Kathleen Kelly, MPA

kkelly@caregiver.org

415.434.3388
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
- FCA CareJourney information and login access
- Online Learning Center information and access
Getting Started

CARE REVIEW

“Intake”

Family Caregiver

- Instant info loading to personal dashboard
- Registration for online classes
- Can request call to FCA Resource Specialist

Info sent via email/packet mail

FCA

Good to go, but can always return

FCA service region caregivers may go on for fuller assessment and interventions

www.caregiver.org
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
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

© 2016 Family Caregiver Alliance.
Questions Include:

- Demographics
- referral source
- years caregiving
- living with care recipient
Questions Include:
- living situation/demo
- medical conditions
- eligibility Medicaid/VA
- living with care recipient
Questions Include:

- common caregiving scenarios, questions
- key risk factors for caregivers
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.
Intensive Services

CARE EVALUATION

“Assessment”

FCA

Conducted by phone or in-home

ACTION PLAN

Always with FCA staff by phone or in-person

Conducted online
- Expanded personal dashboard
- My Resources
- Services links
- Online training
- Peer support

In person/community

Online/On demand

www.caregiver.org
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 your 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 - Let's 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
Questions Include:

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

### 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?

<table>
<thead>
<tr>
<th>Activity</th>
<th>Does by self/Needs no help</th>
<th>Needs reminders/A little help</th>
<th>Needs help most of the time</th>
<th>Needs help all the time/Unable to do activity</th>
<th>Do you need more information about this activity?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating (cutting food, buttering bread)</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
<tr>
<td>Bathing/showering (washing, getting dressed)</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
</tbody>
</table>
Questions Include:
- health insurance (cgr and care recipient)
- health conditions (cgr and care recipient)
- legal planning completed
- sources of paid and unpaid help
Questions Include:

- healthcare utilization (cgr and care recipient)
- stress
- depression
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
From Claire Roberts, 3/15/16 2:56pm
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 Inglis, LCSW, FCA Resource Specialist, 3/14/16 2:40pm
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...
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
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 IIE 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
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
Measures Team:
Benjamin Rose Institute on Aging
  Carol J. Whitlatch, PhD
  Sarah Szabo
  Silva Orsulic-Jeras

IT Development Team:
Quality Process
  Brad Silen and staff

National Advisors:
David Bass, PhD, Margaret Blenkner Research Institute
Donna Benton, PhD, University of Southern California, LA CRC
Michael Costa, Costa and Associates
Lynn Friss Feinberg, MSW, AARP Public Policy Institute
Robyn Golden, MA, College of Nursing, Rush Medical Center
David A. Lindeman, PhD, CITRIS, University of California
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Kate Wilbur, Ph.D., USC Andrus School of Gerontology

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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:**

- [facebook.com/FamilyCaregiverAlliance](http://facebook.com/FamilyCaregiverAlliance)
- [twitter.com/CaregiverAlly](http://twitter.com/CaregiverAlly)
- [linkedin.com/company/family-caregiver-alliance](http://linkedin.com/company/family-caregiver-alliance)
- [google.com/+CAREGIVERdotORG](http://google.com/+CAREGIVERdotORG)
- [youtube.com/CAREGIVERdotORG](http://youtube.com/CAREGIVERdotORG)
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

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

Developing practical tools for self-discovery and community awareness

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
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
Gabrielle — motion & sound

Motion data

Sound data

midnight
1:40 am
3:20 am
4:00 am
4:30 am
6:00 am

midnight
1:40 am
6:00 am
Nadine — care map

Near
Less than 20 minutes away

Larry (teens)
Nadine's son

Jerry (50s)
Nadine's husband

Friend 1

Karl (teens)
Nadine's son
Type-1 diabetes

Nadine (50s)

Nadine's home

Neighbors

Friend 2

Online community

Support groups

Middle
Between 20 minutes and 2 hours away

Endocrinologist

Far
More than 2 hours away

Nadine's parents, siblings
and other family
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

atlasisoffamilycaregiving.com
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
Selected Insights
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

Rajiv Mehta
rajiv@atlasofcaregiving.com
650.823.3274