REFLECTIONS ON THE IMPORTANCE OF ELDER CARE

Victoria Howard and Carole Fleming

Why should we bother to care for frail older people, particularly those who are confused, forgetful and helpless? Is there some reason for this so-called custodial care that goes beyond simple kindness to living beings? What possible benefit could it bring to our families, our communities and our species for us to spend our time and resources in this way?

OVERVIEW

To approach the topic of caring for our elders, we must look at the awareness of death embodied in our old people. The dawning knowledge of mortality characterizes this last phase of life and is a process that we each engage in at our own rate, in accordance with our life experience. In extreme old age this process deepens.

The physical slowing that characterizes aging gives rise to a quality of awareness that differs from any other stage of life. Memory and thoughts slow as well as physical activity. The mind becomes spacious, the thought flow has more gaps. What dawns in this contemplative state is an awareness of detail that can become obsessive, a direct experience of mortality that can become panic, and a sense of openness that can become confusion. As one's state of mind loses speed, the individual lets go of a solid sense of self. According to Chogyam Trungpa, Rinpoche, "Egolesssness comes more or less as a by-product of seeing the transitory, transparent nature of the world outside . . . when we are able to see the projection as non-substantial, ego becomes transparent correspondingly."[1] This can be enlightening or terrifying depending on the support and feedback of the environment.

By the time we are sixty or seventy years old, we have experienced a tremendous amount of loss and change. Sometimes we barely remember people we once loved or hated passionately. The dream-like nature of our lives can become increasingly vivid. We may have lived through our worst fears, experienced a variety of successes and defeats. There is the possibility of developing a larger perspective as the drama of youth passes and we no longer take ourselves so seriously.

In working with memory loss and confusion in old age, there are a number of factors that must be considered: physical, chemical, behavioral and psychological. The psychological process of old age is rarely taken into account in families or in care settings. One notices the mental condition of old age only when it becomes a problem. Since the psychological disorders of old age cannot be addressed by traditional insight therapy and since the tacit assumption of most health care providers is that memory loss, confusion and depression in old age are the natural by-products of physical deterioration, the culture and the health care system continue to collude in undermining already vulnerable and frail seniors.

In Eastern cultures, preparation for death has long been viewed as work common to warriors and to elders. The summing up, transmitting and letting go of a lifetime is a monumental process. It is not necessarily conceptual, or even conscious. Nor is it dependent on accurate recall or clarity of mind. Older people who are quite "far gone" can present their "death poems" with the elegance of a samurai, if given the appropriate support.

In our youth-oriented culture, with its fast foods and fast cars, where "instant" is better and everything is disposable, the slow, spacious quality of advanced age is not valued and the tasks of this stage of life cannot unfold. Life review requires the participation of an interested listener. An older person cannot transmit the sum of her wisdom unless there is someone with the time and willingness to receive it.[2]

Dr. Robert Butler has coined the term "ageism" to describe our culture's attitude toward aging and the abuse to which it gives rise.[3] Older people are regarded as worthless and senile. These environ-

mental messages are internalized by seniors and the labels become a self-fulfilling prophesy.[4]

This view of old age has not been true historically in our culture nor is it the prevailing view of all cultures. Eric Ericson presents an alternative perspective:

> Elders of society were the transmitters of tradition, the guardians of the ancestral values and the providers of continuity. They were awarded such titles as sage, patriarch, seer, and venerable counselor and were consulted as advisors and sometimes as prophets, since long-range memories make predictions founded on experience trustworthy. Their life histories provided the warp on which the lively threads of the ongoing community were in the process of being woven. This interconnectedness of the social fabric, which stressed the interdependence of all age groups, tended to establish a harmonious wholeness.[5]

This interconnectedness of the physical, the social and the environment determines how we learn and grow and whether our developmental progress is hampered or facilitated. This seems a mundane truth, but it is rarely taken into account in the plan and design of care settings. Most institutional care facilities, whether meant to serve the physically or mentally ill or the frail elderly, like a bad parent, design schedules and routines for the convenience of the caretaker rather than in support of the personal preferences of the individual receiving care. This mechanistic approach to nurture is as destructive to the elderly as it is to infants.

The social and cultural environment receives richness from its elders only if it provides them an environment supportive of their inner distillation and integration. This process is emotional and spiritual. Long repressed memories, issues and complexes need to be invited and felt. Beliefs and philosophies need to be expanded to include the experience of a lifetime. Often this effort is only partly conscious. This work is not conceptual or linear. The older person may seem preoccupied or absorbed. She may fall into a trance-like state or appear to lose her train of thought. A younger person who takes the time to sit with an older person and relax into her slower pace can become aware of a rumination process, a sense of inner "cooking", that is taking place. This process does not yield a prod-

uct in the usual sense, but to devalue it or disregard it is to wound the essence of our collective humanity.

In working with elders, a supportive, or to use D.W. Winnicott's term, a "holding environment" must be created to facilitate the letting go process.[6] The goal is to enable the older person to relax and feel a sense of well-being, connectedness and trust. Then whatever obstacles there have been to this inner unfolding will gradually fall away. This works even for those suffering chronic illness and organic impairment. As long as there is some consciousness and perception taking place, there is the possibility of contact and relaxation in the moment.

The physical aspect of the holding environment is a living space that is personal to the elder beng cared for; it should reflect her personality and preferences and contain her valued possessions. The space should be treated as an extension of the elder's state of mind, whatever that may be, and arranged with attention. The space should be inviting, with bright spots that can provide reference points in those moments when the elder "comes back" to being present. It is most important that the elder have a "seat," a strong sense of her personal place in the environment. The placement of a favorite chair and objects around it, the arrangement of a bed and bedside table can help to ground a senior who may be in danger of "losing her mind." One can actually evaluate the quality of care, in an Alzheimer's unit, for example, by the extent to which the residents are grounded or seated in the environment. If the unit feels like a fish tank with confused elders floating about aimlessly, the quality of care is in question.

The relational aspect of the holding environment is the world of communication and activity provided for the senior. No one individual, no matter how skilled or dedicated a caregiver, can create a holding environment—it takes a team, a group of individuals each bringing the richness of their particular talents and perspectives. The communication and connection between the team members, the nurture and training provided by the team supervisor, the integration of the elder's family members with the team and the team

members' roles of ally to the senior in communicating with the environment—all of these factors serve to create a strong and caring world in which a senior can relax, and in which the relational world of all involved can be enriched. The elder's daily schedule which develops from an ongoing dialogue about his or her needs and preferences creates a flexible structure which serves to orient and reassure.

Dr. Edward Podvoll has described in his book, *The Seduction of Madness,* a team approach for working with psychosis. He refers to this approach as basic attendance, "a specific form of treatment which provides the attention the patient or anyone needs to recover his physical or mental health."[7] The practice of "basic attendance" with an elder needing care means slowing to her pace and, in as many details as possible, surrendering control to the elder and serving as her ally in accomplishing her goals. For a team member this means literally matching the rate of breathing, movement and speech of the senior, settling into her environment and seeing it from the senior's point of view. This requires great attention to detail and curiosity about the history, values, beliefs and preferences of the individual elder. Team members need to talk to each other about these details, each sharing their accumulated information and opinions about the elder. In this way, a web of connection and caring is woven that will contain the elder as he or she lets go into relaxation. This might spark the resumption of past interest such as music or bird-watching, or it might ease the dying process, depending on the senior's state of health.

Fear of losing control is a major issue in old age. Loss and disability bring home our powerlessness. We cannot halt or reverse impermanence. In old age this truth is as real as our own bodies. In order to bear this almost unbearable fact, elders need to be granted control in every way possible. Giving and discussing choices is a means of empowering seniors and helping to quell the fear of losing control. This practice of deferring to the elder is another facet of basic attendance for old age.

The atmosphere of the holding environment is an attitude of

appreciation. The team must be educated about the state of mind of old age, be willing to look at their own fears and preconceptions and to develop appreciation for the courage and ruggedness it takes to face old age and death. The team members must be trained to work with the feelings that come up for them as they sit with their elders. Boredom, irritation, claustrophobia come up along with appreciation and tenderness. Team members need to acknowledge the full range. This attitude of openness makes it possible for the elder to accomplish the psychological tasks of old age, particularly transmission; the older person passes on the seed of her experience. The receptivity of the team member makes the completion of this exchange possible. It may be that a team member is listening, probably not for the first time, to an elder's painstaking description of the proper way to fold a plastic bag and in that moment some mysterious seed is passed that is the sum of that elder's lifetime. Or it may be that the team member meets the eyes of an elder and feels an inexplicable opening of the heart. Transmission takes place in flashes, in the most ordinary situations. Professionals who work long hours with the elderly and the dying are quite familiar with the experience, although it is rarely discussed. For the team to talk about and value these moments facilitates the "exchange process" and helps to nurture the team members by highlighting the fruition of their work.

Most of the teams that have been fielded by members of The Naropa Institute faculty have worked in the client's home or in a household set up by the team. Maitri Psychological Services provided in-home care for people suffering from psychosis. Dana Home Care provided in-home care to the frail elderly and dying. Both organizations proved to be extraordinary learning experiences for the staff involved. Both services developed almost ideal care models demonstrating the possibilities of recovery and fruition for clients ordinarily regarded as hopeless. Unfortunately such care is prohibitively expensive. Both of the above organizations went on to apply what they had learned to the development of small group residences. Large traditional institutional settings were avoided

since their approach seemed antithetical to all that we had learned. Yet financial realities dictate the continuing existence of nursing homes. Hundreds of thousands of elders will end their days in such facilities. The question then becomes, is it possible to work within such settings?

CASE STUDY

The following is an account of a seventy year old woman named Anna for whom we provided team care during the last year of her life. In that year, Anna lived in two different nursing homes. The first facility, serving primarily Medicaid patients like Anna, was shockingly inadequate in everything from staffing to linens. (Not long after we had moved Anna to a second facility the former residence was shut down by the Health Department.) The nursing home where Anna finished her life was a much more benign, caring environment. Although still limited to an institutional structure and methodology, the staff welcomed the supplementary care of the team, relieved that someone was able to give the individual attention for which they had no time.

Anna's team was formed in the fall of 1989 at the request of one of Anna's daughters. All seven of the team members had some experience and training in basic attendance and were students in the M.A. Psychology Program in Contemplative Psychotherapy at The Naropa Institute. Each team member made a six month commitment to the team and agreed to spend one two-hour shift with Anna and attend one team meeting each week. Victoria Howard, co-author of this article and instructor for the Psychology of Aging class at The Naropa Institute, was the team's supervisor. The long-term goal of the team was to facilitate Anna's return to her own home. The short-term goal was to make friends with Anna and to get to know her world.

Entering Anna's world meant entering the institutional world of the nursing home. We found it to be a discordant environment in which residents, whose movements were slowed by the aging pro-

cess, illness, medications, (or all three) struggled to function and make themselves heard in a world characterized by the speed of harried staff moving quickly down the halls. The residents moved slowly with walkers or in wheelchairs or sat in wheelchairs in doorways or at the ends of the hallways staring vacantly or reaching out with trembling hands to touch a passer-by. The nurses and aides busy with tasks seemed inured to requests for assistance and in their haste to keep to the schedule, often offered verbal responses without making eye contact with the resident. As the team members made their way down the hall to Anna's room they felt sensory overload from the mingled odors of urine and disinfectant, the jangled sounds of T.V., buzzers, intercom messages and the distressed calls of elders for help. It was a relief to arrive at Anna's door and take a seat in the relative quiet of her room. At our first team meeting one of the team members remarked that if it was a relief for us to take sanctuary in her room, it seemed reasonable to assume that staying in bed had become a sort of refuge for Anna.

We decided as a team to enter this environment slowly, without an agenda. We spent time simply sitting with Anna, reading, looking out the window, or engaging in conversation. At first it was difficult for her to tolerate complete attention for two hours, but gradually she began to relax with the team and let us into her shrinking world. She began to realize that we were not going to make her do anything. She noticed that we listened to her and a genuine verbal exchange with members of the team began. For two hours a day Anna had the undivided attention of another human being who listened and took her experience seriously.

The time Anna spent with team members contrasted sharply with the time she spent with nurses and aides in the home. They had a schedule to maintain and little time to spend with residents individually. There appeared to be an assumption by the staff and Anna's physician that Anna was difficult and uncooperative because she resisted staff efforts to make her walk, feed herself and attend the recreational activities provided. An atmosphere of struggle and hostility developed as the staff pushed for cooperation and Anna

resisted. On the other hand, the team listened to Anna and took her complaints seriously, validating her perceptions and feelings. As a result the team began to experience some of the hostility the staff directed toward Anna.

Entering the environment slowly also enabled the team members to become more a part of it. We were able to become advocates for Anna in the system and to absorb some of the hostility that was expressed between Anna and the staff. This had the effect of softening staff attitudes over time. However, the team always walked a fine line with the staff because we asked questions and advocated treatment that honored Anna's preferences and wishes. It is important to note that this was done with an attitude of appreciation for the efforts of the staff in an impossible situation.

We became part of the routine of Anna's day. As Anna relaxed with the team, we began to notice that the tug-of-war in which she was engaged with the staff had to do with control: the fact that she had no control over when she was wakened, fed or showered. Every detail of her life was scheduled for her. If she resisted any of this her reasons were not acknowledged and she was demeaned for being uncooperative.

As often happens with the elderly, this power struggle manifested around bowel control. In the third week of the team visits with Anna, she began to mention that she was constipated and complained that the staff would not give her laxatives for fear she would become dependent on them. The team designed a chart on which a daily record of Anna's bowel movements could be kept at her bed for the staff, Anna and the team to use. The team also placed four over-the-counter laxative tablets in her bedside drawer for her to use "in case of emergency." Anna felt acknowledged; constipation ceased to be a daily issue and to our knowledge, Anna never used the laxatives.

Anna's physician and the staff maintained that she could walk and feed herself if she really wanted to, while Anna insisted that she could not. The team advocated for an outside opinion, a medical review by a neurologist, who validated Anna's assertion that she

could not walk. She was also taken off her medication, Haldol, to see if this would relieve her muscle stiffness.

Without the mask of medication something very real began to occur—Anna did for herself what she could manage. She could hold a glass and drink on her own, but still required assistance with feeding, and now the staff provided it. She became more irritable. She became more aware that it bothered her to lie in her own urine and would insist that the staff change her pads. Some psychotic process did return. She would converse with her inner voices, but also would engage with the staff when requested.

The team presence fostered relaxation for Anna because she began to feel valued just as she was. Struggle with the environment lessened and became more of an ironic appreciation of the absurdity of her situation. We began to notice a shift in her state of mind. An unfolding began to occur which we recognized as part of the process described by Victoria Howard as unique to old age: slowing, life review, transmission and letting go.[8] At this point the team meetings began to focus less on how we could get Anna back home and more on how we could facilitate what we saw unfolding.

Slowing was apparent. Anna was bedridden and got up only to be wheeled to meals or showers. Anna was not participating in the frenzy around her. It became the task of the team to slow or relax "into being rather than doing" to match her pace.[9] This was difficult at first as we rushed to the nursing home for our two-hour shifts from an already busy day. However, we began to experience our time with Anna as a kind of oasis in our day. It was a time when we could just sit and be. Sometimes we listened to Anna's music, or simply sat and read while she napped. We let Anna set the pace. Because of her lively wit and her intelligence, there were also times of intense engagement.

One of the team members had the idea of using old family photo albums as a way to get Anna to talk about her life. We had knowledge of her psychiatric history, her daughters, and her accomplishments as a pianist. However, it seemed that pictures might prompt further memories. This simple activity of looking at pictures to-

gether opened the door to a vast richness for Anna and for each of us. We learned about her parents, marriages, children and divorces. We talked about her first love affair with a dashing World War II pilot. What Anna and the team saw through this review was how full and textured her life had been. The opportunity for her to take stock of her life in this way required time and someone with whom to do it. The team provided this.

Slowing down and reviewing fostered another important process: transmission. Because a different one of us came each day, Anna had seven individuals with whom to share her accumulated knowledge and wisdom. She imparted her appreciation and love of music, advice on marriage and childrearing, and what it is like to be part of a mental health system for fifty years.

About four weeks after the change in her medications, Anna suffered a stroke. She spent two weeks in the hospital and then was transferred to a different nursing home. It proved to be better staffed and managed. Anna lived for two months, moving in and out of consciousness. Because of the interest and accomodation of the staff, we were able to work with them on Anna's care: bathing her, turning her and massaging her. We played her music, we placed fresh flowers within her view, we talked of our families, we told her not to be afraid, that we were with her, we held her hand, we breathed difficult breaths with her. We told her it was okay to let go; she was not alone.

Throughout our year with Anna, we kept a daily journal of our shifts with her. We included her remarks in the notations and read her ours. During the course of our time with Anna, we always felt that we were learning from her, that somehow she was our teacher even though we had come into her life to assist her. What happened in the process of entering her world was enriching for each one of us. She laughed with us, she snarled at us, she argued with us, she advised and coached us. We brought her apple juice; she shared music and chocolates. She shared with us the wisdom of seventy years. She let us see her courage, her stubbornness, her rage, her sense of humor and her sense of the absurd that had carried her

through all the pain of her life. She shared her daughters with us. Ultimately Anna showed us how to let go and die.

Early in our time with Anna a team member posed the question to her, "if you were a flower, what flower would you be?" Anna replied, "a weed, I am a weed." Shortly before her death the same team member inquired, "what kind of flower are you today, Anna?" Without hesitation, she looked up with a quick flash of her sharp blue eyes and announced, "A daisy. I think I'm a daisy."

CONCLUSION

Anna's story reveals the interplay of a number of environments—the one created by the team specifically around Anna and the two contrasting nursing homes environments with which the team interacted on Anna's behalf. (We have discovered that in an institutional environment, the presence of allies, whom Alice Miller called "enlightened witnesses," are very important. Allies who acknowledge with the residents the reality of their perceptions and who work to mitigate the harshness of the environment can make the difference between dignity and destruction.)[10] Anna's death was a victorious one, the fruition of her personal relaxation and accomplishment of the psychological tasks of old age. Anna's family was with her to share her last days. Over our year together the team did not spend a great deal of time with Anna—no more than two hours a day, five to seven days a week. This minimal effort affected Anna and her family powerfully. The reorganization of institutional settings to include an application of team structure and the practice of basic attendance might mitigate some of the destructive aspects of institutional environments. To quote Gay Luce, founder of the SAGE Project (Senior Actualization and Growth Exploration, an intergenerational group that began in California in 1974 to explore the myths anad realities of the aging process), "We could construct a program that would counter the negatives, avoidances and lies we learned to live with, such as the pretense that life is unending and

death will never happen."[11] With the appropriate environmental support, old age could be a time when we can become truly ourselves.

NOTES

1. Trungpa, Chogyam. *Glimpses of Abhidharma.* Boston, Ma.: Shambhala Publications Inc., 1975, p. 1.
2. In this text feminine personal pronouns will be used to refer both to males and females for the sake of convenience and because most of the frail elderly are women.
3. Butler, Dr. Robert. *Why Survive? Growing Old in America.* New York, New York: Harper and Row, 1975, p. 11.
4. Henig, Robin M. *The Myth of Senility.* Washington, D.C.: American Association of Retired Persons, 1988, pp. 2-3, 4-6, 17, 46, 47, 258.
5. Ericson, Ericson, & Kivnik. *Vital Involvement in Old Age.* New York and London: W.W. Norton & Co., 1986, p. 2.
6. Winnicott, D.W. *Playing and Reality,* London and New York: Tavistock Publications, 1971, p. 112.
7. Podvoll, Dr. Edward. *The Seduction of Madness.* New York, New York: Harper Collins Publishers, 1990, pp. 247-284.
8. Howard (formerly Fitch), Victoria. *"The Psychological Tasks of Old Age,"* The Naropa Institute Journal of Psychology, volume III, pp. 90-106.
9. Ibid, p. 92.
10. Miller, Alice. *Banished Knowledge.* New York and London: Anchor Books, Doubleday, 1990, p. 175.
11. Luce, Gay Gaer. *Your Second Life.* New York, New York: Dell Publishing Co., Inc., 1979, p. 8.