

## USING OBJECTS TO CREATE A MORE HOMELIKE ENVIRONMENT

I am a survivor in 2001 of an acute phase of Guillain-Barre syndrome, a rare neuromuscular disorder - causing me almost total paralysis. Because of my level of disability I am total care and live in an institution - a nursing home in Braintree, Massachusetts.

I often think about the ordinary everyday objects I had the privilege to live with in my prior home and how they benefited me.

Reflecting back on this home in a triple decker I have good memories and a sense of loss. Treasured objects of my life were left behind in my apartment when my life was upended. I think of my back porch open to the sky with a railing. It had red clay flower pots on it with string that went down two floors to the backyard, up which morning glories grew in summer.

I think of my art room with my art supplies, especially my woodblock printing supplies - carving tools, plexiglass for ink, rollers, rice paper and wooden spoons to transfer the images to paper. Woodblock is a form of printmaking I could do at home as the process does not require access to a press in a studio to transfer the images, as is required for monoprints, for example.

It was with a measure of both sadness and delight when a close friend brought to me in Braintree a box. Inside was some of my photography equipment - a Nikon 35 mm camera, a Polaroid Land camera and an Eastman Kodak Brownie camera along with tongs I used to develop my film and print my images. I kept, and still have, the loupe I used to look at the film I'd developed to decide which images were best to print.

I think of my kitchen stove where I had been able to make homemade vegetable soup from fresh vegetables, a healthy delicious soup we never get in my facility. All our soups here are either canned or made with frozen vegetables.

Living in a nursing home is not a god place to live. The problems are numerous. As we are isolated from mainstream culture in the community outside ours is not a real home.

There are oppressive hierarchical assigned roles for staff and residents, policies, rules and codes of conduct. There are ongoing attempts to force us to accept and adapt to unreasonable norms.

There is a lack of privacy. I only have half a room where I have had many roommates in the more than 19 years I have lived here - at least 25 - none of my choosing. There are hundreds of people in the building daily - residents, staff, physicians, hospice workers, vendors, others.

Peace and quiet is sometimes hard to get when residents repeatedly scream loudly for a long time. Some residents pull the fire alarms as pranks. Some other residents are actually dangerous. I have been assaulted by residents three times.

Our elevators are a problem. I have been slammed in my power chair by the doors. My clothes were regularly being lost in the laundry until I got them washed separately. The charger for my power chair was damaged beyond repair by a nursing assistant.

Intentional shortstaffing of aides results in heavy assignments. This understaffing leads to poor care, and to stress for aides - who then complain repeatedly to residents like myself if our care takes a long time - which can be abusive.

We have only one shower a week, even in summer when one sweats all day, due to an insufficient number of aides. Cheap rough towels, when used to wash me, caused skin breakdown.

There are unnecessary restrictions on personal liberty when residents are told they need permission to leave their units or go outside. The fact is that residents have the federal right to interact with members of the community and to participate in community activities both inside and outside the facility, unless there is a clear safety issue.

A lot of the food served in my facility is truly excellent. But the fact is that we are on a 4-week cycle and having the same exact meals repeatedly makes it difficult to find them appetizing. More problematic is that a lot of inexpensive unhealthy food - high in refined grains, sodium, added sugar and saturated fat - is served daily. Some of the food served has been processed in a factory. Healthy eating is hard to get. So I go out to my local supermarket and buy some of my food as others do who are living in their own homes.

There is often poor medical care. Unnecessary pills and insulin were ordered by my physician here for me, a well-known problem of the use of unnecessary drugs in nursing facilities. I got off 9 medications.

Management and staff have varying personalities. Some even have personality impairments. These vary from kind, intelligent, respectful, hardworking, helpful, skilled and supportive to unfocused, disorganized, lazy, cold, argumentative, entitled, arrogant, bossy, uninformed, neglectful, abusive. We want caregivers we are comfortable with, can communicate with and trust.

My main stressor is that nursing home residents have the right to self-determination, autonomy and choice - a basic human right to live with dignity. We have the right to choices consistent with our values, preferences, and own individuality - what is significant to us in all areas of care and life in the facility. These include, but are not limited to, activities, schedules, health care and healthcare providers consistent with our interests.

Unfortunately self-determination and independence are often denied us, or difficult to get - because staff are not properly trained in our rights. These staff often think they are the experts rather than our partners. Their approach is too often paternalistic and dehumanizing, rather than a relationship-based resident-empowered one.

It is expected residents will accept these institutional values, roles, practices and staff behaviors. There is an assumption we will comply with this social system where staff try to dominate us, that we will adapt to our assigned status and behave accordingly. I personally reject these values.

I have suffered emotional consequences - frustration, anger and exhaustion - that affect my overall well-being.

Because of these barriers in my facility I have no feeling of being in my own home. This environment is definitely not a real home like I had before. So I developed a coping strategy of using objects to create a more homelike environment, a real living space. I use objects to mitigate the stress of institutional life, to compensate for, and reframe, my circumstances by creating a more homelike environment.

Our facility provides me with furniture for my room - a hospital bed with an alternating air mattress, a call light, an overbed light, an overbed table, two bookcases with shelves, a dresser with four drawers, a nightstand and a small closet with a rack and shelves.

My bed is next to a 5 by 6 foot picture window which has a large shelf-type windowsill. It is not operable. I choose to keep the blinds up so I can see the sky and clouds, sunlight and moonlight. Light streams through this window with daily and seasonal changes. The color of the sky may be white, light or dark grey, blue, red or overcast black. I can check to see if it is raining or snowing.

There is a beautiful Maple tree directly outside which I also follow seasonally. Behind the tree are two private homes with interesting architectural details. Natural light, views of nature and peoples' private homes provide a powerful restorative environment of energy and peace as they are not institutional.

To orient myself to time I had a large clock put on the wall across from my bed.

To orient myself to place - as I sometimes think I still live in my own home in my previous town - I have a bulletin board devoted to Braintree, MA where I actually live. I have pictures of John Hancock, first signer of the Declaration of Independence and of presidents John and John Quincy Adams there. I also have a picture of Sylvanus Thayer, known as the "Father of West Point". All these men were born in Braintree. Their pictures continually remind me that I am now living in a different place and home, one with an important role in American history.

I have five posters on my wall highlighting some of my federal rights as a nursing home resident - right to dignity, right to privacy and confidentiality, right to voice my concerns, right to participate in my care and right to make my own choices. These posters empower me to stand up for myself so I can get both the quality of care and the quality of life I am legally entitled to.

I don't use institutional objects unless I absolutely have to. Rather, I buy objects to personalize my room and make it my own home. I redesigned my environment in the following ways. The fluorescent light provided to me over the head of my bed illuminated my whole room like a supermarket or operating room. I had it replaced with a more-typical bedroom light. I then bought a softer-light light bulb for it from my local hardware store.

The facility provides me with linen. I bought some blankets myself for beauty and function. Several were also given to me as gifts. All these are prettier and warmer than those the facility provides. They are of varying colors and designs. They are soft to the touch. I bought pillowcases to make them my own. I purchased pajamas for comfort and dignity, unlike johnnies which are short, sleeveless, cold and revealingly open in the back. Personal linen and sleepwear are not institutional.

We are offered toothbrushes, hairbrushes, soap and deodorant, none of these high-quality. Their toothbrushes don't clean well. The bristles on their hair brushes are too short to do my hair properly. Their soap is cheap, not good body wash. Although not for grooming, another example of poor quality supplies are our facility coat hangers with notches that have put holes in the shoulders of my shirts. I bought my own hangers. If supplies are not what I need I buy my own so they are more homelike.

My facility even has clothes available for us from donations, or from having belonged to other residents who died. I want my own for dignity - smart and pretty through various colors, patterns, styles and fabrics. The clothes I select and buy are vehicles of self-expression, individuality, self-esteem and confidence. Choosing my own clothes I am the person who I am - wearing quality, fresh, stylish, right-size items which make me feel good.

In my room I have many personally-meaningful objects. I have two portfolios of the artwork I previously was able to do living in my own home - all works on paper: photographs, watercolors and different types of prints: etchings, monotypes and woodblock. I have objects that hold important memories of my previous lives - slides of Strasbourg in Alsace, France where I spent my junior university year abroad, a gold chain with a pendant of Carnelian given to me by an Iranian student when I taught English at Boston University.

I have framed photographs of several friends who are no longer with us. These friends who have departed this planet, whose pictures, and cards I can look at and read, allow me to feel they remain fully present. Most poignantly I have a note from a dear now-deceased friend who wrote me saying goodbye three days before she died.

These homelike objects in my room are restorative of my identity and biography as a student, traveler, academic, artist and friend.

I have snacks in my room - nuts, popcorn and sugar-free candy - that are healthier than most of the facility snacks which are high in sugar like graham crackers, animal crackers and fig bars. I buy mine at my local supermarket like others living in their own homes.

There is a lack of meaningful activities in our facility. For leisure activities instead of the coloring books, crossword puzzle books and popular magazines available, I have a variety of reading materials. I have books. I have scholarly geriatrics and gerontology journals. I have current newspapers. Reading the Boston Globe daily and the Braintree Forum weekly are essential to my staying connected to events in the larger world.

I have office supplies including pens and legal pads to draft articles for publication. I maintain the intellectual life I had in my previous home.

With these personalized objects I try to duplicate as much as possible the real home I lived in in the community before living in a nursing home.

Within driving distance in my power chair is Braintree town center called South Braintree Square. I am able to shop at a supermarket, pharmacies, a small department store, a hardware store and an arts and crafts store. I go to my bank, eat out, go to the post office, visit my local public library, vote at Town Hall, see my dentist and get a pedicure.

In the Square I can also check out yard sales. In summer I go to our Farmers Market for fresh vegetables and homemade prepared foods. One year I was able to buy a unique batik wallet there made by a woman in Uganda as part of an initiative called Project Have Hope.

These are all activities folks living in their own homes do.

All these positive community experiences that help me to be independent, active, involved and happy are facilitated by technology - by my having an electric wheelchair. My chair is more than an essential object in my life. It is a platform for physical functioning, normalcy and inclusion. While in my chair outside I am community-dwelling.

Personal objects normalize me making my life in a nursing home more homelike. But the fact is that nursing homes will never be real homes. Given this reality I find the best way to reclaim myself, and not be institutionalized, is to be out of that environment into an empowering community one.

Environment is everything.

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