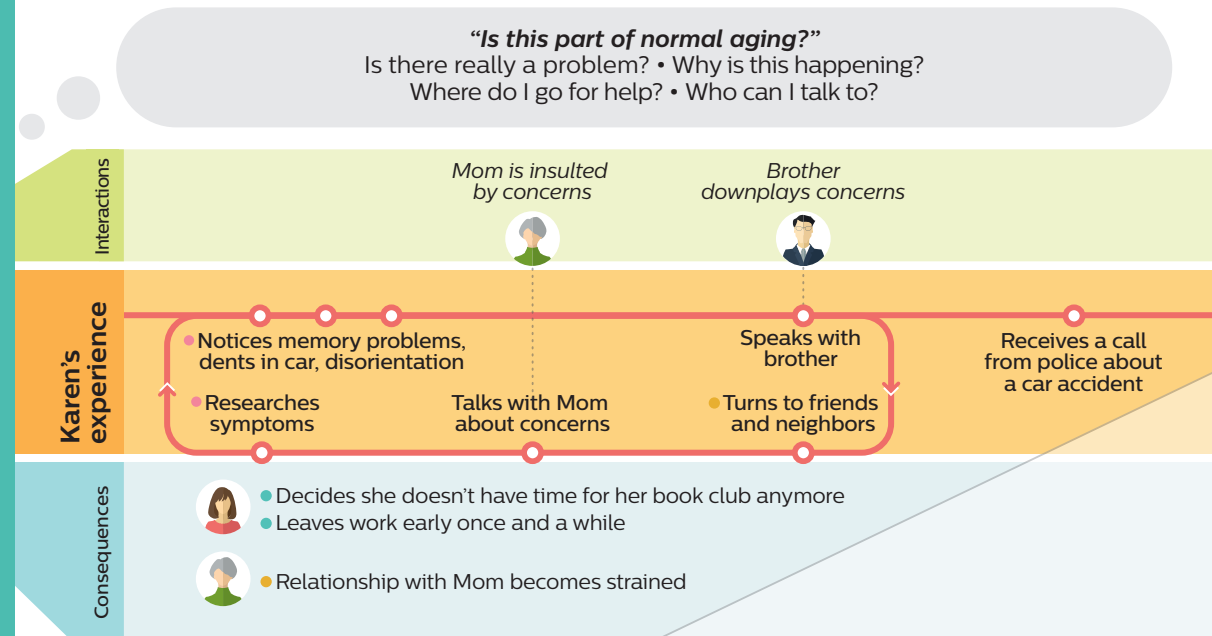
Caregiver journey — a project of

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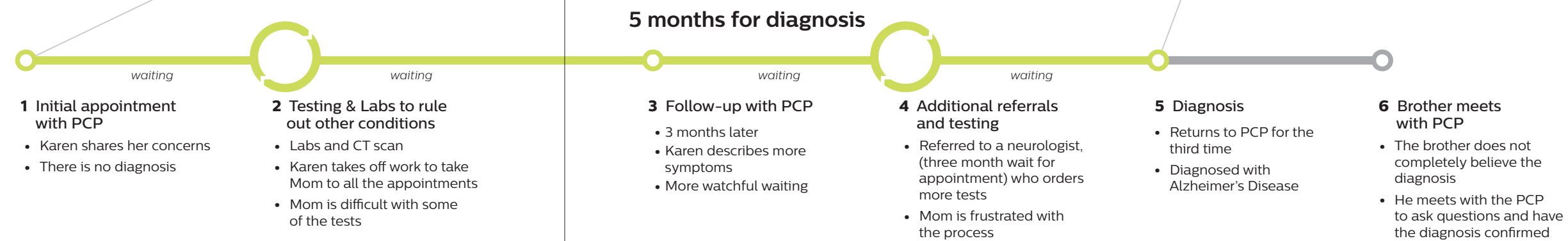
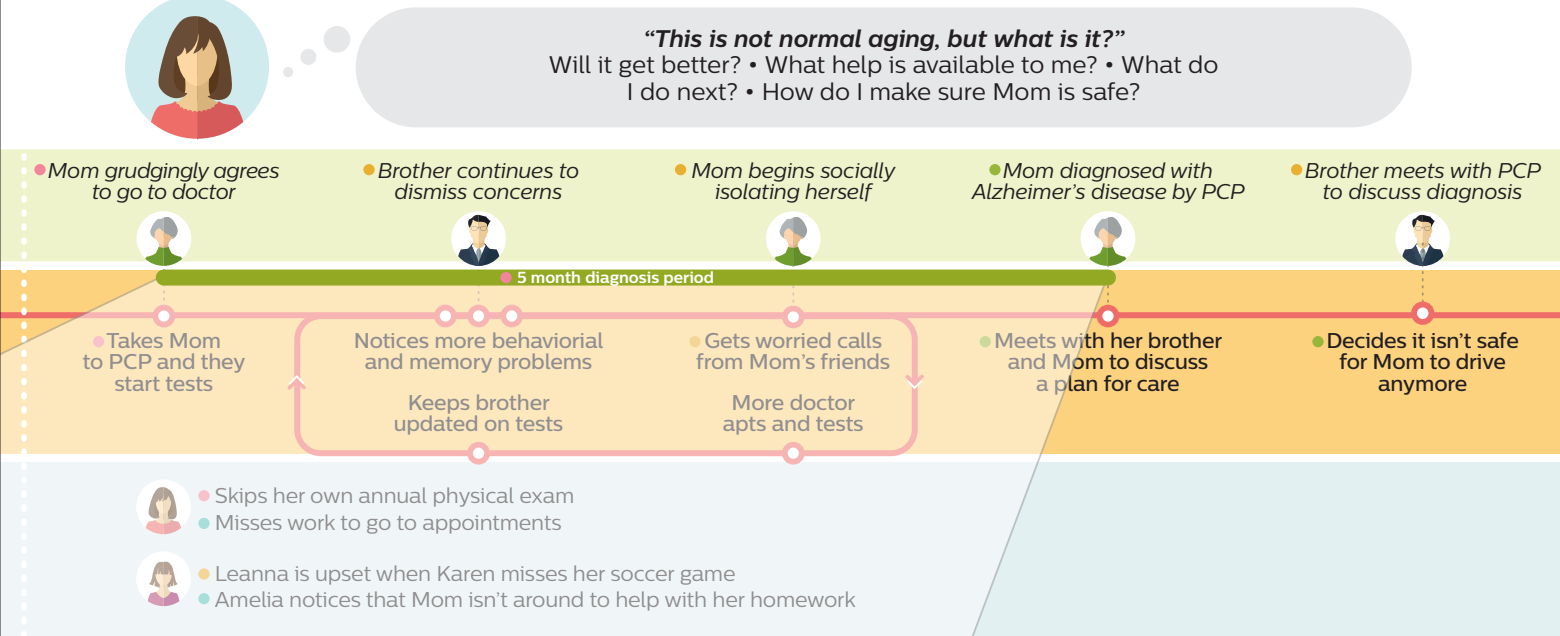
Spotlight: Debbie's diagnosis

The diagnosis of Karen's mom is explored with a timeline of key events and a list of pain points and emotions from the experience.

Phase 1 Noticing changes (2 years)



Phase 2 Making adjustments (1 year)



Debbie's diagnosis

Problems

- Time-consuming and expensive process
- Requires daughter to proactively attend appointments and raise concerns
- No direct path to diagnosis, uses process of elimination
- Discomfort from tests
- Family must wait in the dark while the symptoms continue or get worse
- Little guidance after diagnosis
- Difficult to pass information to long distance family members

Emotions

- Frustrated, nervous, confused
- Relieved to have a diagnosis

Special thanks

Working team

The following individuals contributed their time and expertise to the development of the baseline caregiver journey map for individuals caring for a loved one with Alzheimer's or other severe dementia:

- Kai Bode, Consumer Lead, *Customer Centricity, Customer Strategy and Innovation*, **Merck & Co, Inc.**
- Dr. George Hennawi, *Director, Geriatrics*, **MedStar Good Samaritan Hospital**
- Gail Hunt, *President and CEO*, **National Alliance for Caregiving**
- Adrienne Kilby, *Geriatric Social Worker, Center for Successful Aging*, **MedStar Good Samaritan Hospital**
- Ladan Manteghi, *Executive Director*, **Georgetown University's Global Social Enterprise Initiative**
- Steve McGrew, *Design Director*, **Philips**
- Sydney Mercurio, *Experience Researcher and Designer*, **Human Spark**
- Doug Pace, *Director, Alzheimer's and Dementia Care*, **Alzheimer's Association**
- Linda Schertzer, *Upstream Senior Global Product Manager*, **Philips**
- Diane Ty, *Project Director*, **Georgetown University's Global Social Enterprise Initiative**
- Michael Reese Wittke, *Director of Advocacy*, **National Alliance for Caregiving**
- Lisa Wright, *Account Director, Account Management, US Customer Solutions*, **Merck & Co., Inc.**

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- Margaret Campbell-Kotler, *National Manager, Caregiver Education and Training*, **Department of Veterans Affairs**
- Eric Hazzard, *Vice President, Health Economics and Outcomes Research*, **TupeloLife**
- Drew Holzapfel, *ReACT and Partner*, **High Lantern Group**
- Margi Lenz, *Geriatric Social Worker, Center for Successful Aging*, **MedStar Good Samaritan Hospital**
- Dirk Peters, *CEO*, **CareGeneral**
- Shalini Sinha, *Student Leader*, **Georgetown University's Global Social Enterprise Initiative**
- Bryan Vodicka, *MBA Candidate and Student Leader*, **Georgetown University's Global Social Enterprise Initiative**



General supporting data

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- *2017 Alzheimer's Disease Facts and Figures*, Alzheimer's Association, 2017.
- *Catalyzing Technology to Support Family Caregiving*, National Alliance for Caregiving, July 2014.
- *Caregiving in the US: 2015 Report*, AARP Public Policy Institute and National Alliance for Caregiving.
- *Disrupting Alzheimer's: The Opportunities for Technology in Alzheimer's Disease*: ReACT and Global Council on Alzheimer's Disease.
- *Determining the Return on Investment: Supportive Policies for Employee Caregivers*, AARP and ReACT.
- Kelly, Amy S.,MD; Kathleen McGarry, PHD; Rebecca Gorges, MA; Jonathan S. Skinner, PhD, *The Burden of Health Care Costs of Patients with Dementia in the Last 5 Years of Life*, Annals of Internal Medicine, November 17, 2015.
- www.ncbi.nlm.nih.gov/pmc/articles/PMC4809412/
- *What Made You Think Your Mom Had Alzheimer's*, Pfizer and National Alliance for Caregiving.
- Fox, Susannah, Maeve Duggan & Kristen Purcel, *Family Caregivers are Wired for Health*, Pew Research Center, June 20, 2013.
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- Kantar Health Tables, Custom data analysis prepared for Merck, Inc., Fall 2016.
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Persona supporting data

Karen: Adult-aged daughter

- 2/3 of caregivers are female, average of 49 years old. *2015 Report: Caregiving in the US*.
- 49% care for a parent or parent in law. *2015 Report: Caregiving in the US*.
- 60% of working caregivers have to make a work place accommodation as a result of caregiving. *2015 Report: Caregiving in the US*.
- 45% of caregivers for someone with dementia or Alzheimer's report the presence of paid help. *2015 Report: Caregiving in the US*.
- 60% of caregivers caring for a parent feel they had no choice in taking on the caregiver role. *2015 Report: Caregiving in the US*.
- 65% of caregivers take on the role because of a desire to keep the family member at home. *Alzheimer's Assoc 2017 report*.
- 2/3 of caregivers are married. *Alzheimer's Assoc 2017 report*.
- 1/4 of Alzheimer's caregivers are "sandwich generation" (caring for aging parent and children under 18). *Alzheimer's Assoc 2017 report*.
- 1/3 of dementia caregivers are daughters. *Alzheimer's Assoc 2017 report*.

Debbie: Alzheimer's patient

- One in four Americans has multiple chronic conditions, those that last a year or more and require ongoing medical attention or that limit activities of daily living. That number rises to three in four Americans aged 65 and older. *Multiple Chronic Diseases, Center for Disease Control, Nov 18, 2014*.
- The first quarter 2017 homeownership rates were highest for households ages 65 years and over (78.6%). *Residential Vacancies and Homeownership, U.S. Census Bureau Data, April 27, 2017*.
- Among the patients with dementia, 12.34% had dementia as the only diagnosis, 69.61% showed at least two comorbidities and 48.05% showed at least three. The two most frequent comorbidities both for men and women with dementia were hypertension and diabetes. *Comorbidity of Dementia: A Cross-sectional Study of Primary Care Older Patients, NCBI 2014*.

Supporting data by phase of disease

General

- Among all older adults with dementia, 77% receive assistance with ADLs or household activities compared to 20% of older adults without dementia. Caregivers of older adults with Alzheimer's disease help with an average of two ADLs and five iADLs. *2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association*.
- 57% of all family caregivers of care recipients living in the community had provided care for four or more years. *Alzheimer's Assoc 2017 report*.
- *Caregiving Innovation Frontiers: Advancing technologies and improving solutions for America's family caregivers, informal helpers, and care recipients*, June 2017.

Noticing Changes

- Data from the 2013 Behavior Risk Factor Surveillance System (BRFSS) survey showed that 11% of Americans age 45 and older reported experiencing worsening confusion or memory loss, but 76% had not consulted a health care professional about it. This helps explain how someone with mild Alzheimer's symptoms can go on for some time without seeking help or a diagnosis. *2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association*.

Making Adjustments

- 49% of Alzheimer's caregivers agree or strongly agree with the statement, "I have eliminated things from my schedule since caring for the patient" vs. 40% of caregivers taking care of adult relative with a disease other than Alzheimer's. *Kantar Health Tables, custom data analysis prepared for Merck, Inc.*

Shifting Priorities

- Close to half arrange for outside services (45 percent), and nearly four of five communicate with health care professionals (79 percent), and manage their finances (65%). *National Alliance for Caregiving and AARP. Caregiving in the US, 2015*
- Caregivers of people with dementia are more likely to coordinate health care for the care recipient than caregivers of people without dementia (86 percent versus 72 percent). *2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association*.

Increasing Demands

Activities of daily living (ADLs):

- The most difficult ADLs involve personal care activities, like managing incontinence or diapers (40%), helping the recipient get to and from the toilet (33%), and bathing/showering assistance (31%). *Caregiving in the US: 2015 Report, AARP Public Policy Institute & National Alliance for Caregiving*.

- Transportation, meal preparation, grocery shopping, housework, medication management, or arranging for outside services

Instrumental Activities of Daily Living (iADLs):

- Caregivers help, on average with 4.2 out of 7 iADLs, including transportation (78%), grocery shopping (76%), or housework (72%). *2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association*.

Medical tasks

- Medical tasks include injections, tube feedings, catheter and colostomy care, and many other complex care responsibilities. About 6 in 10 caregivers assist with medical/nursing tasks (57%), and higher-hour caregivers are more often performing these tasks. Fourteen percent of those caregivers who assist with medical/nursing tasks find it difficult. Higher-hour caregivers are more likely to feel that performing medical/nursing tasks is difficult, as are those caring for someone with Alzheimer's or dementia (22%) and those who have been providing care for 5 years or more (21%). *2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association*.

Impact on Caregiver Employment

- Many care contributors reported that they had to work fewer hours or stop working entirely to support the person with dementia. 35% of care contributors reported HH income losses as a result of these employment changes. Care contributors and their families who experienced income losses lost an average of \$15,194 compared with their income the previous year. *2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association*.
- Over 23% of Alzheimer's caregivers agree or strongly agree with the statement, "I have to stop in the middle of work to tend to caregiving duties" vs. 19% of caregivers taking care of adult relative with a disease other than Alzheimer's. *Kantar Health Tables, custom data analysis prepared for Merck, Inc., Fall 2016*.

Impact on Caregiver Finances

- Many care contributors reported that they had to work fewer hours or stop working entirely to support the person with dementia. 35% of care contributors reported HH income losses as a result of these employment changes. Care contributors and their families who experienced income losses lost an average of \$15,194 compared with their income the previous year. *2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association.*
- Over 32% of Alzheimer's caregivers agree or strongly agree with the statement, "Caring for the care recipient has put a financial strain on my family" vs. 29% of caregivers taking care of adult relative with a disease other than Alzheimer's. *Kantar Health Tables, custom data analysis prepared for Merck, Inc., Fall 2016.*
- Out-of-pocket costs for those with Alzheimer's and other dementias were more than twice those of people with cancer and 74 percent higher than those for people with cardiovascular disease. *2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association.*
- 11 percent of Alzheimer caregivers report cutting back on their children's educational expenses. *2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association.*
- Thirteen percent of care contributors sold assets to help pay expenses for their friend or family member with dementia. Among the assets sold were vehicles (42 percent), jewelry and other collectibles (22 percent), furniture (15 percent), electronics (14 percent) and a dwelling (12 percent).

Impact on Health and emotional well-being

- Alarmingly, 20 percent of care contributors cut back on going to the doctor themselves, 11 percent cut back on buying medicine for themselves. *2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association.*
- Over 30% of Alzheimer's caregivers agree or strongly agree with the statement, "My health has gotten worse since I've been caring for the patient" vs. 24% of caregivers taking care of adult relative with a disease other than Alzheimer's. *Kantar Health Tables, custom data analysis prepared for Merck, Inc., Fall 2016.*
- 59% of family caregivers of people with Alzheimer's rated the emotional stress of caregiving as high or very high. *2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association.*

- Around 40% of family caregivers of people with dementia suffer from depressions, compared with 5 to 17% of non-caregivers of similar ages. Rates of depression increase with the severity of cognitive impairment of the person with dementia. *2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association.*

Full-time care

- Employees are eligible to take FMLA leave if they have worked for their employer for at least 12 months, have worked for at least 1,250 hours over the previous 12 months, and work at a location where at least 50 employees are employed by the employer within 75 miles. *U.S. Department of Labor: The Family and Medical Leave Act*
- Of the 5.7 million companies in the U.S., 90% have less than 20 employees. *Kiersz, Andy, "The Impact of Small Business on the U.S. economy in 2 extreme charts," Business Insider, June 16, 2015.*


End of life

- Within the overall adult population, 18 and over, only 26.3% have an advance care directive. Among adults 50-64, the level rises to 29.3% and at 65+, the level rises to 51%. *Rao, Jaya K.; Anderson, Lynda A.; Lin, Feng-Cheng; Laux, Jeffrey P. Completion of Advance Directives Among U.S. Consumers, American Journal of Preventative Medicine, Volume 46, Issue 1, pp. 65-70, January 2014*
- 2/3 with dementia die in nursing homes. *2017 Alzheimer's Association Facts & Figures, p. 29.*
- In 2017, typical annual cost of a private room in a nursing home was about \$92,000; for a shared room about \$82,000. Costs for home care are about \$20/hour. For a typical amount of home care at an average of 30 hours /week, the cost comes to \$32,000/year. *Houser, Ari; AARP Fact Sheet: "Women and Long-Term Service and Supports," AARP Public Policy Institute, April 2017.*

Secondary personas

The baseline journey map can be adapted to capture the experience of any of these secondary personas as well as other disease states.

Peter



Distant caregiver

Age: 42
Care recipient: His father, Frank
Diseases: Dementia
Living situation: Lives four hours away
Support: Part-time paid nurse
Career: Full-time middle school teacher


Core challenges

- Understanding the complete situation from a far
- Knowing what to expect in the future
- Affording the type of care Frank needs
- Guilt for not being closer
- Speaking to his dad's doctors to understand his illness
- Predicting how much money will be needed long term

• Only child
 • His mother passed away last year
 • His father lives alone in the house he grew up in
 • Married with three kids
 • Calls Frank once a day but his dad doesn't tell him much information
 • Tries to get a report from the nurse at least once a week to understand Frank's condition
 • Visits every couple month to go to some doctor appointments with his father

"I just hope Dad will be okay."

Janet



Co-residing caregiver

Age: 48
Care recipient: Her mother, Ann
Diseases: Alzheimer's disease and other illnesses
Living situation: Her mother lives with her family
Support: Distant sister
Career: Part-time speech therapist


Core challenges

- Making ends meet now that she has reduced her work hours
- Integrating her mother into her home
- Comfortably leaving her mother alone in the house
- Finding time to focus on her family
- Remembering all the appointments in Ann's care plan
- Keeping her sister up to date about their mother's condition
- Concerns about how they will afford long term care

• The eldest daughter in her family
 • Her younger sister lives across the country but wants to stay informed
 • Married with one teenage son
 • Reduced her work to part-time when her mother's health declined
 • Shuttles her mom to all her doctor and specialist appointments
 • Keeps track of her mom's medicines
 • Spends a lot of time researching Alzheimer's Disease.

"At times it feels like a full-time job, but you can never do enough"

Robert



Husband caregiver

Age: 74
Care recipient: His wife, Mary
Diseases: Alzheimer's disease and COPD
Living situation: Living together
Support: Two sons
Career: Retired electrician

Core challenges

- Wants to learn more about Alzheimer's but doesn't know how
- Focused on the day to day activities and doesn't have time for long term planning
- Managing his and Mary's medication
- Keeping up with all their doctor appointments
- Overwhelmed and tired by stress and workload
- Knowing when something is serious or when to just wait it out
- Cost of care

• Married to Mary for 50 years
 • Retired 12 years ago from working as an electrician
 • Tries to take care of Mary alone but calls their two sons when he needs more support
 • Sons check in by phone a couple times a week
 • Had start cooking, cleaning the house, and grocery shopping for the first time
 • Still drives to doctor appointments and the grocery store
 • Has diabetes and also is hard of hearing
 • Is too frail to bathe or lifting Mary
 • Still has lots of questions after meeting with doctors

"I am trying my best to take care of Mary as long as I can."

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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