Environmental & Architectural Phenomenology Newsletter

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This issue focuses on the theme of "body, illness, and environment." We are pleased to have essays by philosopher Kay Toombs and landscape architect and poet Gwendolyn Scott.

Toombs draws on her firsthand experience of multiple sclerosis to delineate aspects of a phenomenology of illness. Her description of a routine travel experience--going on a professional trip--is an eye-opening picture of the environmental difficulties that a physically-disabled person must regularly face.

Scott recounts her recent experience of caring for her brother as he succumbed to Lou Gehrigs's Disease, a motor-neuron illness that causes muscles to atrophy. She presents her efforts to find privacy during a time when her brother required continuous attention. She also describes the projects he designed to help himself better cope with his progressive deterioration.

In addition, we include regular items as well as two reviews: the first, of a quarterly magazine, *This England*; the second, of a book, *Streets and the Shaping of Towns and Cities*, by architect Michael Southworth and landscape architect Eran Ben-Joseph. Illustrations this issue are from this book.

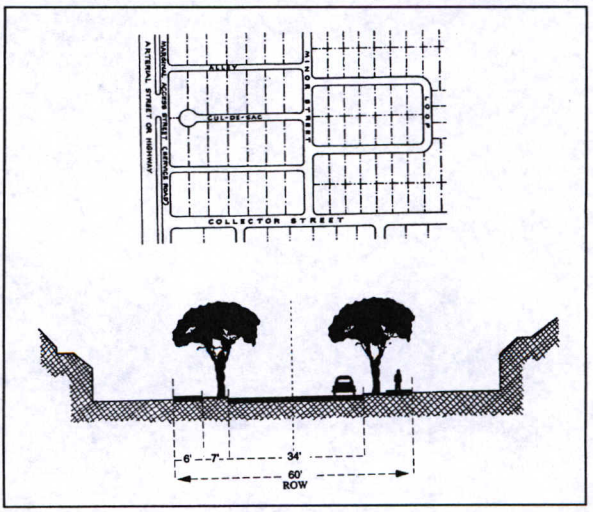
CONFERENCES

Making Sacred Spaces is the theme for the next **Built Form and Culture Conference**, to be held at the University of Cincinnati, 16-19 October 1997. Topics include: (1) sacred landscapes, rituals, markings, and communities; (2) spiritual or sacred aspects of environments addressing architecture, art and design; (3) sacred aspects related to construction and creative processes. Contact: James Postell, SAID, ML 0016, University of Cincinnati, Cincinnati, OH 45221-0016.

The annual meeting of the **Society for Phenomenology and the Human Sciences** (SPHS) will be held 16-18 October at the University of Kentucky in Lexington in conjunctions with meetings of the **Society for Phenomenology and Existential Philosophy** (SPEP). Contact: Maureen Connolly, Brock University, Physical Education Department, St. Catherines, Ontario L2S 3A1 (905-688-5550).

The 16th annual **International Human Science Research Conference** will be held in Trondheim, Norway sometime in summer, 1997 [date not determined at press time]. The conference theme is "The Challenges for the Human Sciences in a Technological World." Contact: Ingunn Hagen, Psychology Department, Norwegian University of Science & Technology, N-7055 Dragvoll, Norway (+47-7359-6649).

Current U.S. street standards, emphasizing traffic efficiency and neighborhood privacy, specify discontinuous pathways and wide pavements. *See p. 4.*



ITEMS OF INTEREST

The second biennial conference of the **Association for the Study of Literature and Environment** (ASLE) will take place at the University of Montana, Missoula, July 17-19. Contact: J. Tallmadge, 6538 Teakwood Court, Cincinnati, OH 45224-2112 (513-681-0944).

The **1st International Space Syntax Symposium** will be held in London, 15-18 April 1997. Themes will include urban analysis, complex buildings, and domestic space. Contact: Mark Major, Bartlett School of Graduate Studies, University College, London, 1-19 Torrington Place WC1E 6BT UK.

Building with Nature is published bi-monthly by architect Carol Venolia, whose aim is "to inform and inspire designers, builders, and inhabitants of built environments who are dedicated to transforming the way we relate to place." Each issue focuses on a particular topic such as "earth materials," "wood," "people and places," "recycling," "southern California," and "small houses." *BWN*, PO Box 4417, Santa Rosa, CA 95402-4417.

The 1997-98 issue of **Undercurrents**, a journal of environmental studies, is seeking contributions that focus on "divisions, boundaries, territories." Contact: *Undercurrents*, Faculty of Envrtl. Studies, York Univ., 4700 Keele St., N. York, Ontario M3J 1P3.

Below: "Over the past century American conceptions of the residential street network have changed dramatically from the interconnected rectilinear grid of the turn-of-the-century (a), to the fragmented grid and warped parallel strets of the 1930s and 1940s (b), to the discontinuous insular patterns of cul-de-sacs and loops preferred since the 1950s" (© M. Southworth). See review, p. 4.

MEMBERSHIP NEWS

Bruce K. Kirchoff is an Associate Professor of biology at the UNiversity of North Carolina at Greensboro. One of his research interests is how important aspects of understanding are ommitted from the standard science curriculum. To help bridge this gap, he teaches a course in "Science as a Way of Knowing," which brings students in touch with the social environment in which science is done and the effect of this environment on scientific thought. He has recently published "Scientific Communities, Objectivity and the Transformation of Science," an article that discusses "the relationship between our perceptions of what we take to be the objective world and the 'reality' that underlies these perceptions." To order: Institute of Noetic Sciences, 475 Gate Five Rd, St 300, Sausalito, CA 94965.

William Hurrle is Principal of *Community Builders*, a design-build firm in Green Bay, Wisconsin. He writes: "*EAP* is worth it--just the book reviews alone keep me aware of how much more I could read. I'm much of the organic persuasion--a techno-peasant into solar hardware and organic gardening. Places have spirits and we violate them to our peril. The task is to find ways to fit into the circles of life." 1494 Cedar Street, Green Bay, WI 54302.

David Russo is a first-year law student at New England School of Law in Boston. He studied phenomenology with philosopher Richard Capobianco while a student at Stonehill College in North Easton, Massacusetts. He spent four months in England in a foreign study program and in this issue of *EAP* reviews the quarterly publication *This England* (see p. 3). 106 Forest St., Watertown, MA 02172.

PERIODICAL REVIEW

This England [a quarterly magazine published in Cheltenham, England, and edited by Roy Faiers; $30/yr & available from: PO Box 301129, Escondito, CA 92030].

This England is a quarterly picture book that invites the reader to linger on each photograph, taking in and living all the spirit that is "this England." Feature articles celebrate the long and rich traditions of England and the strength of its people. Ideologically, however, this magazine implicitly suggests the statement: *This England...* as opposed to *that* one.

The goal of the magazine is the protection and preservation of the English space, including natural space, lived space, legends, local poems and pop culture of a previous time. English space appears in traditional terms that are unchanging and solidly part of the long English tradition, including ancient structures, natural topography, gardens and local custom. The reader is presented with a wide array of interesting and valuable English phenomena, which today may otherwise have few opportunities for expression.

One highly regarded manifestation of the English spirit is the garden, which is seen as a schematic of the English spirit. Gardens and other natural spaces are rightfully sources of refuge, replenishment and strength where the English spirit is said to dwell and thrive. Natural spaces are places where people create a livelihood, grow sustenance, labor, relax, entertain and have fun. And although this phenomenon is at least partly true in that narrow sense, it is incomplete. More accurately, the English spirit, in a basic phenomenological way, is engendered in a vast array of spaces and manifestations. The English spirit rightfully dwells in England's natural spaces as well as its modern contexts.

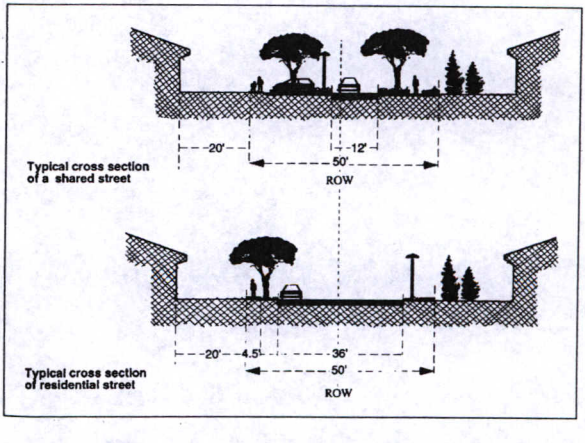
Consequently, *This England* reacts strongly against perceived incursions of technology and modernization. The editor raises consciousness, in a healthy manner, about those valuable aspects of English life and culture that are believed to be in danger of obliteration. He proudly highlights aspects of culture on its own merit. No attempt is made to unnaturally change culture to appeal to an audience.

The magazine revels in English tradition, investigating ancient origins of modern English surnames, exploring the varied texture of English country villages and even jostling with the silly--e.g., "Forty Strange Facts about Devonshire" or "Promotion and Display of the Union Jack." Subsequently, a local vernacular becomes more and more apparent to the reader. All of these avenues serve to successfully recreate and present a phenomenology of England, at least of the past.

This England is more than a nostalgia magazine; it succeeds in its project of preserving England's valuable island story. The editor is rightfully concerned with the obliteration of many local customs, traditions and spaces. Impositions of government, modernization, technology and communication on local topography, custom and tradition can threaten the many valuable traditions and places of England. However, the magazine is overly narrow in its definition of an appropriate English space and does not see the possibilities of new and modern environments as places where the English spirit can dwell and thrive. In this sense, *This England* must broaden its purview to gain insight into today's phenomena of English place and experience.

--David J. Russo

Below: Typical American street (bottom) and shared Dutch street, or woonerf *(top), designed to slow traffic and to support play and social uses (* © *E. Ben-Joseph). See review, p. 4.*



BOOK REVIEW

Michael Southworth and Eran Ben-Joseph, 1997. *Streets and the Shaping of Towns and Cities*. NY: McGraw-Hill. ISBN 0-07-059808-8.

This book on American streets takes up its task with clarity and precision. Southworth and Ben-Joseph, architect and landscape architect respectively, have no theoretical or ideological agendas; rather, their aim is to trace the evolution of American residential street standards, using technical publications and built projects as evidence.

In an introduction and six chapters, all well illustrated, the authors identify major historical shifts in the development of street guidelines. The first period, 1820-1870, incorporates the early British and American suburbs inspired by the picturesque movement in landscape design (e.g., John Nash's Park Village and Frederick Law Olmsted and Calvert Vaux's Riverside Illinois).

Chapter 2 examines the period 1870-1930, a time when legislation for residential street standards was passed because of poor living conditions in the early-industrial English city. These rigid requirements spurred a reaction from designers like Raymond Unwin and Norman Shaw, who sought more flexible and creative ways to plan residential communities. Also during this period, technological developments, especially the invention of the automobile, had a major impact on community design, as shown in different ways by the work of Clarence Stein, Henry Wright, LeCorbusier, and Walter Gropius.

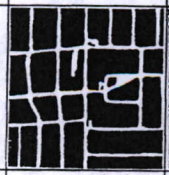
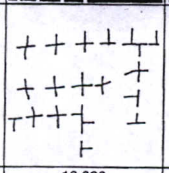
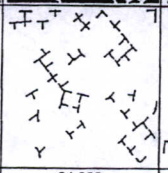
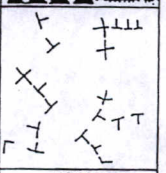
Chapter 3 covers 1930-1950, a time when the modern suburban form became institutionalized with the establishement of the Federal Housing Administration, "which disseminated street design guidelines and standards as part of FHA loan programs" (p. 8). In the last period, 1950-1985, transportation planning became dominant, and street design focused almost exclusively on the needs of automobiles, driver comfort, and traffic safety. The emphasis was on fast, efficient movement through the city as a whole and little concern about the impact this kind of movement and its design needs (e.g., wider through lanes and parking lanes) would have on the specific parts of the city, especially neighborhoods.

For *EAP* readers, the book's last two chapters will probably be the most insightful because the authors explore street standards that might regenerate a sense of community and place. Chapter 5 focuses on two current alternatives: first, the "New Urbanism" movement, which seeks to design walkable, mixed-use neighborhoods where buildings of a unified architectural style form coherent public spaces where people see and interact with each other; and, second, the "shared-street" concept, in which the street becomes a place for social contacts and public activities as well as for vehicular traffic.

This chapter provides an insightful comparison and contrast of Elmwood, a traditional streetcar neighborhood in Berkeley, California; and Kentwood, Maryland, and Laguna West, California, two neotraditional developments--the first designed by A. Duany and E. Plater-Zuberk; the second designed by P. Calthorpe and Associates.

For example, the table, next page, compares traditional and neotraditional street patterns as illustrated by these three neighborhoods. Using simple countings, the authors conclude that the street arrangements of the two neotraditional designs are, in several ways, closer to the hierarchical layout of other planned suburban developments than they are to Elmwood's more permeable modified rectangular grid composed of various-sized blocks. For example, in terms of loops and cul-de-sacs--"the essence of discontinuous suburban street forms"--Elmwood has only 1, while the neotraditional communities have 10 and 15, respectively.

Using additional information besides that in the table, the authors also point out that, in terms of total access points per neighborhood, Kentlands and Laguna West are weakly connected with the surrounding urban context. Reaching a conclusion that contradicts much of what the New Urbanists claim in their rhetoric, Southworth and Ben-Joseph argue that these two neotraditional designs are much less permeable than Elmwood and, like conventional planned suburban developments, minimize multiple routes and flow-through.

	ELMWOOD (1905)	KENTLANDS (1989)	LAGUNA WEST (1990s)
Street Patterns			
Intersections			
Lineal Feet of Streets	18,000	24,000 (alleys 7, 000)	19,000
Number of Blocks	23	24 (w.o. alleys 14)	16
Number of Intersections	20	41 (with alleys)	20
Number of Access Points	17	22	14
Number of Loops & Cul-de-sacs	1	10	15

Above: "Comparative analysis of Traditional and Neotraditional Street Pattterns. Elmwood is clearly the most rectilinear pattern and has the least amount of street length. Laguna West is more like other suburbs in terms of number of blocks, access to the larger context, and number of loops and cul-de-sacs. Squares are 2,000 feet on each side and contain approximately 100 acres" (© M. Southworth).

Chapter 6 examines the future of residential streets and suggests that "currrent problems in subdivision street design may be attributed to a single-minded focus on trafic control and a lack of intergration between concern for functional accessibility and livability" (p. 131). The authors conclude by presenting seven criteria "to evaluate existing residential streets and street standards, as well as to guide the making of new ones" (p. 142):

1. Support varied uses of residential streets including children's play and adult recreation.
2. Design and manage street space for the comfort and safety of residents.
3. Provide a well-connected, interesting pedestrian network.
4. Provide convenient access for people who live on the street but discourage through traffic; allow traffic movement but do not facilitate it.
5. Differentiate streets by function.
6. Relate street design to the natural and historical setting.
7. Conserve land by minimizing the amount of land devoted to streets.

COMMENTARY

Perhaps this book's most interesting point is the perceived shift in what a street should be: until the start of suburban development in the late 19th century, the street was seen largely as a space of interconnected movements that held the larger settlement together as it also provided a local place for social interaction. Phenomenologically, it could be said that there was a balance between movement and rest--between the street as a place to live and a space to move. In this sense, streets contributed to the lived character of particular places within the settlement as, at the same time, they provided passageways linking that place with other places. The whole and part worked together and sustained each other.

Over time, as residential privacy became important and the automobile ever-present, there grew a division between movement and rest as suburban development--with its cul de sacs and loops--established, on one hand, an insular neighborhood and, on the other hand, a set of overworked through streets.

Southworth and Ben-Joseph suggest, that, ironically, neotraditional communities mostly extend this insular model (though, to be fair, the authors also emphasize that some of the designs--e.g., Kentlands--try to provide some connectedness within and between neigborhoods).

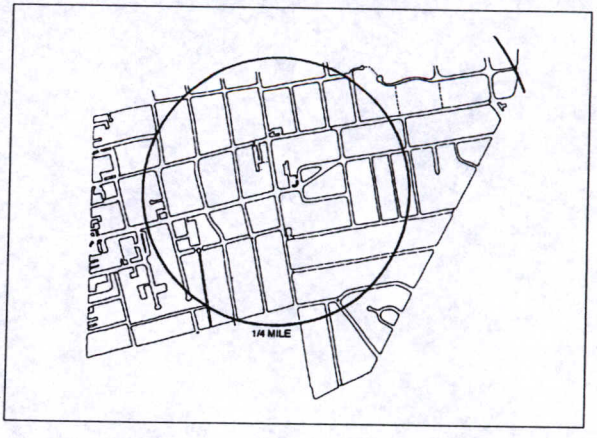
In this regard, it is disappointing that the authors use only empirical standards and projects for their conclusions. Also crucial to the discussion of how streets work is Bill Hillier's space-syntax studies that explore geometrically how pathway systems have

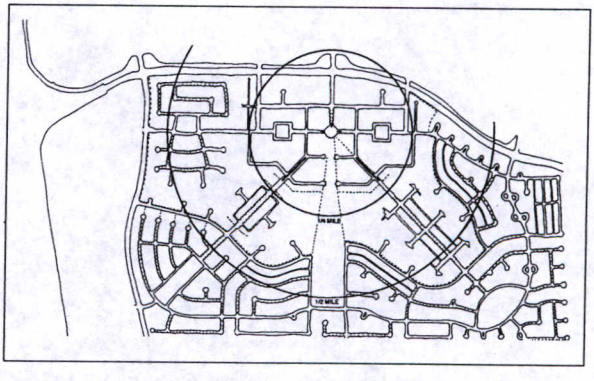
both settlement-wide and local significance (see *EAP*, *4*, 2). Hillier's concepts and findings are crucial to the authors' argument, since he demonstrates quite convincingly that streets must work on the settlement-wide level (i.e. promote movement, connectivity, and exchange) before the local neigbhorhood can be healthy.

Hillier also points out that, in traditional settlements, the most active streets and areas abutted the most quiet areas: In other words, the places of street life, publicness and strangers' mixing with localites were very near to the more private residential areas used by localites alone. Movement and rest, activity and place, locality and greater surrounds were apart yet together!

As Southworth and Ben-Joseph occasionally suggest, this need to reunite movement and rest through community design is crucial, and the efforts of neo-traditional design are an important start but probably do not go far enough. As the authors' seven proposals above suggest, there is still too much emphasis on the insular locality not easily accessible to its larger surroundings. In this regard, Bentley et al's *Responsive Environments*, partly derived from Hillier's conclusions (see *EAP*, *2*, 2), is one of the few practical design efforts that seeks to recreate a balance between movement and rest and permeability and local sense of place.

Below: Street patterns and study areas of Berkeley's streetcar neighborhood, Elmwood (above), and neo-traditional Laguna West (below) (© M. Southworth).





In spite of this criticism, however, *Streets...* is a clear summary of changing street standards and a provocative presentation of how perceptions of these standards have shifted, especially the wavering fortunes of the orthogonal and deformed grid arrangements that dominated settlement patterns until the late 19th century.

If we trust Hillier, we must somehow return to a permeable grid pattern that will also allow for local neighborhood life. Though Southworth and Ben-Joseph probably give too much weight to local street activity, at the expense of larger-scale permeability, they get us thinking about what streets are and what they might be.

The need is to compliment the authors' historical and empirical insights with the conceptual vision of Hillier so that pathways will stimulate the sociability of the city as a whole as, at the same time, they contribute to the vitality of the city's local places. As I have argued before, probably the best conceptual context for understanding this parts/whole relationship of pathway systems is the language of phenomenology because it allows one to integrate the formal and lived qualities of environment and place.

--David Seamon

ILLNESS AND THE WAY OF THE BODY

S. Kay Toombs

Toombs is a philosopher who has written The Meaning of Illness *(Kluwer, 1992), an insightful phenomenological account of the strikingly different understandings of illness held by physician and patient. For over 20 years, Toombs has lived with multiple sclerosis--an incurable, progressively disabling disease of the central nervous system. This illness has, among other things, affected her ability to see, to hear, to sit, and to stand. She must now use a wheelchair because she can no longer lift her legs to walk.*

Many of Toombs' scholarly works, including the following selections, use her illness experience as a foundation for phenomenological inquiry. The first selection below is the first part of a paper, "The Way of the Body: Embodied Practice as Therapeutic Intervention," presented at the 1996 annual meeting of the Society for Phenomenology and Human Sciences (SPHS) in Washington, D.C. The second part of the paper, not included here, examines "the therapeutic value of embodied practice as a means of achieving a renewed sense of connectedness and harmony."

The second selection below is from "The Lived Experience of Disability," an article originally published in the journal Human Studies. *This article is a vivid, heartfelt phenomenological account of the human experience of disability. Address: Philosophy Department, Baylor University, PO Box 97273, Waco, TX 76798.*

On July 16, 1995, I suffered a serious accident as I was returning home after attending a professional meeting in Canada. As I boarded a bus at an airport, I flipped straight over backwards in my wheelchair as I moved from the elevated wheelchair lift into the interior of the vehicle.

Although I sustained injuries to my head, neck, shoulders, back and hips, the most devastating result of my accident was--for the most part--invisible. Diagnosed several weeks later as post-traumatic stress disorder, my most serious injury was an immediate, and all-encompassing, uncontrollable terror of being in my wheelchair. Recovering from this trauma has taken many months but it has been a transformative experience in unexpected ways.

In this essay, I explore this lived experience and suggest that paying explicit attention to embodiment can be an integrative practice that results in a renewed sense of personal wholeness. In describing what it is like to live in the aftermath of this kind of physical trauma, I briefly discuss three manifestations of terror: first, an immediate and profound transformation of the surrounding world; second, an acute sense of separation between body and self; and, third, a strange and disordered experience of sensory awareness with respect to bodily movement and spatial location.

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In my previous work on the phenomenology of illness and physical disability (Toombs 1992a, 1992b), I have detailed a number of changes that occur in the surrounding world. To give one example: loss of mobility causes one to experience physical space as unusually constrictive. When one is sick, the world shrinks to the confines of one's house or to the limits of one's room. What was formerly regarded as near (work, the neighbor's house, the doctor's office) is now experienced as far.

Moreover, body and world are so interrelated that dimensions of the surrounding world change according to the range of possible movements (Toombs, 1995). From a wheelchair, for instance, most shelves in the grocery store have the characteristic of being impossibly high, beyond attainable reach. A problem with the body is concurrently a problem with the environment

My accident transformed the surrounding world in a different but startling--and intensely disturbing--manner. It was not simply that certain physical features of the environment presented themselves as problematic but rather that the world as a whole threatened in a myriad of ways.

Instead of being at home in a relatively safe and predictable landscape that I had learned successfully to negotiate in my wheelchair, I now felt constantly endangered by my hostile surroundings. Flat surfaces menaced since they concealed hidden obstacles, modest curb cuts were breathtakingly steep (so much so that just imagining wheeling up the ramp literally took my breath away). Uneven surfaces were inherently treacherous. Indeed, so ominous was the surrounding world that I found it impossible to venture outside the house in my wheelchair.

The terrain inside my house appeared only slightly less hazardous. Every time one of my wheels went over an insignificant bump such as a door threshold, or I unthinkingly shifted my weight so that my spine

pressed against the back of the chair, I was immediately overcome by the terrifying sensation of falling--reliving again and again a gut-churning sensation of flipping over backwards.

"It is like walking through a minefield," I wrote in my journal, "forgetting for a moment that there is jeopardy and then tripping on a stone and knowing it could be a mine that will blow up in your face." It made absolutely no difference that I had installed stabilizers on my wheelchair, making it virtually impossible to overturn, or that I knew, in my heart of hearts, that my fear was irrational.

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Many months later, in a moment of reflection about my experience, I recognized the importance of Sartre's (1948, p.91) observation that in true emotion the world is apprehended as "magical"--a global transformation that renders inoperative common sense knowledge and interpretation.

In discussing this transformation, Sartre gives the example of catching sight of a grinning face flattened against the window pane. On seeing the face, Sartre notes, "I feel invaded by terror" (ibid., p. 82)--a feeling "that destroys all the structures of the world that might reject the magical and reduce the event to its proper proportions" (ibid., p. 86). The window is perceived as the frame of the horrible face rather than as "an object which must be broken." Its location is menacingly present rather than appearing at "a distance of ten yards."

In this act of consciousness, the world is coherent but stripped of its instrumental quality: "The face that frightens us through the window acts upon us without instruments. There is no need for the window to open, for a man to leap into the room and walk upon the floor" (ibid., pp. 87-90). I apprehend my surroundings through the lens of my emotional state. I experience the world as fearful because I am afraid.

Following my accident, the surrounding world was also transformed in the sense that I no longer trusted my tacit "knowing how" to negotiate space. As Merleau-Ponty notes, with habitual use objects such as a wheelchair are incorporated into the body becoming an extension of bodily space.

Just as the person on two feet unreflectively judges how high to lift a foot to clear a curb, so the person in a wheelchair unthinkingly performs physical movements and intuitively allows for the dimensions of the chair in navigating the environment.

My accident compromised this embodied knowledge. Since I had unexpectedly flipped backwards while performing a routine maneuver (one that I do every day when I get into my own van), I no longer trusted my senses. Nothing had alerted me to the possibility that I might overturn. How could I now judge correctly when it was safe to move and when it was not?

This loss of confidence ruptured the embodied connection with my wheelchair. I no longer experienced my wheelchair as an integral aspect of my embodiment. Rather, I viewed it with suspicion as an object that I was forced to use, knowing that it could cause me great harm.

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My experience of terror also manifested itself through a particular kind of bodily alienation--an alienation that reveals another aspect of the dynamic relation between body/environment. Not only does a problem with the physical body engender a problem with the surrounding world, but it is equally true that a transformation in world results in a transformation in bodily being.

In responding to the world-as-threat, my body was its own barometer. *It* reacted, *it* assessed the situation, *it* judged when and how to respond to perceived danger or possible threat. Without warning and without my conscious involvement, my lungs would become suffocatingly short of breath, my heart would develop a rapidly escalating and erratic beat, the muscles in my shoulders, back and neck would become taut, the pit of my stomach would constrict, and--as a kind of crescendo--my body would endure the terrifying physical sensation of flipping over backwards. Although I could predict these bodily responses in certain situations, such as closing my eyes and imagining that I was wheeling up a slope, on most occasions my body reacted to a perceived danger of which I was not consciously aware. Consequently, I experienced my body as separate in a particularly disconcerting manner. Not only did it seem Other-than-me with its own physical nature but it seemed overtly to have a mind of its own, deciding

when and how to react.

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As this description makes clear, another manifestation of my accident was a strange and disordered experience of sensory awareness. My tactile and visual senses no longer provided accurate information with respect to bodily movement and my body's location in space.

Under normal circumstances kinesthetic sensation and proprioception give one a sense of where one's body is in space. If, for example, I reach for a glass of water, I know the position of my arm as it moves towards the glass. I am also implicitly aware that my body is facing in a certain direction and occupying a steady, and balanced, seated position at my particular place at the dinner table.

I also know that if I perform certain movements such as bending towards the floor to retrieve my dropped napkin, or leaning backwards so that the front legs of the chair no longer have contact with the floor, my sense of stability, motion, and direction will change accordingly.

My accident severed my moorings in space. I felt adrift in a completely unpredictable and terrifyingly unstable environment. I might, for example, be seated motionless at my desk with eyes focused on the computer screen in front of me when a sudden, inexplicable shift of bodily position would initiate the visual, auditory, tactile, and visceral sensations of catapulting backwards towards the ground.

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Many months later, as I reflect back on this traumatic recurring sensation of falling, I am struck by the fact that such experiences appear to involve what Husserl described as primary--rather than secondary--memory. That is, as lived through, the sensation is a pre-reflective originary experience rather than a reflective "as if" presentation that involves recollection.

In other words, my experience was not a "flashback" to the actual incident of falling in the bus at the airport but rather an immediate sensory awareness that my body was moving rapidly backwards through space in the present moment and at the present location. This means that the perceived danger remains vividly present, losing none of its potency despite the fact that these recurring experiences result in no actual physical harm.

Moreover, the present traumatic event is experienced as a temporal unity in Husserl's sense that the "now" moment includes an anticipation of the embodied experience that is to come and a retention of the embodied experience just past.

This process of retention and anticipation contributes to an escalating feeling of terror that is integral to each recurring episode. Since each episode is a pre-reflective originary experience (and not a recollection), it is important that therapeutic intervention is explicitly directed towards relieving the lived immediacy of embodied distress.

The experience of fear is a temporal unity in another respect. The present moment of terror not only incorporates a reference to meanings derived from past experience ("last time I fell, I hurt myself," or, in my own case, "since I take anticoagulants it is dangerous to hit my head") but fear is also future directed ("what will happen if this occurs?" "if I hit my head will I bleed into my brain," "what will my future state be now that this has happened?") Therapy must address the temporal meaning of the trauma, recognizing that this meaning will be different for each individual.

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I have described my experience in some detail to emphasize that emotions are concretely embodied. Post-traumatic stress disorder is not simply an illness that is "in one's head" as opposed to "in one's body." It represents a crisis of being-in-the-world. Living with this crisis has involved (and continues to involve) learning to reconnect with my body, to rediscover or remake the world as a habitable dwelling place and to pay explicit attention to deeply seated feelings.

REFERENCES

Sartre, J.P. 1948. *The Emotions: Outline of a Theory* (NY: Philosophical Library).

Toombs, S. K. 1992a. The Body in Multiple Sclerosis: A Patient's Perspective, in D. Leder, ed., *The Body in Medical Thought and Practice* (Dordrecht, the Netherlands: Kluwer).

_____ 1992b. *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient* (Dordrecht, the Netherlands: Kluwer).

_____ 1995. The Lived Experience of Disability, *Human Studies*, *18*: 9-23.

RECOUNTING A ROUTINE EXPERIENCE: GOING ON A PROFESSIONAL TRIP[1]

S. Kay Toombs

To give some idea of the changed interaction with the surrounding world that occurs with loss of mobility, let me recount a *typical* experience.

On arriving at the regional airport to begin a professional trip, I look for a parking space that is wide enough to lower the wheelchair lift so that I can get out of my handicapped-equipped van. There is no handicapped parking space that is "van accessible" so I must find a space at the end of a row in order to put down the lift. If there is no space, then I must find a person who is willing to park my van for me and drop me off.

Once I am out of the van I look for a ramp to get into the terminus on my scooter. There is only one in the whole length of the sidewalk. However, the rental cars awaiting customers are routinely parked in front of the ramp blocking access. This means I must alert someone *inside* the terminus and wait for the cars to be moved before I can get into the building. Now that I have a cellular phone--as long as I have the appropriate phone number--I can alert someone in the building. Otherwise, I must wait for an upright person to arrive and request them to go inside and get assistance for me.

Once in the terminus I go to the airline check-in counter. In my battery-operated scooter I am approximately three and a half feet tall and the counter is on a level with my head. All my transactions with the person behind the counter take place at the level of my ear. The person behind the counter must stretch over it in order to take my tickets, and I must crane my neck and shout in order to be heard.

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The small commuter plane arrives and there are steps leading into the cabin. Since I cannot walk, I must be carried on board--a process that requires a transfer from my scooter to a device that looks rather like a barstool on wheels.

To transfer, I turn the scooter seat, manually lifting my legs and putting my feet on the ground. I can then be pulled into a standing position and lowered onto the carry-on device that has been placed adjacent to my scooter. Someone then picks up my legs, places them on the footrest and I am strapped in and requested to fold my arms over my chest (in the manner of a corpse!).

I am then wheeled out to the plane and two people lift the carry-on device--as one does a stretcher--and carry me up the steps. Once on board, I again transfer to get into my assigned seat. This whole operation is, of course, performed in full view of all the people in the airport lobby. They also watch as I am lifted into the plane. At the first destination, when all other passengers have alighted, I am carried off the plane, necessitating a repeat of the transfer procedure from airplane seat, to carry-on device, and then to scooter or wheelchair.

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We arrive at the terminal building to find that the only entrance is up two flights of stairs and the elevator has been broken for two days! Once again I must transfer so that I can be carried up the stairs into the terminal. The necessity to repeat this procedure numerous times is not only difficult and frustrating for me but, judging from their words and actions, it is obviously irritating to those who are carrying me.

In the terminal building, I am outside the security checkpoint. However, it is not possible to go through the security gate in a wheelchair or scooter. Consequently, I am taken to the side, once again in full view of everyone who happens to be in the area. My whole body--from armpits to fingertips, from the top of my head to the base of my spine, from groin to ankle, from under my chin and over my breasts and abdomen--is "patted down" ("frisked") by an airport employee.

I leave and go to the restroom. Although the door is wide enough, the "handicapped accessible" stall is too short to accommodate the length of my scooter. I must, therefore, sit in it with the door open. Obviously, if that particular stall is occupied--whether by

a person with a disability or by an "able bodied" individual--I must wait until it is vacant, since I cannot get through the door of the "normal" sized stalls with a wheelchair or scooter.)

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I leave on the second "leg" of my trip. Although I do not have to negotiate steps to board the larger plane that will take me to my destination I must still be carried to my seat (and off the plane) since the aisle between the seats on an airplane is not wide enough to accommodate a wheelchair.

This also means that, in the event of a long trip, I must request an "aisle chair" (a smaller narrower version of the "barstool on wheels") to get to the restroom during the flight. Not only is it extremely undignified having to request this assistance but I must wait until it is "convenient" for the personnel servicing the flight to attend to my needs. In practical terms, I have learned that this means I should request assistance about thirty minutes before I think I will need it--and never at a time when the meal/drink carts are out of the galley. I am then wheeled to the restroom in full view of most of the passengers who watch as I transfer from aisle chair to toilet!

After arriving at my destination, de-planing, and getting to the hotel--a trip that necessitates taking a taxi since the airport limousine cannot accommodate a person in a scooter or wheelchair--I find that (the *Americans With Disabilities Act* notwithstanding) not one of the four hotel restaurants is accessible from *inside* the building. Each one can only be reached by going up steps from the hotel lobby. Limited access is available from *outside* the building but this necessitates going two blocks in the pouring rain.

Later, I discover that a colleague and I are unable to walk from the hotel to a nearby place of interest since we can go no farther than a block *in any direction*--there are no curb cuts that would enable me to ride my scooter off one sidewalk and on to another.

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I should note that this experience I've just described represents just the "tip of the iceberg." I am no longer able to travel alone because, more often than not, so-called "handicapped accessible" rooms in hotels do *not* have wheelchair accessible bathrooms, let alone accessible showers or commodes. Consequently, my travelling companion has to be able to manually assist/lift me/hold me up if I am to be able to use the bathroom.

It is simply a fact of life that the majority of bathrooms/restrooms in modern buildings (including private houses) are constructed in such a way that the doorways are not wide enough for wheelchairs to pass through.

A routine invitation to a restaurant, a theater, someone's house for dinner, a business meeting, a friend's apartment, or a shopping excursion requires that I ascertain if I can get into and out of buildings, if there is adequate parking, if there are ramps and elevators, if I am blocked by stairs (either into the house or inside it), if rooms/hallways/bedrooms are so arranged in private houses that it will be possible to negotiate around furniture in my wheelchair, if I can get in and out of automobiles, if I can transfer from my wheelchair to the toilet. As bodily capacities decrease, the challenges posed in the negotiation of space obviously become more numerous.

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The *routine* experience I've described above illustrates another aspect of the changed experience of space that occurs with loss of mobility. The surrounding world appears (feels) different than it did prior to bodily dysfunction.

In particular, the world is experienced as overtly obstructive, surprisingly non-accommodating. Actions are sensed as *effortful*, where hitherto they had been *effortless*. On occasion the world threatens even. And often it presents itself as questionable. The "knowing how" of one's engagement in the world is rendered circumspect.

The effortful nature of worldly involvement that is characteristic of incapacitating disorders can engender a sense of fatigue that I shall call "existential fatigue." To organize and carry out projects requires not only physical ability but, as importantly, an exercise of will. When ceaseless and ongoing effort is required to perform the simplest of tasks (getting out of bed, dressing, taking a shower, going on a trip), there is a powerful impulse to withdraw, to

cease doing what is required. Consequently, physical incapacity exerts a centripetal force in another sense. The person with a disability is tempted severely to curtail involvements in the world.

Note

1. This selection is reprinted, with the permission of Kluwer publishers, from pp. 13-15 & p. 22 of "The Lived Experience of Disability," *Human Studies, 18* (1995): 9-23.

AT THE END

Gwendolyn Scott

Gwendolyn Scott is a poet and landscape architect who did her MLA at Kansas State University. She originally contributed the following two-part essay to EAP *as two separate pieces about her recent experiences of caring for her brother as he succumbed to ALS (amyotrophic lateral sclerosis). Better known as Lou Gehrig's Disease, this motor-neuron illness causes a person's muscles to atrophy because electro-chemical connections are increasingly unable to signal bodily movement.*

Scott writes: "My brother died peacefully at home in February, 1996, after two and a half years of living with ALS and the attendant pain in his joints and skin. In what follows, the reader might get the sense that only my mother and I took turns seeing to my brother's needs. Not so. We had the help of at least twenty others, including night-shift friends, hospice nurses, counselors, and case workers. My mother and I could barely believe the 'circus,' as we called it, that our normally quiet life had become. It was this sense of 'unreality' that prompted me to consider the theme of privacy."

The second part of Scott's essay was written after her brother's death and describes some of the projects he designed after he contracted ALS. She continues: "Before my brother died, we had a number of conversations about his design work. That is, he signed in Morse Code: pursed lips like a kiss signified a dot, a smile signified a dash. He would wiggle his eyebrows at the end of a word, and I would respond vocally. This method of communication was time-consuming and frustrating. It was amazing, however, how communicative, almost verbal, his face became. He used almost every part to communicate with us." Address: 524 West 4th Street, Medford, OR 97501.

PART I. CREATING PRIVACY

Recently, I moved from a small town in Iowa, where I worked as a resource specialist inventorying various parts of the Loess Hills Scenic Byway. With my cat, Stella, I lived in a small two-bedroom house with a large back yard. I now live north of San Francisco in a small two-bedroom house with my mother and younger brother, who is dying of ALS--the motor-neuron disease that killed Lou Gerhig.

My mother has one bedroom and my brother the other. I have a small triangular space at the far end of the living room where I have my futon couch/bed, my mother's low Japanese desk used as a night table, a night stand, and my great-aunt's sewing table on which sits my computer. My clothes are in a chest in the hall which separates my mother's room from the bathroom. I have less than half of one closet and a third of another in which to hang clothes.

My space is delineated by the tire tracks of my brother's wheelchair as he crosses the open space to the sliding glass doors on his way out to the deck. As I sit writing at my computer, I'm aware that I'm a sitting target for anyone who feels he or she can come talk to me because I'm in the "public space" known as the living room.

I remember reading that Jane Austen wrote in her family's sitting room and had to hide her work when others entered the room. I feel the same way when some one approaches, not because he or she would be upset by my writing, but because I do not want to explain what I am doing. I am not sure where what I am writing is going and want to explore by myself.

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The need for creating privacy became apparent as I settled in, not just for myself but also for my mother and brother. We use a number of tactics to meet each other's needs.

One tactic is schedules. My mother and I have worked out how to do our morning rituals, while using a baby monitor to hear my brother when he groans for something he needs. We each do our own separate rituals, eat breakfast separately, before my brother is ready to start his day. We also adhere to afternoon schedules as much as possible. When I have time off, I make sure I leave the house and not

continue to do things for my brother.

Another tactic is to leave the house, which I do daily, even if it is only for a short walk down the hill and back. Most of the time I go hiking in the nearby hills. The canyons of oak, madrone, redwood, and bay are quiet during the week days. I rarely see anyone else. I feel sheltered as I walk under the filtered canopy of oaks or the deep shade of redwoods. There is enough change between oak savannah and forest that I do not feel claustrophobic.

I also go to a coffee house to draw. An acquaintance thinks it interesting that I should choose a coffee house for privacy, since he frequents the place for companionship. Yet there is a table, coffee and concentration.

Another tactic I have is to keep my friends separate from the friends of my mother and brother who help us on night shift. My friends are mostly professionals who live too far away to help with my brother. We meet for lunch and talk about our lives. I try to limit how much I talk about my brother. I would rather focus on other aspects of life that have been put on the shelf, at least for the moment. I also drive north 375 miles every other weekend to visit my sweetheart for three and a half days.

My brother also needs privacy. My rule is not to use his room as a passage to the bathroom. I go around to the bathroom door in the hallway instead of cutting through my brother's room to enter. I knock on his door, as well as my mother's, if either is shut.

Though I know that my situation here is temporary, I'm surprised at how not having my own room has affected my ability to feel creative and loving. I have had my own room since I was eleven. As an adult, I always have had some kind of office. I have had space in which to think, create, write, to shut the door and simply be.

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I write this after a long holiday weekend with my brother but with no break from his usual Friday caretaker, who needed time with her family. During the weekend, I despaired of ever finishing this essay. Time did not flow smoothly but stretched outward to the horizon. Would I ever make it through with some kind of equanimity? In fact, I did not. I reached the point past burnout. I knew I had reached it. I do not think I have ever felt so used up and spit out. My sleep was restless, no relief. I woke dazed.

Fortunately, my mother took me to church, where the minister spoke movingly about dreams as a connection to the divine. We went to lunch and I began to feel myself again.

Next, I went for a long hike in the hills to see if I could spot the white umbrella under which my brother sat on the southeast deck. No such luck--our Oregon White Oak hides the house. But I was up on the ridge tops with a wonderful view of the north San Francisco Bay. The north wind had blown the smog elsewhere, and I could see the Richmond Hills.

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It would be easy at this point to bring up Virginia Woolf's ideas about *A Room of One's Own* and from there to discuss how not having privacy or space could lead to subjugation of self and the whole of womankind. Instead, my aim has been to look at what happens to me, who has had and will again have a private space. My mother was wishing that I had some way to "take ten." My thought, though I did not say it aloud, was "take ten where?"

As a landscape architect, I now truly have in my bones the knowledge of the need for garden as refuge. One of my challenges will be to extend that knowledge to public spaces. I am reminded of the pattern in Alexander's *Pattern Language* (Alexander 1977) concerning sleeping in public places. I am also reminded of Alexander's failed Mexacali project in which he used his patterns to create low-income housing that the residents built themselves (Alexander 1985; Fromm & Bosselman 1983-84).

One way in which the experiment failed was its use of outside entrances to an inner courtyard available to all the residents. Outsiders used the space as a shortcut--a behavior disruptive to the residents' ability to create private zones near their dwellings and to use the courtyard as a communal space. Partly because of this failed courtyard, there was no way for them to create rituals or common courtesies to knit them together as a community.

This experience underlines a long-held thought: that privacy and community go hand in hand. For me to want to reach out in a loving way to others, I need time and space to myself.

PART II. DESIGNING FROM THE BODY

When I wrote the section above, I was thinking about myself as a designer and how I coped with a set of circumstances. I am not, however, the only designer in my family, and I want to describe some of the projects my brother designed after he contracted ALS.

My brother spent most of his adult life as a designer-builder, having gone the usual route of apprentice to journeyman to carpenter to contractor. The person he apprenticed with is an imaginative designer as well as builder, known for his curving structures and use of a router to round the boards themselves.

Though my brother had no formal training, he was influenced by the Art Nouveau style and Frank Lloyd Wright, as well Bernard Maybeck and the Arts and Crafts movement. The year before he contracted ALS, he had a change of heart and mind and enrolled at the local junior college in preparation for nursing school.

The more I worked with my brother and the weaker he became, the more impressed I was with the way he continued to design for his comfort and for his caretakers. I had helped him with building some of his inventions and thought he might have something to say about his design process. I talked to him about the possibility of writing an article about his designs and inventions. He responded in Morse Code:

My experience of designing has come from a hands-on approach. I would say to get out of the mind and into the hands. Energy follows attention. Let the mind follow the body.

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Indeed, my brother's designs followed his course of ALS. That is, while he had bodily strength, he designed on a large scale. The weaker he became, the smaller and lighter were his projects. One of the first projects I helped him and his mentor with was a turntable platform for his van. As the wheelchair access by mechanical lift was on the right side of the vehicle, the wheelchair faced sideways once it was inside, since there was no room to maneuver it face forward. The platform allowed the caregiver to turn the wheelchair with my brother in it around to face front. The shape of the platform was oval on one end and straight on the other with a beveled edge to allow the chair easy ascent.

At first, my brother wanted some kind of caster for the platform. However, it took several tries and hardware stores to find the parts right for what would work in the situation. Eventually, he used hard rubber wheels on steel axles inserted into the sides of the wheel slots. Once the platform with its non-slip strips was in place, tie-down belts for the wheelchair were installed so it would not roll around.

What interested me most about this particular project was watching my brother come up against the fact that what he had in mind--the idea of casters--was not going to work--that he had to let go of the idea to see what would really work.

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For the first year and a half, my brother lived in his home on the side of Mt. Tamalpais. His handmade house of one long main room and three side rooms was built over the hillside with three steps down to accommodate the landform. As his legs steadily became weaker, these stairs presented a problem. He had a barn track installed along the main ridge beam and used a pulley system attached to the track and a bosun's seat attached to the pulleys to carry him from his wheelchair to his bed. The caregiver could then gently let him down into bed, which was at the far end of the track. My role in this project was to be the strength standard. That is, if I could barely lift him, then we had to increase the ratio of the pulleys. Once I could lift him, then his other caregivers gave it a try. The pulley system finally worked at an 8 to 1 ratio by modifying two pulleys to work as one.

One might ask why my brother didn't install a ramp. For one reason, the area outside the front sliding glass doors wasn't big enough to maneuver the wheelchair to enter easily. Second, the house wasn't big enough to accommodate the wheelchair once it was inside. Third, the slope ratio was too steep for safety. Fourth, even if he could have designed around the above impediments, the idea of leaving the chair outside and gliding across the room was a fun, whimsical way of handling an ongoing

painful situation.

Though I did not work on it, another project my brother designed was called Little Nemo's Flying Bed. His hospital bed was placed on a platform that was mounted between four columns, which held rope threaded through winches attached to a single motor under his bed. When the motor was turned on, the ropes lifted the bed platform up and out of the sliding skylight. The point of this invention was to be able to be outside once he was confined to his bed. On the outside wall next to his bed, he had designed a built-out cabinet to house his stereo equipment, computer, television, and CD collection. Unfortunately, my brother's body weakened too thoroughly to live alone before the bed platform and cabinet could be completed.

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After my brother moved into my mother's house, he designed a small fold-out table on which his computer rested, either out and ready for use or folded up and out of the way. To remain slightly independent, he collaborated with family members to design a toe-driven electronic system which allowed him to turn on the TV and change channels, to raise and lower the hospital bed, and to use his computer without his hands.

This method of using his big toe worked for a couple of months before his toe became too weak to push the button. Then we worked together to redesign the control device. My brother suggested a baseball cap with a light wand sewn on top, which could be directed at a light-sensitive source that could be wired into the blue plastic box that held all the electronic circuits. For the light-sensitive source to pick up the wand's beam, the room would have to be very dark. This scheme was not practical, however, since by this time my younger brother often had two or three people in the room caring for him. The final outcome of the project was a long copper antenna sewn onto the top of a baseball cap, which, when my brother slightly turned his head side to side, connected to two other antennae hooked into a board at the top of the bed. He was able to use this device for about two weeks before his neck muscles became too weak and painful to turn even slightly.

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Over time, my brother's body lost most of the muscle mass a healthy, vigorous 38-year-old male body usually has. He barely had enough muscle in his legs to help with transferring from his bed to the wheelchair. This did not stop him from continuing to design and redesign for his body's deterioration, especially after he was bedridden.

The down pillow he had been using to cushion his hands on his lap reflected too much body heat. My brother suggested a folded towel in a pillow case. When I went to move his hands from palms down to palms up, however, his hands would not stay where I put them. My brother spotted the cardboard at the same time I did, and I cut it down to fit the inside the towel. The resulting "pillow" was light enough for his legs, stiff enough to prop up his hands, and could wick away any perspiration.

As his neck muscles weakened, we tried folding his down pillow to better bolster and support his neck. He could not, however, stay comfortable for very long. Finally, he hit on the idea of cutting some foam pieces into wedges, with which we could prop his head and take the pressure off his neck.

Another problem arose while he slept. His whole upper body would slump over to the side, and he could not right himself. Only his groaning woke the night attendant, who would then carefully pull him upright. To stop this, my brother suggested using a stiff foam pillow we had been using for his wheelchair as a "stopper" between his pillow and the wall. To keep this stop gap from sliding down, we used a 4" x 4" x 18" piece of foam wedged in at the bottom of the pillow and the wall.

My brother lived for another month, during which we kept him as comfortable as we could. As painful as it was to watch him deteriorate, I felt honored to work with him. I could see how, to the end, his projects and problem solving followed his dictum of "Let the mind follow the body."

REFERENCES

Alexander, C., Ishikawa, S., & Silverstein, M., 1977. *A Pattern Language*. NY: Oxford Univ. Press.

Alexander, C., 1985. *The Production of Houses*. NY: Oxford Univ. Press.

Fromm, D. & Bosselman, P., 1983-84. Mexacali Revisited: Seven Years Later. *Places*, *1*, 78-90.