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
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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.

**Foundational journey map**

**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.

**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.

**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's experience:
- Notices memory problems, dents in car, disorientation
- Researches symptoms

Interactions:
- Mom is insulted by concerns
- Brother downplays concerns
- Speaks with brother
- Turns to friends and neighbors
- Receives a call from police about a car accident

Consequences:
- Decides she doesn't have time for her book club anymore
- Leaves work early once and a while
- Relationship with Mom becomes strained

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...

- Takes care of car maintenance
- Reminds her to take medication
- Cleans out fridge
- Helps remember appointments

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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’s experience

- Takes Mom to PCP and they start tests
- Notices more behavioral & memory problems
- Keeps brother updated on tests
- Gets worried calls from Mom’s friends
- More doctor appts and tests
- Meets with her brother and Mom to discuss a plan for care
- Decides it isn’t safe for Mom to drive anymore

Karen does...

- Mom grudgingly agrees to go to doctor
- Brother continues to dismiss concerns
- Mom begins socially isolating herself
- Mom diagnosed with Alzheimer’s disease by PCP
- Brother meets with PCP to discuss diagnosis

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

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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’s experience

Interactions

- Mom struggles to maintain independence
- Mom wants to stay at home
- Brother second guesses her decisions
- Mom calls Karen many times a day
- Pretends to be mom when talking to the bank and other providers
- Has physical altercation with Mom after she wanders out of the house
- Researches how Mom can continue to live at home alone
- Takes over Mom’s finances
- Starts sleeping at Mom’s house sometimes

Consequences

- Stops going to her exercise class
- Feels isolated from friends and family
- Reprimanded for arriving late to work
- Husband takes over more household responsibilities
- Complains that Karen is missing their family movie nights
- Family cancels their spring break trip
- Family depends on take-out for meals
- Amelia’s school grades go down
- Mom resents being treated like a child as Karen becomes the guardian

Karen does...

Karen needs...

Health and safety

Cares for people who are sick, injured, or have mental health issues.

Social wellbeing

Cares for people's emotional and social needs.

Care coordination

Helps people manage their care and treatment plans.

Financial/legal

Manages financial and legal matters.

Caregiver quality of life

Cares for the caregiver's own well-being.

EVERY OTHER DAY VISITS

Health and safety
Coordinates house upkeep
Drives to all doctor appointments
Cleans house • Reminds to shower
Prepares some meals • Does laundry

Social wellbeing
Updates brother and Mom’s friends on conditions
Takes Mom to see friends

Care coordination
Makes doctor appointments
Watches medication

Financial
Pays all the bills

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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 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

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

Karen's experience
- Karen notices issues with her mom’s 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.

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.

Caregiving
- Once a week visits
- Twice a week visits
- Every other day visits
- Daily visits
- 24 hours a day

Caregiving needs
- Personal
- Work
- Family

Karen's career
- Full-time office manager
- Care recipient
- Caregiver
- Disease
- Living situation
- Career

Karen's ecosystem
- Debbie: Karen’s mother
- Paul: Karen’s husband
- Paul: Karen’s younger brother
- Bill: Karen’s daughter
- Leanna & Amelia: Karen’s daughters
- Karen: Nearby caregiver

Karen’s needs
- 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.

Karen’s life
- 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 continues to deal with issues of debt, grief, and family discord.

Caregiving
- 24 hours a day

Karen’s experiences
- Karen continues to deal with issues of debt, grief, and family discord.

Karen’s ecosystem
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