

Patient and Care Partner Reflections

WHITE PAPER

Elevating Experience for Those Living with Dementia

Every individual sees the world through their own lens. In healthcare, the perspectives of patients and families are often different from those who deliver care. Anywhere you see the “eyeglass” icon, enjoy a companion resource written through the lens of patients and families.

INTENTION

The intention of reflecting on this white paper through the lens of patients and families is to support patients, families and PFAs by providing a more relatable entry point for The Beryl Institute’s resources. This accessibility through a peer voice enables patients, families and PFAs to be more effective and engaged members of the PX Community.



Each of these reflections fits within the Experience Framework. This reflection falls under the following Strategic Lens:

PATIENT, FAMILY & COMMUNITY ENGAGEMENT

The “Why”

Central to any experience effort are the voices of, contributions from and partnerships with those receiving care and the community served.

The “Impact”

When the experience of patients and families are included in all of the organizations’ processes and executive leadership strategies, patients and families feel respected and valued as both integral part of their healthcare team and change agents for the organization.

ABOUT THE AUTHOR: Rosie Bartel



I am a wife, mother, grandmother and an educator. In August of 2009, I underwent a total right knee replacement that developed into a MRSA staph infection. This healthcare acquired infection has led to 55 surgeries, over 200 hospitalizations, 100 blood transfusions, a right leg amputation six inches above the knee, and, eventually, a total hip amputation with the removal of part of her pelvic bone. I have also experienced sepsis and septic shock twelve times.

As I continue to battle this infection in my body, I am driven to share my story of survival. Everyday, I use the story of my journey to advise or advocate for others. I believe in helping patients and caregivers find their voice. As an educator, I used stories to teach children and adults. Today, I use my own story to co-design with medical professionals and researchers and to advise and advocate for patients and their caregivers.

AUTHOR PERSPECTIVE

Because I cared for my mother, who had Alzheimer's and vascular dementia, I could relate to this white paper. When my father died suddenly, I realized that he had been covering my mother's health issues. I knew something was not right because she cried about being lonely everyday. I lived nine hours away but I knew I had to move home because she needed me. If she had been diagnosed with dementia, she was in complete denial. She would suggest others must have dementia because they didn't remember something.

My husband and I built a duplex with us living on one side and moved her into the other side. It was our way of helping her without her realizing her ability to care for herself was changing. This system worked for eight years until she fell. Even though there were no injuries, she was sure she could not walk. It was at that point I convinced her primary care provider to do a head CT Scan because she had hit her head. What the CT Scan showed was that she had several small strokes, an Alzheimer's indication and also signs of vascular dementia. He said she had hid it well over the years and he felt she was spiraling downward due to the fall.

I couldn't keep her at home because she refused to help herself, so I had to look at a long-term care facility. Because we live in a rural area there was only a few places to choose from so I picked the one closest to my home and it turned out to be the best decision for her care. They were a small, local facility that really catered to the wishes of the patients. They gave her four years of happiness in her new home. She might have thought I was her mother, but she never thought she was in a long-term

care facility because she thought it was her "home" with lots of visitors. This facility lived in the spirit of this white paper.

GENERAL SUMMARY

This white paper focuses on dementia as an experience instead of it being an illness. The patient with dementia doesn't need to lose their voice when they are diagnosed; they need to feel they are being listened to even if it is in a different way. Dementia patients have the same rights as every other patient.

When a dementia patient is hospitalized or placed in assisted living or long-term care, everyone needs to treat them as a patient with a disease. In order to treat this patient successfully, it might be necessary to find new ways to provide care. For example, this white paper advocates not putting dementia patients in isolated areas for their safety. In many cases, people with dementia do better when they are to spend time with other residents, patients and/or caregivers.

Our society might have to look at new ways to treat this disease. This will come with new staffing requirements, new schedules for patients and new ways of reimbursement for treatments. While some medication can help with dementia, it may be more important to understand how the patient's experiences are changing and, based on that, develop a plan for treatment with the patient and the patient's care partner.

So, what can we do to better understand a person with dementia? Observe, listen and learn from them. Recognize their needs by spending time with them. You might eat meals with them, sleepover or just be with them. Their behaviors will tell you volumes even if they aren't speaking. Listen and look for their physical clues when they are speaking to you. Sometimes they don't have words but they are still speaking to you.

KEY POINTS TO CONSIDER AS A PATIENT OR FAMILY CAREGIVER

Concepts, ideas or practices worth sharing with your organizations as a PFA:

Dementia has a huge impact on families so consider family support programs

Elevate the experience of people living with dementia by capturing their lived experience

When improving dementia care, remember to shift from person-centered care to person-directed care

Improvement for dementia care requires extinguishing any stigma about those living with dementia

Advocate for reimbursement models that include at-home care

Advocate for careful communication when delivering a diagnosis to those with dementia

FINAL THOUGHTS

The patient care partner has a key role in the care of a dementia patient. They understand the patient's fears, anger and suspensions. In order to truly understand what is happening to your love one, you need to understand the disease. Many times, a care partner feels isolated with nowhere to turn for help.

Care partners are encouraged to find support groups that focus on helping to understand what you are dealing with right now and what to expect in the future. These support groups might be online because the care partner can't take the time away from patient and their families. Flexibility is key when it comes to providing support for the care partner.

Remember, as a care partner, you are the dementia patient's advocate and they really need your help in order to manage this disease. Exploring this white paper can support caregivers in understanding the more modern ways of approaching the treatment and engagement of a person with dementia. Hopefully, this information will be empowering. This white paper also gives PFAs a framework when working on projects or programs that impact patients with dementia and their families. By using this white paper as a source of support for your feedback, it can help to drive home your ideas and comments.