

The logo features the letters 'FOA' in white on a gold square background, with a nautilus shell design integrated into the 'O'. To the right, the words 'Care Journey' are written in a teal, sans-serif font. Below this, a teal horizontal bar contains the text 'PERSONAL CAREGIVER SUPPORT' in white, uppercase, sans-serif font.

FOA Care Journey  
PERSONAL CAREGIVER SUPPORT

Kathleen Kelly, MPA

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415.434.3388



FAMILY CAREGIVER ALLIANCE®  
*National Center on Caregiving*

785 Market Street, Suite 750  
San Francisco, CA 94103  
800.445.8106 | 415.434.3388

[www.caregiver.org](http://www.caregiver.org)

## What Problems Are We Trying to Solve?

- Scale
- Time deficits
- Quality
- Data

## What Are the Components of FCA CareJourney?

*FCA CareJourney is a system approach that combines data and services together to deliver tailored supports over the long term using a secure, mobile ready technologies*

- Caregiver assessment and interactive personal caregiver record with dashboard that can be configured to meet organizational need
- Service delivery of high quality consumer information, online training and tested interventions for caregiver stress, care skills competency, wellness and care planning
- Data collection that set benchmarks for outcome-driven results
- Channel for bi-directional communications



[About FCA](#)
[Caregiver Education](#)
[Policy & Advocacy](#)
[Caregiver Connect](#)
[Press](#)
[Contact Us](#)

• FCA CareJourney login

FCA CareJourney



Family Caregiver Alliance supports and sustains nationwide the important work of family caregivers caring for those with chronic, disabling health conditions.

- ▶ Help FCA help family caregivers
- ▶ Subscribe to our monthly e-newsletters
- ▶ Resources in Spanish, Chinese, Vietnamese, and Korean
- ▶ FCA CareJourney partnership opportunities

• FCA CareJourney information and login access

**PERSONAL CAREGIVER SUPPORT**

Welcome to FCA CareJourney, a secure online solution for quality information, support, and resources for family caregivers of adults with chronic physical or cognitive conditions such as Alzheimer's, stroke, Parkinson's, and other illnesses. By joining CareJourney you will be asked a brief set of questions that lead to a personal dashboard loaded with information that matches your unique caregiving needs, such as:

- ▶ FCA fact and tip sheets, videos, online classes, and support
- ▶ Caregiving resources nationally and by state
- ▶ Access to skilled FCA Resource Navigator
- ▶ Dashboard to track your information and find support

[Learn more and start your CareJourney](#)

**FAMILY CARE NAVIGATOR**  
Click on Your State

[ View larger map ]

• Online Learning Center information and access

FCA Blog

▶ What is Palliative Care and Is it Right for Your Family?

[Note: The following FCA Blog post was originally published in 2012.]

[Blog](#)

What's New

Winners announced in the 2015 Rosalinde Gilbert Innovations in Alzheimer's Disease Caregiving Legacy Awards

Family Caregiver Alliance (FCA) and The Rosalinde and Arthur Gilbert Foundation are pleased to announce the recipients of the 2015 Rosalinde Gilbert Innovations in Alzheimer's Disease Caregiving Legacy Awards.

2015 Rosalinde Gilbert Innovations in Alzheimer's Disease Caregiving Legacy Awards

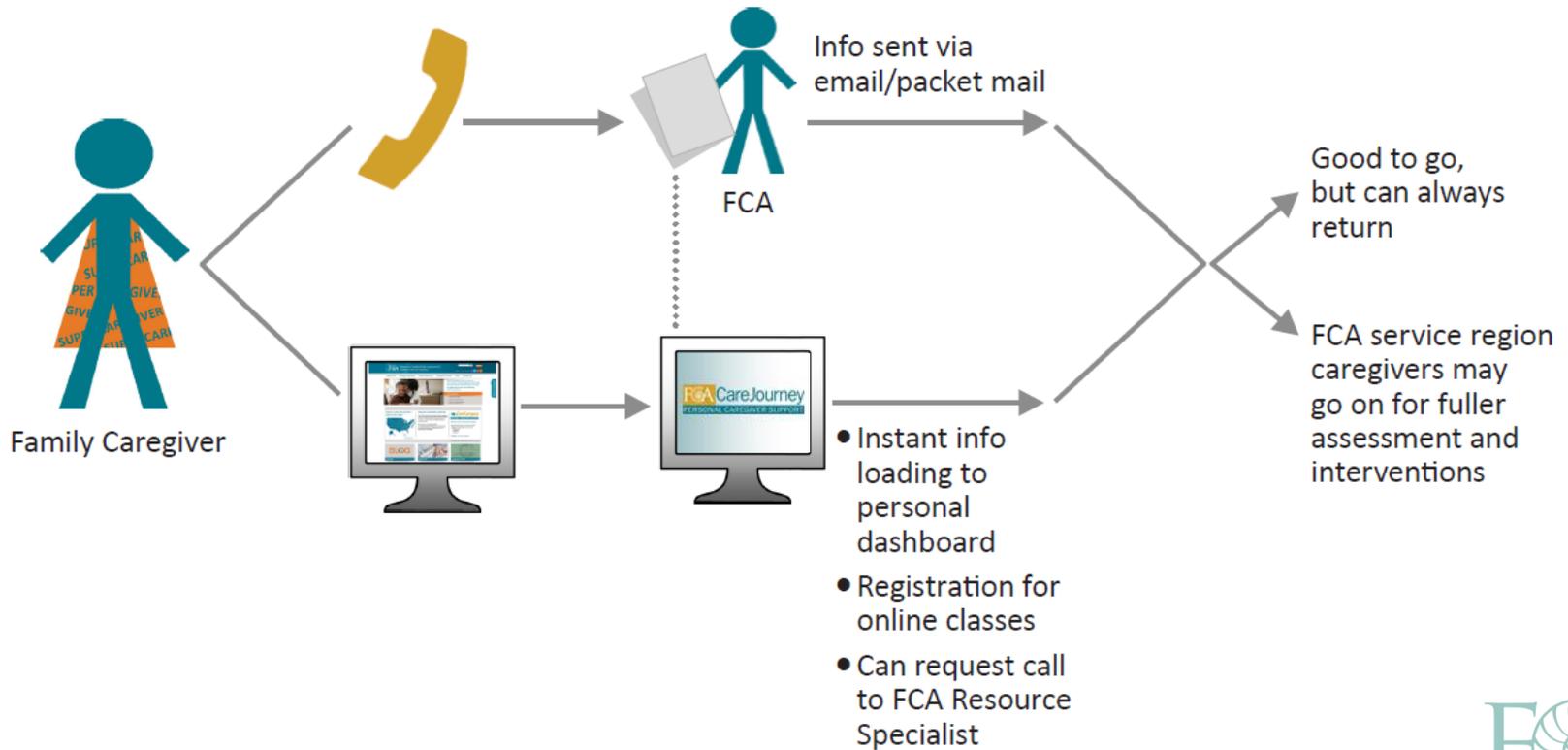
And the winners are...

Caregiving Products

▶ GeriJoy — Virtual Care Companions  
GeriJoy provides virtual senior care through teams of specially-trained remote caregivers who interact with seniors through tablet-based avatars.

[More products](#)

# Getting Started **CARE REVIEW** “Intake”





FOA CareJourney

### Welcome to CareJourney

We are glad you are here! CareJourney is designed to provide you with on-demand information, training, and guides to help you make the best decisions for you, your loved one, and family.

Benefits include:

- Supportive Membership community to meet you where you are in your caregiving journey
- Tailored information for you care situation
- Timely and practical connections to services
- Brief consultations with care experts
- Privacy Statement: FCA does not sell or provide contact lists to commercial ventures

### Login to CareJourney

Email Address

Password

[I forgot my password](#)

### Become a Member

Email Address

Password

Repeat Password

Zip Code

The screenshot displays the FOA CareJourney website interface. At the top left is the FOA logo and the text 'CareJourney PERSONAL CAREGIVER SUPPORT'. On the right, the user's email 'croberts@gmail.com' and a 'Logout' link are visible. A navigation bar contains five steps: '1 CARE REVIEW' (highlighted), '2 About Me', '3 Caring For', '4 Current Needs', and '5 DASHBOARD'. The main content area is titled 'Care Review' and includes the heading 'We'd like to learn a little about you.' followed by a paragraph explaining the purpose of the review. Below this are two buttons: 'Yes, Let's Get Started' and 'I'd Prefer to Do This Later'. On the right side, there are two expandable sections: 'My Resources' with two resource locator links for California and National Care Resources, and 'My Documents' with a list of document types. A vertical sidebar on the right edge of the interface is labeled 'FOA CareJourney'. At the bottom left, the copyright notice '© 2016 Family Caregiver Alliance.' is present.

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1 CARE REVIEW 2 About Me 3 Caring For 4 Current Needs 5 DASHBOARD

## Care Review

### We'd like to learn a little about you.

In order to assist you, we would like to begin by asking you some questions about yourself and the person you care for. These questions will take approximately 10 to 15 minutes to complete. Based on your answers, tailored informational materials will be uploaded to your "My Resources" page. All of your responses and comments will be kept confidential. Please be reassured that there are no wrong answers. Please mark only one answer per question, unless otherwise noted.

[Yes, Let's Get Started](#) [I'd Prefer to Do This Later](#)

#### My Resources

RESOURCE LOCATOR CALIFORNIA CARE RESOURCES

RESOURCE LOCATOR NATIONAL CARE RESOURCES

#### My Documents

- Complaint, Concerns and Grievances Process
- Legal Consultation Information
- Service Authorization Form Sample

FOA CareJourney

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1 CARE REVIEW 2 **About Me** 3 Caring For 4 Current Needs 5 DASHBOARD

### About Me

In order to assist you, we would like to begin by asking you some questions about yourself and the person you care for. These questions will take approximately 10 to 15 minutes to complete. Based on your answers, tailored informational materials will be uploaded to your "My Resources" page. All of your responses and comments will be kept confidential. Please be reassured that there are no wrong answers. Please mark only one answer per question, unless otherwise noted.

**Name**

Claire Roberts

**What is your gender identity?**

Male  Female  Other: Other

**What year were you born?**

05/21/1970

**Are you employed?**

Full time  
 Part time  
 Retired  
 Unemployed  
 Leave of Absence  
 Decline to state

**Are you eligible to receive veteran's benefits?**

Yes  No  Unsure

**What is your address?**

Street  
940 York Street

City State Zip code

**My Resources**

- DIRECT CARE CAREGIVER'S GUIDE TO UNDERSTANDING DEMENTIA BEHAVIORS
- DIRECT CARE TEN REAL-LIFE STRATEGIES FOR DEMENTIA CAREGIVING
- DIRECT CARE DEMENTIA, CAREGIVING AND CONTROLLING FRUSTRATION
- DIRECT CARE DEMENTIA AND DRIVING

FCA CareJourney

**Questions Include:**

- Demographics
- referral source
- years caregiving
- living with care recipient

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1 CARE REVIEW 2 About Me 3 Caring For 4 Current Needs 5 DASHBOARD

### Caring For: Lydia Roberts

Now we would like to ask you some questions about Lydia.

What is the name of the person you are caring for?

Lydia Roberts

What is Lydia's gender identity?

Male  Female  Other

What year was Lydia born?

12/31/1942

What is your relationship to Lydia?

Husband  
 Wife  
 Domestic Partner  
 Other Relative  
 Daughter/Daughter-in-law  
 Son/Son-in-law  
 Non-relative  
 Declined to state

Are you the person who is providing the most care to Lydia?

Yes  No

How long have you been providing care to Lydia?

0-2 years  2-5 years  5+ years

What is Lydia's zip code?

94117

**My Resources** Collapse

- DIRECT CARE CAREGIVER'S GUIDE TO UNDERSTANDING DEMENTIA BEHAVIORS
- DIRECT CARE TEN REAL-LIFE STRATEGIES FOR DEMENTIA CAREGIVING
- DIRECT CARE DEMENTIA, CAREGIVING AND CONTROLLING FRUSTRATION
- DIRECT CARE HANDS-ON SKILLS FOR CAREGIVERS

FCA CareJourney

**Questions Include:**

- living situation/demo
- medical conditions
- eligibility Medicaid/VA
- living with care recipient

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1 CARE REVIEW 2 About Me 3 Caring For 4 **Current Needs** 5 DASHBOARD

### Current Needs

Next we would like to ask you some questions about the type(s) of information or help that you may need. You may only feel this way or need a certain type of help some of the time. If so, please select "yes" even if you experience any of below only some of the time.

Do you ever feel your level of stress as a caregiver is more than you could handle?  
 Yes  No

Do you ever feel sad, depressed, or anxious?  
 Yes  No

Do you need any help or information about finances or assistance with paying for (check all that apply):  
 Food  Healthcare  Services

Do you need help in managing difficult behaviors (i.e. relative behaves aggressively, wanders, difficult ways that are hard to handle)?  
 Yes  No

Do you have any health conditions that have gotten worse or been neglected because of your helping your relative?  
 Yes  No

Why did you contact us today? Check all those that apply.

- To get help managing difficult behaviors (repetitive questions and actions, incontinence, wandering, refusal to stop driving...)
- Want to know how to get a break or respite from caregiving responsibilities
- Want information about hiring in-home help
- Want information about out-of-home placement options (nursing home, residential care homes, assisted living facilities)
- Want to know how to get paid for caring for Lydia
- Want information about legal issues (power of attorney, living will, advanced directives, etc.)
- Want to know how to provide better care to Lydia (bathing, eating, mobility)
- Need direction on how to get emotional support (support groups, individual counseling)

### My Resources

- DIRECT CARE CAREGIVER'S GUIDE TO UNDERSTANDING DEMENTIA BEHAVIORS
- DIRECT CARE TEN REAL-LIFE STRATEGIES FOR DEMENTIA CAREGIVING
- DIRECT CARE DEMENTIA, CAREGIVING AND CONTROLLING FRUSTRATION
- DIRECT CARE HANDS-ON SKILLS FOR CAREGIVERS
- DIRECT CARE STROKE
- SELF-CARE FOR FAMILY CAREGIVERS

FCA CareJourney

**Questions Include:**

- common caregiving scenarios, questions
- key risk factors for caregivers

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1 DASHBOARD

## Claire's Dashboard

### Care Review Completed!

Thank you for completing the CARE REVIEW process. Based on your responses we have provided some suggested resources and support options.

An FCA Family Consultant will be assigned to support you.

### My Support Team

- Caregiver  
Claire Roberts
- Currently Caring For  
Lydia Roberts
- FCA Resource Specialist  
415.434.3388  
800.445.8106

### My Resources

- DIRECT CARE CAREGIVER'S GUIDE TO UNDERSTANDING DEMENTIA BEHAVIORS
- DIRECT CARE TEN REAL-LIFE STRATEGIES FOR DEMENTIA CAREGIVING
- DIRECT CARE DEMENTIA, CAREGIVING AND CONTROLLING FRUSTRATION
- DIRECT CARE HANDS-ON SKILLS FOR CAREGIVERS
- DIRECT CARE STROKE
- SELF CARE TAKING CARE OF YOU: SELF-CARE FOR FAMILY CAREGIVERS

All My Resources Find More

### My Documents

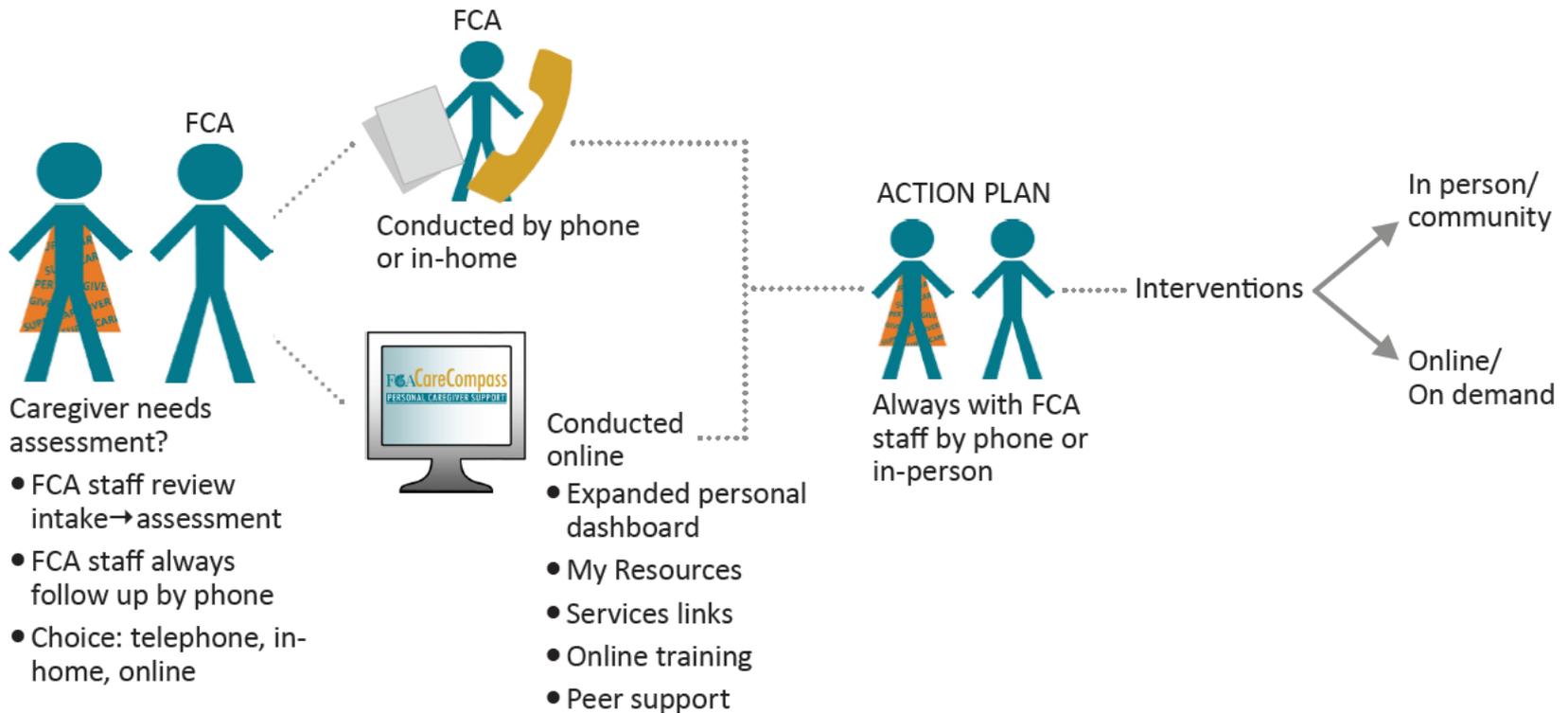
- Complaint, Concerns and Grievances Process

FCA CareJourney

# Intensive Services

## CARE EVALUATION

“Assessment”





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1 DASHBOARD
2 CARE EVAL
3 Direct Care
4 Plan Care
5 Self Care

**Welcome back!** ✕

Caregiver Evaluation Recommended!

When you are ready, please proceed through the CARE EVAL, Direct Care, Plan Care, and Self Care evaluation steps. When finished, press the "Go To My CareJourney" button at the end of the Self Care section.

## Care Evaluation

### Please tell us more about your care situation

The questions in the Care Evaluation section provide more detail about your needs in providing direct care to your relative or friend, planning or coordinating care and finally, questions about your own self-care needs such as your health, stress and support you have or need to continue care.

**"Are you currently performing any medical tasks for Lydia, such as wound care, operating medical equipment, administering medications, or preparing a special diet?"**

Yes
  No
  Not Sure

If you are not sure about the question, just click "Not Sure - Lets Take a Look" to determine if any of the tasks apply to you. If you find the questions apply to you, check them. If not, move on to the next question.

We estimate that it will take between 30 to 40 minutes to complete all sections. If you need to step away from the questionnaire, don't worry. You will be returned to your stop point in the questionnaire when you return. Answering all the questions that apply to your care situation guides the next step in the process: developing a plan of action with steps and support you may need. This will be done with your Family Consultant who will help shape an Action Plan that covers the issues most important to you.

Start Evaluation
I'd prefer to do this Later

### My Support Team

Collapse

- 👤 **Caregiver**  
Claire Roberts
- 👤 **Currently Caring For**  
Lydia Roberts
- 👤 **FCA Resource Specialist**  
415.434.3388  
800.445.8106

### My Resources

Collapse

- 📍 RESOURCE LOCATOR  
CALIFORNIA CARE RESOURCES
- 📍 RESOURCE LOCATOR  
NATIONAL CARE RESOURCES
- 📄 DIRECT CARE  
CAREGIVER'S GUIDE TO UNDERSTANDING  
DEMENTIA BEHAVIORS
- 📄 DIRECT CARE  
DEMENTIA, CAREGIVING AND CONTROLLING  
FRUSTRATION
- 📄 DIRECT CARE  
BEHAVIOR ISSUES
- 📄 PLANNING FOR CARE  
WHERE TO FIND MY IMPORTANT PAPERS

All My Resources
Find More

### My Documents

Collapse

- Complaint, Concerns and Grievances Process
- Legal Consultation Information
- Service Authorization Form Sample

FCA CareJourney

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1 DASHBOARD 2 CARE EVAL 3 **Direct Care** 4 Plan Care 5 Self Care

## Direct Care

Thank you for taking the time to answer the initial questions about yourself and the person you are caring for. Next, we will ask you more detailed questions to learn more about your care situation. When the questionnaire is complete, your Family Consultant will contact you about next steps and services. The estimated time needed to complete this questionnaire is 30 to 40 minutes and you can stop and return to the questionnaire as needed. We ask that you complete the questionnaire within 7 days so we can schedule a time to meet with you on next steps.

**First, we would like to ask you more about the type of help Lydia needs with daily activities.**

How much help does Lydia need with the following daily activities?

Activity	Does by self/Needs no help	Needs reminders/A little help	Needs help most of the time	Needs help all the time/Unable to do activity	Do you need more information about this activity?
Eating (cutting food, buttering bread)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="checkbox"/>
Bathing/showering (washing, getting in/out of tub or shower)	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
Grooming (brushing hair, combing hair, or dressing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="checkbox"/>
Using the toilet (getting to toilet, undressing, cleaning himself/herself)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="checkbox"/>
Preparing meals (opening or preparing food, cleaning up)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="checkbox"/>
Driving (getting in car, driving, or getting out of car)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
Preparing meals (opening or preparing food, cleaning up)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="checkbox"/>

### My Support Team

- Caregiver**  
Claire Roberts
- Currently Caring For**  
Lydia Roberts
- FCA Resource Specialist**  
415.434.3388  
800.445.8106

### My Resources

- RESOURCE LOCATOR CALIFORNIA CARE RESOURCES
- RESOURCE LOCATOR NATIONAL CARE RESOURCES
- DIRECT CARE CAREGIVER'S GUIDE TO UNDERSTANDING DEMENTIA BEHAVIORS
- DIRECT CARE DEMENTIA, CAREGIVING AND CONTROLLING FRUSTRATION
- DIRECT CARE BEHAVIOR ISSUES
- PLANNING FOR CARE WHERE TO FIND MY IMPORTANT PAPERS

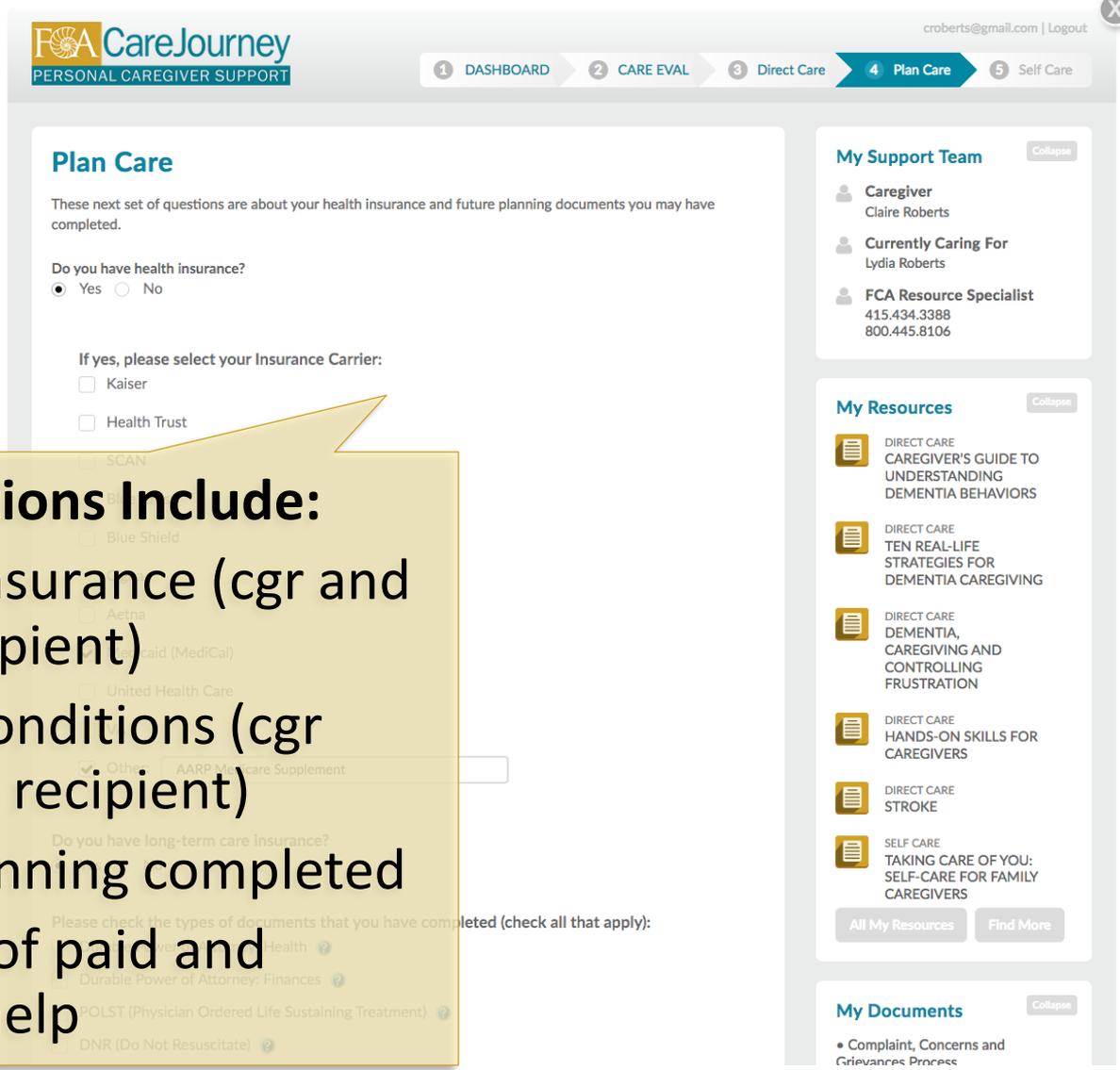
All My Resources Find More

### My Documents

- Complaint, Concerns and Grievances Process
- Legal Consultation Information
- Service Authorization Form Sample

**Questions Include:**

- ADL/IADLs & Med tasks plus training needed
- Technology readiness
- behavioral issues plus training needed



**Questions Include:**

- health insurance (cgr and care recipient)
- health conditions (cgr and care recipient)
- legal planning completed
- sources of paid and unpaid help

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1 DASHBOARD 2 CARE EVAL 3 Direct Care 4 Plan Care 5 Self Care

## Self Care

Many people who provide care for a loved one experience changes in their physical or emotional health. These next questions will provide us with information about your health and any conditions you may be experiencing.

How would you rate your overall health at this time?

Excellent  Good  Fair  Poor

Is your health now better, about the same, or worse than it was 6 months ago?

Better  About the Same  Worse

Please check the names of all health problems or conditions that you have experienced in the past 12 months.

Arthritis

Diabetes

Respiratory Issues/asthma/emphysema

Eyes/ears/nose (vision, hearing problems)

Blood Pressure/Hypertension

Stomach/Gastrointestinal

Broken bones/osteoporosis

Headaches/Migraines

Stroke

Cancer

High Cholesterol

Weight Loss/Gain

Dental Problems (teeth, gums, dentures)

### My Support Team

**Caregiver**  
Claire Roberts

**Currently Caring For**  
Lydia Roberts

**FCA Resource Specialist**  
415.434.3388  
800.445.8106

### My Resources

- RESOURCE LOCATOR CALIFORNIA CARE RESOURCES
- RESOURCE LOCATOR NATIONAL CARE RESOURCES
- DIRECT CARE CAREGIVER'S GUIDE TO UNDERSTANDING DEMENTIA BEHAVIORS
- DIRECT CARE DRESSING AND GROOMING (FOR DEMENTIA)
- DIRECT CARE TEN REAL-LIFE STRATEGIES FOR DEMENTIA CAREGIVING
- DIRECT CARE COMMUNICATION (FOR DEMENTIA)

All My Resources Find More

### My Documents

- Complaint, Concerns and Grievances Process
- Legal Consultation Information

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**Questions Include:**

- healthcare utilization (cgr and care recipient)
- stress
- depression


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X

1 DASHBOARD

### Claire's Dashboard

Caregiver Evaluation Completed!

You have completed the Assessment process.

Your FCA Family Consultant will be evaluating your situation and preparing recommendations and a customized Action Plan to support you.

**Inbox** 3

from Claire Roberts, 3/15/16 2:55pm

Hi Christina, Thank you for messaging me so quickly. Tomorrow, at noon, during my lunch break would work great. Please call my cell phone. Thanks, Claire

from Christina Irving, LCSW, FCA Resource Specialist, 3/14/16 2:00pm

Hi Claire, I'm Christina, Family Consultant, messaging you to follow up on the assessment you recently completed. Let's schedule a time that works best for you to talk. When are you available?

from FCA, 3/11/16 8:15pm

Care Evaluation Complete. An FCA Resource Specialist will be in touch to schedule an appointment. Contact information to reach your personal FCA Care Navigator by phone or

**My Records** Collapse

- Action Plan
- Other Reports

**Calendar** Collapse

**Support Group**  
[General Caregiver Support Group - San Francisco County](#)  
 Wednesday March 16,  
 6pm - 7:30pm PST

**Webinars**

**My Support Team** Collapse

- Caregiver**  
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Lydia Roberts
- FCA Resource Specialist**  
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800.445.8106

**My Resources** Collapse

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- DIRECT CARE TEN REAL-LIFE STRATEGIES FOR DEMENTIA CAREGIVING**
- DIRECT CARE COMMUNICATION (FOR DEMENTIA)**

All My Resources
Find More

**My Documents** Collapse

- Complaint, Concerns and Grievances Process
- Legal Consultation Information

FCA CareJourney

## Claire's Dashboard

[Dashboard](#) > [Action Plan](#)

## Caregiver Action Plan

### Issue #1

#### Problem/Concern

Your mom is resistant to any outside help but is having more difficulty caring for herself.

#### Goal

To increase her care and have more information about her current condition and functioning.

#### Steps

- 1) You may want to email a summary of the symptoms you have seen to the staff at the Memory Clinic.
- 2) I have included an article with tips on overcoming resistance. [Read Article](#)
- 3) Contact one of the Placement Referral Agencies that Kaiser gave you to find Board & Care Homes that your mom can afford. Use the [evaluation checklists](#) when visiting.
- 4) Go to the bank and have them help your mom complete a Durable Power of Attorney for Finances.

#### Notes

### My Support Team

Collapse

-  **Caregiver**  
Claire Roberts
-  **Currently Caring For**  
Lydia Roberts
-  **FCA Resource Specialist**  
415.434.3388  
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### My Resources

Collapse

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-  RESOURCE LOCATOR  
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-  DIRECT CARE  
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DEMENTIA BEHAVIORS
-  DIRECT CARE  
DRESSING AND GROOMING (FOR  
DEMENTIA)
-  DIRECT CARE  
TEN REAL-LIFE STRATEGIES FOR  
DEMENTIA CAREGIVING
-  DIRECT CARE  
COMMUNICATION (FOR  
DEMENTIA)

All My Resources

Find More

### My Documents

Collapse

- Complaint, Concerns and Grievances Process
- Legal Consultation Information

FCA CareJourney

# Data: Intake, Assessment, Reassessment

## **Intake** aka “Care Review”

- Demographics
- Diagnosis
- Length of caregiving
- Living with care receiver
- Referral source

## **Assessment** aka “Care Evaluation”

### **Direct Care**

- ADLs, IADLs, medical tasks (training needed)
- Technology readiness
- Behavior issues (training needed)

# Data: Intake, Assessment, Reassessment

## Plan Care

- Health insurance (cgr, cr)
- Health conditions (cgr, cr)
- Legal planning (cgr, cr)
- Sources of paid and unpaid help

## Self-Care of Caregiver

- Healthcare utilization (cgr, cr)
- Stress
- Depression

# Units of Service

## Tracked by Individual Client

- NFCSP Title III-E units

## Customized

- State or other contract units — eg: FCA CRC contract
  - Family consultation
  - Counseling
  - Respite
  - Training
  - Psychoeducational groups— ie: Powerful Tools
  - Legal/financial consultation

# Data: Site Specific

## Internal Tracking of Caregiver Actions on FCA CareJourney site

- Self administration of intake and assessment
- Open rate and time spent on resources tagged
- Frequency /use of communications channels

## FCA Online Learning Center Site

- Classes taken
- Videos watched
- Information viewed and downloaded

# Evaluation

- Data on caregivers and care receivers intake, assessment, reassessment
- Data: Site Specific
- Data: Units of Service tracked by client
- All client information is exportable

# Reporting

- Standard information for NFCSP Title III E
- Standard information for state or other contracts

## What's Next?

- Launch/Beta Test: September
- Integration of Online Learning Community: October launch with additional classes added for next 12+ months
- Pilots: National (FCA); SF Bay Area CRC (FCA); LACRC (USC)
- Evaluation: USC Andrus School of Gerontology; CA Dept of Public Health Alzheimer Research Grant; LeadingAge for online training
- Additional pilots & licensing: TBD

# Acknowledgements

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## **Social Impact Investors**

### **Foundations and Corporate:**

The Archstone Foundation: Lead for Caregiver Assessment 2.0

Private Family Foundation: Lead for Online Learning Community

The Foster Foundation

Private Family Foundation

Genentech

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Sarah Szabo

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Quality Process

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## National Advisors:

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Michael Costa, Costa and Associates

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Helene Martel, MA, Kaiser Permanente

Kathy Raffel, MSW, MBA, PhD, LISW-S, University of San Francisco

John Shen, Health Management Associates

Margaret I. Wallhagen, PhD, GNP-BC, AGSF, FGSA, FAAN, University of California, San Francisco

# Acknowledgements

## **National Consultants:**

### Elder Abuse Risk Factors

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University of Southern California & National Center on Elder Abuse

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--CareJourney: Evaluation of Caregivers of Adults with Alzheimer's:  
Kate Wilbur, Ph.D., USC Andrus School of Gerontology

*Special acknowledgement to the Board of Directors and Staff of  
Family Caregiver Alliance/National Center on Caregiving*

# About FCA

**Family Caregiver Alliance** offers education, services, research, and advocacy based on the real needs of caregivers. Founded in the late 1970s, FCA is the first community-based nonprofit organization in the United States to address the needs of families and friends providing long-term care for loved ones at home.

**National Center on Caregiving (NCC)** was established by FCA to advance the development of high-quality, cost effective programs and policies for caregivers in every state. NCC sponsors the Family Care Navigator, a state-by-state resource locator designed to help caregivers find support services in their communities.

**Bay Area Caregiver Resource Center** — operated by FCA for the six-county San Francisco Bay Area — provides support to family caregivers. FCA's staff of family consultants through education programs and direct support offer effective tools to manage the complex and demanding tasks of caregiving.

**Be sure to visit FCA on social media:**



[facebook.com/FamilyCaregiverAlliance](https://www.facebook.com/FamilyCaregiverAlliance)



[twitter.com/CaregiverAlly](https://twitter.com/CaregiverAlly)



[linkedin.com/company/family-caregiver-alliance](https://www.linkedin.com/company/family-caregiver-alliance)



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[youtube.com/CAREGIVERdotORG](https://www.youtube.com/CAREGIVERdotORG)



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*National Center on Caregiving*

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[www.caregiver.org](http://www.caregiver.org)

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**Envision a world ...**

**Where family caregivers are supported and valued as fundamental to a healthy society**

**Where caregiving is easier *and* more effective**

# Our contribution

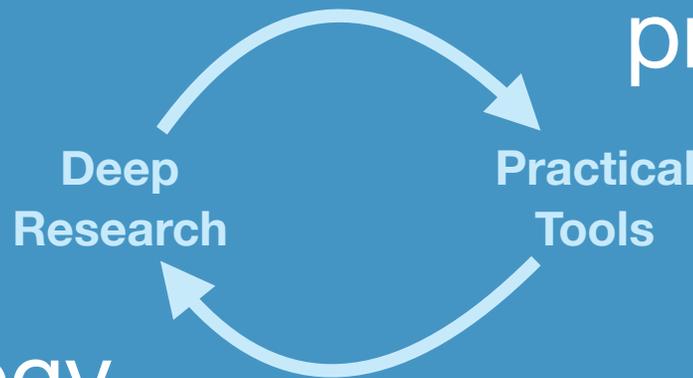


Pioneering deep  
research  
combining  
ethnography  
and technology



# Our contribution

Pioneering deep  
research  
combining  
ethnography  
and technology



Developing  
practical tools for  
self-discovery  
and community  
awareness

# Our contribution



Pioneering deep  
research  
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Developing  
practical tools for  
self-discovery  
and community  
awareness

Transforming  
Data into Action

Guiding and informing family caregivers  
and all who support them



# Pilot — Deep Research

# Deep research in Pilot study



**14 diverse families  
participated**



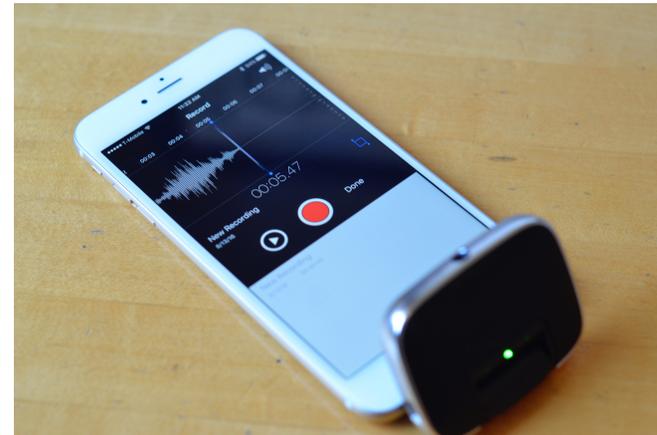
# Deep research in Pilot study



14 diverse families  
participated

**Data collected for ~30 hours  
using multiple methods:**

- Interviews



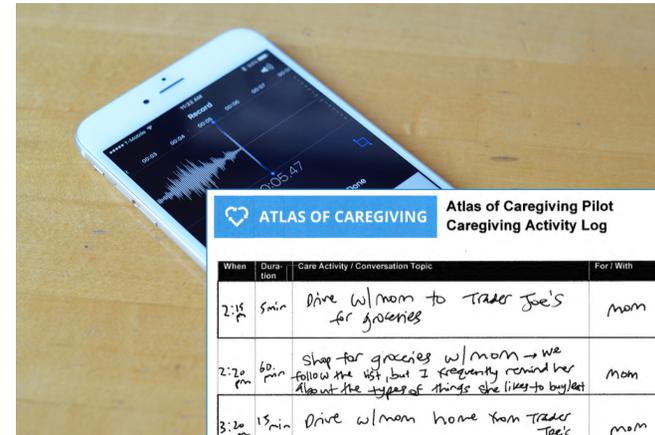
# Deep research in Pilot study



14 diverse families participated

Data collected for ~30 hours using multiple methods:

- Interviews
- Log



ATLAS OF CAREGIVING		Atlas of Caregiving Pilot Caregiving Activity Log				
When	Duration	Care Activity / Conversation Topic	For / With	Level of Assistance	Level of Cooperation	Stress
2:15 pm	5 min	Drive w/ mom to Trader Joe's for groceries	mom	<input type="checkbox"/> None <input type="checkbox"/> Remind <input type="checkbox"/> Supervise <input type="checkbox"/> Help <input checked="" type="checkbox"/> Do all	<input type="checkbox"/> Obstructive <input type="checkbox"/> Passive <input checked="" type="checkbox"/> Cooperative	No stress  Very stressful
2:20 pm	60 min	Shop for groceries w/ mom - we follow the list but I frequently remind her about the types of things she likes to buy/let	mom	<input type="checkbox"/> None <input type="checkbox"/> Remind <input type="checkbox"/> Supervise <input checked="" type="checkbox"/> Help <input type="checkbox"/> Do all	<input type="checkbox"/> Obstructive <input type="checkbox"/> Passive <input checked="" type="checkbox"/> Cooperative	No stress  Very stressful
3:20 pm	15 min	Drive w/ mom home from Trader Joe's	mom	<input type="checkbox"/> None <input type="checkbox"/> Remind <input type="checkbox"/> Supervise <input checked="" type="checkbox"/> Help <input type="checkbox"/> Do all	<input type="checkbox"/> Obstructive <input type="checkbox"/> Passive <input checked="" type="checkbox"/> Cooperative	No stress  Very stressful
3:35 pm	10 min	Unload car & put groceries away w/ mom	mom	<input type="checkbox"/> None <input type="checkbox"/> Remind <input type="checkbox"/> Supervise <input checked="" type="checkbox"/> Help <input type="checkbox"/> Do all	<input type="checkbox"/> Obstructive <input type="checkbox"/> Passive <input checked="" type="checkbox"/> Cooperative	No stress  Very stressful
3:45 pm	2 min	Mom tells me she is having bad back pain & I give her pain medication	mom	<input type="checkbox"/> None <input type="checkbox"/> Remind <input type="checkbox"/> Supervise <input checked="" type="checkbox"/> Help <input type="checkbox"/> Do all	<input type="checkbox"/> Obstructive <input type="checkbox"/> Passive <input checked="" type="checkbox"/> Cooperative	No stress  Very stressful
3:55 pm	5 min	Make phone calls to estate planning lawyer	Self/ mom	<input type="checkbox"/> None <input type="checkbox"/> Remind <input type="checkbox"/> Supervise <input checked="" type="checkbox"/> Help <input type="checkbox"/> Do all	<input type="checkbox"/> Obstructive <input type="checkbox"/> Passive <input checked="" type="checkbox"/> Cooperative	No stress  Very stressful
3:58 pm		Our apartment begins to vibrate due to unannounced construction in the apartment below us - we were told it would end by 1 PM	Self/ mom	<input type="checkbox"/> None <input type="checkbox"/> Remind <input type="checkbox"/> Supervise <input checked="" type="checkbox"/> Help <input type="checkbox"/> Do all	<input type="checkbox"/> Obstructive <input type="checkbox"/> Passive <input checked="" type="checkbox"/> Cooperative	No stress  Very stressful

# Deep research in Pilot study



14 diverse families participated

Data collected for ~30 hours using multiple methods:

- Interviews
- Log
- Technology: Wearable and environmental sensors, camera

**ATLAS OF CAREGIVING** Atlas of Caregiving Pilot Caregiving Activity Log

When	Duration	Care Activity / Conversation Topic	For / With	Level of Assistance	Level of Cooperation	Stress
2:15 pm	5 min	Drive w/ mom to Trader Joe's for groceries	mom	<input type="checkbox"/> None <input type="checkbox"/> Remind <input type="checkbox"/> Supervise <input checked="" type="checkbox"/> Help <input type="checkbox"/> Do all	<input type="checkbox"/> Obstructive <input type="checkbox"/> Passive <input checked="" type="checkbox"/> Cooperative	No stress
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4:00 pm		mom tells me she is having bad		<input type="checkbox"/> None <input type="checkbox"/> Remind <input type="checkbox"/> Supervise	<input type="checkbox"/> Obstructive <input type="checkbox"/> Passive <input checked="" type="checkbox"/> Cooperative	No stress

SmartSense Motion Sensors, Netatmo Weather Stations, Narrative Clip, Empatica E4, SmartSense Presence, SmartThings Hub

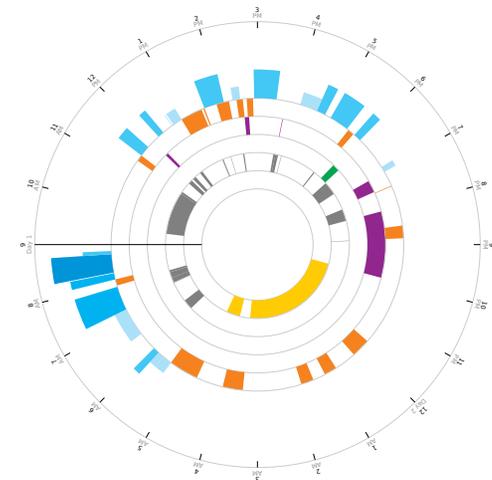
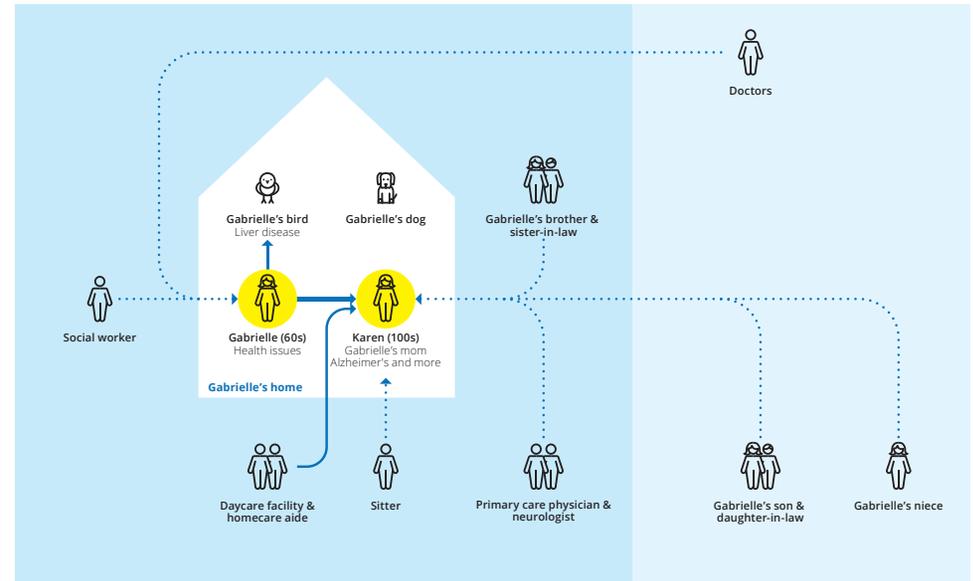
# Deep research in Pilot study



14 diverse families participated

Data collected for ~30 hours using multiple methods

**New visualizations developed**



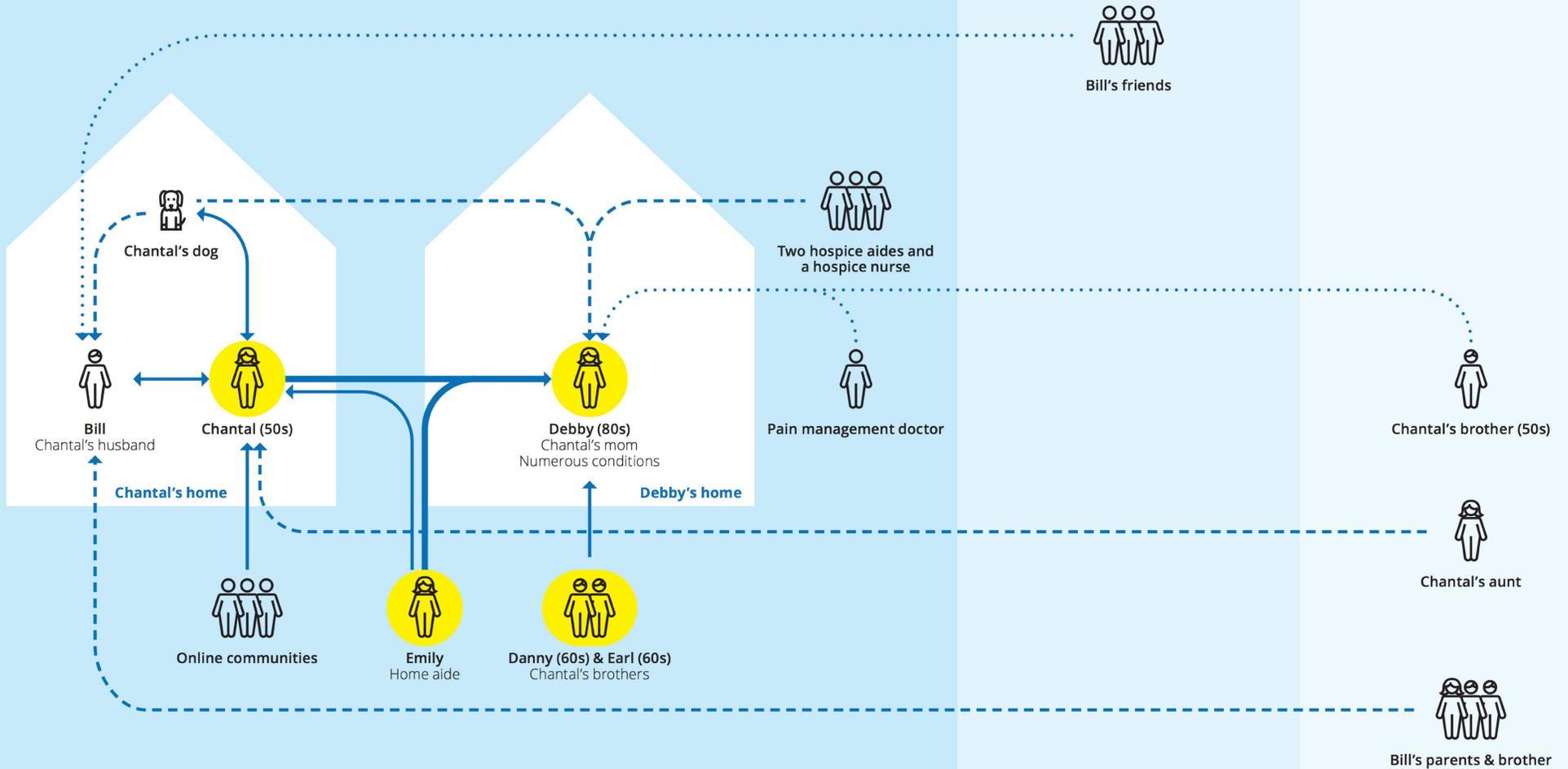
# Chantal – care map



**Near**  
Less than 20 minutes away

**Middle**  
Between 20 minutes and 2 hours away

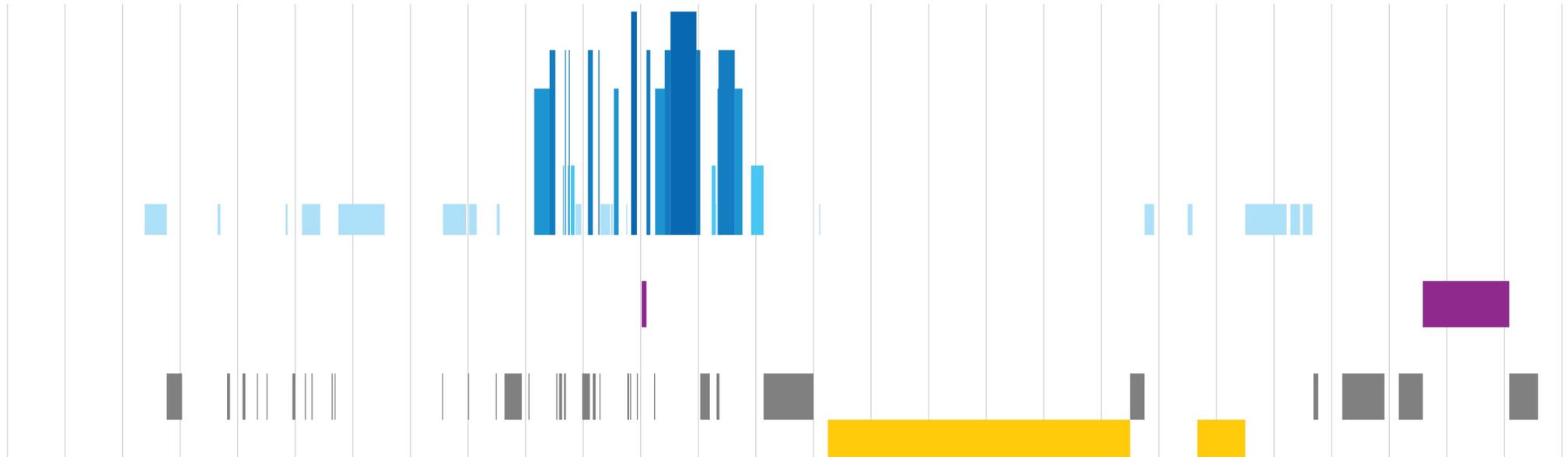
**Far**  
More than 2 hours away



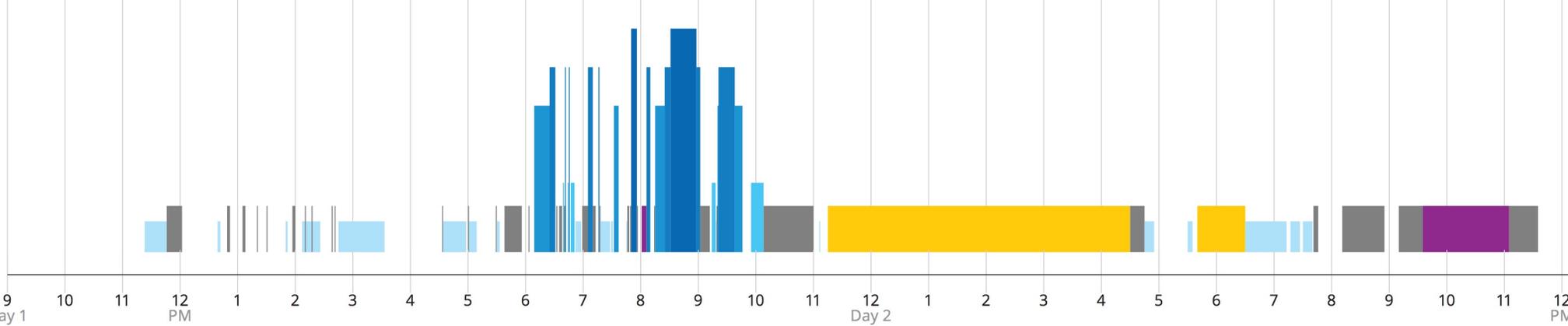
# Chantal — activities



## ACTIVITIES BROKEN OUT



## ACTIVITIES COMBINED



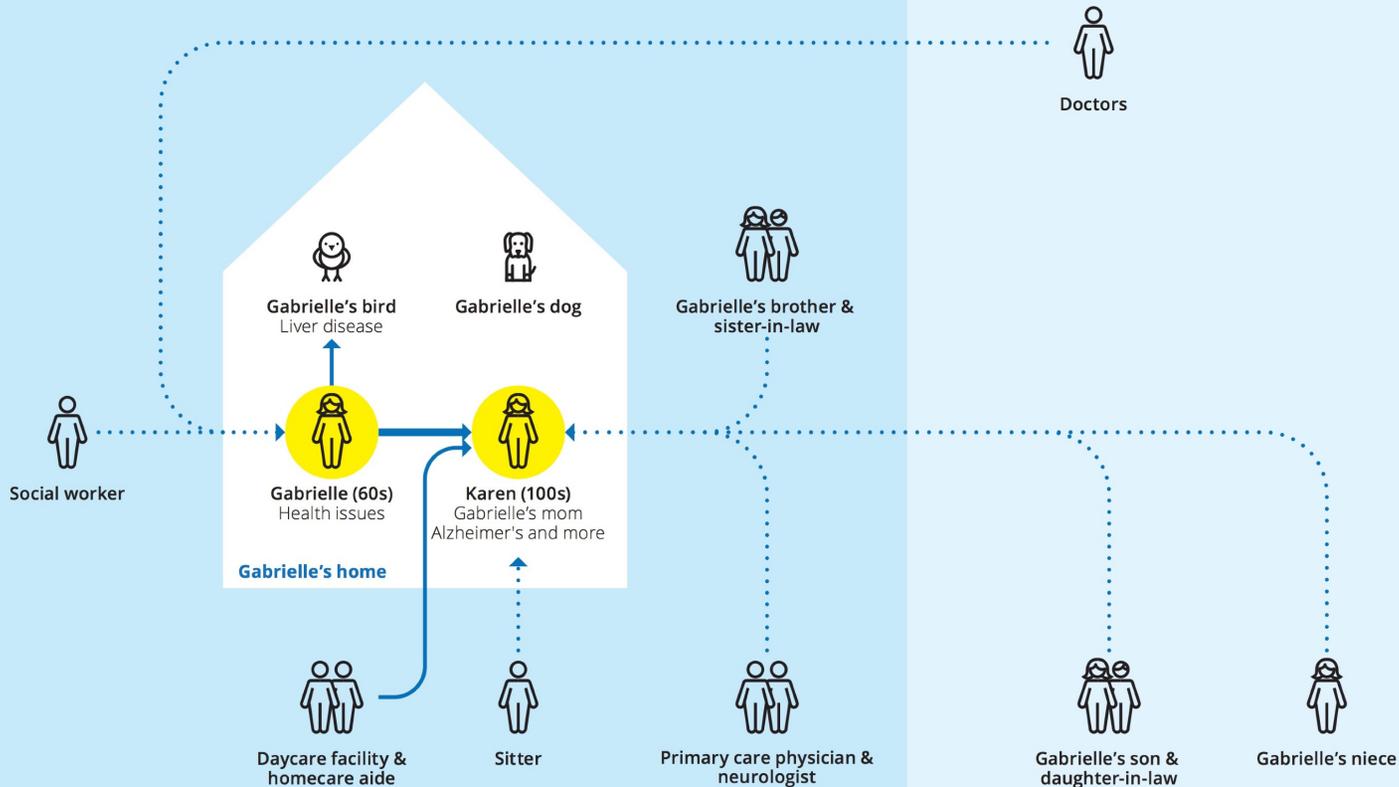
# Gabrielle — care map



**Near**  
Less than 20 minutes away

**Middle**  
Between 20 minutes and 2 hours away

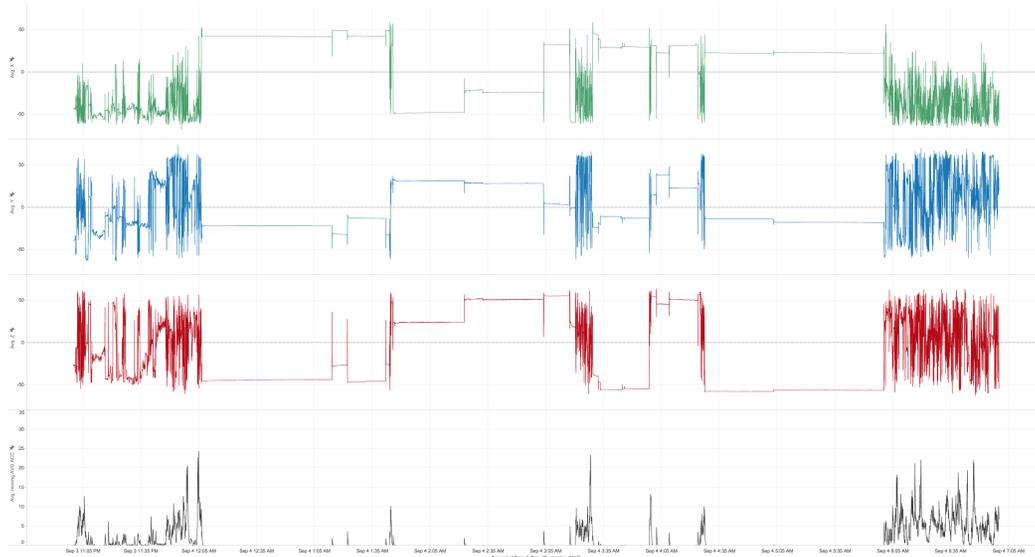
**Far**  
More than 2 hours away



# Gabrielle — motion & sound



Motion data



midnight

1:40 am

3:20 am

4:00 am

4:30 am

6:00 am

Sound data



12:00 am

04:00 am

08:00 am

midnight

1:40 am

6:00 am

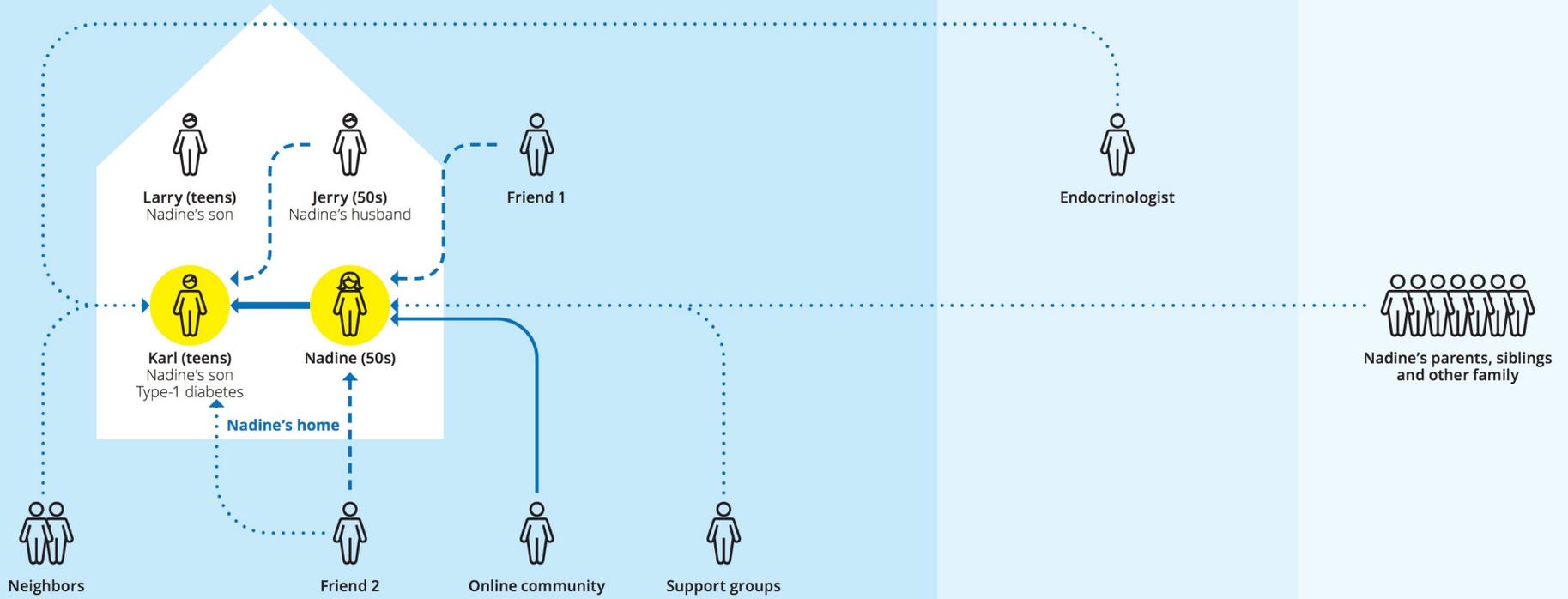
# Nadine — care map



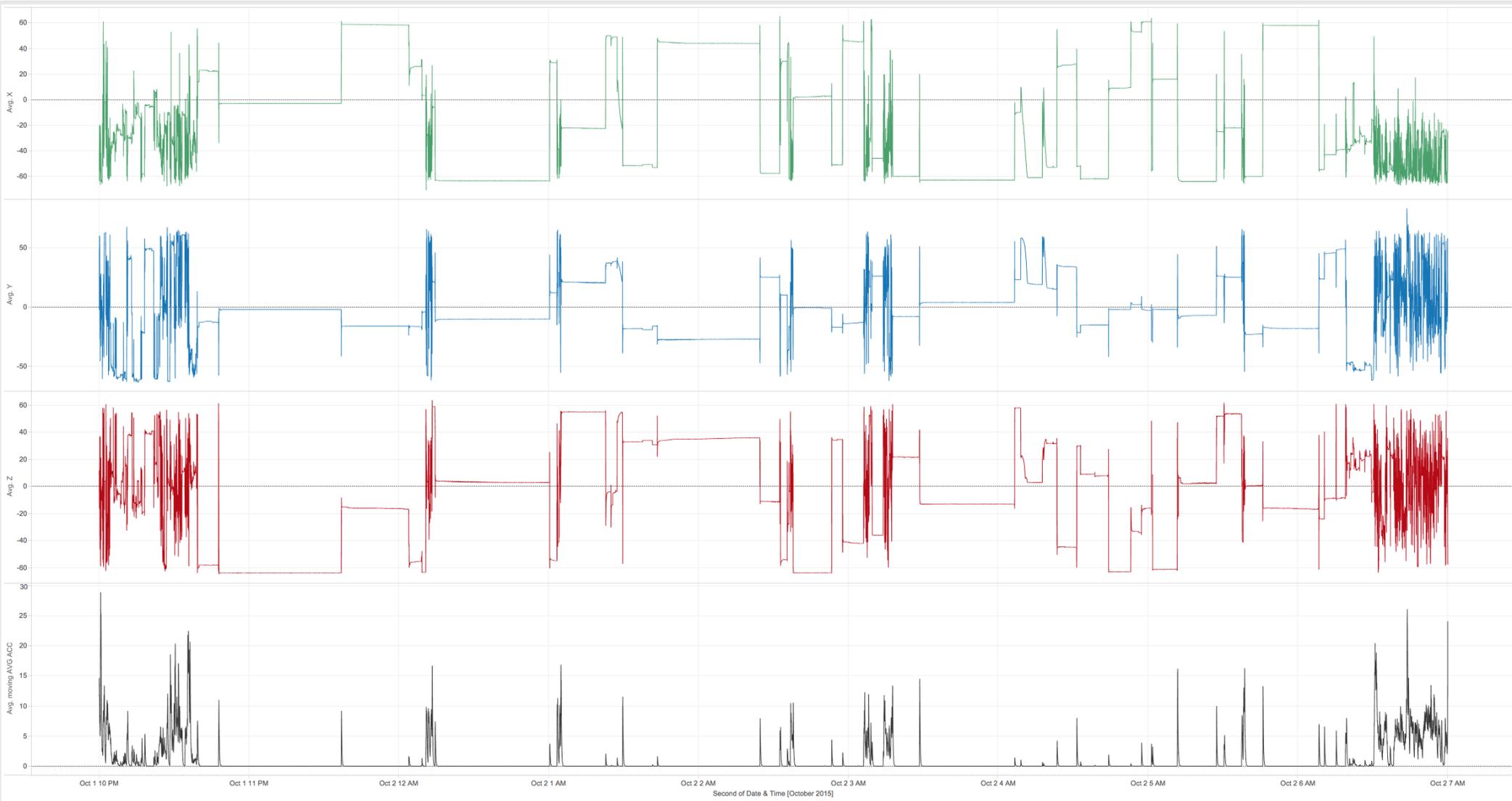
**Near**  
Less than 20 minutes away

**Middle**  
Between 20 minutes and 2 hours away

**Far**  
More than 2 hours away



# Nadine — motion



10:45

12:15

1:00

2:30

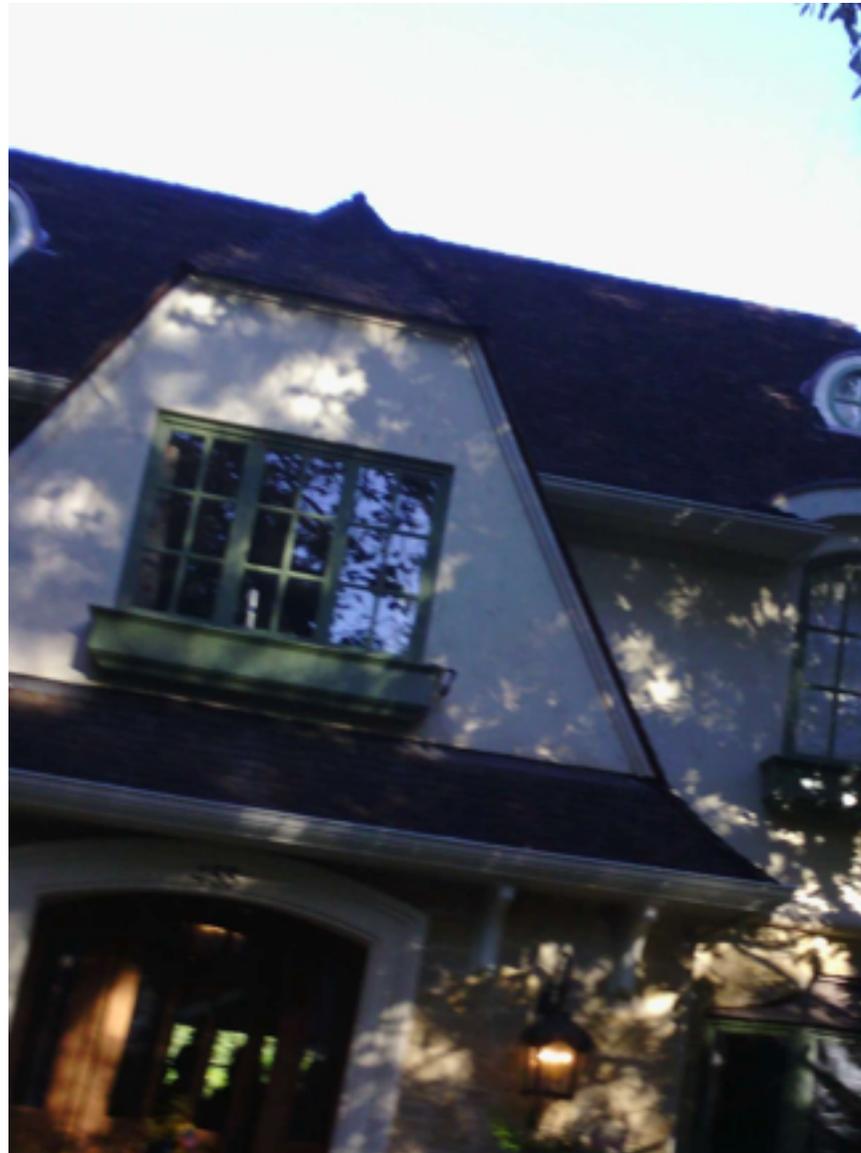
3:10

3:20

5:40

6:30

# Nadine — image



# Deep research in Pilot study



14 diverse families  
participated

Data collected for ~30 hours  
using multiple methods

New visualizations developed

**With many collaborators**

## Funding

- Robert Wood Johnson Foundation

## Core Team

- Bhageera Consulting
- Dubberly Design
- Family Caregiver Alliance
- Intel Labs
- United Hospital Fund

## Collaborators

- Caring Across Generations
- Cincinnati Children's Hospital
- Cystic Fibrosis Foundation
- Dartmouth
- Empatica
- Health 2.0
- Mount Sinai Health System
- Narrative
- Quantified Self Labs
- ReACT
- Sapient
- SmartPatients

# Deep research in Pilot study



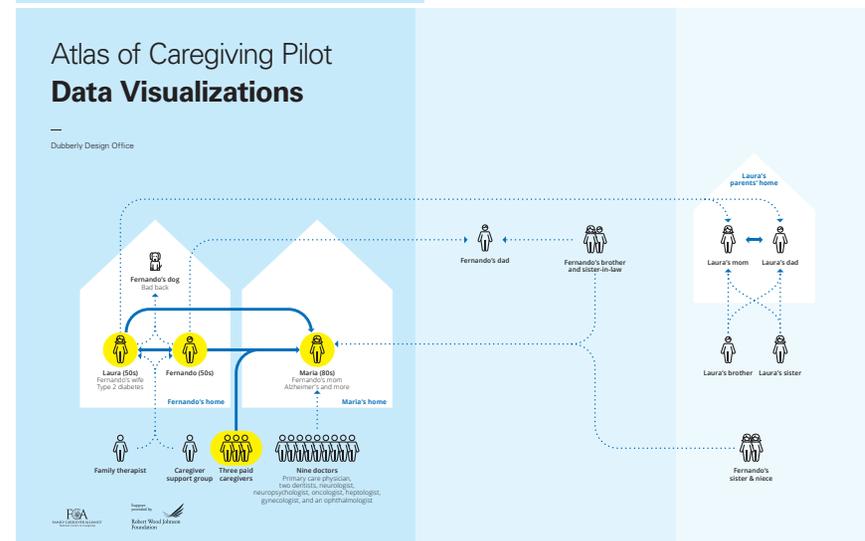
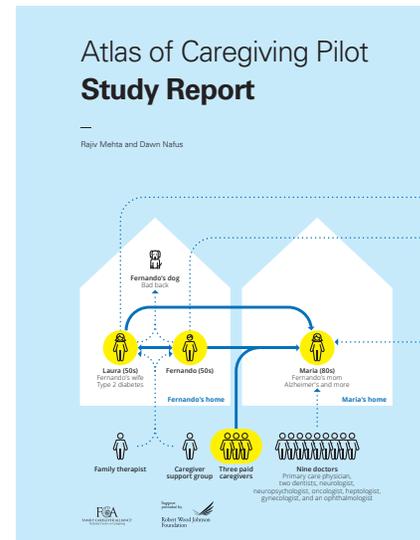
14 diverse families participated

Data collected for ~30 hours using multiple methods

New visualizations developed

With many collaborators

**Insights into family caregiving & implications for advocates and supporters**



Study results available at:  
[atlasofcaregiving.com/studies](https://atlasofcaregiving.com/studies)



# Selected Insights

# Assist caregivers in developing self-knowledge



## Participation increased self-knowledge, leading to direct benefits

- Led to “what if ...?”
- Better self-efficacy
- Better self-advocacy

## Incomplete self-awareness is problem worth addressing

- Incomplete / inaccurate information to professional providers
- Inability to recognize potentially useful products and services
- Lower self-esteem

## What can healthcare and social services organizations do to improve patient/family self-discovery?

# Understanding complexity and variation in caregiving critical to good support



**Even “light caregiving” can significantly impact productivity**

**Complex care makes respite both necessary and difficult**

**Defining the caregiving experience by disease / condition / age is myopic.**

- Very different needs though same conditions
- Common needs though seemingly very different contexts

# Support must be personalized for each care ecosystem



## **Not simple dyad of “caregiver” and “care-recipient”**

- Multiple caregivers and multiple care-recipients
- People can be caregivers and care-recipients
- Involvement and importance of specific caregivers can vary by topic and timing
- ... complex, living networks

**Seemingly simple requests of “primary family caregiver” may involve unexpected network dynamics, making difficult situation much more difficult**

**Multiple family members may benefit from education and training**

**Knowledge and authority may be dispersed**

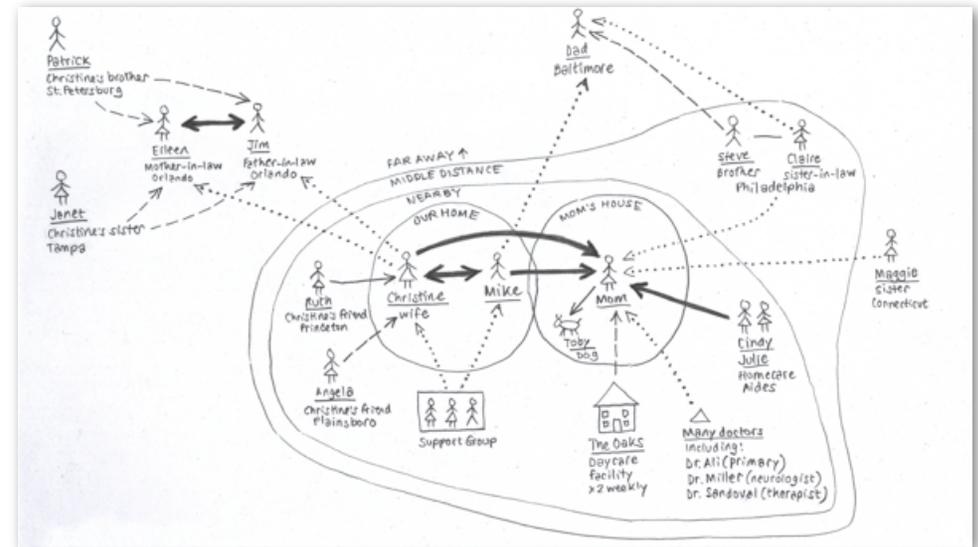


# Pilot — Practical Tools

# Practical tools in Pilot study



## Care Maps resonated



# Practical tools in Pilot study



Care Maps resonated

## “Care Map Workshops” with Santa Barbara Foundation

- 75 participants
- Family caregivers / Social workers & care managers

### Impact:

- Enthusiasm & Engagement
- Entered into practice
- Impacted community





# What's Next?

# Moving Forward



## Deep Research

- More people
- Longer time
- Better methods
- Identify metrics
- Deeper collaboration

# Moving Forward



## Deep Research

- More people
- Longer time
- Better methods
- Identify metrics
- Deeper collaboration

## Practical Tools

- Accelerate adoption
- Integrate into systems
- Develop digital care map tool
- Develop ecosystem analysis methods
- Build collaborative community



# Thanks

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650.823.3274