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FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

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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



• FCA CareJourney login



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

• 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]

The FCA Learning Center is an online learning community offering caregiver content, skill-building classes and more on your schedule. Look for our launch soon!

• Online Learning Center information and access



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

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

[Blog](#)



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

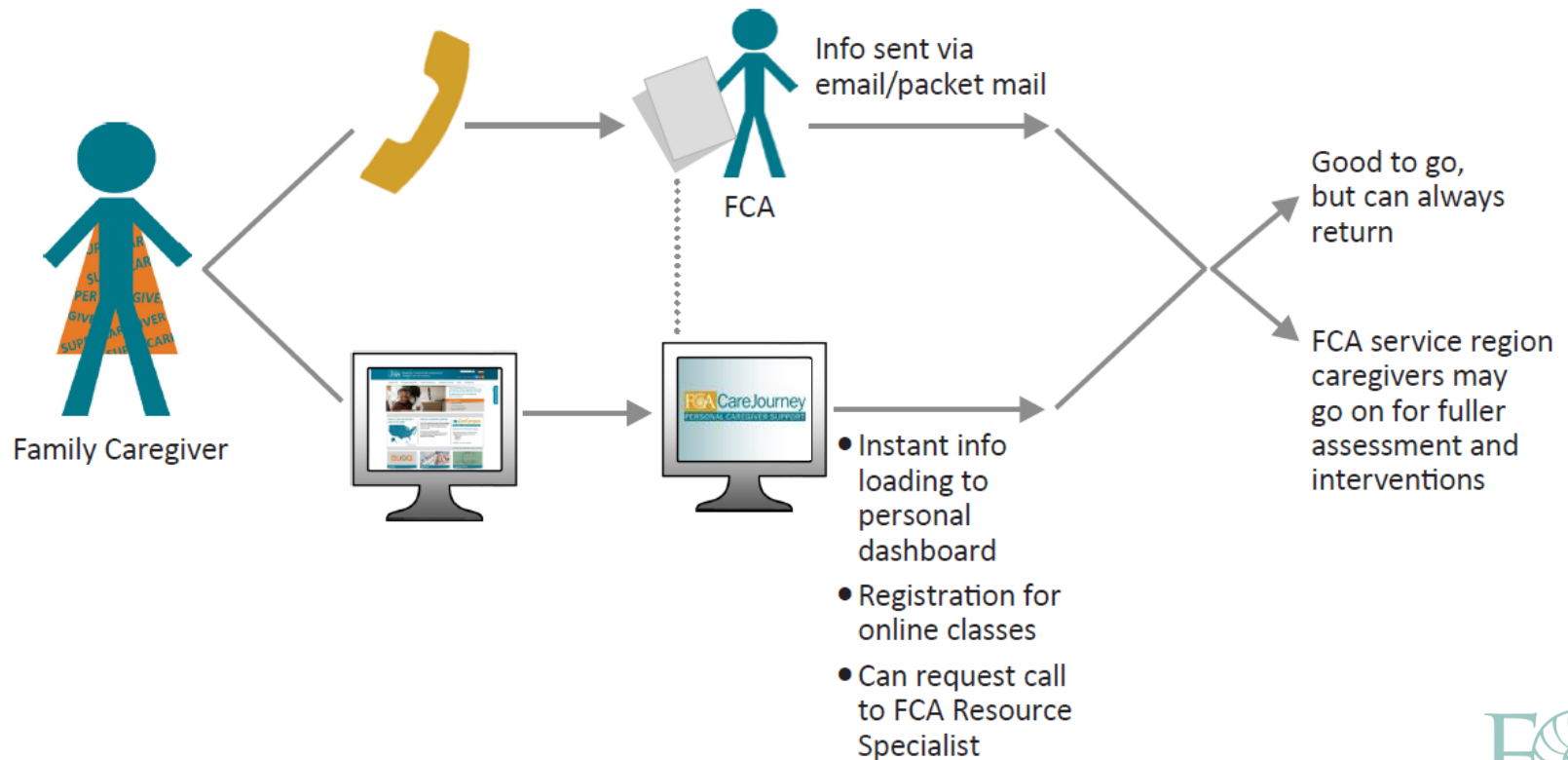
Family Caregiver Alliance (FCA) and The Rosalinde and Arthur Gilbert Foundation are pleased to announce the recipients of the 2015 Rosalinde Gilbert Innovations in Alzheimer's Disease Caregiving Legacy Awards.



- ▶ 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”



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 your 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](#)

Login

Become a Member

Email Address


Password

Repeat Password

Zip Code

Join

FCA CareJourney

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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

Collapse

 RESOURCE LOCATOR
CALIFORNIA CARE
RESOURCES

 RESOURCE LOCATOR
NATIONAL CARE
RESOURCES

My Documents

Collapse

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

FCA 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

My Documents

Medications and Aging

Legal Consultation Information

Service Authorization Form

FCA Care.burney

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?

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?

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](#)

[DECISIONS: WHAT ARE YOUR IMPORTANT PAPERS?](#)

[TAKING CARE OF YOU: SELF-CARE FOR FAMILY CAREGIVERS](#)

[Complaint, Consent and Service Authorization Form Sample](#)

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


Complaints, Concerns and...

Service Authorization Form Sample

FCA Care.burney

Questions Include:

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

 **CareJourney**
PERSONAL CAREGIVER SUPPORT

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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

Collapse

Caregiver
Claire Roberts

Currently Caring For
Lydia Roberts

FCA Resource Specialist
415.434.3388
800.445.8106

My Resources

Collapse

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FRUSTRATION

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CAREGIVERS

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STROKE

SELF CARE
TAKING CARE OF YOU:
SELF-CARE FOR FAMILY
CAREGIVERS

All My Resources Find More

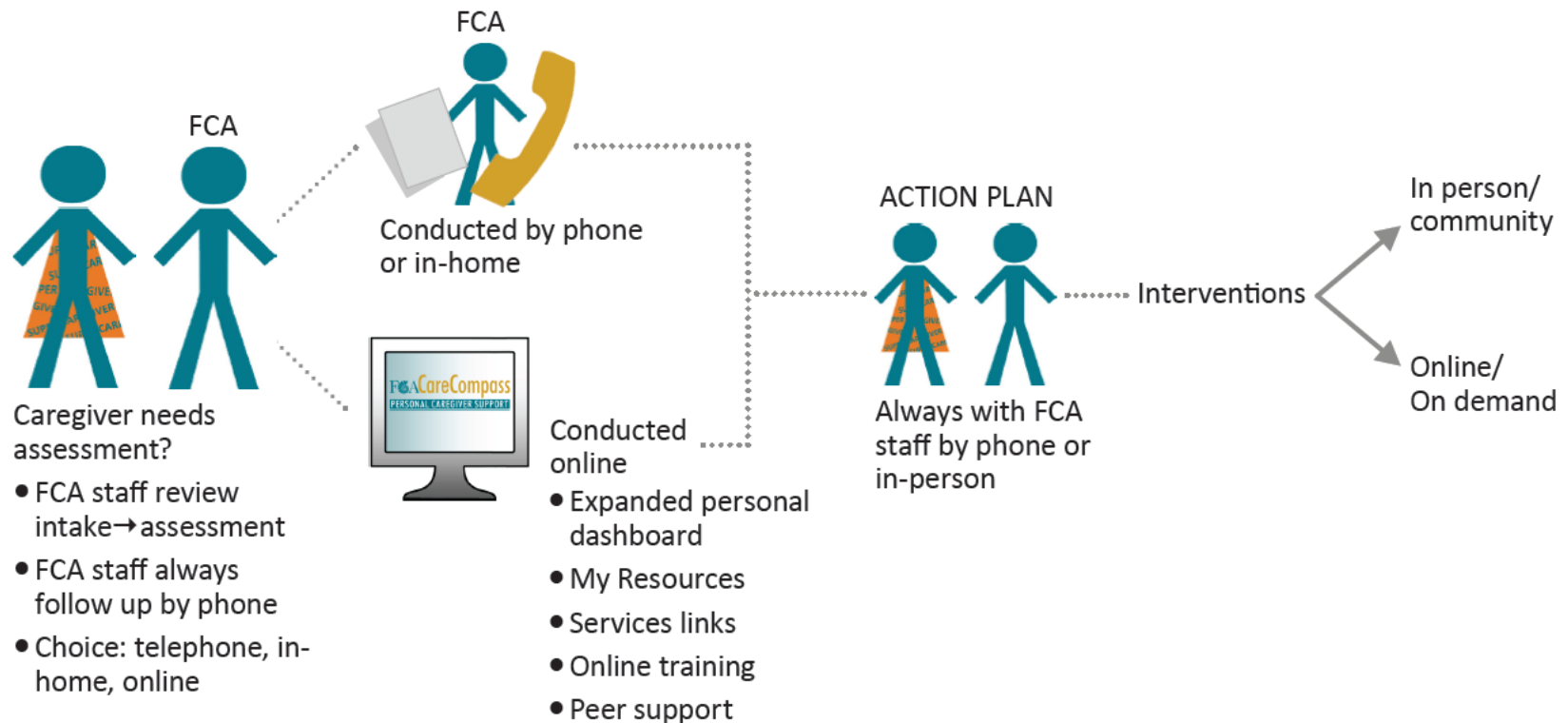
My Documents


Collapse

- Complaint, Concerns and
Grievances Process

FCA CareJourney

Intensive Services **CARE EVALUATION** “Assessment”




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 PERSONAL CAREGIVER SUPPORT

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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

Caregiver
Claire Roberts

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Lydia Roberts

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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

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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"/>
Dressing (putting on/taking off clothes)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="checkbox"/>
Grooming (brushing hair, combing hair, shaving)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="checkbox"/>
Using the toilet (getting to bathroom, sitting on toilet, cleaning himself/herself)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="checkbox"/>
Transferring (moving from one place to another, e.g., from bed to chair)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
Preparing meals (cooking or preparing food)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="checkbox"/>
Housework (cleaning, laundry, shopping)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>

My Support Team

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My Resources

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CALIFORNIA CARE RESOURCES

RESOURCE LOCATOR
NATIONAL CARE RESOURCES

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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

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PERSONAL CAREGIVER SUPPORT

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

Plan Care

These next set of questions are about your health insurance and future planning documents you may have completed.

Do you have health insurance?

☒ Yes ☐ No

If yes, please select your Insurance Carrier:

☐ Kaiser

☐ Health Trust

SCAN

☐ Blue Shield

☐ Aetna

☐ Medicaid (MediCal)

☐ United Health Care

☒ Other ☐ AARP Medicare Supplement

Do you have long-term care insurance?

Please check the types of documents that you have completed (check all that apply):

☐ Health

☐ Durable Power of Attorney: Finances

☐ POLST (Physician Ordered Life Sustaining Treatment)

☐ DNR (Do Not Resuscitate)

My Support Team

Caregiver
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My Resources

DIRECT CARE
CAREGIVER'S GUIDE TO UNDERSTANDING DEMENTIA BEHAVIORS

DIRECT CARE
TEN REAL-LIFE STRATEGIES FOR DEMENTIA CAREGIVING

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DEMENTIA, CAREGIVING AND CONTROLLING FRUSTRATION

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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

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

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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

FCA CareJourney

Questions Include:

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

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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 Support Team

- Caregiver**
Claire Roberts
- Currently Caring For**
Lydia Roberts
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My Resources

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- RESOURCE LOCATOR
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- 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


My Records

- Action Plan
- Other Reports

Calendar

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

www.caregiver.org


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 PERSONAL CAREGIVER SUPPORT

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1 DASHBOARD

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
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My Resources

[Collapse](#)

-  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

[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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Private Family Foundation: Lead for Online Learning Community

The Foster Foundation

Private Family Foundation

Genentech

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Quality Process

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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:



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youtube.com/CAREGIVERdotORG



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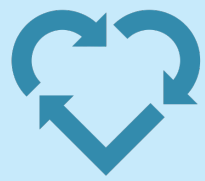
National Center on Caregiving

785 Market Street, Suite 750

San Francisco, CA 94103

800.445.8106 | 415.434.3388

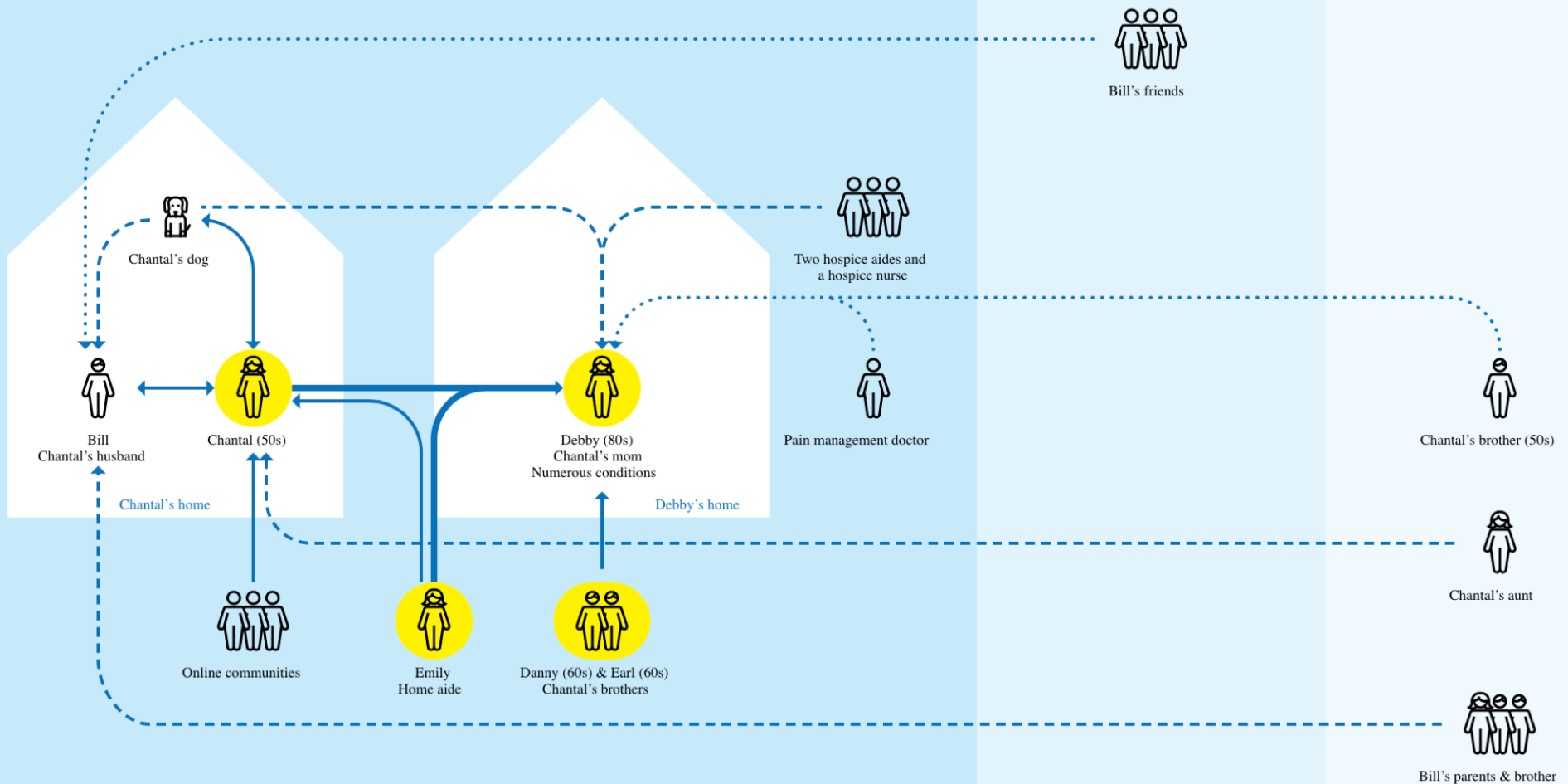
www.caregiver.org



Atlas of Caregiving

31 Aug 2016 • National Home and Community Based Services (HCBS) Conference

Rajiv Mehta • rajiv@atlasofcaregiving.com • 650.823.3274





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
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and technology

Deep
Research

Practical
Tools

Developing
practical tools for
self-discovery
and community
awareness

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Deep
Research

Practical
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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

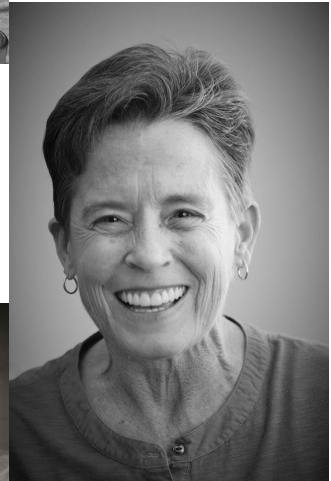


Pilot — Deep Research

Deep research in Pilot study



**14 diverse families
participated**



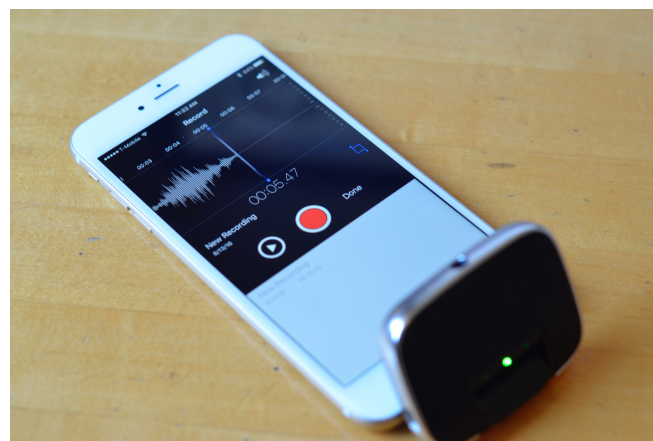
Deep research in Pilot study



14 diverse families
participated

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

- Interviews



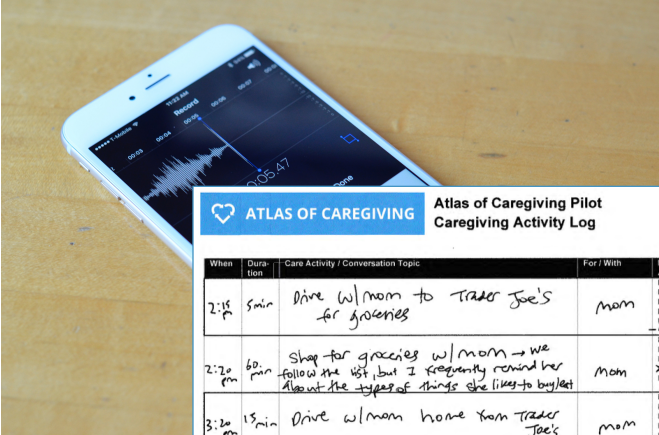
Deep research in Pilot study



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 <input type="checkbox"/> None <input type="checkbox"/> Remind <input type="checkbox"/> Supervise <input type="checkbox"/> Help <input type="checkbox"/> Do all	Level of Cooperation <input type="checkbox"/> Obstructive <input type="checkbox"/> Passive <input checked="" type="checkbox"/> Cooperative	Stress No stress Very stressful
2:15 p	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
2:20 p	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
3:20 p	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
3:35 p	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
3:45 p	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
3:55 p	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
3:58 p		Our apartment begins to vibrate due to unannounced construction in the apt below us → we were told it would end by 4pm	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

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



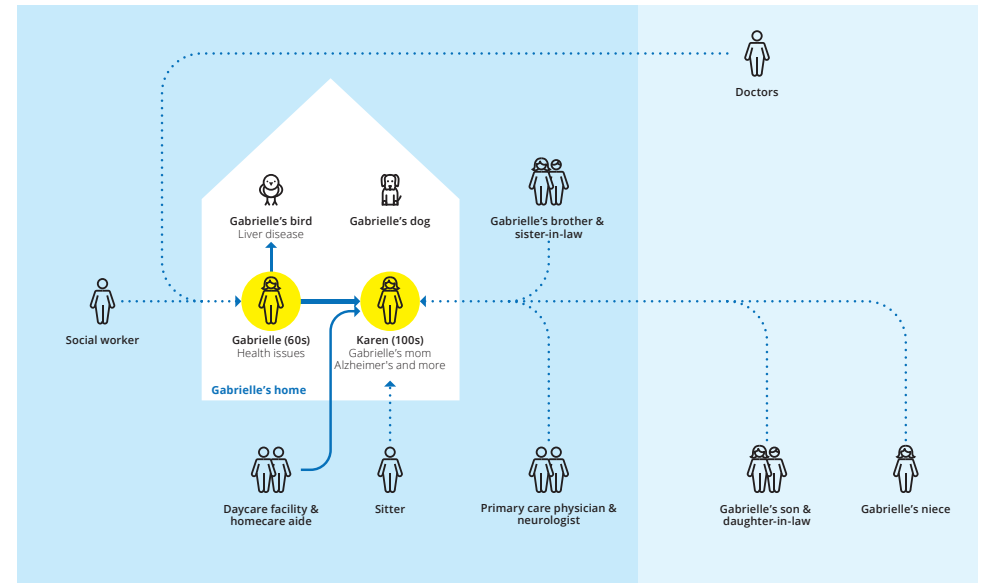
Deep research in Pilot study



14 diverse families
participated

Data collected for ~30 hours
using multiple methods

New visualizations developed



Chantal — care map



Near

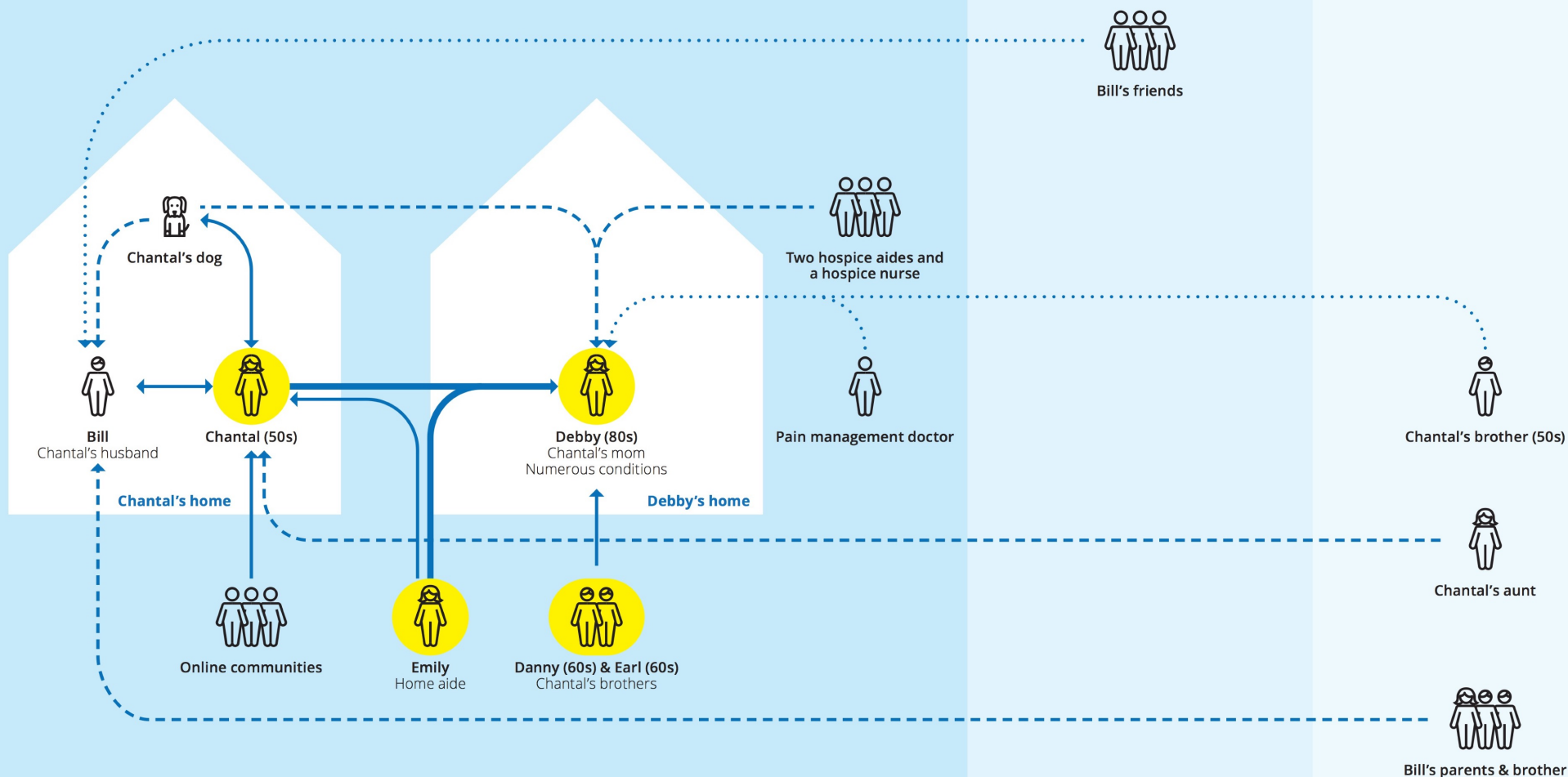
Less than 20 minutes away

Middle

Between 20 minutes and 2 hours away

Far

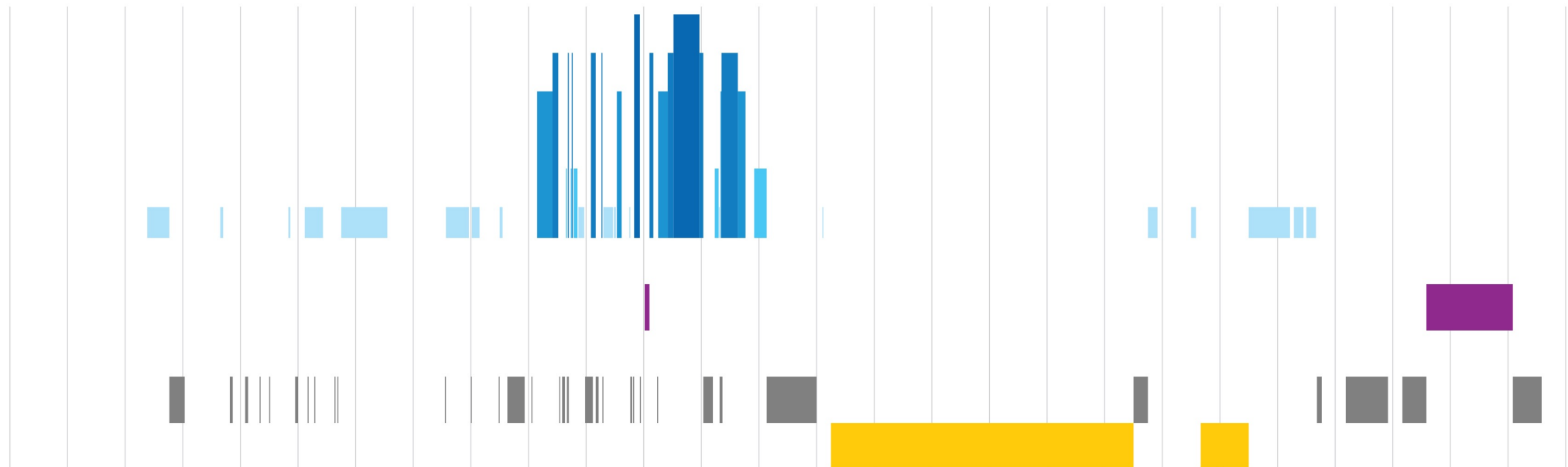
More than 2 hours away



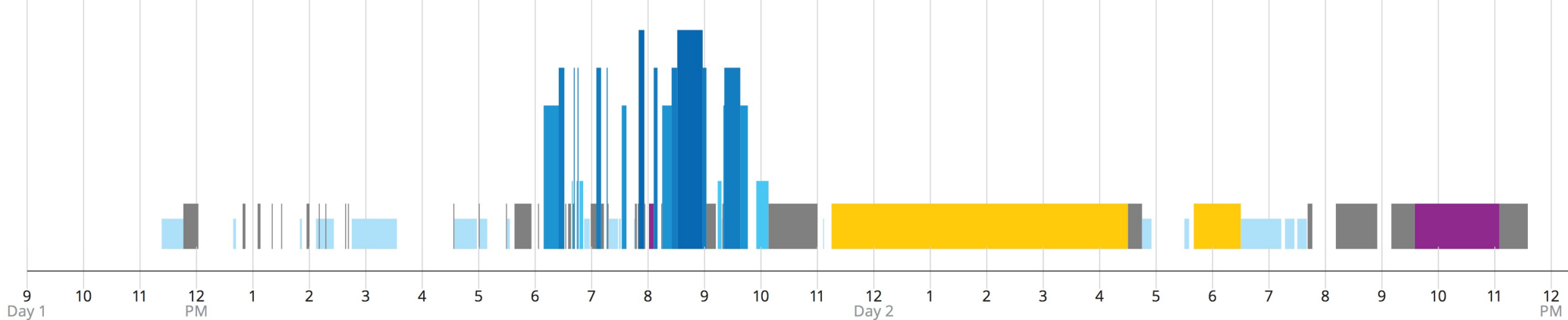
Chantal — activities



ACTIVITIES BROKEN OUT



ACTIVITIES COMBINED



Gabrielle — care map



Near

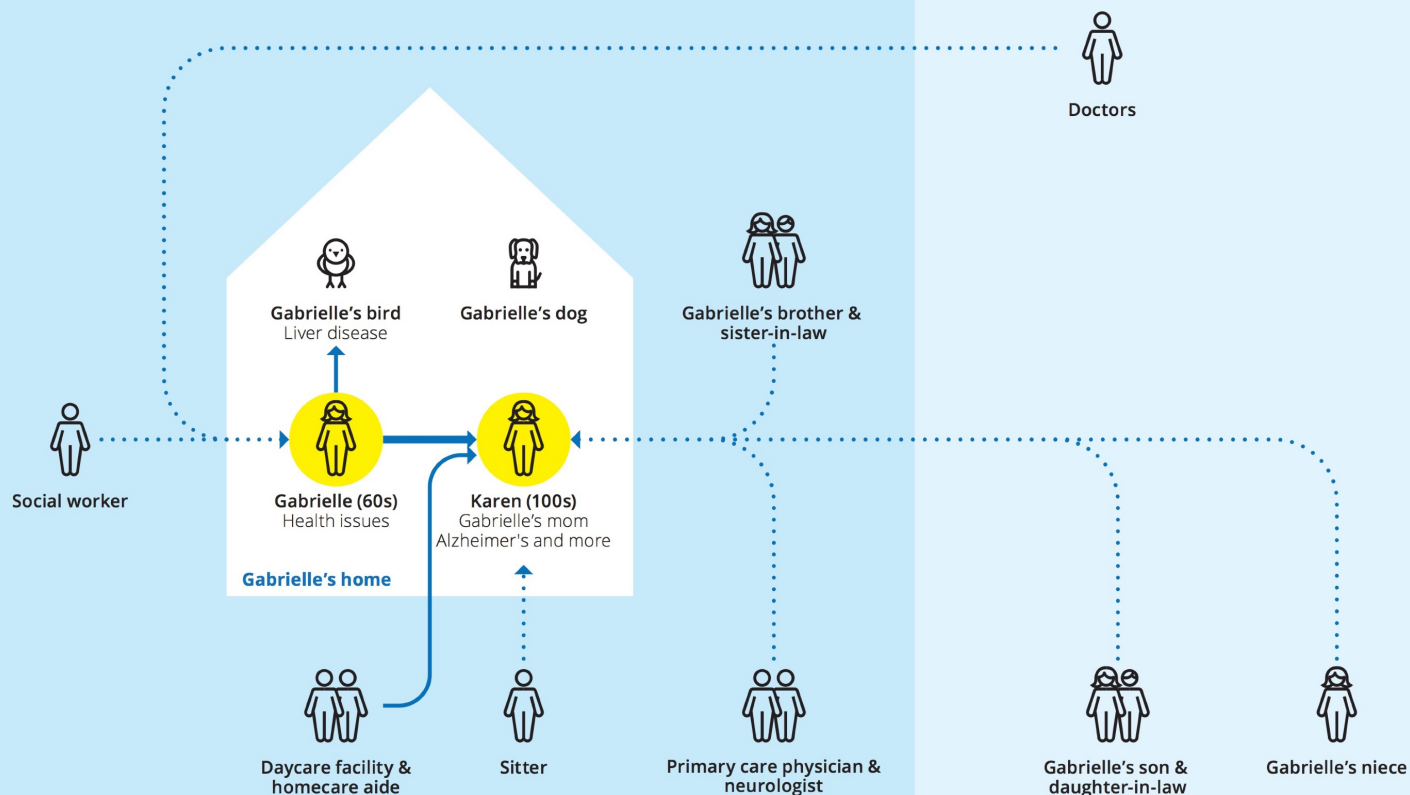
Less than 20 minutes away

Middle

Between 20 minutes and 2 hours away

Far

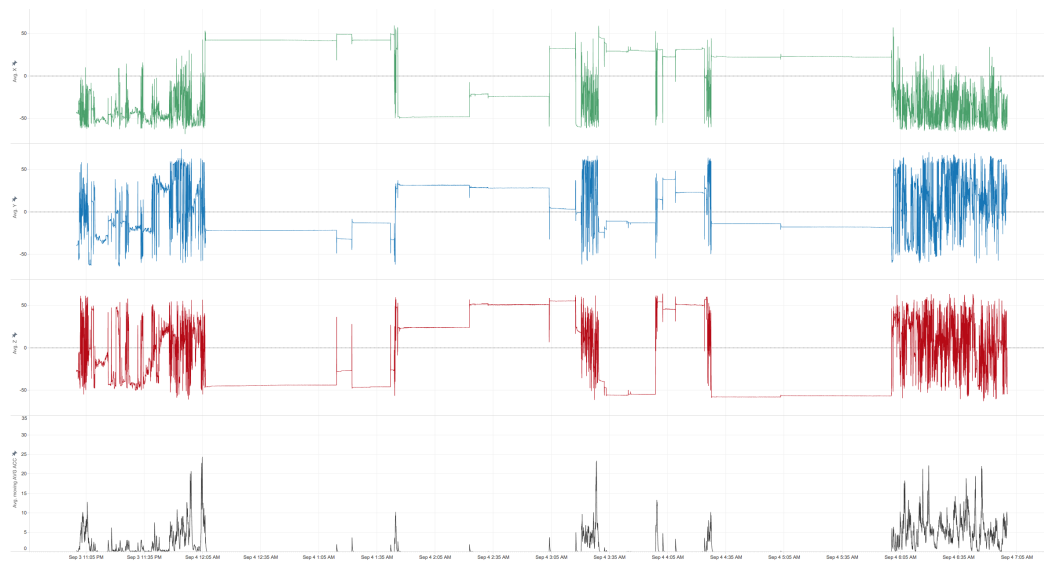
More than 2 hours away



Gabrielle — motion & sound



Motion data



midnight

1:40 am

3:20 am

4:00 am

4:30 am

6:00 am

Sound data



midnight

1:40 am

6:00 am

Nadine — care map



Near

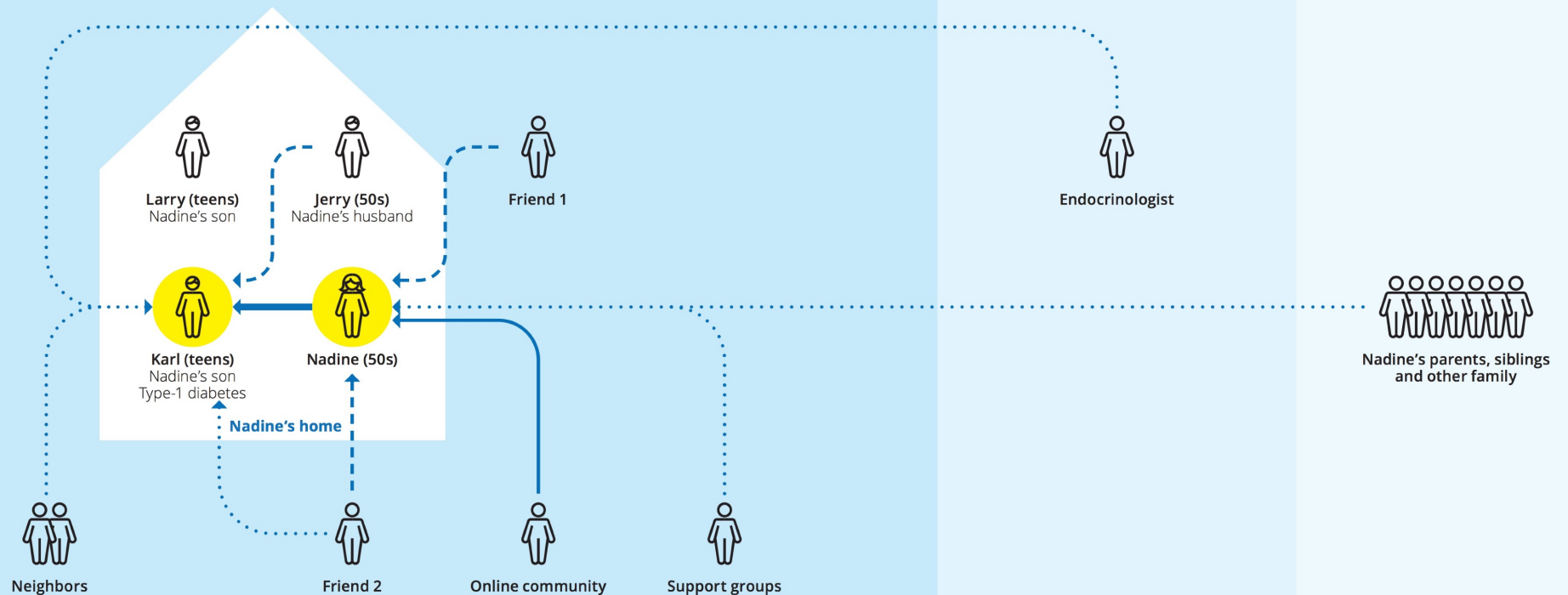
Less than 20 minutes away

Middle

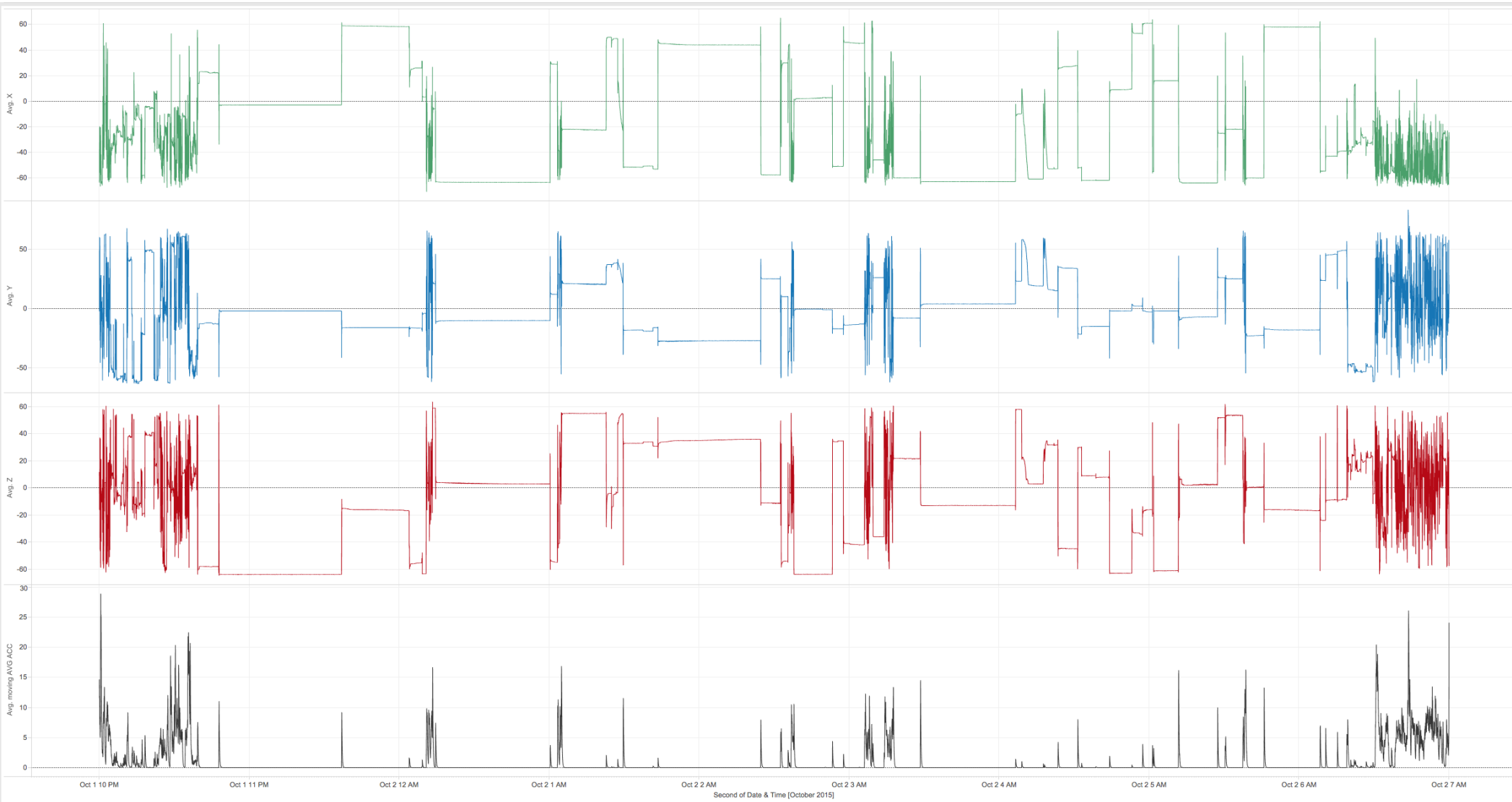
Between 20 minutes and 2 hours away

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



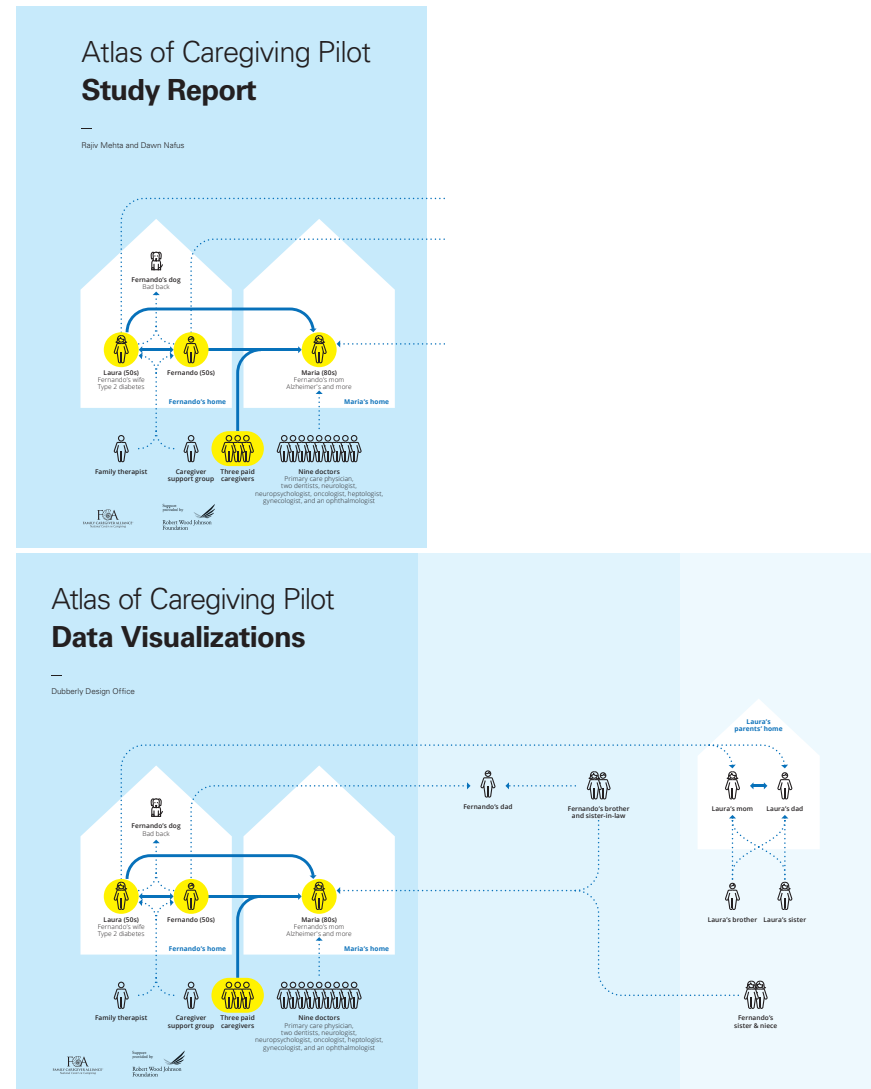
14 diverse families participated

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New visualizations developed

With many collaborators

Insights into family caregiving & implications for advocates and supporters



Study results available at:
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

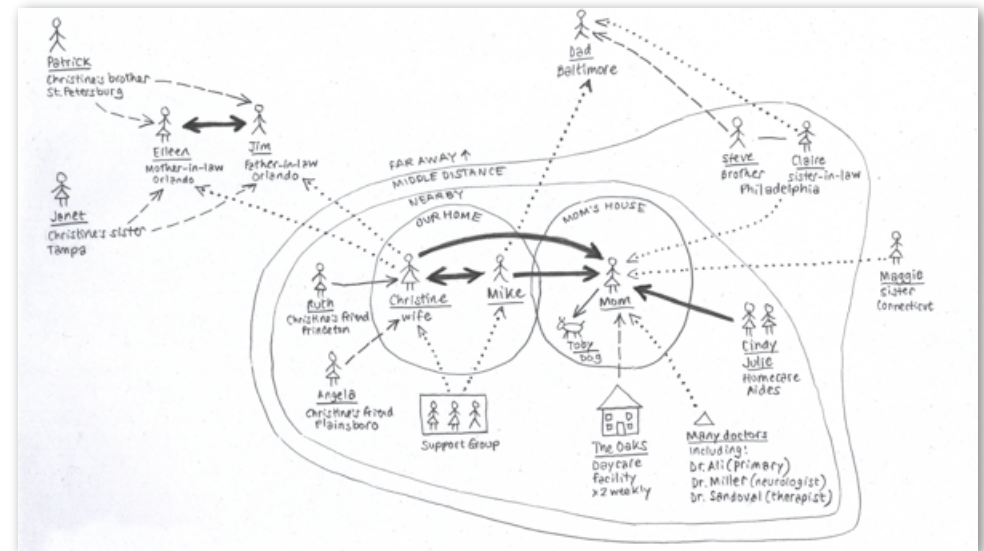


Pilot — Practical Tools

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