

chapter 3

Home Is a Basic Necessity

"As far as we can discern, the sole purpose of human existence is to kindle a light of meaning in the darkness of mere being." - Carl Gustav Jung

We need to remember what home means in our own lives. For most of us, home is a basic necessity for a wholesome and balanced life. It is where we retreat, regroup and find sustenance.

Home is, in fact, an extension of our self-identity, which we alone create. Whether our persona is that of a painfully shy person or life-of-the-party, it is the one with which we establish our place in the world. Nowhere is our self-identity reinforced more than at home.

For this reason, the Household Model sets great store in the belief that the creation of a true home for elders is paramount. There are some who may question that it is a fundamental building block for long-term care. Here we attempt to firmly establish the importance of home as an essential need for all, at all times.

During our lifetimes we may have lived in several different houses, but each was our home because we made it so with our rituals, routines and personal touch. No matter where we lived, we took control by working to create a comfortable living space suited to our particular needs and tastes - one that reflects who we are.

We continue to assume control over our home environment after we retire. These are our golden years, our reward for a life of hard work. We spend years talking about what we are going to do when we retire. Our plans are endless and all appeal to our unique sense of self. Though the plans are filled with adventure, there is an unspoken assumption of home.

Home is the place we will come back to, where we will rest between expeditions, where we will detail the plans of the next phase. Home is not necessarily the house we lived in while working - but wherever it is, however it is configured, it will be home. It will be a reflection of self. Within it will be all that we need. Finally, we will be able to enjoy our home to the fullest.

This post retirement period is also the time when we most need the stability of home and the sense of self it provides, for this typically is not only a time for new

discoveries, but a time of profound loss. Retirement can diminish our feeling of self worth because we consider ourselves less useful than when we were employed. Social support slips as friends and family members die or move away. Our health may decline and perhaps we become more dependent on others.

We feel guilty when we have to ask our loving but busy daughter for a ride to church. We feel old and in the way when our grandchildren frown impatiently as they help us into the car.

Still, as long as we live at home – even if it is a small apartment or condo – we retain control over our life and respect from friends and relatives. Our children tell their friends, "Mom and Dad decided to move out of that big old house and are living in senior housing. Actually, it's quite nice. Now they can travel and never worry about their yard."

But the mood changes when we are admitted to a nursing home: "We had to place mom in a nursing home. It's been really hard. You know how persnickety she was about her house – everything had to be just the way she liked. She always loved to cook and now she can't even go into the kitchen. I told her 'Mom, you just have to sit back and let others do for you.'" (Translation: "You are done. Stop being yourself.")

Relationships with family members change. They feel uncomfortable visiting us in this strange new environment with the lack of privacy it affords. Conversations are strained as we struggle to find something in common to discuss. The things we used to talk about – the yard, the birds, the dog, the leaky faucet, the neighbors, plans for a small party, friends at church – are gone or so far away they seem unimportant.

Compounding the trauma of moving into an alien environment is a sense of denial. When elders come into nursing homes, they often arrive in a waiting mode much like when they enter a hospital. They tell themselves, "I'm just here for a while *then* I'm going home." They do not acknowledge it, but many will wait the rest of their lives.

Their expectation of eventually returning home obscures the reality of their situation, so they forfeit even the choice to surrender to their new surroundings. While they wait, the all-pervasive institution with its assembly-line culture diminishes their individuality and their power of self. If we feel a bit cowed visiting the doctor's office, think how intimidated elders must feel residing permanently amid the hustle and bustle of a nursing home.

When we are admitted to a nursing home, we are no longer expected – or allowed – to be in control. "Mom, you just have to sit back and let others do for you." (Translation: "You are done. Stop being yourself.")

Home is Self

A group of researchers and practitioners struggled together recently to identify the domains of well-being embedded so naturally in our lifestyles of home. In their work, *Well-being Beyond Quality of Life, a Metamorphosis of Eldercare*, the authors spoke of seven domains of well-being: identity, growth, autonomy, security, connectedness, meaning and joy. All appear to change as the frail elder enters into the institutional system of care. The authors state that the risks of slipping from a state of well-being "increases dramatically for nursing home residents disconnected from the past by loss of familiar places and personal possessions, and from the future by loss of hopes and dreams."

When talking about ourselves we speak the language of these domains of well-being, but we rarely consider that these are also the gifts of home. The house we love to drive up to, the yard of sunshine and rain, the porch that boundaries the stranger, the kitchen and coffee pot that welcomes the neighbor, the chair and cushion under the reading lamp, the bath that soothes and pleasures, the freedom of movement from room to room, the old box of photos and the treasures always available in the attic to remind us of the life we've led – all are merely the accoutrements of home. But when they are gone, the deeper sense of well-being embedded in home is endangered as well.

Losing Home, Losing Self

Living in an institutional care environment we resign ourselves to this loss. The losses are often compounded as time goes on. Even the ability to walk is frequently sacrificed to the needs of the system. There is a schedule to keep and no time to shuffle with a walker to the dining room, so elders are put into a wheelchair and whisked down the corridor until they lose all ability to walk.

We once heard a nurse aide call out to a resident who was trying to stand up, "Sit down. Your walking days are over." The aide was in fact a very loving woman, and we feel sure she had no idea of the harshness of her words.

Having no obvious purpose but to be cared for – i.e., warehoused until shipped out – the elder's self-identity seeps away, unnoticed at first, until none of the original identity is left around which to organize. The elder's diagnosis and room number becomes his or her identity. We suspect if a time-lapse video were made following an elder's entry into a traditional nursing home it would show much the same progression (or rather, regression) as a wilting flower. The final frames would reveal what is commonly known in long-term care as "slumping." The elder with vacant eyes drools and slouches in a wheelchair as if the body, like an old car, has been abandoned by the driver.

When residents arrive at that state, we attend to them, but unconsciously disregard them as persons, focusing our emotional energies instead on those who have not yet lost themselves. It is from the latter we take the strength needed to sustain our work in a system that is just as repressive to us as it is to them. Unlike the residents who have succumbed, we survive because we have a measure of control and more stamina, which unfortunately we use to perpetuate the system.

Many would argue that slumping is the result of age and disease. Yet, we have witnessed time after time how the condition reverses and elders begin to blossom once the warehousing approach to nursing care is replaced by environments elders can identify as "home."

We can't feel a sense of wholeness, safety and belonging, exercise autonomy, experience joy, build community or fully actualize without the sanctuary of home.

Homelessness: A Reality of Nursing Homes

To support this premise of loss of home, we rarely hear residents describe the facility they live in as "home." Rather, they wistfully speak of home as something in the past stripped forever from their grasp. They talk longingly and unrealistically about "going home." When relatives come to visit, they may find their loved one in the doorway with purse in hand, pleading to go home.

The reason is simple; no one views a nursing home as a true home for those living there. For us who work there, it is *our* place, not theirs. *We* run it. *We* make the decisions. Further logical analysis leads to only one conclusion; people who reside in nursing homes are homeless with a roof over their heads.

Research at a nursing home in Connecticut by Judith Carboni, RN, MSN, CS, reinforces the idea that institutionalized elders are in effect homeless. She defines home as "a fluid and dynamic intimate relationship between the individual and the environment...a lived experience that possesses deep existential meaning for the individual."

What she found was just the opposite: "When one is homeless, there is no private place to which one can withdraw, and this lack of privacy was evident for all residents of the nursing home. There seemed to be no retreat to call one's own, save for a retreat into self. Homelessness engenders feelings of powerlessness and dependency.

These feelings were predominantly experienced by the (resident) informants. They were aware that the institution, not they, made the rules, and that routine

dominated the day. As a result of this lack of autonomy and imposition of rules, informants demonstrated increasing inability to make decisions for themselves. Endless repetition directed their lives and meaningless tasks seemed to add to the numbness that resulted in boredom and low energy. Both informants and group members shared feelings of anxiety, fearfulness, and uncertainty, indicating that to be in an institution and homeless is to be insecure in an uncertain world; it is to be filled with doubts and to be a stranger.

To not have a home is to not have a safe haven in which to find protection. When one is homeless, one is vulnerable and in danger at all times. This clearly describes both informants and the majority of nursing home residents who say little, disclose even less, and distrust most people around them."

Observe the striking similarities in the posture and demeanor of a homeless person on the street to that of a slumping elder parked at the nurses' station. Neither have control over their physical space or a way to shut out the world other than to mentally disengage and escape deep within. It is as if slumping, with eyes downcast and vacant, is their way of locking the door.

Passersby treat slumping elders and bag ladies much the same. When we cross paths with one of the latter, do we make eye contact, smile and say "what a lovely day" as we would to a well-dressed stranger we encounter on the street? What keeps us from doing so? Perhaps because we have already made up our minds about the person based on her outward appearance, or maybe we are afraid she is going to ask something of us. The unconventional dress and demeanor of the homeless make us ill at ease, and we begin to see them more as objects than as persons.

We objectify elders who slump in much the same way. They make us feel uncomfortable, or maybe we just don't have time to stop and acknowledge them as we delve into our paperwork or hurry to the next meeting. But what must it feel like from their point of view? Do they think we don't see them or don't care; that they're living alone in a crowd? It becomes a downward spiral: the elders feel even more disengaged and invisible, leading to further discomfort and aloofness on the part of staff.

Failing health should not render us homeless. Depriving a person of a need so fundamental as home, even with the best of intentions, violates a basic human right.

Begin at Home to Create Home

We must begin at home to create a home. When we, as long-term care leaders begin changing the culture of nursing homes in our own communities, everybody and everything else will follow suit.

The industrial assembly line of care must be eradicated in this home we work to create. Life-long possessions, simple pleasures and routines must be re-instated to each unique person living in a nursing home. The hallway outside the bedrooms must no longer be a public street where complete strangers can walk by and where others, known only by name badges, can walk into residents' rooms at any moment without knocking.

Dignity must be returned to the bathing experience, eliminating the embarrassing trip down the busy corridor in a wheelchair wearing only a nightgown and the "hoist and dip" bathing method that treats humans like boxes of widgets.

We must design home that acts in tandem with the lifestyle and tastes of those living within. The physical layout must stimulate the cultural norms of privacy, relationships, autonomy and pleasure so that each person who lives within will have the opportunity to be at home.

Moving Toward a Future of Possibilities

Now that we have faced the reality of today in these early chapters, the balance of this book begins a pathway for you to take the nursing home system you have inherited and reshape it into something whole and healthy, thereby creating a deep, lasting legacy in your community.

The information in the following pages will enable you to transform lives, including your own, in ways that will humble and astound you, and liberate legions of elders and caregivers you will never meet.

Does life have a stronger measure?