

# Bay State Nurse **NEWS**

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## Listening to 'The Patient's Voice'

A excerpt from *The Patient's Voice: Experiences of Illness*  
by Jeanine Young-Mason, Ed.D., R.N., C.S., F.A.A.N.

*I have been asked how the book The Patient's Voice came about and must say to the reader that it had its beginnings long ago. It is a book about compassion, the search for it, what it is, and how it works. In other writings I have talked about compassion as central to all interactions and actions in health care. It must never, in my estimation, be viewed as merely a kindly feeling of sympathy toward another who is suffering. Compassion demands far, far more from us. And it offers much more than pity.*

*The 16 contributors to The Patient's Voice write with authenticity and courage about their lived experiences and in so doing offer to students of the human condition a unique body of information not ordinarily available in textbooks. This information is both insightful and pragmatic and has the potential to enlighten and enrich the practitioner's personal and professional life. Each account teaches us something about the experience of illness and loss and deepens our understanding of suffering and the restorative power of compassion. Furthermore, the accounts instruct us on how to deal practically and even politically with such conditions in contexts in which individuals find themselves disadvantaged and vulnerable.*

*One of the 16 accounts from The Patient's Voice follows.*

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### Mastery of Life

by Allan H. Macurdy, J.D.

Muscular dystrophy and I are lifelong companions, and though I know our mortal enmity will some day be tested (and I will lose), we have maintained a relationship of wary coexistence. The disease and I were first introduced in second grade when I was diagnosed, but we had been intimately connected from the moment my parents conceived me, their eldest son. As a genetic disorder, muscular dystrophy is as much a part of my identity as my eye color, my height, or my resemblance to my parents. It was never an invader; the disease and I have fought for control over territory to which we both felt entitled.

Our introduction took the form of a death sentence, albeit in clinical language. When I was 8 years old my parents were told that I had the disease and that it would lead to my demise, probably by age 15. Oblivious to the positivist echoes attached to the word, the medical community describes Duchenne's muscular dystrophy as a "progressive" disorder, meaning only that the disease continues to destroy

muscle tissue until it kills you. First, I would lose the voluntary muscles that enabled me to use my arms and legs. Then the muscles in the abdomen that permitted standing or sitting without support would fail. Finally, the disease would move on to my respiratory and cardiac muscles and I would die. However devastating to my parents, all this was beyond my understanding as an 8-year-old, but at least there was now an answer when I asked why I fell down a lot or why I walked funny.

During my childhood, I rarely saw my disease-companion sitting at my table, and even more rarely thought about the role the disease played, and was to play, in my life. Such dark thoughts were not a feature of my happy childhood. Indeed, I lived the typical life of a small boy in suburbia, full of tree forts, puppies, and baseball. Friends were everything, did everything. We pretended we were superheroes or professional athletes. We delighted in mischief. We disliked girls intensely. But muscular dystrophy was involved in much of my life and determined that my experiences would be atypical.

At age 8 or 9, when my friends would play in the school yard, I began to notice that I couldn't keep up with the other kids. I was always last in races and was frequently tagged out, as were many kids, but it seemed that I never had enough energy for play. My most hated activity was the long climb to the second floor for art class. Each step in the flight was a new battle to get both feet on the next step while hanging on to the banister for support. But I also had classmates who were terrible at sports or winded by that same flight of stairs.

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### Allan H. Macurdy, J.D.

Allan H. Macurdy is a lecturer in law at Boston University School of Law, a staff attorney at Pike Institute on Law and Disability, and an adjunct professor of law at Boston College, Northeastern University, and New England School of Law. He earned his JD at Boston University School of Law and his BA in history at Boston University.

When Allan H. Macurdy was 8 years old, he and his parents were told that he had muscular dystrophy, which would lead to his "demise, probably by the age of 15." Despite the presence and progression of the disease, Macurdy is now a practicing lawyer in his mid-thirties who lives with his wife and dog and teaches law students full-time. Through his experiences with his "disease-companion" and the politics of health care, he has fashioned four principles that govern his interactions with health care professionals and the medical system and track, to a great extent, the manner in which he conducts his life as an individual with a disability.

## Celebrate National Home Care Month

## Mastery of Life

Continued from Page 1

It was my experiences with the medical system, however, that most clearly differed from anything in my friend's lives. Although I was examined by many different doctors in my parents' effort to have my condition diagnosed, my earliest memory of hospitals and doctors came during second grade, when I spent a week in Riverview Hospital undergoing tests. Having been to school, I knew I didn't like tests, but these were so strange that I almost began to enjoy them. In one room, some man glued wires to my head, dimmed the lights, and told me to think about a rabbit. In another room, a beautiful lady took a scary needle and put it in my leg, but it didn't hurt. Because these people were friendly and took the time to explain what was happening and why, this was not a terrifying experience.

After the doctors determined that I did indeed have muscular dystrophy, I encountered the health care world in brief visits with various professionals. I saw my orthopedist and the physical therapist on a monthly basis, with occasional trips to the brace maker or hospital x-ray department. But my battle with the disease at this stage of my life was fought largely apart from doctors and therapists. After all, they were focused upon slowing the inevitable march of deterioration, rather than the day-to-day realities of trying to be a kid. Not that our goals were in conflict: Inactivity would not only be intolerable for a child, but it would also accelerate the destruction of muscle tissue. So with the blessing of the medical world, the challenge of climbing the stairs to my bedroom or rising to my feet after a fall were the tangible victories I sought, and savored.

By adolescence, however, my weakened muscles could no longer support the efforts of my growing body. I could no longer climb those stairs, and if I fell, I was now required to wait until someone came along to help. To a teenager, reliance upon other people, particularly adults, is the perpetuation of childhood. From this perspective, to be an adult is to have achieved the perfection of independence. Anything that restricts any desire that a teen might have is perceived as an injustice, an effort to prevent entrance into adult privilege. For most teens, the source of those restrictions, and therefore those injustices, is their parents. But for me, the disease played that role. In fact, it was the inevitability that muscular dystrophy would prevent me from achieving the independence I so desperately wanted that bothered me the most. I had never really thought about it before, but at 13, I realized that I would probably be dead in 2 years. In the face of that reality, all my struggle against the disease seemed futile. And what could be more unjust?

For a time, my anger and frustration threatened to overwhelm me. That sense of powerlessness pervaded my inner self, and though time moved on, to me

it appeared that I would never get beyond my rage. But I soon tired of the melodrama and began to get on with my life. For some reason, as I neared the end of junior high school, I was no longer so angry, no longer caught up in the futility of fighting the disease. More and more, I was seeing that there were more reasons to fight than to give up. I cannot point to any crystallizing moment when I found a purpose for my life or came to value the people around me. All I know, and all my parents knew, is that by this point I had gained faith that my life had value, and, for this reason, I was much easier to deal with. I was now able to concentrate on both being a kid and developing the social techniques to work around others' reactions to my disability.

Over the next decade, my life proceeded in much the same way as did the lives of my peers. I went to college, graduated, went on to law school, and prepared to enter my profession. Because the disease created only orthopedic problems, I learned to compensate for my physical limitations so effectively that the disease

was nearly irrelevant. I was started on a course of antibiotics and chest physical therapy, but after two days in the hospital it became apparent that I would need some form of mechanical breathing assistance, at least until I had fought off the infection.

What happened then is a parable on the failings of the medical model to consider the person behind the symptoms. In treating respiratory failure brought on by muscular dystrophy, Dr. Hill had begun using the iron lung, a device long associated with the polio epidemic of the 1950s. I had a vague memory of seeing an old photograph of an iron lung in a book, but I was totally unprepared for the realities of using one — or the fear. Someone wheeled this huge steel cylinder with a mechanical bellows at one end into my room. Behind it, much like infantrymen advancing behind the cover of a Sherman tank, came a squad of residents and medical students chattering about test results and pressure settings. With little more than a passing acknowledgment that I existed, the resident in charge ordered the nurses to put me into the

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Now I find that I prefer to invite my  
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than search for his eyes in the dark.'*

iron lung and began to quiz his squad on the technical minutiae of my case.

Pause for a moment to consider the situation I faced. There I was in this intensive care unit, fevered, my lungs full of secretions, and unable to get enough air. Such circumstances are frightening enough by themselves. In the midst of all that activity, my anxiety was heightened by the fact that no one was listening to me, no one seemed to be aware that I existed beyond the data in my chart. But more terrifying still was the iron lung, and the procedure necessary to being placed inside. First, the cylinder was opened and I was laid down completely flat inside, a position that made breathing even more difficult for me. Next, I was slid up so that my head passed through a hole in the end of the cylinder and rested on a shelf outside. I lay face up with a 3-foot steel ring around my neck like some grotesque Elizabethan ruff, unable to move my head more than half an inch in any direction.

All of this alone was enough to induce claustrophobia, but add an inability to breathe, carbon dioxide toxicity, a fever, and the result was abject terror. None of the residents seemed to notice, however. At a time when the right words could have allayed my fear, or at least pushed it back, instead I met words that trivialized and excluded. The residents chattered on among themselves with great enthusiasm about arterial blood gas levels,

titer volumes, and the comparative advantages of negative versus positive pressure ventilation. But direct interaction with me consisted of awkward, perfunctory monologues, delivered with impatience and never followed by listening. Because stress makes breathing much more difficult, respiratory patients cannot fully benefit from treatment without controlling their emotions. I needed both information and the assurance that I would not be sacrificed to some other agenda, even when I could not devote breath to speech. My questions, and forthright answers, were central to my ability to cope with the anxiety of this crisis.

That the residents were completely lacking in respect or empathy was not only clear to me but also angered the nurses. Once the decision to put me into the iron lung had been made, the nurse assigned to my case — call him John — had to get me inside while dealing with my anxiety. John tried to explain what was to occur, and to offer calm reassurance, but each time he finished readying me for the process, the residents would transform my room into a noisy, chaotic disaster, and he had to begin again. After the second false start, John asked the residents, quite nicely, if they would mind taking their discussion out of the room. They complied with his request, but their compliance was short-lived.

Finally, John had had enough. Raising his voice above the din he said, "If you aren't going to help, get the hell out of here! You're making this ten times harder on Allan." The residents were instantly aroused to righteous indignation, but nonetheless they filed back out. Once they were gone for good, we succeeded in getting me from the bed into the lung. The cylinder was closed, a seal was made at my neck, and the bellows went into action. I had never before experienced that sense of total helplessness and vulnerability, and it was primarily the result of the residents' (and many other health professionals') failure to treat me as the decision maker, the most interested party, and an individual whose feelings counted. For all the attention they paid, I could easily not have even been in the room. I vowed never again to be marginalized by medical personnel.

In that hospital experience I learned many things about the medical system that had nothing to do with treating disease or caring, but everything to do with power. This system, like any other human system, is made up of political phenomena: hierarchies of professionals, chains of command, patterns of authority, institutional agendas. Seen as such, it no longer seems alien. Indeed, I have a political mind, so the system plays directly to my strength. Legally, all legitimate power is vested in the patient, providing, of course, that he or she is mentally competent and conscious. I was clearly both, but power will not tolerate a vacuum, so if I failed to use my power, someone else would. The device best suited to enhance the

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power of health professionals is their virtual monopoly on medical knowledge. Lack of access to information, except through such a professional, is extremely intimidating and causes the patient to give up a great deal of power. The institutions also coerce the patient through the loss of both privacy and scheduling autonomy.

Even the everyday language is laden with authoritarian nuance. If I as a patient were to decide, for any reason, not to take a given medication I would be described as "refusing" treatment, not "making a decision." If I were asked if I were in pain and answered in the negative, I would be "denying" pain, as if the pain exists but I just will not admit it. And if I were to "deny" or "refuse" too often, I would be labeled "non-compliant" with the supposedly legitimate authority of the medical professional. These few examples are indicative of at least a habit of mind, if not a system of belief, that regards patients as, at best, children in need of parental figures to make decisions for them, and confers superior status on the practitioner.

To be sure, most health professionals do not view their relationships with patients in such terms. Quite the opposite. Individuals are often drawn to the medical field out of a desire to care for others; if asked what they like most about being doctors, nurses, or therapists, they would cite the satisfactions of caring. But I submit that one can be a caring professional, endeavoring in good faith to help others, and still participate in a system that seeks to diminish and marginalize the patient. Indeed, the caring ethic masks the power inequity by convincing practitioners (and the rest of us) that because they are here to help others, no one is oppressed, no one could be victimized, and power just isn't relevant. Such is not reality, however. Politics is as real as physiology, even in the medical system.

With this in mind, then, I fashioned a set of principles that now govern my interactions with the health care professionals and the medical system and track to a great extent the manner in which I conduct my life as an individual with a disability outside of my medical needs. These standards evoke for me dozens of relevant stories, and I will share some of them by way of illustration.

First, as the person with the greatest stake in my health care, I make the decisions, and no health professional can overrule my preferences. This seems, at first, a somewhat indisputable position. In practice, however, health professionals have difficulty when the decisions I make are in direct conflict with their advice or preference. These need not even be conflicts over weighty health problems, and they quickly deteriorate into absurdity. One spring afternoon, a month or two after I had begun using a portable ventilator, I was outside getting some fresh air, strolling with one of my nurses in the park that runs down the middle of the avenue where I live. Side streets cross the park at one block intervals, and traffic from the avenue often turns onto the

side street. As I reached one of the side streets, I checked to see if cars were turning left from the avenue and approaching me from my right. Concluding that it was safe to proceed, and *not* consulting the nurse, I crossed the street.

When I reached the other side, it was abundantly clear that the nurse was unhappy with what had just occurred. She stopped and said, "You should wait until I say it's safe to cross because if something happens, I'm responsible." I had been living in Boston for nearly 10 years, so my first inclination was to burst out laughing, but instead I asked, "Are you responsible because I'm a fellow human being or because you're a nurse?" She replied that it was because I am a fellow human being, but neither of us believed her. I then said, "If you want to continue on this case you had better get this straight: You have no decision-making authority whatsoever. You are here for your medical advice and as an emergency backup. I am not mentally incompetent, and therefore you can't make decisions on my behalf, and you certainly can't decide when I cross the street. If you cannot abide by these conditions then you should not be working here." I have not seen her since. This problem is the result, at least in part, of the work experiences of nurses in intensive care units where patients are gravely ill and in need of surrogate decision makers. Some nurses cannot comprehend that home care with me is very different. But even professionals that seem to understand, that appear to "get it," will catch themselves or be caught making decisions for me and acting unilaterally. The ideology is deeply embedded.

The second principle that governs my relationship with the medical system flows from the first. As I am the only legitimate decision maker, no one else is permitted to speak for me. Again, this principle seems unassailable, but in practice it is a position more often observed in the breach. Far too commonly, a doctor or nurse enters my hospital room and speaks to another professional or to a family member rather than to me. Medical staff have also tried to order for me in restaurants, make requests for me in department stores, and take it upon themselves to reprimand the concierge in my apartment building because the elevator was not working — all in the name of my health care. Such actions are not only corrosive to my self-esteem but undermine my personal interactions and professional integrity by advancing the perception that my needs are so extensive as to render me irrelevant and nearly invisible.

So if I am to speak for myself and make the decisions, it follows that I must have complete information, and that is the third principle. The system is remarkably prone to keep information about a patient's condition and treatment away from the patient, while the professionals blithely discuss patient information in crowded elevators and cafeterias. At one point in

the intensive care unit I asked to see my chart. The head nurse for the unit first stated that hospital policy did not allow her to show me the chart. When I informed her that such a policy was in violation of the state patient rights law, she then said that she needed the approval of my doctor before she could produce the chart. The doctor told her that I was to have access to the chart whenever I deemed it necessary, but clearly the presumption that patients may not see their charts was well entrenched.

Another telling example was the behavior of residents during morning rounds. All of the important information and discussion about my case would occur outside of my room, before the residents came in to see me. Because my hearing is acute, I noticed that what they discussed outside was nothing like the subsequent conversation with me, so I would cut past the small talk to ask questions about the other conversation. Years of seeking complete information have transformed me into a sophisticated medical consumer, and I am no longer intimidated by medical data and technical jargon.

Failure to provide me with information about what is actually happening to me, or what the doctors do not yet know, is a cause of great frustration and even anguish. In the summer of 1992, a ventilator malfunctioned; I went into respiratory arrest and had to be resuscitated. When I regained consciousness, I was transported to the hospital and tests were undertaken to determine if there had been any neurological or cardiac damage. Early indications were that no damage had occurred, and my wife and I were told unequivocally that I would be released in two days. Unbeknownst to the two of us, the doctors were waiting for the results of a certain enzyme test that would determine whether I could leave the hospital. On the morning I was to be released I was suddenly transferred from the intensive care unit to the cardiac care unit (CCU) with little explanation. Between the experience of nearly dying and, now, the fear elicited by this sudden and drastic change of plans, we were devastated. Add to this the aggravation of a nasty, high-handed nurse in the CCU, and the result was an incredibly stressful and upsetting situation. All this distress could have been avoided if only the doctors had told us that I could go home if the results of that last enzyme test were satisfactory.

The fourth principle of dealing with the medical system involves the role my health care is allowed to play in the rest of my life. Health care is a means to a full and meaningful life; it is not an end in itself. But because the professionals deal only with the medical aspects of my life, they often lose sight of the impact of their recommendations on my career, home life, and relationships. If their efforts are not resisted, the medical agenda will overwhelm the human agenda — the tail will wag the dog.

Consider two examples. Because

the ventilator delivers air directly to the lungs, bypassing the sinuses, I am required to drink a large amount of fluid to maintain sufficient hydration. We have a system for a rough recording of the intake, and renal function has never been one of my problems. I use cups that are all larger than 240 cc (8 ounces). For convenience we record each cup as 240 cc, since the point is to take in as much fluid as possible and any excess is in our favor. One of the nurses wanted to mark all of our cups and mugs (even the wedding china!) with a china marker to indicate the exact volume contained in each. The proposal would have delighted Franz Kafka.

The second example not only reflects the attempted hegemony of the medical sphere but also illustrates how various needs must be juggled to maintain the life I desire. I have a tracheostomy, a direct opening in my throat, and am particularly susceptible to respiratory infection. Given the deterioration of my chest muscles, any infection can potentially develop into pneumonia, and any pneumonia can be lethal. Some have argued, therefore, that I should eliminate all sources of risk and protect myself at all costs. But that could happen only if I were willing to live apart from other people in some kind of bubble. I would not be able to teach, represent clients, see friends, have an intimate life with my wife, play with my nephews and godchildren, or hug my dog. In other words, all those things that give my life value, purpose, and meaning would be sacrificed in order to protect my from infections that might kill me. Who would want to have such a barren, empty, life? So instead we take what precautions are reasonable, in the context of the life I choose to lead, and accept the risks and the consequences of a meaningful existence. I am fully aware of the dangers, and my choices are the result of a rational decision-making process, but even if these choices are arbitrary and irrational, they are *my* choices and may not be gainsaid.

After nearly 35 years, my relationship with muscular dystrophy, like any other long-term relationship, has grown exceedingly close and complex. We have forged a bond as fellow travelers, and traveling the road together has taught me to fight but also to cherish life and the people who give that life meaning. For a long time I believed that the disease could not be real if I refused to acknowledge its existence — if I kept it out of sight. But I have always known my disease-companion to be close by, waiting just beyond my vision. Now I find that I prefer to invite my companion into the light of the fire rather than search for his eyes in the dark.

BayState Nurse News thanks Jeannine Young-Mason, Ed.D., R.N., C.S., F.A.A.N., F.A. Davis Co., and Allan H. Macurdy, J.D., for the opportunity to reprint this excerpt. Young-Mason is a professor in the School of Nursing at UMass Amherst. See the June 1995 issue of BayState Nurse News for the article "Teaching the Art of Nursing," which describes some of her work with undergraduate and graduate nursing students.