

# Patient and Care Partner Reflections

## WHITE PAPER

*Becoming the Best Place To Be: Elevating the Human Experience in Senior Living Communities*



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(s):

## 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 is included in all of an organization’s processes and executive leadership strategies, patients and families feel respected and valued as both an integral part of their healthcare team and change agents for the organization.

## ABOUT THE AUTHOR: Rosie Bartel



I am a widow, 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 58 surgeries, over 200 hospitalizations, 100 blood transfusions, a right leg amputation six inches above the knee and a total hip amputation with the removal of part of the 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. Every day, I use the story of my healthcare journey to advise or advocate for others. I believe in helping patients and caregivers find their voice. Previously 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'S PERSPECTIVE

My reflection on this paper is from my perspective as an older adult living with disabilities. I live in a disability-accessible apartment that I am able to navigate in my wheelchair without assistance, and I find this environment makes me feel independent, happy, and safe. These are the same elements of experience that are most important to senior living residents, as presented in this paper.

My personal story with senior living is connected to my mother. I was my mother's advocate as she struggled with Alzheimer's Disease. At first, she lived in a duplex that was attached to the home where my late husband, David, and I lived. When she had a fall and lost her ability to walk, I made the decision to move her to a nursing home for her safety; she needed more around-the-clock care than I was able to provide. I spent a lot of time with my mother at the nursing home, and because of my personal journey with a healthcare-acquired infection, I became involved in doing presentations and workshops for long-term care facilities about how to prevent infections among their residents. One of the most popular presentations was on hand hygiene, because this is one of the most important strategies for infection prevention in healthcare settings, especially in long-term care facilities.

In the early stages of COVID-19, I created a roadmap for senior living communities on how to involve residents in outcomes-based research. This roadmap gives residents a voice in research that is being conducted in senior living settings, contributing to them feeling valued and appreciated as individuals and as human beings. This element of experience – having a sense of control over outcomes within the place you call home – was also reflected as important to the residents interviewed for this paper.

## GENERAL SUMMARY

In collaboration with Pioneer Network, The Beryl Institute examines human experience in senior living communities through the eyes of those who live there as well as professionals in the field. The paper reflects the voices of 12 residents from four senior living environments across the United States, including independent living, assisted living and skilled nursing communities. Thirty-three professionals in the field offer their perspectives across a diverse spectrum of topics on senior living. Through dedicated focus groups with residents and professionals based on each of the eight strategic lenses, data was collected and shared on how to create the best resident experiences.

The paper explores what is important to residents, which is to feel respected, validated and empowered to live a meaningful life of their choice. It also offers reflections from experts on the importance of experience in this setting and actions to ensure the voices of residents are part of every conversation.

### Key Points to Consider as a Patient or Family Caregiver

The key takeaways focused on how to elevate the human experience for residents in any type of senior living community so they feel safe, protected and valued as a person. The focus on human experience in senior living communities ensures residents are at the center of the world in which they live and are afforded the opportunity to direct their own lives.

Residents and care partners can and should be engaged in improvements in senior living communities because they offer unique and valuable perspectives on their experiences. If COVID-19 taught us anything about senior living communities, it was that the voice of the resident and their care partners are critical to the health, safety and happiness of the residents and their families.

Here are some ways individuals living in senior living communities can increase engagement of residents, care partners and families:

- Ask your senior living community to establish a resident and family council. If one has already been established, inquire about how to join. For guidance on how to build a RFAC (Resident and Family Advisory Council), use resources from The Beryl Institute on building a PFAC. Here is one to get you started:
  - <https://www.theberylinstitute.org/page/WEBPXPLANLAUNCHPFAC>
- Make sure your senior living community offers multiple ways to provide feedback on quality and experience
- Advocate for activities and resident engagement opportunities that address the diversity of the community
- Use technology to connect with other residents, care partners, families and religious or other communities that “feed the soul.” COVID-19 made this especially important.

## FINAL THOUGHTS

Every resident's voice deserves to be heard and their choices honored. Many thanks to The Beryl Institute and Pioneer Network for recognizing the need and hearing the call to learn about the resident experience in senior living. It is hoped that this paper moves forward efforts to create a culture of aging where all seniors are respected and empowered to live their lives how and where they choose, no matter their age or abilities.