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
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.

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 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.

A caregiver’s journey

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
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.

**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.

Approximately **2/3 of caregivers are women; 34% of them are age 65 or older**
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
Baseline journey map of adult daughter caring for mother with Alzheimer’s disease (Pre-diagnosis to end-of-life)

Phase 2: 2017
Identify pain points and potential innovations. Financial model for true cost

Possible phase 3
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).

Karen Nearby caregiver

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

Caregiver ecosystem

“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

- 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 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
- 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
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.

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**Caregiving through all stages**
The working team mapped the stages of caregiving to match the stages of Alzheimer’s disease.

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**Foundational journey map**

**Stages of Alzheimer’s**
- Sudden event
- Diagnosis
- Early
- Moderate
- Advanced
- End of life
- Grief support

**Gradual loss of function**

**Phases of disease**
- Noticing changes
- Making adjustments
- Shifting responsibilities
- Increasing demands
- Full-time care
- End of life

**Karen’s experience**

**Karen does...**

**Karen needs...**

**Grief support**
Phase 1 Noticing changes (2 years)

Karen thinks...
- Notices memory problems, dents in car, disorientation
- Receives a call from police about a car accident
- Talks with Mom about concerns
- Speaks with Brother
- Turns to friends and neighbors
- Decides she doesn't have time for her book club anymore
- Leaves work early once and a while
- Relationship with Mom becomes strained

Karen does...
- Takes care of car maintenance
- Reminds her to take medication
- Cleans out fridge
- Goes to most doctor appts
- Fills prescriptions
- Reminds to pay bills
- Goes to most doctor appts
- Fills prescriptions
- Reminds to pay bills

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 about her concerns
- Care coordination
  - A way to monitor Mom’s symptoms
- Financial/legal
  - Flexible schedule at her work

Karen does...
- 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
- Care coordination
  - Help with Mom’s home and running errands
  - Info on what to expect with the disease to aid in planning
- 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

Karen needs...
- Health and safety
  - 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?
- Social wellbeing
  - 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?
- Care coordination
  - More doctor appts and tests
- Financial/legal
  - “This is not normal aging, but what is it?”
  - “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?”

Karen does...
- Health and safety
  - Takes Mom to PCP and they start tests
  - Mom grudgingly agrees to go to doctor
  - Brother continues to dismiss concerns
  - More doctor appts and tests
  - Decides it isn’t safe for Mom to drive anymore
- Social wellbeing
  - Mom grudgingly agrees to go to doctor
  - More doctor appts and tests
  - Decides it isn’t safe for Mom to drive anymore
- Care coordination
  - Mom begins socially isolating herself
  - More doctor appts and tests
  - Decides it isn’t safe for Mom to drive anymore
- Financial/legal
  - Mom diagnosed with Alzheimer’s disease by PCP
  - More doctor appts and tests
  - Decides it isn’t safe for Mom to drive anymore

Karen needs...
- Caregiver quality of life
  - A shared understanding of the disease and the caregiving needed
- Caregiver quality of life
  - Time to focus on her work, with less distractions

Karen does...
- Caregiver quality of life
  - “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?
- Care coordination
  - Meets with her brother and Mom to discuss a plan for care
  - More doctor appts and tests
  - Decides it isn’t safe for Mom to drive anymore
Karen's experience
Pretends to be mom when talking to the bank and other providers
Takes...private environment at work to discuss her caregiving situation
• A break from caregiving
• Time to take care of herself

EVERY OTHER DAY VISITS
Health and safety
Coordinates house upkeep
• Drives to all doctor appointments
• Cleans house • Reminds to shower
Social wellbeing
• Updates brother and Mom's friends
• Takes Mom to see friends
Care coordination
• Make doctor appointments
• Refills prescription medications

Phase 3 Shifting priorities (2 years)
Karen's experience
Pretends to be mom when talking to the bank and other providers
Takes...private environment at work to discuss her caregiving situation
• A break from caregiving
• Time to take care of herself

EVERY DAY VISITS
Health and safety
Helps 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 tocommunicate 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

Karen does...
Health and safety
Helps 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
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• 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

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• 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

EVERY OTHER DAY VISITS
Health and safety
Helps 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

Karen does...
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 • Better understanding of Mom's eligibility for Medicare/Medicare • 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
Karen's experience
Moves Mom in with her family after rehab
Husband is supportive, drives to some apt in the middle of the night
Daughters spend more time at friends' houses
Karen does... 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 and select ones that fit Mom's needs • Communication coordination with brother • Education on dementia for her family:
Financial
Sells Mom's assets • Manages Mom's money to pay for part-time care

Karen needs... Health and safety
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
Social wellbeing
An understanding of work-life balance
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

“Do I have time to do this?”
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?

Caregiver journey — a project of agingwellhub*

Phase 5 Full-time care
(1 year)

“Caregiving has become the only thing about which I think all the time.”
Karen does... 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 and select ones that fit Mom's needs • Communication coordination with brother • Education on dementia for her family:
Financial
Sells Mom's assets • Manages Mom's money to pay for part-time care

Karen needs... Health and safety
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
Social wellbeing
An understanding of work-life balance
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

“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?

Caregiver journey — a project of agingwellhub*

Phase 6 End of life
(6 months)

“End of life care — when is the right time?”
Karen does... 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 make care decisions 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

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 make care decisions 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

*Appignet 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.
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.

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

Debbie’s diagnosis

Phase 1 Noticing changes (2 years)
- Notices memory problems, dents in car, disorientation
- Receives a call from police about a car accident
- Researches symptoms
- Talks with Mom about concerns
- Speaks with brother
- Turns to friends and neighbors
- Decides she doesn’t have time for her book club anymore
- Leaves work early once and a while
- Relationship with Mom becomes strained

Four months for diagnosis
1 Initial appointment with PCP
- Karen shares her concerns
- There is no diagnosis

5 months for diagnosis
2 Testing & Labs to rule out other conditions
- Labs and CT scan
- Karen takes off work to take Mom to all the appointments
- Mom is difficult with some of the tests

3 Follow-up with PCP
- 3 months later
- Karen describes more symptoms
- More watchful waiting

4 Additional referrals and testing
- Referred to a neurologist, (three month wait for appointment) who orders more tests
- Mom is frustrated with the process

5 Diagnosis
- Returns to PCP for the third time
- Diagnosed with Alzheimer’s Disease

6 Brother meets with PCP
- The brother does not completely believe the diagnosis
- He meets with the PCP to ask questions and have the diagnosis confirmed

Phase 2 Making adjustments (1 year)
- Takes Mom to PCP and they start tests
- Mom grudgingly agrees to go to doctor
- Brother continues to dismiss concerns
- Mom begins socially isolating herself
- Mother diagnosed with Alzheimer’s disease by PCP
- More doctor appts and tests

5 months for diagnosis
6 Brother meets with PCP
- The brother does not completely believe the diagnosis
- He meets with the PCP to ask questions and have the diagnosis confirmed

5 month diagnosis period
- Frustrated, nervous, confused
- Relieved to have a diagnosis

Emotions

Caregiver journey — a project of 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
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:

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• 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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- What Made You Think Your Mom Had Alzheimer’s? 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/
- Comorbidity of Dementia: A Cross-sectional Study of Primary Care Older Patients, NCBI 2014.

Persona supporting data

**Karen: Adult-aged daughter**
- 2/3 of caregivers are female, average of 49 years old. 2015 Report: Caregiving in the U.S.
- 49% care for a parent or parent in law. 2015 Report: Caregiving in the U.S.
- 60% of working caregivers have to make a work place accommodation as a result of caregiving. 2015 Report: Caregiving in the U.S.
- 45% of caregivers for someone with dementia or Alzheimer’s report the presence of paid help. 2015 Report: Caregiving in the U.S.
- 60% of caregivers caring for a parent feel they had no choice in taking on the caregiver role. 2015 Report: Caregiving in the U.S.
- 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 and Prevention, 2015.
- The first quarter 2017 homeownership rates were highest for households ages 65 and over (79.6%). Residential Vacancies and Homeownership, U.S. Census Bureau Data, April 17, 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. Alzheimer’s Assoc 2017 report. Caregiving in the U.S.
- 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.
- 51% of all family caregivers of care recipients living in the community had provided care for four or more years. Alzheimer’s Assoc 2017 report.
- 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.
- 49% care for a parent or parent in law. 2015 Report: Caregiving in the U.S.

**Increasing Demands**
- 48% 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.
- 49% care for a parent or parent in law. 2015 Report: Caregiving in the U.S.
- Among all older adults with dementia, 77% receive assistance with ADLs. Alzheimer’s Assoc 2017 report. Caregiving in the U.S.
- 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.
- 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.
- 49% care for a parent or parent in law. 2015 Report: Caregiving in the U.S.
- Among all older adults with dementia, 77% receive assistance with ADLs. Alzheimer’s Assoc 2017 report. Caregiving in the U.S.
- 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.
- 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.
Appendix

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 caregivers 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 relatives with a disease other than Alzheimer’s. Kantar Health Tabels, 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 full-time care hours or stop working entirely to support the person with Alzheimer’s disease. 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. Kantor Health Tabels, 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 company 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 rose to 29.3% and at 65+, the level rises to 31.7. Foz, Joya K., Anderson, Lynda A., Lin, Feng-Cheng, Loux, Jeffrey P. Completion of Advance Directives Among U.S. Consumers, American Journal of Preventive 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 3-3.5 hours/week, the cost comes to $32,000/year. Houser, Ann. 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
Career: Full-time middle scholar teacher
Support: Husband, two sons
Distant sister
Care recipient: His father, Frank
Age: 82
Care recipient: His wife, Mary
Diseases: Alzheimer’s disease and COPD
Living situation: Lives four hours away
Lives four hours away
Healthcare contributors:
• John, Frank’s brother
• Janet, Frank’s sister
• His two sons
Care contributors:
• His father, Frank
• His wife, Mary

Core challenges
• Knowing what to expect in the situation from a far
• Understanding the complete needs
• Predicting how much money will be needed long term
• Guilt for not being closer

Information
• I just hope Dad will be okay.

Making ends meet now that she has reduced her work hours to stay informed
• Guilt for not being closer

Janet
Care recipient: His wife, Mary
Distant sister
Care recipient: His daughter, Mary
Living situation: Married to Mary for 50 years
Living situation: Married with one teenage son
Care contributors:
• Her husband, Peter
• Her two sons
Care contributors:
• Peter
• Her two sons

Core challenges
• Making ends meet now that she has reduced her work hours for long term planning
• Guilt for not being closer

Making ends meet now that she has reduced her work hours
• Making ends meet now that she has reduced her work hours

Robert
Husband caregiver
Age: 48
Career: Full-time speech therapist
Support: Retired electrician
Distant sister
Care recipient: His mother, Mary
Age: 74
Care recipient: His wife, Mary
Diseases: Alzheimer’s but doesn’t know how to understand Frank’s condition
Living situation: Comfortably leaving her mother
Lives four hours away
Healthcare contributors:
• Janet, Frank’s sister
• His two sons
• Tries to take care of Mary alone but calls their two sons when serious or when to just wait it out

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

Making ends meet now that she has reduced her work hours
• Making ends meet now that she has reduced her work hours
• Making ends meet now that she has reduced her work hours
• Making ends meet now that she has reduced her work hours
• Making ends meet now that she has reduced her work hours

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