



The Advocate

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We believe there is an **opportunity** to provide family caregivers with **care management tools** that **empower** them to ensure the highest **quality of life** possible for both the **care recipients** and the **caregivers** themselves.

What is the need?

- **Problem** » The healthcare system is complex, specialized, and overburdened — causing fragmented and poor care and communication between and among healthcare providers, care recipients, and caregivers.
- **Effect** » Navigating the healthcare system is challenging. There are unwritten rules and unknown rights. It is time and administratively intensive. Providers may communicate poorly, especially given medical jargon or time constraints. Documentation of the care trajectory is poorly accessible. Patients are viewed as their diagnoses and not holistically, especially by specialists and within a system designed to treat one condition at a time.
- **Objective Outcomes** » Care recipients may experience poor health outcomes from unnecessary medical interventions, overmedication, medical error [1]. As for family caregivers, 17-35% view their health as fair to poor [2].
- **Subjective Outcomes** » Care recipients and their caregivers often experience disempowerment and confusion. Older adults suffer pervasive ageism and may feel invisible. It can be intimidating with the patient-provider power structure.

Who does this impact?

- There are ~35M family caregivers for a 50+ yo in America. [3]
- Women, racial minorities, and low-income family caregivers are disproportionately burdened.
 - 60% are women.
 - <18% is White. Hispanics, Asian Americans, and African Americans comprise ~20% each.
 - Of caregivers with <\$30k in household income, 30% report fair or poor health vs. 7% of caregivers with >\$100k [4].
- 2 of 3 older Americans have multiple chronic conditions. Treatment for this population accounts for 66% of the country's healthcare budget [5].
- Older adults who could particularly benefit from advocates include those with cognitive and/or physical impairments, and those who don't speak English well.

What's their experience?

CR Interaction with Healthcare

- “Your life is surrounded by appointments”
- “Blind trust when it comes to doctors”
- Numerous stories of malpractice

CR Need for Advocate

- “They're the patient and they're non-existent.”
- “They tend to talk to me [the caregiver] or the aide; they assume that 93 means senile.”
- “They don't pay as much attention unless there's somebody from the outside.”

CG Interaction with Healthcare

- “You don't know what's going on unless you get their mobile number and you hound them”
- “You had to be educated, forceful. It shouldn't be that way.”

Job of Advocate

- “I make sure the doctor knows her”
- “Ask 50 million questions.”
- “Play tape recorder.”
- “I would be the case manager.”

How is it addressed today?

- **Family Caregivers** » Family caregivers often undertake the responsibilities of advocating for care recipients navigating the healthcare system themselves. They are often given minimal support or education, resulting in ineffective or inefficient outcomes.
- **Human Resources** » Hospitalists, care case managers, social workers and ombudsmen. They often have limited resources (time, training, funding) to provide individual, quality, holistic care. Private patient navigators, geriatric care managers, certified senior advisors and professional health advocates charge \$50-\$450/hour [6].
- **Other Resources** » Mobile calendar apps, physical notebooks, and human memory are used as tools but may not be collaborative, integrated with existing EMRs, or accessible via the cloud. There are also checklists and other resources but they are typically fragmented and not widely adopted.

How might a new solution help?

Pre-Appointment (Actions for CG)	During Appointment (Actions for CG)	Post-Appointment (Actions for CG)	Subjective Outcomes	Objective Outcomes
Schedule appointment	Communicate or advocate for CR's wants and needs	Schedule follow-ups	CG + CR: Feel confident about the care plan	CG: Decrease stress and emotional toll
Arrange transportation of CR	Understand care plan and why it is the best given alternatives	Ensure compliance with recommendations (e.g., diet)	CG + CR: Feel confident to make informed decisions	CG: Increase efficiency and time savings
Prepare necessary documents (e.g., medical, financial, legal)	Understand all options and consequences to make informed decisions	Update care plan and documents for CR; communicate to future providers	CG + CR: Not feel intimidated	CG: Increase efficacy as advocate
Understand care recipient's wants and needs	Hold medical professionals accountable		CG: Feel empowered as a valued, respected member of the care team	CG: Improve relationship with CR
Prepare questions and concerns	Sound the bell given potential for adverse health consequences		CR: Not feel minimized in ability; feel acknowledged	CR: Improve quality of life
Arrange personal logistics (e.g., childcare, time off work, transportation)	Document care trajectory including diagnoses, treatments, alternatives, options			CR: Decrease medical error or neglect

Thank you!

References

[1] Makary, M.A. "Medical error—the third leading cause of death in the US." *The British Medical Journal*. 03 May 2016. <http://www.bmj.com/content/353/bmj.i2139>.

[2] [4] Family Caregiver Alliance. "Caregiver Statistics: Health, Technology, and Caregiving Resources." 2016.
<https://www.caregiver.org/caregiver-statistics-health-technology-and-caregiving-resources>.

[3] The National Alliance for Caregiving (NAC) and the AARP Public Policy Institute. "Caregiving in the U.S." 2015.
<http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>.

[5] Centers for Disease Control and Prevention. "The State of Aging and Health in America 2013."
<https://www.cdc.gov/aging/pdf/State-Aging-Health-in-America-2013.pdf>.

[6] Gustke, Constance. "Patient Advocates Help Navigate Health Care." *The New York Times*. 19 August 2016.
<https://www.nytimes.com/2016/08/20/business/patient-advocates-help-navigate-health-care.html>.