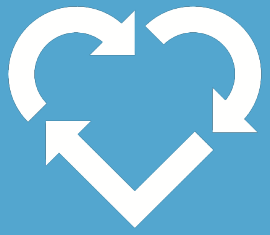


ATLAS OF CAREGIVING

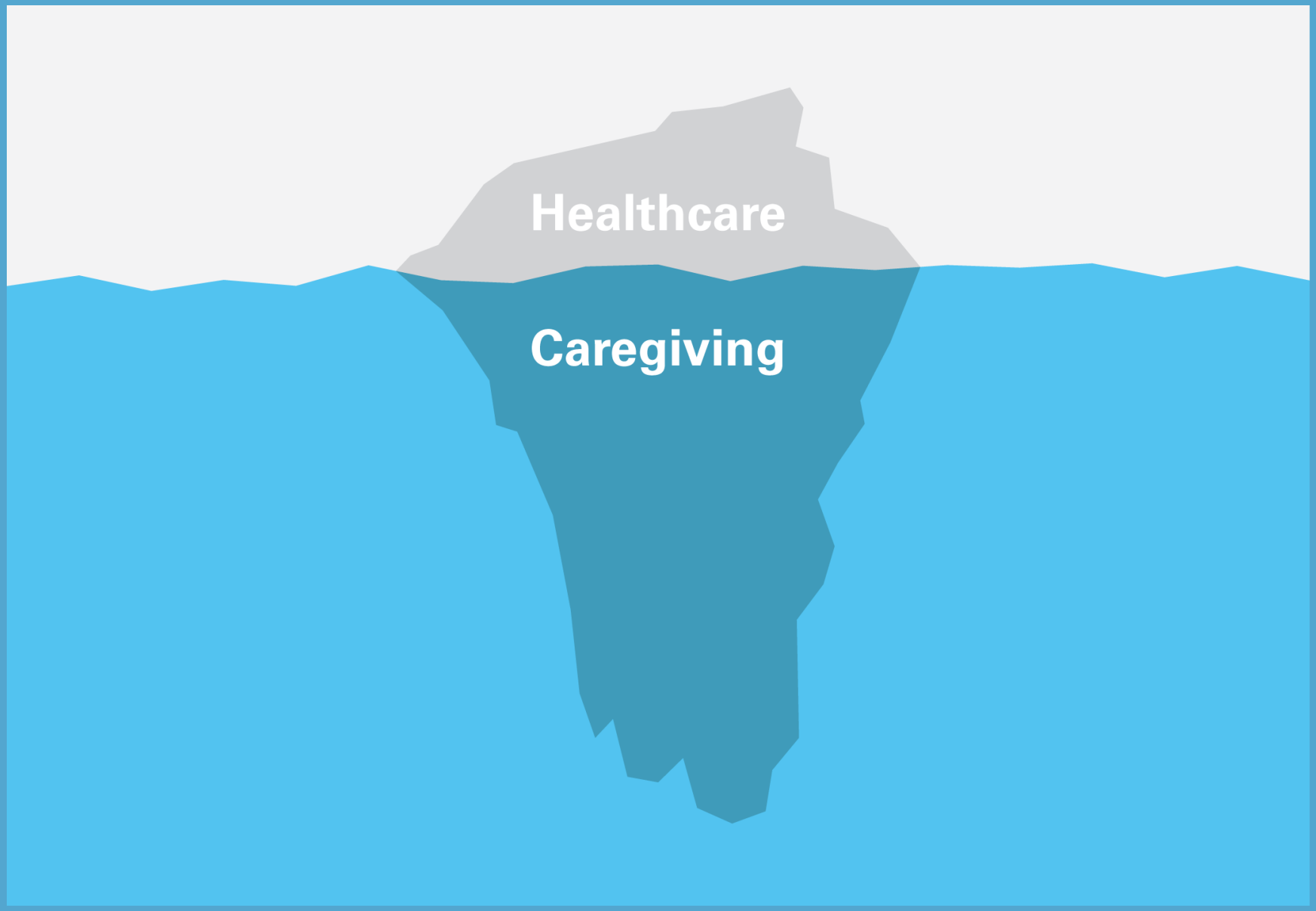
Rajiv Mehta

Current and Future Challenges in Caregiving, Concordia University, Montreal

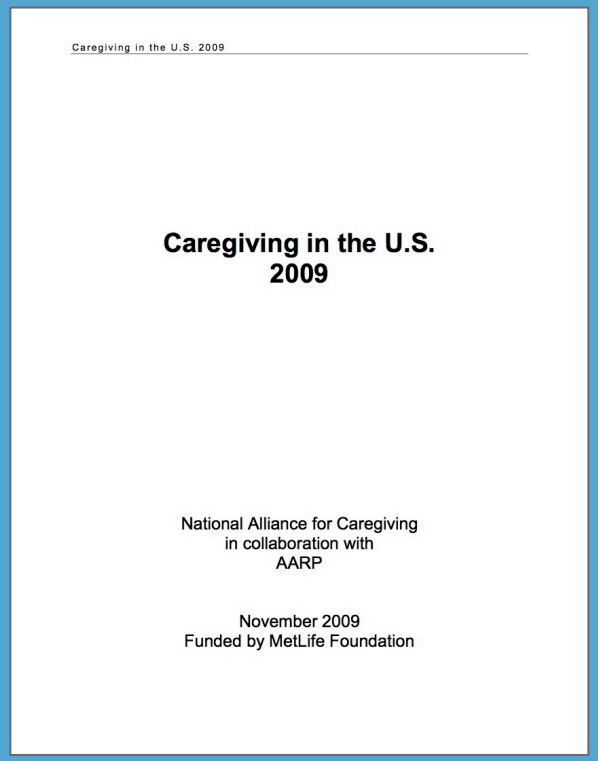
10 November 2016

We can’t value what we don’t see

We don’t improve what we can’t value

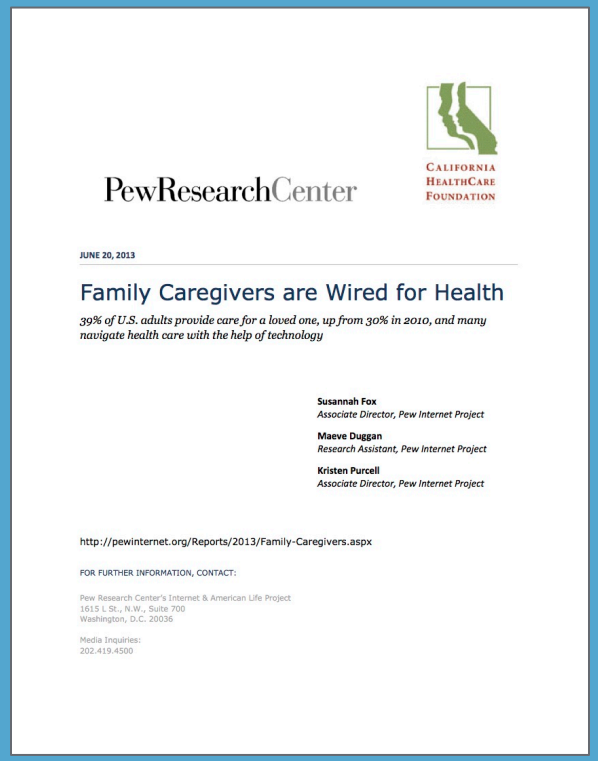

Healthcare
Caregiving

How many American adult caregivers?



2009

65.7 million



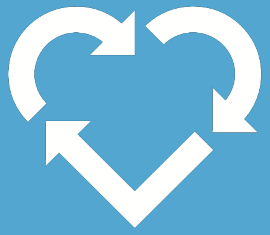
2013

~100 million

2015

43.5 million

What is the lived reality of day-to-day family caregiving?



ATLAS OF CAREGIVING

Ethnography

+

Self-tracking

+

Sensors

+

Data analytics

+

Visualization

Atlas of Caregiving
2015 Pilot Study

Overview

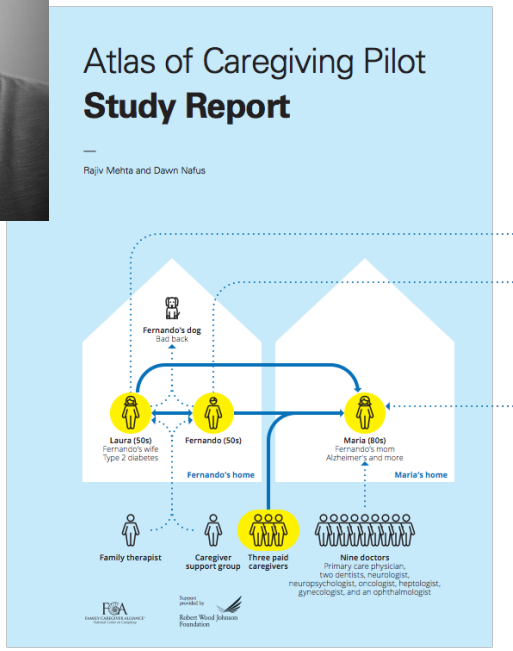
14 families, diversity of care situations and conditions

Data collected for ~30 hours using multiple methods

New visualizations developed

Insights into family caregiving & implications for advocates and supporters

Results published April 2015



Download report at atlasofcaregiving.com/studies

Collaborators

Caregiving

- **Family Caregiver Alliance**
- **United Hospital Fund**
- Caring Across Generations
- ReACT

Technology

- **Intel Labs**
- Empatica
- Narrative
- Quantified Self Labs
- Sapient

Healthcare

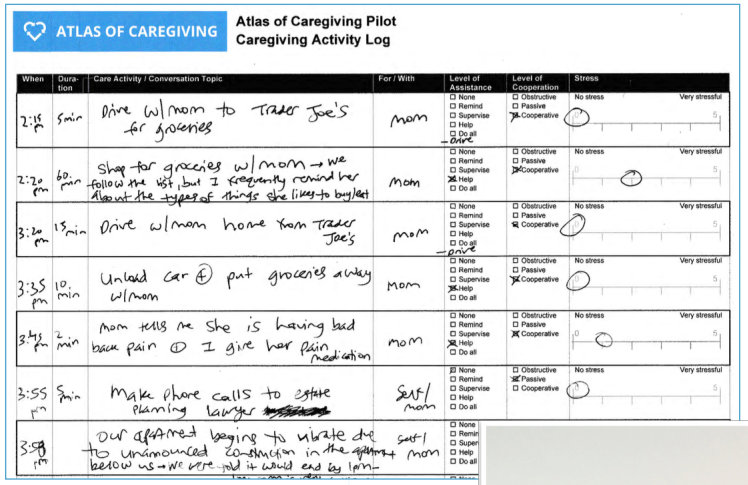
- Cincinnati Children's Hospital
- Cystic Fibrosis Foundation
- Dartmouth Medical School
- Health 2.0
- Mount Sinai Health System
- SmartPatients

Design

- **Dubberly Design Office**

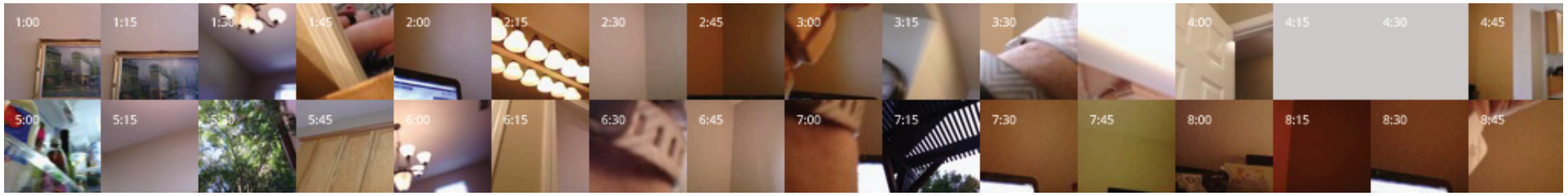
Data Collection

- Interviews
- Activity Logs
- Clip camera
- Wearable sensors
- Environmental monitors

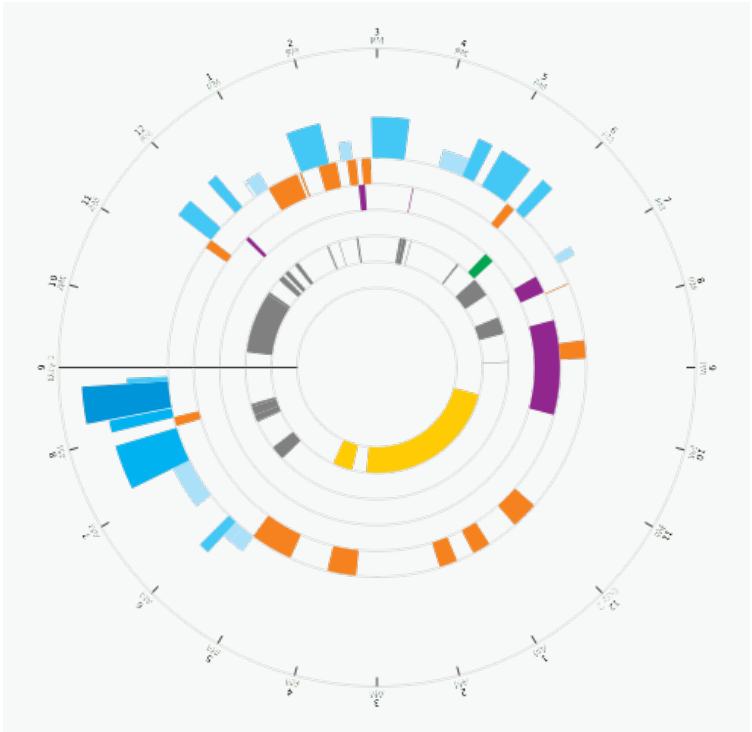

ATLAS OF CAREGIVING

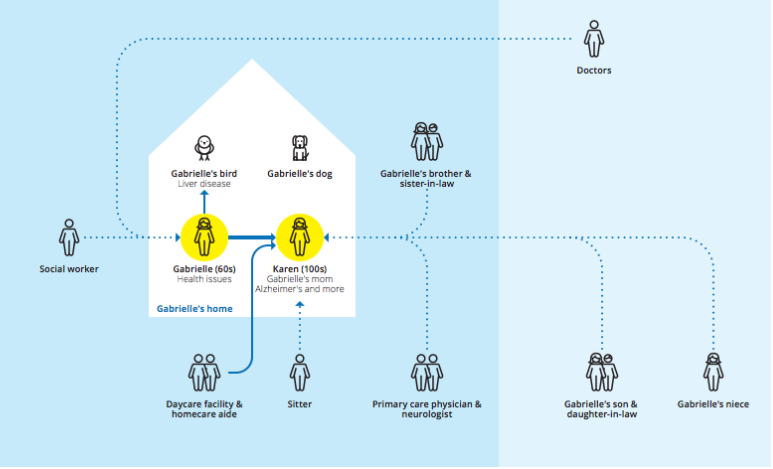
Atlas of Caregiving Pilot
Caregiving Activity Log

When	Duration	Care Activity / Conversation Topic	For / With	Level of Assistance	Level of Cooperation	Stress
2:15 pm	5min	Drive w/mom to Trader Joe's for groceries	mom	☐ None ☐ Remind ☐ Supervise ☐ Help ☐ Do all — drive	☐ Obstructive ☐ Passive ☒ 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/eat	mom	☐ None ☐ Remind ☐ Supervise ☒ Help ☐ Do all	☐ Obstructive ☐ Passive ☒ Cooperative	No stress — Very stressful
3:20 pm	15 min	Drive w/mom home from Trader Joe's	mom	☐ None ☐ Remind ☐ Supervise ☐ Help ☐ Do all — drive	☐ Obstructive ☐ Passive ☒ Cooperative	No stress — Very stressful
3:35 pm	10. min	Unload car & put groceries away w/mom	mom	☐ None ☐ Remind ☐ Supervise ☒ Help ☐ Do all	☐ Obstructive ☐ Passive ☒ 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	☐ None ☐ Remind ☐ Supervise ☒ Help ☐ Do all	☐ Obstructive ☐ Passive ☒ Cooperative	No stress — Very stressful
3:55 pm	5min	Make phone calls to estate planning lawyer [redacted]	Self/ mom	☐ None ☐ Remind ☐ Supervise ☐ Help ☐ Do all	☒ Obstructive ☐ Passive ☐ Cooperative	No stress — Very stressful
3:59 pm		our apartment begins to vibrate due to unannounced construction in the apartment below us → we were told it would end by 1pm	mom	☐ None ☐ Remin ☐ Super ☐ Help ☐ Do all		



Visualizations

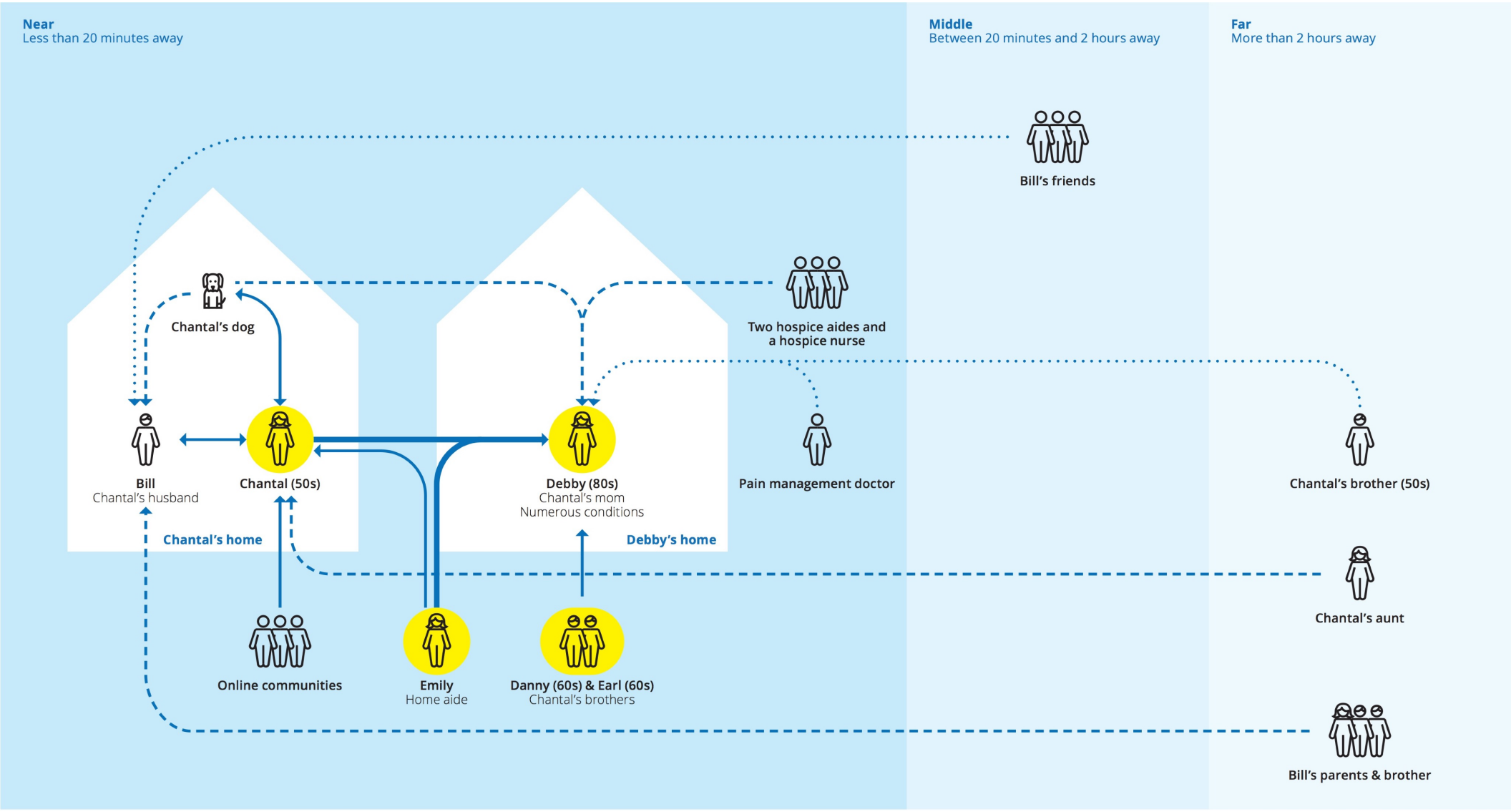




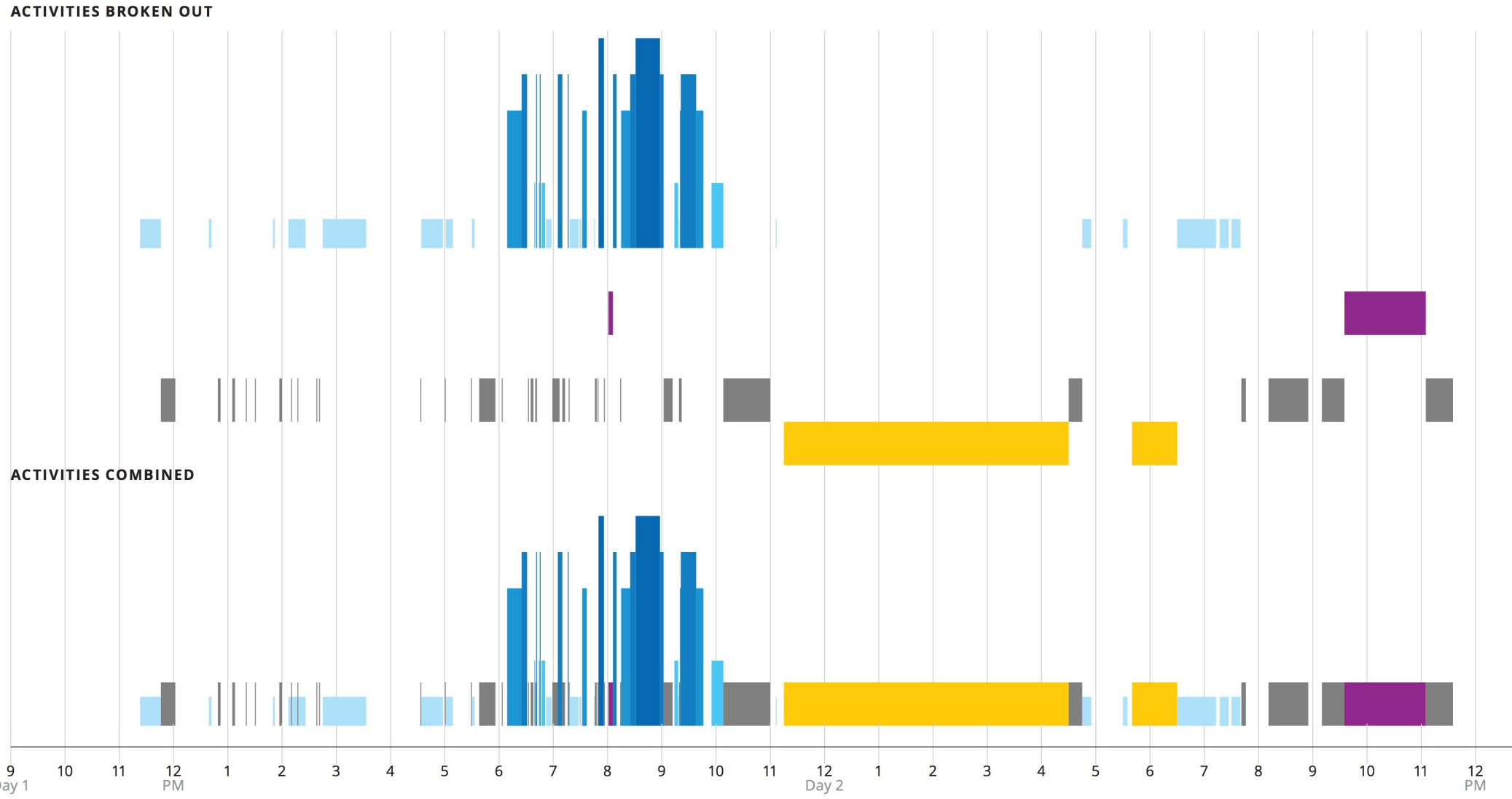
MINUTES SPENT ON CAREGIVING

36	Medications and supplements (including injections, IVs, oxygen, etc.)	**Medical Activities**
	Exercise, physical therapy	
	Equipment preparation and maintenance	
17	Wound management	
	Tracking symptoms and body measurements (weight, temp, etc.)	
	Preparing special meals	
	Arranging appointments	**Healthcare Management**
	Communicating with health professionals	
	Visits with health professionals	
	Buying prescriptions and supplies	
	Insurance and payments	
	Researching conditions and treatments	
	Researching healthcare costs	
	Keeping family and friends informed	**Care Communication & Coordination**
	Managing family and paid caregivers	
	Managing community services (paratransit, meals on wheels, etc.)	
	Bathing and toileting	**"ADLs" Help with Personal Activities**
	Dressing and grooming	
6	Feeding	
	Getting in/out of bed, chair, etc	
	Moving around the home	
	Cleaning	**"IADLs" Household Chores**
9	Cooking	
5	Laundry	
77	Shopping	
12	Getting/Moving/Using things	
22	Managing bills and savings	
60	Transportation to/from home	
32	Companionship	**Social Support**
37	Emotional support	
38	Plan and support participation in social activities	
5	Be constantly "on alert" for any needs	**Be Available**
	Be "on-call" for problems	
356		Total

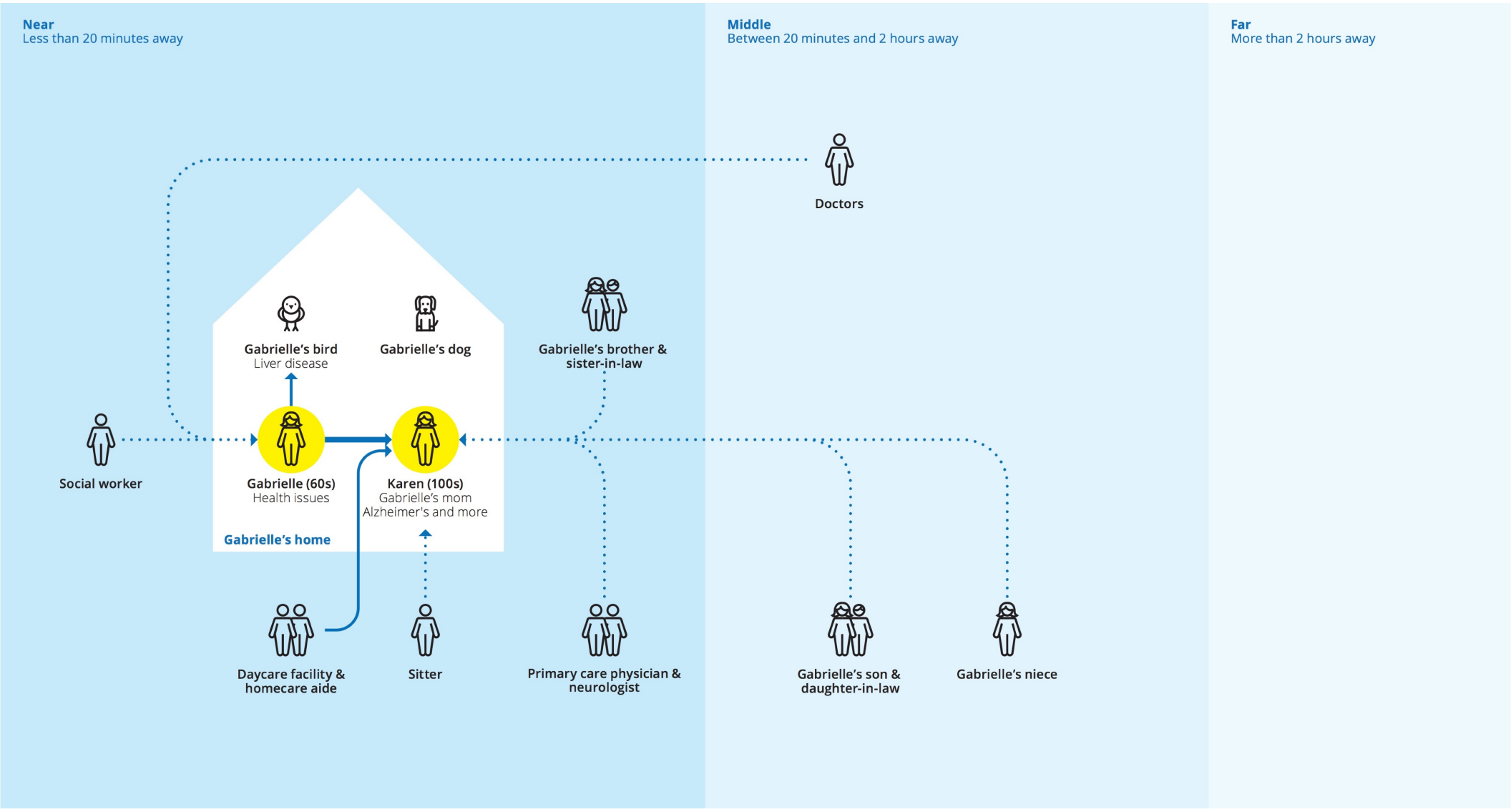
Care Map | Chantal



Activities | Chantal

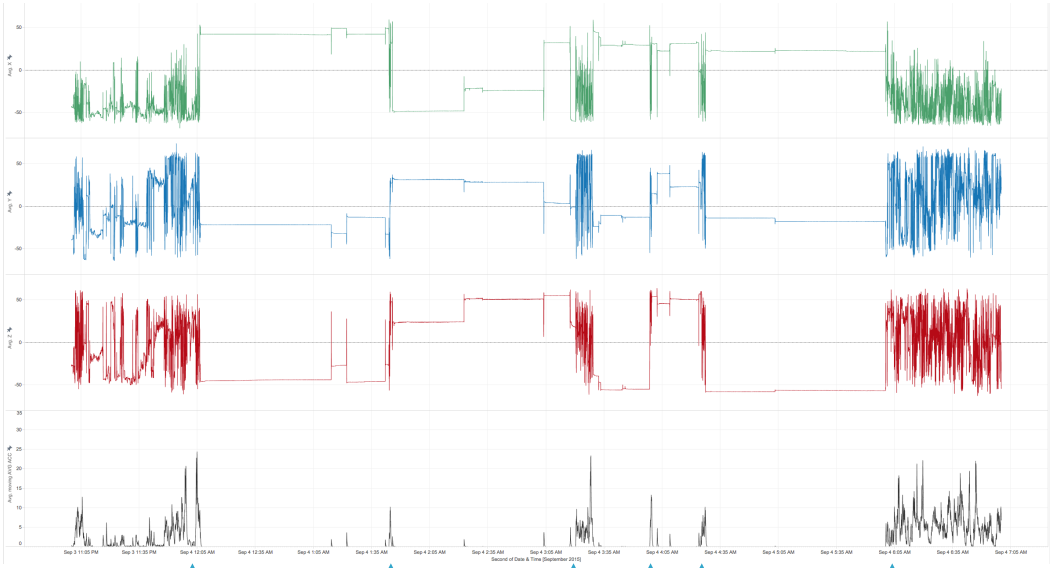


Care Map | Gabrielle



Motion & Sound | Gabrielle

Motion data



midnight

1:40 am

3:20 am

4:00 am

4:30 am

6:00 am

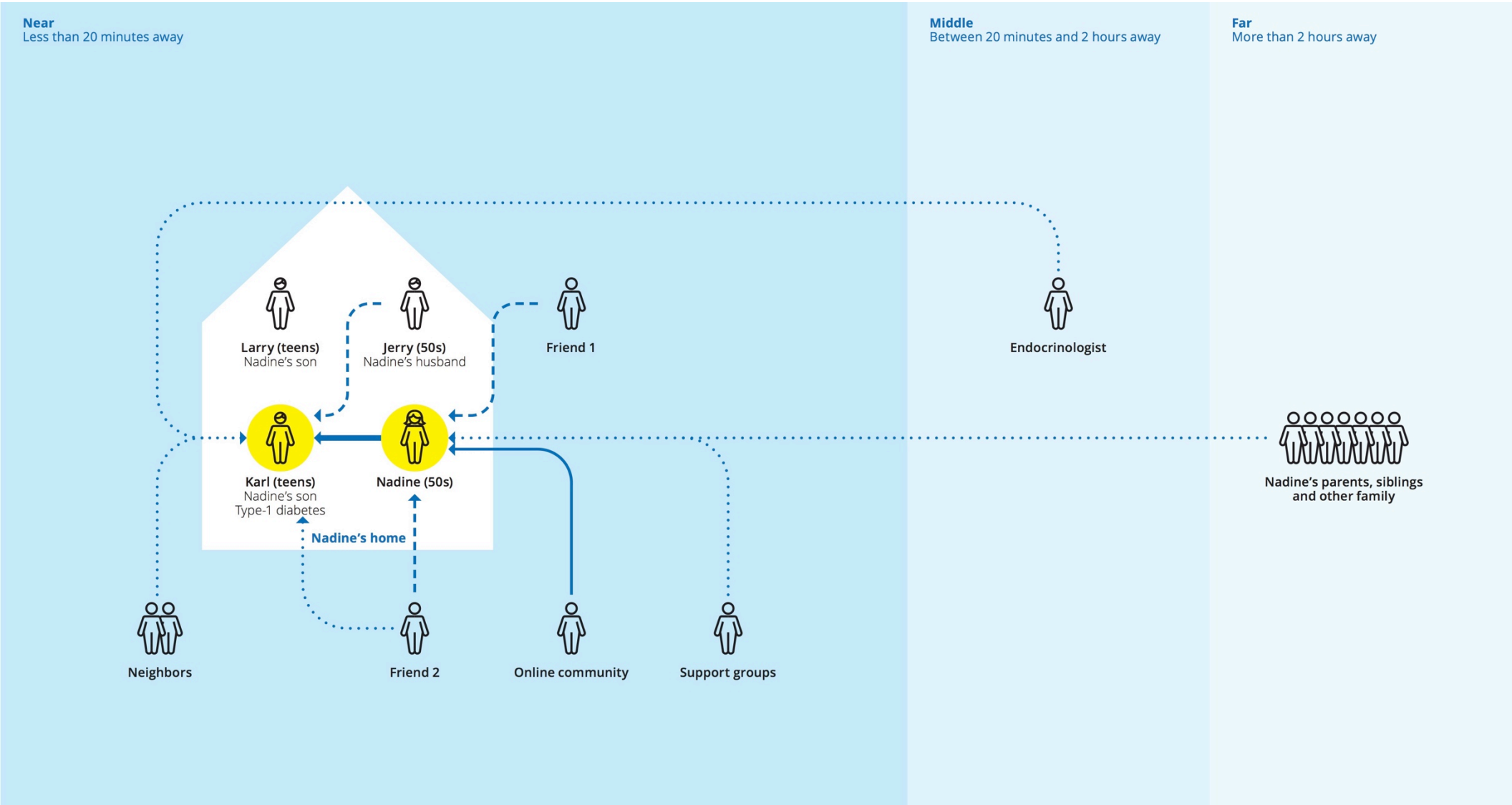
Sound data

midnight

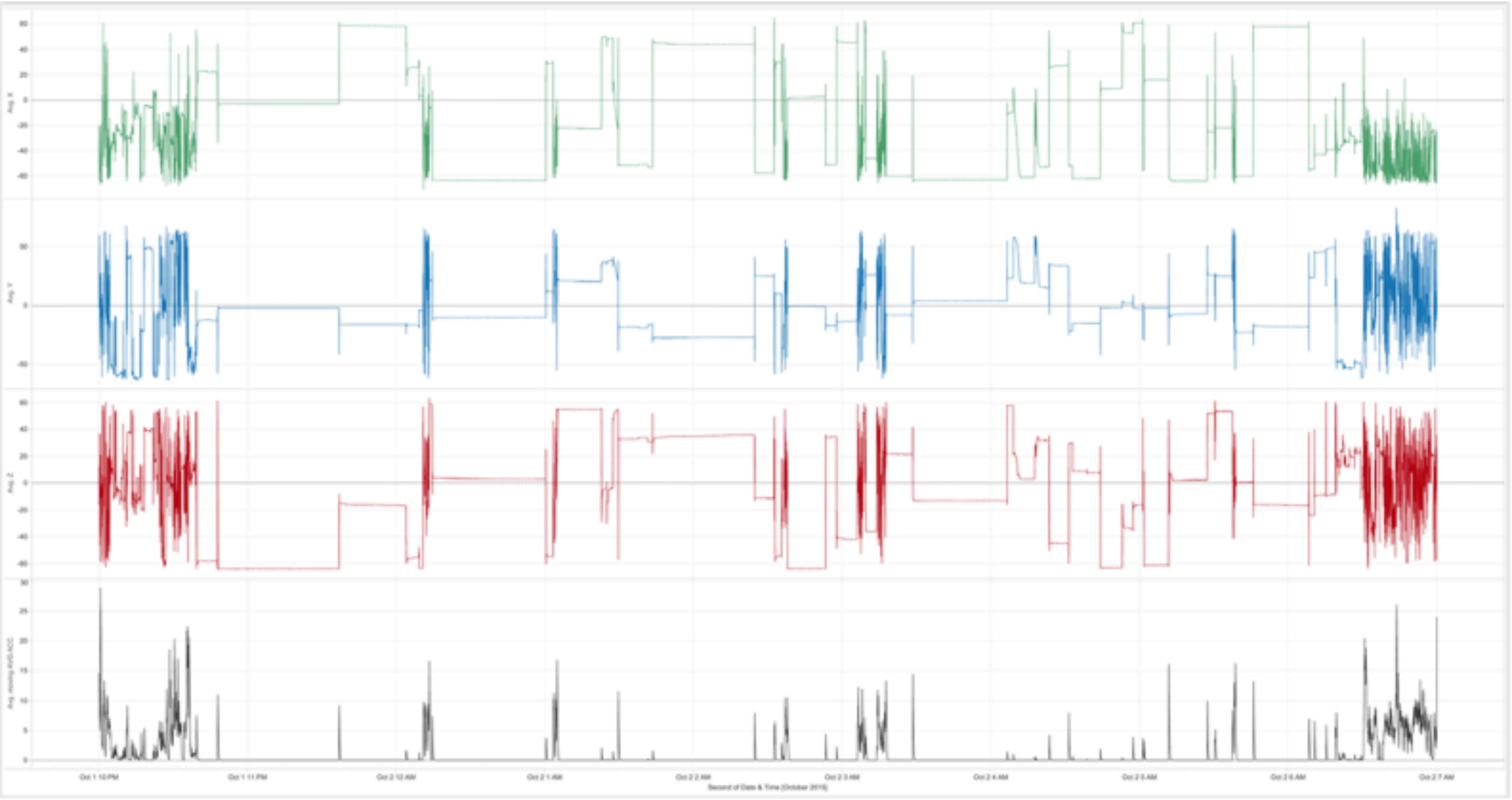
1:40 am

6:00 am

Care Map | Nadine



Motion | Nadine



10:45 12:15 1:00 2:30 3:10 3:20 5:40 6:30

Images | Nadine

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 a problem worth addressing

- More complete / accurate information to professional providers
- Improved ability to recognize potentially useful products and services

Healthcare and social services organizations can encourage and assist improved 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 health conditions
- Common needs though seemingly very different contexts
- Need better ways to define common-need sub-groups

Support must be personalized for each care ecosystem

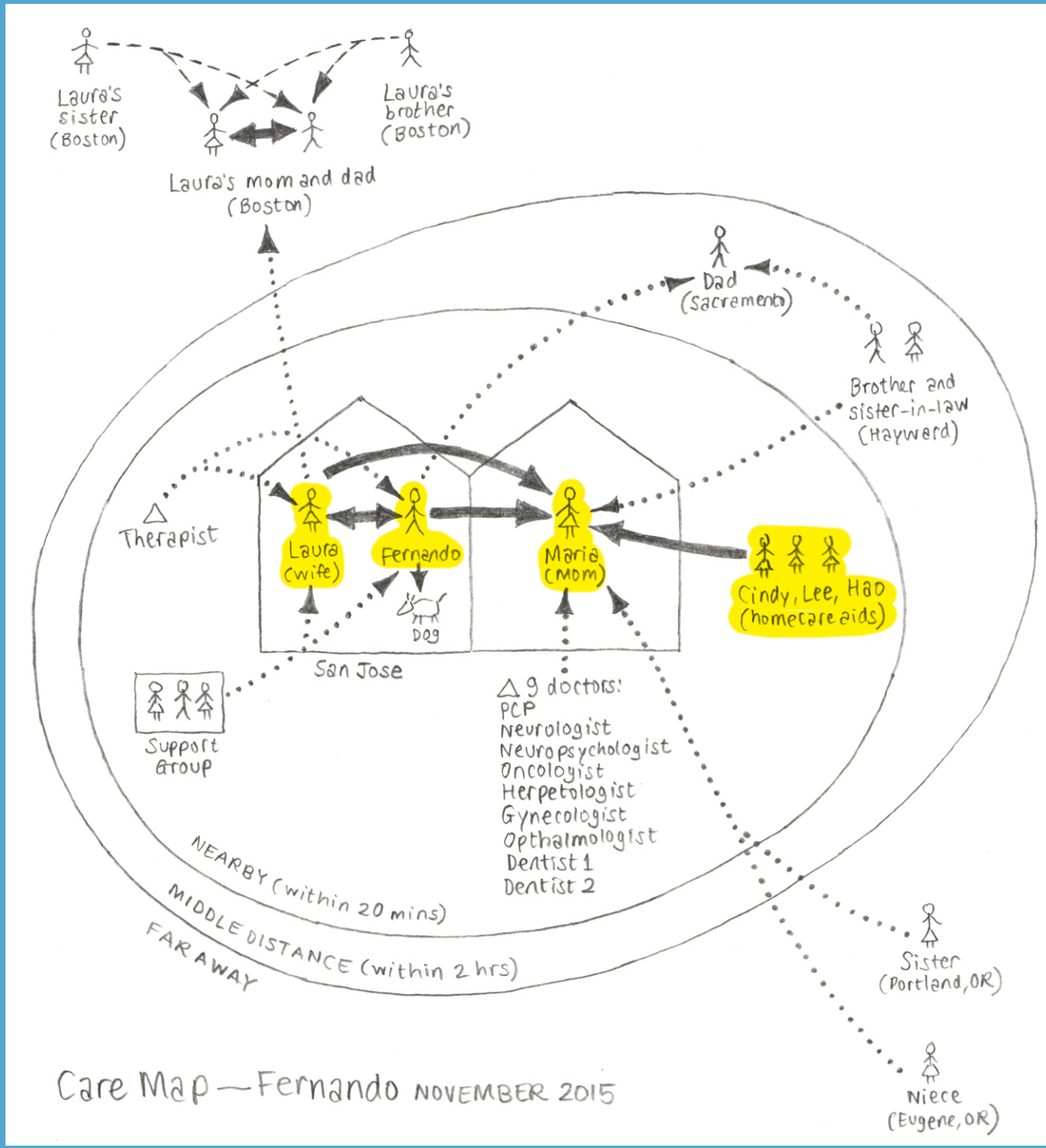
Dyad of “caregiver” and “care-recipient” too simplistic

- Multiple caregivers and multiple care-recipients
- People can be caregivers and care-recipients simultaneously
- 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


Laura's sister (Boston)
Laura's brother (Boston)
Laura's mom and dad (Boston)
Dad (Sacramento)
Brother and sister-in-law (Hayward)
Therapist
Laura (wife)
Fernando
Dog
Maria (Mom)
Cindy, Lee, HAD (homecare aids)
San Jose
Support Group
9 doctors:
PCP
Neurologist
Neuropsychologist
Oncologist
Herpetologist
Gynecologist
Opthalmologist
Dentist 1
Dentist 2
NEARBY (within 20 mins)
MIDDLE DISTANCE (within 2 hrs)
FAR AWAY
Sister (Portland, OR)
Niece (Eugene, OR)
Care Map — Fernando NOVEMBER 2015

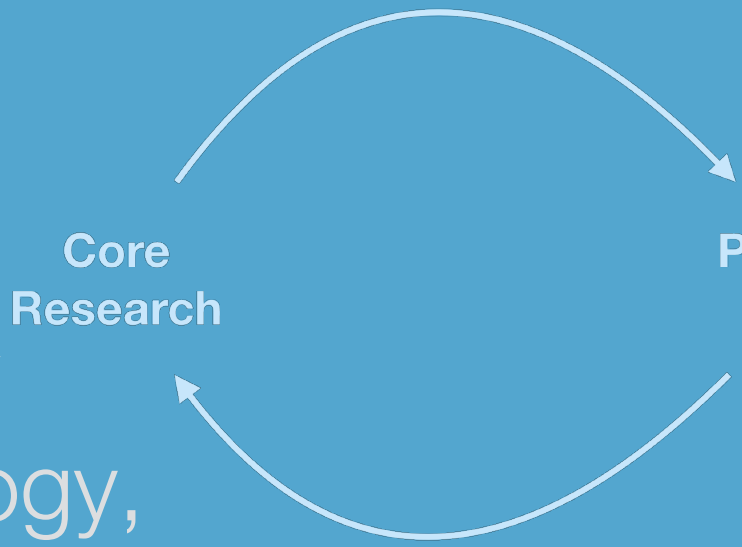
SANTA BARBARA
FOUNDATION

Community-based Action-Research

Pioneering research, combining ethnography and technology, in close collaboration with communities

Community-based Action-Research

Pioneering research, combining ethnography and technology, in close collaboration with communities



Practical Tools

Developing practical tools for self-discovery and community awareness

Thank You!

@atlasofcare
www.atlasofcaregiving.com
Rajiv Mehta | rajiv@atlasofcaregiving.com