

the street from the small brick house where Tom lived. I don't recall now whether he lived with his mother or with his aunt, but in any event he was such a dominant person that we noticed them only because they conveyed Tom across the street into our world. On nice days from April to November, and often in winter too, Tom was there under the oak trees in his wheelchair, holding court or enjoying a quiet conversation with one of the regulars. When a group was there he talked loud, laughed a lot, and got excited to the point that we sometimes had to wait a good while for a word to come out, especially during the punch line of a joke. "C'mon, Tom, tell it," somebody would plead. "You just want to hear the dirty part," he would squawk and laugh. He led the local free speech movement a decade before it arrived in California.

If I were riding my bike after school and found Tom with an older person, both of them looking serious and Tom talking softly and without much body movement, I usually waved, called his name, and kept going, for I knew he was talking news or politics and preferred not to be disturbed. I didn't mind.

It's not that Tom was just a voice. He was somebody, and we came to understand the relationship between words and persons — between meaning and being — in a subtle way that may not have been possible without his lesson. Our culturally approved vanities and virtues were given the lie by our friend of the riotous body. He made us forget physical attractiveness, athletic prowess, fashionable clothing, vaulting ambition. Since we accepted Tom and admired him without qualification, we implicitly affirmed values related to being, not having. His language reflected the poetry of human existence and taught us that the song of life can be sung in ways other than those mandated by our acquisitive culture.

It is heartening to know that after I left York, Tom became more and more involved in civic life. He was invited to meetings, consulted on topics other than those relevant to the handicapped, given active roles on municipal and county committees, and awarded medals and honors, especially for his work with young people. He died ten or fifteen years ago, of some illness and at some age, both irrelevant because he achieved his identity as few people do. It is not what we die of or when that matters, but what we do with the days that are ours to live.

If only I could find a way for my students to see why I care about Tom, Helen, and Stephen. However, words won't quite do it justice. That's the trouble with trying to teach the ineffable.

In Search of Common Ground

by Paul H. Levy

People with disabilities have fought to secure access to common arenas of daily living: jobs, transportation, education, and community services. The opportunity to claim equal rights emerged only after disabled and non-disabled persons began to recognize and accept each other as peers and neighbors.

In health care, the challenge for disabled persons has been to effectively represent themselves so that providers offer reliable, affordable care. Unfor-

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tunately, the gap between what's actually available to a disabled person and what the medical profession is willing to provide remains wide. We must always keep in mind both sides of the conversation: the person with disabilities seeking competent, accessible medical services, and professionals trained to care for ill, dependent people attempting to live an independent lifestyle.

Before measurable changes can be expected in guaranteeing satisfactory health care for the disabled, the medical community must educate itself about disability and the people who live with it. The first step has to be honest conversa-

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tion about several key areas of concern: awareness, communication, attitude, consideration, access, and choice.

Awareness

Physicians and nurses are too often uninformed or misinformed about the basic identifying factors of various disabilities. Moreover, health professionals often do not know the common dysfunctions associated with a disabling disease or injury. The disabled person needs to educate as well as be educated. Lack of awareness and knowledge often appears as insensitivity. One way partially to remedy this is for disabled people to work with medical, dental, and nursing schools.

Once someone with a disability is understood and appreciated for his differences, he or she can easily be seen as a person who has feelings, desires, and goals similar to those of a non-disabled person. We may look and move differently, but we are alive and able to work with others as equals.

As a disabled person, I look forward to the day when I am not met with surprise when I appear for medical services. My first visit to my primary physician at an HMO was revealing. I waited in an examining room, sitting in my power wheelchair. The doctor entered and did a double-take when he saw me. I asked what was wrong and he said, "I never know who I'm going to get next." Would he have been as startled if he had seen me first, instead of the wheelchair?

Another time a situation occurred at my eye doctor's office. I wheeled up to a young woman in white to tell her I was there. She looked past me, then asked somewhat bewildered, "Isn't someone with you?" I smiled and replied, "It's almost like I'm grown up, isn't it?" I was 40 at the time.

Communication

The health care provider should speak directly to the person with disabilities and respect him as a competent individual, not as someone needing to be

accompanied by a relative or care attendant. Even if I am not alone, I am still the one relating directly to the medical professional. The disabled person is his or her own advocate. If medical services are required, the person with disabilities speaks for himself and articulates his concerns as coherently as possible to the care provider.

As I share my views with the physician or nurse, I want them to speak to *me*, and take a little extra time to **explain**, as well as answer, questions. This is the same courtesy non-disabled persons expect. Indirect communication can have damaging effects.

Before I knew what my disability was, and in an attempt to find out what was happening in my body, I went to a teaching hospital to be seen by the director of neurosurgery. I sat in a cubicle wearing only my undershorts. In walked not just the doctor, but four medical students.

Without saying a word to me, he proceeded to test my reflexes and examine me, all the while talking to the medical students. He suddenly pronounced a diagnosis, telling them that he was seeing a "typical case of multiple sclerosis." Having heard my diagnosis second hand, I was quite taken aback.

Nearly twenty years later, I saw a physiatrist about the increased tightening of my upper body that made it difficult to maneuver my wheelchair. Alongside the doctor was an intern specializing in rehabilitation medicine. While examining me, the doctor talked directly to the intern; she referred to me as a "high quad." No one had ever said that about me. She also told the intern that there were few "high quads" in the city.

After returning home, I thought more about those two words, "high quad." Rather than being upset about the doctor's insensitivity, I could only smile and

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laugh. These words meant nothing to me, and why they should mean anything to her or to anyone else didn't make sense. Indeed, those words became a rallying point. My fantasies grew and I soon envisioned myself in the Kingdom

of Quad, where sojourners asked at the palace gate to see the exalted High Quad. So much for labels.

Attitude

Physicians may make assumptions about people with disabilities that are based on nothing more than subjective observation. One area that is easily misperceived is our capacity to have sexual intercourse. All my quadriplegic friends are sexually active.

I spoke to a urologist at my HMO about surgery to insert a suprapubic catheter, a tube inserted through the abdomen below my navel that would drain my bladder. He didn't understand my reason for preferring the extra effort of surgery. It took another appointment for my wife and I to explain that I have uses for my penis other than emptying my bladder of urine. The surgery would allow me to function sexually. He performed the surgery a week later.

Consideration

People living with disabilities usually accept personal responsibility for their bodies and know what is happening. They know what works and what doesn't. Health care professionals must be receptive to suggestions and proposed solutions disabled people offer for their own medical problems.

When I had my first cataract surgery, the ophthalmologist inserted a temporary catheter into my bladder. After the operation the tube was pulled out, causing a spasm that prevented me from urinating. An antibiotic took care of the problem. I pointed this out to the doctor for the sake of future patients. His indifferent response was, "It's okay now, isn't it?"

Three days after having had my suprapubic catheter inserted, I was having trouble. I called my urologist on a Friday evening and he said to meet him at a hospital emergency room. I was in bed. However, since my live-in student aide had transferred me from the wheelchair to bed and was out for the evening, I would have to call an ambulance to take me to the hospital. Having explained this to the doctor, I asked him to come to my house and he did. Everything went smoothly. I wasn't fatigued or hassled, and the HMO saved a few hundred dollars.

Courtesy by the medical profession will improve as awareness expands. For example, physicians need to know more about the cost and availability of transportation for people in wheelchairs. Kansas City offers affordable, accessible van service if a ride is called in by noon the day before it is needed. In case of

emergency, only full-fare van transportation is available and it costs \$20 each way for the first ten miles. This is cheaper than an ambulance, but is still too expensive.

Access

Equal access means acting independently according to ability, including being able to stay in one's own wheelchair to be tested or treated. Some equipment

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in doctors' offices and hospitals is not accessible to persons in wheelchairs. The wheelchair user needs to be able to use equipment from his most natural and comfortable position.

This issue also needs to be addressed by the manufacturers. Equipment used by doctors, dentists, and hospitals can be adjusted in ways that will accommodate persons in wheelchairs. A Yag laser, for example, can be mounted on a platform so that a person's knees fit underneath when sitting in a chair with or without wheels. Optical equipment can be designed to line up at the right height for a person to remain in a wheelchair. Currently, the optometrist must lift the person out of the wheelchair, causing discomfort for both parties.

The challenge of having my eyes checked illustrates the point. I want to take proper care of my eyes and hope the examination will not be too uncomfortable. But in order for my doctor to function properly, he or she needs the best line of vision. For this exam to be successful — for me and for my doctor — each of us needs to be able to see the other as clearly as possible.

At my dentist's office, he and his assistant lift me to the fixed chair positioned so the dentist can use his various instruments. I accept that, realizing I have no choice if I want to continue seeing this dentist. More severely disabled persons can be treated by a dentist in their own home if those procedures can be done using portable tools and equipment.

A podiatrist I was seeing was short in stature and did not like to bend down to work on my toes while I sat in the wheelchair. His assistants helped him transfer me to his work table where he could see my toes at eye level. Never appreciating this discomfort, I asked another time if

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he would work on my toes while I stayed in my chair. He said his back hurt to bend over that much. To his displeasure, I said the problem was he wasn't short enough. Months later at the HMO, a surgeon and nurse willingly squatted on the floor to perform minor surgery on my toes.

Lifting a person from his wheelchair to another seat creates a number of potential problems. For instance, physical problems such as spasticity or brittle bones may make transfer painful. The catheter or ostomy bag may need to be unhooked before moving the patient. Rarely have a doctor and assistants placed me comfortably back in my wheelchair so I could operate it successfully. I have been dropped, once breaking a toe. Assessment of both the need to transfer and the how of transferring should include all parties involved. This is common courtesy.

Just like everyone else, the disabled person wants to be treated with dignity and respect. For example, if the only entrance to a building were blocked by a number of stairs, I would not allow peo-

Equal access means acting independently according to ability.

ple to carry me. I would inform the management as to how to provide an accessible entrance, then agree on an alternative meeting place in the interim.

The same goal of safeguarding a patient's dignity is important in hospitals. Few hospital rooms have wheelchair accessible bathrooms. And with some attention to detail, nurse call buttons and T.V. control devices can be designed for the disabled patient.

Yet there are small successes. At home, I place a recirculating air pad on top of the mattress to prevent skin breakdown. Before my last hospital stay I asked if such a pad could be provided, and the hospital bought one for me and others after me.

Choice

The disabled person occasionally finds a health care practitioner who is unfamiliar with particular aspects of the disability. As a result, a dosage of medication or type of treatment is prescribed that the disabled person knows from personal experience does not work for him.

For instance, I need a larger daily amount of one drug than is recommended in the *Physician's Desk Reference*. I know what does not work for me in maintaining a bowel program. I have learned what works fastest to resolve mild bed sores. An every-other-week schedule drinking cranberry juice keeps my bladder reasonably happy and helps prevent urinary tract infections. My doctors have learned to accept my findings.

A prolonged impaction (hard stool wedged in the bowel and unable to move through) caused me to wonder if my colon (bowels) could hold another meal. My doctor could feel how hard it was, but wanted to confirm that it was an impaction. My body was strapped to a table which was tilted so I was vertical for a colon X-ray. I was sure my knees wouldn't hold and I would fall. It wasn't a pretty picture; neither was my X-ray, which displayed a packed colon. We already knew that, so why put me through an unnecessary procedure?

I was instructed to go to a hospital emergency room where they gave me an enema. It didn't accomplish anything. I explained earlier that enemas don't work for me, so I'd found an alternative solution. A dozen visits to a chiropractor's office for colonic irrigation treatments cleaned me out, from my colon to my wallet.

Conclusion

In conversations with my friends, I've asked them how their doctors deal with

their disabilities. As one might expect, some doctors are sensitive to the special needs of their disabled patients, whereas others seem fairly oblivious. My friends agree on some basic guidelines that can solidify the trust between a physician

Just like every patient in a hospital, a person with a disability wants to be treated with respect and dignity.

and his or her disabled patient: Don't allow stereotypes to prejudice your views about what we can or can't do. Ask for our opinions more frequently. Take time to explain what's going on. Interact directly with us, not with our wheelchairs or crutches or catheters. Learn as much as you can about the lives of disabled people.

The simplest way to learn about disabilities and become more comfortable dealing with them is to visit with people who have them. Many people with disabilities pursue energetic, productive lifestyles, and it is important for our non-disabled peers to appreciate this. It is not unreasonable to expect that all levels of the medical profession should be prepared and willing to provide proper assistance when needed.

Where There's a (Living) Will, Volunteers Find a Way

by Joan D. Killion

Thanks to a cadre of dedicated volunteers, Midwest Bioethics Center responded quickly to over 13,000 requests for living wills in the five weeks following the U.S. Supreme Court's *Cruzan* decision. Thanks to the tireless efforts of these individuals, many thousands of Missouri and Kansas residents have received the comprehen-

sive living will document and information brochure. We wish to extend special thanks to:

Louise and Amy Lang; Donna, Edie, Natalie, & Sydney Blackwood; Truman & Branden Christopher; Lois & Sherry Reynolds; Michael Arnold; Matt Brandmeyer; Zack Rapp; Jeff Worth; Susie Heimann; Kim Montgomery; Clint Brewer; Amy Field; Rae Ann & Susan Nixon; Elizabeth Morrison; Barbara Sandmeyer; Carol Jonas; Todd Crippin; Beverly Hilden; Alleda Cammack; Raschell Smith; Kay Hoech.

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