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Engaging Aging

A View from the Other Side

By Sister Ann Margaret O’Hara, SP

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On July 7, 2017, I experienced an event that changed my entire life. In the midst of heart surgery for mitral valve repair, I had a stroke. It was completely unexpected by me, leaving me in a situation I never imagined and for which I was completely unprepared. Since then, I have faced many challenges, been through countless new experiences, had astonishing moments of care and compassion, and have come to new insights and awareness. I am sharing aspects of my story now in the hope that it can help others, including persons facing unexpected health care challenges and those serving in health care. I hope that my story will illumine some aspects and challenges of health care that, if modified slightly, might help mitigate the trauma to those receiving care and advance the goal of well-being.

“In the midst of all our storms, however, we have the consolation of seeing the religious spirit become solid... and that is not a little thing.”

Saint Mother Theodore Guerin

Let me begin by telling you something of my life prior to July 7, 2017. From early in my life I have known myself to be independent, capable, active, able to think through situations and challenges and to organize a plan of action. I was an “in-charge” kind of person who knew how to fix things and how to get systems to work well.

In the 1980s, I worked for the National Association of Church Personnel Administrators (NACPA). As part of my ministry there, I assessed mother-

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house organizations and congregations' ministries. This experience heightened my awareness of the many aspects of quality care, the importance of having strong cognitive, occupational, and physical support therapies in place, and the importance of patient centered care.

Following this time of ministry with NACPA, I was elected to the General level of administration in my Congregation. During the 15 years I served in leadership, our health care facility was built, licensed and certified. I recall vividly how we rooted our decisions in our charism. One of the original ministries of the congregation was the care of the sick poor in their homes. This new facility would be an extension of that original mission. The whole purpose of building the health care facility was to provide wholistic health care to those most in need.

Following Congregational leadership, I moved to a somewhat slower pace, engaging in a range of ministries within my own Congregation as well as serving as a consultant to the National Religious Retirement Office (NRRO).

Crossing Over to the Other Side

All of these life experiences and events helped to create the person I had become and the life I had come to know as my own. Then, in an instant, all that changed. In the weeks and months following the stroke, as my brain slowly healed and began putting the pieces back together, I felt like I had lost my life. I lost my residence, my ministry, my role in liturgical ministries, and the capacity to drive and to walk. I lost the life I had always known and now had a life I did not recognize. I was seeing life from a perspective I had never had before. I was getting a view from the other side. I had moved from being capable and independent to a dependence I had never known; from being a creator of health care facilities and structures to a recipient of their services; from being totally in

charge of my life to having all decisions made for me; from directing things to being directed to do things.

In this next section I want to use my experience of being on the receiving end of medical care to make some recommendations that may ease another's transition into health care, as well as help medical service professionals better attend to the needs of those whom they serve.

The Receiving End of Care

I want to begin by acknowledging the complexity of the many realities and systems that intersect within the health care environment and the way in which my own personal struggles for healing, growth, and the deepening of my spiritual life intersected with those complexities. I am aware of and grateful for the strong care and support that I have received from my Congregation, our elected leadership, my family and friends, our clinical care coordinator and the many skilled professionals who work in our health care system. It seems important to note that I was being cared for in a five-star quality health care facility and that, even in the finest of facilities, the challenges of offering person-centered care are ever-present.

While I will be making observations about difficult situations and less than desirable responses, I make them not so much as complaints but as an attempt to articulate what the experience feels like from the perspective of the one receiving care. Although my examples are anecdotal and unique, it is my hope that they will contribute to fostering greater understanding both of the experience of receiving care and also some simple adjustments in practice and procedure that might ease the difficulty of situations.

From Independence to Dependence

One of the most difficult aspects of my experience was the sudden shift from independence

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to dependence. As one patient put it, “I feel like a child. They put me to bed, get me up, bathe, dress and change me.” Others become totally in charge of your life. While I, admittedly, needed assistance, I felt I had lost myself. I did not know myself as someone who was dependent.

As I reflect on this experience, I am aware that there is a real difference between the dependence of the child and the dependence of an adult who needs care. Initially, I was neither able to care for myself nor to think clearly to make decisions about the kind of care I wanted. I have no doubt that my struggle between independence and dependence contributed in some way to the difficulties I experienced.

As I slowly began to recover some of my cognitive and physical capacities, I experienced times that I was not included in decisions when I could have been. There seemed to be a presumption of my incapacity and it felt like incapacity was all that was seen. The most difficult times for me were when doctor’s orders were given without my knowledge and appointments made without checking my schedule. One example of such disregard for the patient’s input was shared by another resident. She was told that she had a doctor’s appointment the next day. Though she insisted she did not, the staff took her to the doctor’s office anyway only to discover that the patient had been correct. She did not have an appointment and the doctor was unable to see her. I find myself wondering what would have happened if, instead of presuming that the patient did not know what she was talking

about, the staff had followed up by making a call to confirm the appointment.

One particularly challenging moment for me came when my surgeon’s nurse called, three months after my surgery, to schedule a follow-up appointment. This triggered all the fear and anger I had experienced over the past months and I literally shook all over. This was followed a few months later by the need to have a procedure on my pacemaker. The recommended physician was my original surgeon, and though I knew intellectually that he was a fine surgeon, my previous experience left me too afraid to have him perform the surgery. Fortunately, our clinical care coordinator intervened, calling the surgeon, explaining my fear and the healing that I still needed. As a result, two local physicians were engaged to do the follow-up procedure. Being listened to and included in this decision made a huge difference for me. The procedure



Sr. Ann Margaret O'Hara (right) in a physical therapy session at Providence Health Care, Inc. She is assisted by Ms. Sarah Carson, OTR. (Photo used with permission of Sisters of Providence)

A View from the Other Side, continued



Sister Ann Margaret (right) with Ms. Sarah Carson, OTR. With regular therapy, Sister is progressing in her recovery from the stroke. (Photo used with permission of Sisters of Providence)

went well, and the experience was a large factor in my emotional healing. I finally realized that I no longer needed to carry the burden of fear and anger about my stroke.

What emerges for me as I reflect on the pull between independence and dependence, is the importance of including the patient as much as possible in decisions about her care and not presuming she is unable to participate. While it may seem unnecessary and inefficient to check the schedule of someone in the health care facility when making an appointment, or foolish to engage a new surgeon for a follow up procedure, the simple act of engaging the patient in these decisions greatly enhances the individual's sense of dignity and inclusion while promoting a greater sense of well-being.

Appropriate, Timely and Empathic Communication

There are numerous areas in the health care experience where appropriate, timely and empathic communication can make a huge difference in the patient's sense of dignity. Careful attention to training all personnel in these communication skills is essential. Taking the time for this kind of interaction can actually ease the demands placed on staff. Let me share some of the situations I experienced where a shift in communication might have made all the difference.

A difficult and unavoidable aspect of being on the receiving end of health care is the inevitable loss of privacy. One of the more alarming and disconcerting experiences of this came for me the first night I was in our Congregation's health care facility. Suddenly, at 2 a.m. the door to my room flew open. Someone came over to my bed with a flashlight and, without warning, put her hand down my pajamas to see if I was wet. I later learned that this was a common practice. However, in the moment, it was quite alarming. While many of the staff carry out tasks such as this with dignity and sensitivity, it is an area where some simple communication could have eased my sense of alarm. Had the aide only said, "I'm just going to check to make sure that you are not wet and uncomfortable," the situation would have felt quite different.

In the health care environment, the patient is in a position of needing assistance in ways she has never needed it before. When I first entered our facility, everyone said to me, "If you need assistance, just ring your call bell." However, the reality is that there are many and often unexpected demands on staff and it is not always possible to respond as quickly as the patient might need or desire. How these situations are handled and how the patient is communicated

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with can make an enormous difference in the patient experience.

One instance where my need for assistance was met with inappropriate or unhelpful communication occurred when I was first given a wheelchair for my use. Throughout the morning, as I tried to learn how to use the chair, I kept getting caught in the various wires and cords in the room. That afternoon, the certified nursing assistant (CNA) took me by the shoulder and pushed me in my wheelchair to the nurses' desk where she parked me saying, "You are going to stay right here for the afternoon. You are not going to ring the bell the way you did all morning." Needless to say, I felt scolded and punished like a small child who had been misbehaving and had been sent to the penance corner. In the moment, I was helpless to do anything about it. I wonder how the whole experience might have been different if someone had taken some time to show me how to maneuver the wheelchair without getting tangled in the wires.

Another experience that was particularly painful made me aware of the need for careful and thorough mission orientation for the entire staff. As is the practice in many health care facilities run by religious communities, our facility tries to make provisions for residents to attend liturgy in the motherhouse church. One day during the liturgy, I needed to leave the church to use the restroom. One of the ushers called the nurses' station to have an aide come to pick me up. The next day when I was in line to go to church for liturgy, the nurse told me that if I left church again to use the restroom, I would not be permitted to go to church for mass. I would have to watch it on closed circuit television. I was devastated. It seemed to me that they had no

Sr. Ann Margaret currently resides in independent living, Providence Hall (right), St. Mary-of-the-Woods, Indiana. (Photo courtesy of the Sisters of Providence)

sense of mission and had not been oriented to the important role that community worship plays in the sisters' lives. This is an example of the constant struggle to balance concerns such as staffing needs and cost containment with deep mission values.

Intersecting and Overlapping Systems

Some difficulties arise from the fact that there are overlapping systems in the health care environment along with conflicting demands on the time and services of the caretakers. For instance, CNAs arrive to care for healthcare needs but are also expected to set up and serve meals. They move seamlessly from shower room to dish room. They are the first responders in the health care environment, and they are my heroes. Demands on CNAs are significant and good training and orientation to mission are critical.

Best Practices

In this final section, I want to outline briefly some of the best practices pointed to in these



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experiences. I spoke earlier of the need for an orientation to health care for the patient. I also believe that orientation needs to take place with the staff, helping them to understand the confusion felt by the person who has become a patient. Communication is key. Even when a patient may not be able to understand, the simple effort to explain what's going on and what she can expect will make a difference. Given the vulnerability and often the cognitive limitations of the patient, these explanations need to be repeated over and over again.

It is crucial that patients be treated not as children, but as adults, albeit adults whose physical and/or cognitive functioning have been impaired. Including the patients in decisions which directly affect them is essential for their sense of dignity and respect.

In health care facilities sponsored by religious communities, orientation to mission is central. Staff needs assistance in understanding the religious values which are core to the individual's life and sense of meaning and well-being. These values are absolutely central to healing.

Final Thoughts on the Journey of Healing

As most healing journeys are, mine has been gradual and incremental. The assistance of various therapies, cognitive, occupational, physical, and psychological, have contributed to the healing that is taking place. As I began to understand what had happened to my brain and to learn new ways to care for myself physically, I was also able to face the emotional and psychological pain of my situation. Eventually, I began to rise each morning at 5:00. I would go to the dining room where it was quiet, and a nurse would bring me coffee. I would sit and write, asking myself a series of questions. What happened yesterday? What helped me heal? What caused me concern?

Holy Week of that year was particularly moving for me. I volunteered to lector at the liturgy on Holy Thursday and did so from my wheelchair. I was able to be of service in a meaningful way to my Community. I experienced the Paschal Mystery in a fuller way than I ever had. I felt that I was coming alive again.

The healing continues, and sharing these reflections is a part of that journey for me. I know that I was not an ideal patient. I struggled mightily with the change from self-care to being cared for. In fact, I fell three different times while trying to do something by myself when I really needed assistance. So, I am still in the process of learning about dependence and interdependence, but I am learning how to make friends with my own dependence.

I am aware that the reflections I have offered are unique to me. I offer them in the hope that they will be helpful to others who suddenly find themselves on the other side of independence and self-sufficiency. I also hope that some of these insights might be helpful to those who are in the position of being caretakers.

Finally, I am profoundly grateful for the caring professional staff, as well as friends and community members, who have been and who continue to be with me on this journey of healing. It has been a profound experience of the tangible presence of Providence in my life.

Note: This article was written by Sister Marie McCarthy SP, as told to her by Sister Ann Margaret O'Hara, SP. Currently, Sister Marie is serving as the Associate Director for Program Development for the Leadership Conference of Women Religious. Sister Marie shared that Sister Ann Margaret has returned to her room in the independent living facility of the Sisters of Providence. Sister Ann Margaret is learning to walk again, continuing her journey of physical and emotional healing and spiritual deepening.

From the Editor's Desk

Sister Sherryl White, CSJ, Ph.D.

For some of our readers, the current change in seasons signals the start of hurricane warnings and watches. But when blue skies and sunshine are the view from our windows, it's hard to imagine the terror of those facing torrential rains and winds in excess of 100 miles per hour.



We invite you to join in prayer for all those suffering from the devastation unfolding in the wake of Hurricane Dorian.

In this issue of *Engaging Aging*, we bring you a privileged look inside the struggles of another kind of personal tragedy. Our author, Sister Ann Margaret O'Hara, SP, takes us through a myriad of emotions and thoughts following a stroke that she experienced two years ago. Her story brings to mind the fragility of our lives and the vicissitudes that we can face from one moment to the next. You'll surely be touched by her courage and determination.

Yet, still more striking to me is Sister's continual desire to be of service to others. Her willingness to share the private details of her journey does not have the intention of eliciting sympathy or even compassion for herself. She leads us into the intimate specifics so that she can point a way toward improving care for others.

On the website for Sister Ann Margaret's Congregation, there is a posting of their mission statement. The closing lines read, "... we are passionate about our lives of service, education, prayer and advocacy. We dedicate ourselves to those who might otherwise be forgotten."

We think you'll agree this article gives that statement legs and challenges us to examine our ways of living the life we call religious.

Resources

Simmons, P. *Learning to Fall: The Blessings of an Imperfect Life*. Bantam Books, 2002.

Taylor, J.B. *My Stroke of Insight: A Brain Scientist's Personal Journey*. Penguin Books, 2009.

Don't miss our upcoming webinar!

November 12, 2019, 1:00 p.m. EST
Beads, Bells and Blessing:
Understanding Why the Mass and
Other Catholic Practices
are Essential

Sister Ginger Downey, OLVM, will address the many different Catholic practices that are important to men and women religious, and how staff can assist members in living their religious lives regardless of mental or physical circumstances.

Watch your email for access information!

Calendar 2019

September 19-22

- CMSWR National Assembly; St. Louis, MO

October 1-4

- RCRI National Conference; Dallas, TX

November 12

- Webinar: Beads, Bells and Blessings; Sister Ginger Downey, OLVM

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