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## Dementia Caregiving: Returning to the Village

Posted by John A. Hartford Foundation on March 12, 2015



The Amjad Family "village" in 2014.

At the age of 4, Halima Amjad was already telling people she wanted to be a doctor. And not just any doctor.

"I used to say that I want to be Mommy and Daddy's doctor," says Amjad, MD, MPH, a clinical and research fellow in geriatric medicine at Johns Hopkins University School of Medicine and winner of the **2014-15 John A. Hartford Foundation Story Contest** (<http://www.jhartfound.org/get-involved/caregiving-story-contest/>). "I don't think I actually meant anything by that, but it ultimately ended up coming true that I chose geriatrics as my parents were getting older."

**[Read our previous post on this year's story contest: Prize Winners in 'Better Caregiving, Better Lives' Story Contest Answer the Challenge \(http://www.jhartfound.org/blog/prize-winners-in-better-caregiving-better-lives-story-contest-answer-the-challenge/\)](http://www.jhartfound.org/blog/prize-winners-in-better-caregiving-better-lives-story-contest-answer-the-challenge/)**

As Dr. Amjad relates in her prize-winning story below, her father—a dentist who came to the United States from Pakistan in the 1970s and built a successful practice in Philadelphia—has frontotemporal dementia (**FTD** (<http://www.theaftd.org/>)), a form of early-onset dementia. The disease thrust his wife and three adult children into the role of caregivers, and that experience was a factor in turning Dr. Amjad's childhood declaration into a prediction as she progressed through her medical training.

"Certainly, I don't think my dad's condition was the only factor in choosing geriatric medicine. But I think once I was starting my fellowship and focusing both my clinical and research interests, his condition certainly had a role," Dr. Amjad says. "That's why for my clinical work, I'm now seeing patients in our memory clinic and all my research activities revolve around caring for people with dementia."

Dr. Amjad feels that her family's experiences caring for their father has provided her with an understanding of the importance of caregivers in dementia treatment that it might have taken years of practice to gain.

"I think with a lot of geriatric dementia patients, the caregiver is just as important as—and sometimes even more important than—the patient who is on your schedule," she says. "I don't know if I would have fully appreciated that without living it myself."

Dr. Amjad says she considers her family fortunate that they can afford private caregiving to help with their father. And she says she hopes her story helps others better understand what the lives of families caring for a loved one with dementia are like, as well as the need for increased support services. She hopes it also helps raise awareness about early-onset dementia, which was heartbreakingly portrayed by this year's Oscar-winning actress Julianne Moore in the film, **Still Alice** (<http://sonyclassics.com/stillalice/>).

"We face the same struggles as those with later onset dementia (such as difficulty paying for necessary support services) but there are unique challenges, including loss of income as the person with dementia is no longer able to work and the primary caregiver either struggles with juggling a paying job and caregiving or has to give one of those duties up," Dr. Amjad says. "Physicians, day cares, and living facilities are often not equipped to care for this unique population."

"I hope my story brings to light the need to create villages and support systems for patients and caregivers to survive and maybe even thrive—and the need for policies that foster the creation, support, and maintenance of these villages. Despite the ongoing struggles, we have been lucky in our journey so far compared to so many others, and I wish others could access even just some of the same resources."

This is the first in a series of posts on our "Better Caregiving, Better Lives" story contest. Our other two prize winners will be featured in the coming weeks.

### **Caring for Dementia: Returning to the Village**

**By Halima Amjad, MD, MPH**



Halima Amjad, MD, MPH

Dr. Amjad wanders into the kitchen where his exhausted wife of 37 years is preparing dinner. When she turns to the stove, he snatches a piece of raw chicken and shoves it into his mouth. She yells and runs toward him, ignoring the pain in her arthritis-filled knee as she yanks the chicken out of his mouth. He laughs loudly and exclaims "Who is this!" in Punjabi, one of two phrases he can still muster in his childhood tongue, before wandering back to the couch. Now 65, Dr. Amjad was living the American dream until the dream fizzled into dementia.

My father, a retired dentist, was diagnosed with frontotemporal dementia (FTD) when he was 60. He first had trouble speaking, and later became gruff, indifferent, and easily frustrated before his disease progressed to difficulty with simple activities, extreme restlessness, inappropriate laughter, and agitation. As a geriatrician-in-training, I have seen many cases of caregiving and too many cases of dementia. But my father's is the only story of caregiving and dementia I have experienced so completely—from the perspective of the physician making the diagnosis, the patient who first sensed something was wrong, the wife whose life revolves around a fading husband, and the children who struggle to provide support while building their own lives.

What I've learned from my father, who forged his way from a rural Pakistani village named Bismillahpur to a comfortable American life, is that caring for a person with dementia takes a village. As my father becomes more childlike, with giggles, stubborn refusals, and diapers, he has sadly come full circle.



Halima Amjad's parents at Acadia National Park in Maine in 2012, on their last trip together.

My mother is the heroic village leader, the primary caregiver robbed of her golden years. Golden now are the moments where my father suddenly understands that she has a migraine and stops pulling the blanket off her to get her up. Despite the pain, fatigue, frustration, and heartbreak, she remains steadfast and strong. She has managed to harness support systems and build an infrastructure that keeps the village standing.

The heart of the village is in the home, in the family that rallies around its patriarch. We each do what we can. We daughters provide emotional support, with daily phone calls and shared tears with mom and kisses and laughs with dad. My brother who lives minutes away provides technical support, serving as dad's personal groomer and on-call emergency service when mom is faced with the dreaded combination of diarrhea and adult diapers that don't hold as much as they should. Aunts, uncles, and cousins who owe their American dream to my father's generosity also join the effort. They tend to the yard, take my dad out for car rides, and even help him use the bathroom.

A thriving village, however, is more than one home or family. A key structure in this village is the local branch of Senior Helpers, through which paid companions come to our home several times a week. We were initially apprehensive, uncertain how dad would react, but certain mom needed a break. My dad jumped at the chance for outings, however, and strangers quickly became family. Linda, his first caregiver, understands what he wants when he gestures or says, "Who is this?" Linda cries with my mom when they notice declines and emphasizes the kindness and humor that still shines in my dad's personality. She and George both laugh rather than scold when he pushes them in excitement. While money can buy respite, there is no price tag for genuine concern, support, and encouragement.

The challenges in caring for my father are endless, from the financial burden of forced retirement and care needs to the physical challenges of bathing, toileting, and sometimes chasing him. But nothing is more difficult than coping with dementia itself and caring for a husband and father who is a shell of the man we loved. In this struggle, we discovered a less visible infrastructure in our village, the solid foundation laid by other caregivers and families. I remember vividly the first caregiver event hosted by the Association for Frontotemporal Degeneration (**AFTD** (<http://www.theaftd.org/>)) that my mother and I attended after my father was diagnosed. Just walking in and seeing all the other families there, I had to swallow the growing lump in my throat. As a speaker acted out how individuals with FTD understand and react to others, my mom could not swallow her tears. We were watching replays of my dad.

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In the emotional roller coaster that followed, my mother joined a local caregiver support group through the AFTD that meets monthly. Re-energized, she would regale us with the stories others had shared. As my father's needs increased, it became difficult to get to meetings. So I looked online. I found Facebook groups that were serving as online support groups for dementia caregivers and made my mom a Facebook account to join these groups. We have both found ourselves active members in FTD caregiver groups, sometimes posting or commenting, but often simply reading, empathizing, and realizing that we are not alone in this nightmare. From these groups, we've learned ways to deal with wandering outside, with an inexpensive homemade barricade of a removable chair and alerting bell attached to the doorknob. We've learned that others also deal with incontinence disasters or "poop-tastrophes" as one person called it. And we've learned that other families are struggling with the same emotions that we are.

Most others would find it crazy to feel jealous of people dealing with other illnesses that drain strength and even life but leave the mind intact. Only families juggling dementia understand the pain of losing a loved one twice, once in mind and later in body. And only these friends understand the emotionally and physically exhausting experience of caring for someone who cannot appreciate you or love you back in the same way.

Compared to a life with dementia in Bismillahpur, my father is still living the American dream in the village my mother has built here. He seems happy, enjoying his grandchildren, desserts, drives, and family photos. For the most part, we keep him from swallowing raw meat and other inedible items. When a new crisis or challenge arises, we tap into different members and networks in the village. As mom recovers from knee replacement surgery, Linda and George come more frequently. When dad developed new jerking body movements, Facebook support group members had seen this problem arise in FTD, and our physician who prescribed medication to address it agreed with their input.

Every dementia story is unique, but it is clear that "It takes a village" applies to more than children. Caregiving in dementia means returning to the village. The key is to build one.

Halima Amjad, MD, MPH, is a clinical and research fellow in geriatric medicine at the Johns Hopkins University School of Medicine with a focus on improving care for older adults with dementia. Dr. Amjad did her pre-med studies at Lehigh University and graduated from Drexel University College of Medicine. She did her internal medicine residency at Yale University.

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## 2 thoughts on Dementia Caregiving: Returning to the Village

Incredible and wish you and your wonderful family our best wishes .

Anjum Vohra on March 13, 2015 at 1:58 pm

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