

# On Not Being Invisible

## Life in a Continuing Care Retirement Community

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In the years that I have lived at Roland Park Place (RPP), a Continuing Care Retirement Community (CCRC) in Baltimore, Maryland, I have created hypotheses about how to adjust to a place like this and subsequently been forced by changes beyond my control to discard a good many of my initial theories. From the moment I learned that the average age of residents here was 86, I began to turn to my background in humanistic gerontology to help me adjust to a place that otherwise might have seemed inappropriate for a person who was only 71. After all, the only reason I had moved in was that my 78-year-old husband Bert needed to be here.

As a newcomer, I expected that there would be a period of adjustment followed by developing a sense of belonging. I knew that some changes in my life would then alter my feelings. After all, I assumed that I would have a big adjustment after he died. Besides that inevitability, in time I would grow older and become more infirm. At that point I might have to move into assisted living or health care, a change that would force me to make another adjustment. What I did not expect was that decisions brought about by a few managers at RPP might alter my sense of belonging much sooner than any physical decline.

## BACKGROUND

In order to understand my reactions, it helps to know how I got interested in humanistic gerontology in the first place and why family history encouraged us to select RPP (Wyatt-Brown, "Once").

From the beginning, my interest in gerontology has included a combination of personal and academic concerns. Initially, my experiences with older relatives drew me into the field. First, in 1967, Bert's mother had two strokes when she was living in Sewanee, Tennessee. She loved Sewanee, the home of the University of the South. Sewanee consisted of the college from which her sons

had graduated, as well as an Episcopal seminary, attended by her husband and Bert's two brothers. The town, however, had no medical facilities for people who needed health care. As a result, Bert's older brother, Charlie, decided to move their mother to Houston, Texas, where he was the rector of Palmer Memorial Church.

Charlie and his wife Sheppy placed his mother in a nursing home fairly near their house. They did not consult her; they simply distributed the furniture to the children that had been designated by Mrs. Wyatt-Brown in a previous will, got rid of the dogs, and sold her house. As a consequence of not being consulted, Bert's mother experienced some moments of depression. She missed her dogs and was horrified when a photograph we had sent her contained a picture of a piece of furniture that had belonged to her. I thought Bert's mother needed therapy to help her deal with the situation, but her doctor put her on medication and hoped for the best. She died nine years later in December 1976.

I learned from her unhappiness two related things. First, it can be dangerous to one's sense of autonomy to try to age in place when a decline in one's health makes that impossible. Second, if older people do not plan for the future, their children will be forced to make life-changing decisions for them. Still, when Mrs. Wyatt-Brown died in 1976, I was only 37, which is much too young to think about planning for the end of one's life.

Although I was too young to worry about my aging, David Van Tassel, Bert's colleague in the history department at Case Western Reserve University (known to us as Reserve), was aware of a dramatic increase in the number of older people in the United States. As a result, he thought it would be important to encourage humanities scholars to study gerontology. Therefore, in 1975, Van Tassel organized a local conference on Human Values and Aging. Because the meetings took place at Reserve, across the street from where I was teaching at the Cleveland Institute of Art, I was able to attend many of the presentations.

David invited scholars and authors who themselves were growing older and asked them to write about their thoughts on the subject of aging. Although some of them had not yet written about the topic, they gave impressive papers. The speakers included Leon Edel, the biographer of Henry James; Leslie Fiedler, a well-known literary critic; and Erik Erikson, a psychoanalyst who had written about stages of life but had not yet emphasized aging. I found the conference stimulating and informative. I was also fascinated by the work of a British historian, Peter Laslett, who reported that in earlier centuries, English rural families lived near each other, but the young members did not take their elders into their houses. Nonetheless, some years later he argued that the family members maintained close emotional ties despite living in separate dwellings. These essays were later published in Van Tassel's 1979 anthology *Aging, Death and the Completion of Being*.

Then in 1981, Van Tassel ran a month-long NEH summer institute at Reserve, called Old Age in History and Literature, hoping to attract faculty members in humanities to the field. My interest in aging had increased because I had discovered the late-life novels of Barbara Pym, a British novelist who had a 17-year hiatus in her publishing career. As a result, I welcomed the chance to become an NEH fellow for that month. Bert said that it was like sending me to day camp. I came back each night full of enthusiasm for the ideas to which I was being exposed.

Two years later, Bert and I moved to the University of Florida (UF). Thanks to Hal Stahmer, Bert's friend from his time at King's College, Cambridge, who had subsequently become a professor of religion at UF, I attended my first GSA conference in 1983 on crutches, having recently shattered my patella. I was allowed to create a poster rather than give a paper. Having no idea what that entailed, I took the paper I had written and posted all six pages in the spot I was assigned. There I met other scholars interested in the humanities and aging so we were able to organize a panel for the following year's meeting. In retrospect, I am grateful that people were helpful to me rather than contemptuous of my inexperience in the world of posters.

Upon reflection, however, I think it's really not surprising that I found gerontology to be a compatible subject. In many ways my childhood had prepared me for my midlife interest. I had grown up in a large extended family, so I had been exposed to several generations of aging people whose choices changed over time. My father's mother and his aunts had stayed in their house in Bolton Hill, Baltimore, using household help as their health declined. This grandmother was bedridden; she lived on the second floor while her sisters and Miss Sadie Poe lived in the rooms on the first floor. The large house allowed the women to create a community but to retire to privacy whenever they so desired. We visited Granny and her sisters every Sunday after church, and Dad's brothers and sisters visited frequently as well. I was too young to know if loneliness was a factor for these elderly women, but few of them complained about their lot. When Granny died at the age of 82 in 1949, hers was the first funeral that I had ever attended.

In the next generation, Dad's brothers and sisters made different choices. First, some moved into the Wyman Court Apartments on Beech Street, quite close to our house in Guilford. We liked to think that Dad's siblings took over the building. When their health declined or dementia set in, they moved to Keswick Multi-Care Center, a few blocks away. When my Uncle Fendall died at Keswick, his widow, Aunt Jane, moved into Broadmead, a CCRC in Cockeysville. She was given a scooter, which allowed her to go anywhere she wanted to in the building. She felt emancipated. Another family widow, Jo, moved into Blakehurst, a Towson retirement community, when her husband died. Both

women enjoyed life once they no longer had to take care of sometimes difficult husbands.

Mother's family was much smaller. Her mother, my great-aunt Virginia, and my Aunt Anne lived first on Preston Street in a second-floor apartment. Then in the 1950s, Aunt Anne inherited some money from her Uncle Ken and bought a house on Rugby Road in Guilford right around the corner from our house on Warrenton Road. As a result, I could hop over the neighbor's fence to visit them. I loved spending time with them because I was named for Grandmother and Aunt Anne, and they made a fuss over me.

Grandmother had a heart attack at the age of 76, and while she was not bedridden she didn't leave the house after that event. The family hired a companion, whose company Grandmother did not like. At the end of her life, only Mother and my uncle visited her; we children were told that company would upset her. Great-aunt Virginia had died much earlier, leaving behind a closetful of dresses that she had never worn, my mother reported scornfully. Aunt Anne had a stroke many years after Grandmother's death that made her housebound for ten years. My brother Luke and his wife, Nancy, were in charge of her when she was bedridden toward the end of her life.

As my parents aged, we discovered that they had different ideas about how to spend their declining years. My mother, like many other people, wanted to stay in her house. Many of their older friends had aged in place, and Mother had followed their stories very closely. She had never lived in a community growing up. Her father had died when she was in eleventh grade after years of being too ill to work. As a result of the drain on their finances, Mother left school without a diploma and never went to college, where dorm life might have prepared her for a community existence. My father, however, wanted to make sure that she would be taken care of after his death. He decided that they would move into RPP, which at that point was very new.

Therefore, in December 1986, my parents called a family meeting to announce that they would be moving into RPP in the fall of 1987. I'm assuming that Dad decided on that place because it was so close to the house where they had been living for about 50 years. Nonetheless, the move was traumatic. Mother wanted to keep an eye on every item when it was packed, which was of course impossible. Dad, on the other hand, was indifferent to most things once he found a good home for his books. Bert and I took many of them, an act that relieved his mind.

Once they moved in, Mother had a much more difficult time than Dad did. Besides lacking community experience, she had glaucoma, a detached retina that had not healed properly, and a cataract in the one good eye. Her doctors didn't want to remove her cataract, because if the operation was unsuccessful, she would be blind. What they didn't realize was how her inadequate vision was making it nearly impossible for her to adjust to life at RPP. Unlike many resi-

dents, Mother did not tell people that she couldn't see. As a result, she feared that she might fail to speak to a friend if she didn't recognize her when walking in the building.

To avoid being inadvertently rude, Mother spent a good deal of time in the apartment, except when a family member came to dinner. In contrast, Dad kept meeting people he hadn't seen since school days. He continued to be active in his law firm as a consultant and had dinner with many people at RPP. The ease with which he found dinner companions was not surprising. There are many more women than men in CCRCs, so new men are snapped up by observant women. My sister, Susan, and I would talk to the head nurse about Mother's isolation, but the nurse said that some people could not be helped. Sadly, my relatively well-adjusted father died in March 1988, whereas Mother lived alone in the apartment until she died in 1993.

## EARLY DAYS AT ROLAND PARK PLACE

What the complicated family history taught me was that one of the most difficult choices of later life can be deciding where to live. My guess is that when one is faced with the necessity of making a change, even gerontologists may not necessarily consult the current literature, especially if circumstances dictate a quick move. Fortunately, in 2015, Stephen Golant composed a comprehensive study of the possible places that an older person could select, *Aging in the Right Place*. He points out that it is almost impossible to avoid messages on television, on the Internet, in books about later life, and in newspapers that insist that the ideal is to age in place (63). In contrast, he discusses the advantages and problems that can emerge when people try to stay in their dwellings. Instead of selecting one kind of possible place, he covers as many alternatives as now exist. Each alternative has advantages and disadvantages, so Golant suggests which kind of place might appeal to different kinds of personalities. His book is comprehensive and helpful, but unfortunately it appeared too late for us to consult it.

As I wrote in the first essay in *The Big Move* ("A Wife's Life"), my account of my early life at RPP, Baltimore had the worst snowstorm in its history in 2010. We decided to move into RPP because it was in the city and the place we knew best. Initially the adjustment was not easy for me, but after a relatively short time both Bert and I felt at home. I had worried about how I would feel once Bert died, but by the time that happened I had made many friends and had also made a new life for myself largely centered around the Fitness Center. Moreover, residents and staff were extremely kind to me after his death, which made me glad that I had decided to stay at RPP. I thought that

my adjustment was complete until the time when my health would begin to deteriorate.

For several years, things continued to be relatively easy for me. Like many widows, I was very busy after Bert's death in November 2012. For one thing, he had completed a book, *A Warring Nation*, just before he died. It was up to me and my sister Susan, who had helped him before his death to answer questions posed by the editor, to see the book through to press. Luckily, Bert and Susan had worked hard to answer as many of the editor's questions as possible. Then, once Bert died, the number of unanswered questions was relatively small, and many friends helped in ways that I acknowledged in an addendum to the acknowledgments. The book was published by the University of Virginia Press early in 2014.

## **A MAJOR CHANGE AT ROLAND PARK PLACE**

In 2014, a change occurred that was a mixture of positive and negative. It had to do with Stewart and Valencio, who had been running the Fitness Center since we had moved in. As I said earlier, taking land and swimming classes at the Fitness Center of RPP and hiring Stewart and Valencio as personal trainers had given me a sense of belonging. Then on May 15, 2014, Stewart and Valencio won the Maryland Department of Aging's 7th Annual Governor's Leadership in Aging Awards. They invited me to attend the meeting because I was active in the Fitness Center. I was delighted by their recognition because both men were doing a fine job working with the residents.

That positive event was later overshadowed by a more complicated one. To our surprise, Stewart announced a career change. After many years at RPP, in 2014 he decided to start working for a degree as an assistant physical therapist. He cut back his hours at RPP dramatically but planned to continue to work part time until the demands of the program made it impossible for him to continue. He told his boss, one of the managers, that he probably would be leaving for good sometime in the middle of 2015.

In many ways Stewart's decision to further his education had been unexpected. Valencio had been working on a PhD in music education, and we all thought that when he completed his degree, he would leave RPP. Instead, he took over many of the classes that Stewart had taught. As a result, I had the pleasure of taking his land classes, as well as the swimming classes that he had taught for eight years. We all appreciated his willingness to take on extra work, and I enjoyed his engaging teaching style.

## PROBLEMS AT ROLAND PARK PLACE

Unfortunately in 2015, the situation at RPP began to deteriorate. What really caused trouble was that the manager had not tried to find a replacement for Stewart. Therefore, when he announced that he would no longer be able to stay at RPP, she had hired no one to teach his classes. Moreover, the manager made an unexpected change in the structure of the Fitness Center at that time. Both Stewart and Valencio had assumed that Valencio would take over Stewart's job of being responsible for running the Center once Stewart left for good. Instead, the manager decided to interview candidates herself, and she also informed Valencio that he would not inherit Stewart's role. That decision upset Valencio as well as those of us who knew how hard he had been working for many months to keep the programs effective. Not only had he taught most of the classes, but also, when the swimming pool needed to be repainted in July 2014, he had done the work himself to spare RPP from the expense of hiring the pool company instead.

At a meeting with the Fitness Committee, to which I had been invited, Valencio told us that he thought not having one person in charge would interfere with the smooth running of the Center. He was, of course, correct. Unfortunately, the manager ignored what he said. To make matters worse, she insisted on hiring a man with little experience with older people, instead of a woman whom Valencio preferred. Once the new man arrived, the manager kept having private meetings with him, during which, according to him, she encouraged him to think that he would ultimately get to run things.

Not surprisingly, Valencio realized that he had no future at RPP. His phone calls to the manager were not returned, and the new employee usually said he was too busy to meet with him. Two months later, Valencio tendered his resignation, and we had a farewell party for him. The manager promptly hired the woman that Valencio had wanted to hire in the first place, and the two newcomers tried to run the Center without much help from the manager, who supposedly was supervising them. The manager had an ill mother, who lived in Florida, a situation that made it difficult for her to observe what was going on in the Fitness Center.

When I looked over my entries in my calendar, I discovered that the two new employees worked together at RPP for only seven months. At the time their stay seemed endless, largely because we had no idea when, if ever, the authorities would intervene. It seemed to us that no one cared what we thought, and as a result we felt very discouraged. In consequence, my emotions began to fluctuate as I responded to changing circumstances, just like those of Olive Kitteridge, the eponymous protagonist of Elizabeth Strout's 2008 novel.

While things were in flux, I came upon an unusual article in *Aging Today*. Most recent newspaper and magazine articles on aging assume that staying

in one's house is the very best approach to living the last days of one's life. In contrast, the article by Peggy Brick was titled "The Case for Aging in Community, *Not* in Place." Brick insists that if one has enough money, aging at a CCRC is preferable to aging in place, provided that the CCRC is a Quaker establishment.

Quaker CCRCs, Brick notes, do not hire activity directors for people in Independent Living. My friends and I were well aware that Broadmead, the Quaker place outside of Baltimore where my Aunt Jane had lived, allowed the residents to run things for themselves. We were also aware that Broadmead had far fewer trips than we did because we have Marie, a remarkable Independent Event Planning Coordinator, and Jennifer, her assistant, who organize our many outings. None of us has the time or the knowledge necessary to plan as many trips as Marie does. We are not against hiring staff to organize things for us; we just hope they will be competent and care about our wellbeing.

Some time in January 2016, while we were trying desperately to adjust to the newcomers running the Fitness Center, I learned that a resident who had only arrived the previous March was about to move out. I heard, second hand from many residents, some of her reasons for leaving, but I decided that I needed to talk to her myself. Like most of us, I was upset that she was leaving largely because the upheaval in the Fitness Center had made me feel less at home. As it turned out, her reasons were different from what mine would have been. Among other things, she could not sell her house, which made the move overly expensive for her. Moreover, she had lived in a supportive neighborhood, with neighbors whose company she really enjoyed. She had complaints, some of which I agreed with. But then in passing she indicated that she was somewhat uncomfortable in the presence of people in wheelchairs, a sight that of course one cannot avoid in any CCRC. After I heard her complaint, I realized that her decision didn't make me feel less at home. Of course, some people are unlikely to adjust to life in a place like ours. After all, as Golant has said, some people find that their friendships in a CCRC are more superficial than prior relations were. Moreover, the fit residents often avoid mixing with those who are frail because they "find it easier and less stressful to be more active and fully engaged" (329–30).

At the end of March and in early April, things began to deteriorate in the Fitness Center. The male employee who had taken over my personal training from Valencio showed up late many times. When I learned that his wife was having a fourth child, I realized that a new baby would make it even more difficult for him to show up on time for my appointments. I decided to hire Glenn, a personal trainer whom I had seen working with Margaret, a resident who has dementia. I was impressed by his kindness to her. When I told my RPP trainer that I was going to shift from him to Glenn, he asked me to send him an email explaining why I was making the change. I wrote him a long email in which I

explained all the problems that working with him entailed and sent a copy to Katherine, who was chair of the Fitness Committee. She asked me to send my message on to Terry Snyder, who is the CEO of RPP.

At first, nothing happened. Then, a short time later when I flew back from Boston where I had been attending a conference, I learned that Terry and Tracy, the head of IT, had asked several residents to explain to them why they supposedly had spoken disrespectfully about the two newcomers who were working in the Fitness Center. The only reason that I was not interviewed was that I had been out of town and therefore had not answered the phone call. Most of the people who had been asked to meet with Terry and Tracy had no idea who might have said mean things about the two newer employees. In fact, I hadn't even heard many complaints about the woman employee. She was working as hard as she could to make the program work. As for the man, whenever I had a complaint, I spoke to him directly.

A month later in early May, the male employee who had taken time off to help with his new baby returned to work. That day, to his surprise, he was fired. I happened to be using the recumbent bike near his office when two men appeared in the Center to escort him out of the building. I was shocked by the speed with which this all happened. Even though I had complaints about his behavior, I thought to escort him out as if he were some sort of criminal was unnecessary. I actually felt sorry for him. Fortunately, the situation did not stay in limbo very long. Terry announced that they had hired a fitness company to take over the running of the Center. A substitute person began teaching some of the classes, and by June 1, a permanent person, Alex, had been put in charge. The woman who had been working in the Center along with the man who was fired stayed until July 15, when she left for good.

Once the change had been announced and new employees began to take over the classes, I was surprised by how quickly we all adjusted to the new situation. Alex and Shea, whom she hired to teach as well, have done a great job taking over in a difficult situation, and as far as I can tell, all of us are more than satisfied by their work.

## LESSONS FROM ROLAND PARK PLACE

Fortunately for me, although the upheaval in the Fitness Center was difficult for us all, at the same time a positive change had occurred in my professional life. Mary Alice Wolf, who was in charge of the book reviews published in *Educational Gerontology*, asked me to review a book titled *Women in the Middle* by Elaine Brody, a well-known gerontological scholar. The book was first published in 1990 and then revised and reissued in 2004. I found the interviews with caregivers to be fascinating. Because in my youth my parents did

not live with their aging relatives, I had no idea that so many people felt morally obliged to take their elders into their dwellings, nor did I know how miserable the situation sometimes made the caregivers and the parents as well.

While writing the review, I discovered that in 2010, at the age of 88, Brody had published another article for *The Gerontologist* related to her research in the book (“On Being”). In it she talks about being in a condo for the elderly. Unlike my facility, it had no health care, but it offered her the company of many lively people. She found that most of them shared the same concerns. In her article she mentions how much she was learning from listening to the comments and asides of her new friends. In fact, she reports that “listening and translating what I hear” had become “organized listening (research)” (9). She recalls that years before, when she had talked to interviewees of older people, they advised her to pay attention to the subtext of what the people were saying, their “cries, whispers and silence” (9). When she moved into the condo, she acknowledged that she was “a very very old person” (9). For the first time she could make direct use of her own experience, in combination with the wealth of knowledge from her professional life. She learned that older people did not like it when their adult children tried to take over the decision making about their lives. Since I was in a situation similar to Brody’s, being a gerontologist who lived in a CCRC, I was enormously impressed by her work and felt that my efforts were supported by her decision to continue doing research while she was in the condo.

As a result of reading some of Brody’s research, I began to understand that the upheavals at RPP could be of interest to other gerontologists. Most important, the loss of Valencio taught me that those who move into a CCRC which has managers, like Roland Park Place, to a certain extent have traded autonomy for the promise of long-term care. In many ways we are dependent on our institution’s employees, a situation that was unnerving when Valencio was forced out of RPP. We have learned that we might face unpleasant situations in the future as well. On the other hand, those who run our place do not want unhappy residents who might discourage newcomers from moving in. As a result, they do take action when residents are unduly upset by what is happening.

Therefore it is most important that would-be residents move in early enough to learn which employees are reliable. Some behave like Atul Gawande, the author of *Being Mortal*, who discovered that he could not help patients unless he asked what made surviving worthwhile. Fortunately, a good many employees want to be helpful and sometimes go out of their way to do so. Others are indifferent to our feelings, and a few rarely speak to residents. Despite that, in time those who are in charge of this place eventually discover that some employees behave in inappropriate ways and as a result decide to part company with them.

I think we residents have to learn to be resilient and resourceful when things seem to be going in the wrong direction. Patience is a very important virtue. Recently, a new employee in the dining room ruffled quite a few feathers. A friend wanted to organize an official letter of complaint signed by many people. I thought that we should wait and see what transpired. As it happened, we learned quite recently that the employee is no longer working here. Apparently, enough individual complaints about his behavior had convinced the authorities to accept his resignation.

Moreover, we are facing a difficult time now that the building is being “repositioned” in order to make RPP financially viable. Most of the rooms on the first floor are being moved around, and some second floor rooms are being changed as well. Once that part of the job is completed, a new section of apartments and parking spaces will be added to the old building. Once again, we residents think that some of the problems of the construction might have been handled more expeditiously if residents had been consulted sooner. Fortunately, however, we recently learned that the architects plan to expand the part of the Fitness Center where our large classes meet. For the time being, the problem of inadequate space has been well handled since the company took over. Alex and Shea doubled the number of classes taught each day. As a result, rarely does a resident find too little space in the classes. Most people are very pleased with the new schedule, and the number of people attending classes has increased.

Of course, having a building under construction is not much fun. On the other hand, some of the changes will allow RPP to offer a more advanced kind of memory care by reconfiguring the assisted-living apartments and health-care rooms. Instead of long corridors, there will be some pods, small groups of rooms around a common room that will permit the employees to work more one-on-one with residents who have dementia.

Like Gawande, I think one should try to find out what qualities of life really matter to the individual. It makes sense to encourage aging people to explore the possibilities of a variety of retirement options when they are young enough to adjust to a different place and a new group of people. It matters what choices we make while we still can do so.

I don't know if I had anticipated the kinds of friendships that I would make at the time we moved in. But as time has passed, I realize that what makes RPP work for me most of the time is the comfort of friendship and companionship. I have had many interactions with residents and some employees that are delightful. I discovered that in times of trouble we can count on people to be supportive. Many residents have lost family members or had health issues that frightened them, so they write notes or say kind things when one's spouse dies or we experience serious health problems. Unlike the outside world, which can make older people feel invisible, as Roger Angell reported in a 2014 article in

*The New Yorker*, fellow residents do not dismiss us. They offer condolences and good wishes in times of trouble.

A group of us eat many meals together in the café and enjoy meeting for Sunday brunch in the main dining room. As a result, we have gotten to know each other very well. Sometimes the conversations are extraordinary. Some Sundays ago, Sally, one of the regulars at brunch, started to mention *The Nightingale*, a novel she was reading about Vichy France in World War II. From that beginning she told us about family members who found themselves trapped in the same place when the war broke out. Some managed to escape, but others did not. Although these tragedies happened many years ago, the feelings they evoked in her were fresh. At times she said that she couldn't continue to tell us what had happened; it was too painful. I think we all realized that we were having a most moving and unusual conversation that could not have happened if our friendships had been superficial.

In conclusion, gerontologists need to draw on their practical experience with aging relatives and friends who have discussed what it is like to live in the many different kinds of places that are currently available for older people. Like Golant, who visited the places he wrote about and interviewed residents, we need to combine our knowledge of the field with our personal observations. Without a combination of the academic and the personal, we will not be able to assist others who are facing the same choices that we confronted.

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