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### Making the Rounds, 1996, V1 N13, March 11

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# MAKING THE ROUNDS

IN HEALTH,  
FAITH,  
& ETHICS

VOLUME 1, NUMBER 13

PUBLISHED SEMIMONTHLY BY THE PARK RIDGE CENTER

MARCH 11, 1996

## Case Story: From Despair to Acceptance in Chronic Illness

Nayda Cole

*The discovery in the late 1970s of a thin, dark layer of clay marking the boundary between the earth's Cretaceous and Tertiary periods excited not only geologists, as one might expect, but dinosaur paleontologists as well. The clay contained high levels of the element iridium, rare on the surface of our planet, suggesting that a collision had taken place at that time between the earth and a body from outer space.*

*The "thin black line," as it is often called, exists all over the planet and marks a significant change of state for our earth. In addition to nonavian dinosaurs, many other animals and plants that had been dominant for millions of years disappeared, to be replaced by quite*

**Fourth in a series  
edited by Arthur W. Frank**

*different forms, some of which had previously existed timidly, in the shadows of their more successful cousins. The*

*thin black line is dramatic evidence of catastrophe providing an opportunity for adaptation and evolution previously not possible.*

*For those of us struggling to come to terms with chronic illness, there is also a thin black line, albeit not such a visible one. It is a hard-won milestone on our journey from a dead-end state of despair to the more evolved, adapted state of acceptance.*

*Be the disaster cosmic or personal, one thing holds true: thin black lines are not laid down gently.*

IF I'D KNOWN MY MIND WAS GOING TO TURN ON ME that day in 1984, I'd have run for my life. Running from my mind would have been about as effective as running from my shadow, but when I'm in the grip of a panic attack, logic holds little sway.

Even now, 11 years and innumerable panic attacks later, I still haven't found an escape route. In common with others who experience these savage attacks, I try to survive from minute to minute, often for hours on end, and remember that I did, somehow, live through past onslaughts more or less intact, albeit depleted of

physical, mental, and emotional resources. Such rational thinking is unfortunately useless during the attacks themselves when my mind recalls, with unnerving clarity, how close I came to *not* surviving last time and how much weaker my resistance must now be from the effects of last time.

(As this is a narrative, not a treatise, about panic disorder, let me very briefly explain that severe, ongoing panic—as distinct from discrete, occasional panic attacks or their less intense [but still very frightening] relatives, known as anxiety attacks—can seriously affect the life and health of those who suffer from it, entirely aside from the all-too-common danger of suicide. The attacks of panic themselves, which are only one of a host of symptoms present in panic disorder, are ferocious “storms” in the brain, which can lead to, or exacerbate, serious physiological and psychological conditions. Although not [yet] categorized as such, it is clear to many of the people involved that panic disorder and post-traumatic stress disorder are extremely close kin; the similarities are striking and numerous.

The outside observer can, to some extent, gauge the prodigious power of panic by noting the effect it has on the lives and minds of its sufferers, and the profound respect with which they treat it. It is important to recognize, too, that the effects of panic are *highly* individual, dependent on many factors as yet ill understood; responses to various treatments are likewise not well understood.)

Having barely heard of panic attacks, I had no idea what was happening to me that cataclysmic Friday afternoon in August 1984. Sheer terror overwhelmed me. Breathing was difficult; I shook uncontrollably; I was close to abandoning my feeble efforts to remain conscious; I could barely remember who and where I was; ice was apparently flowing through my veins; I was sure that in the next second I was going to die or else lose my grip on sanity. Suddenly, there was an enemy within my mind, a part of *me* no less, bent on my destruction, and I didn't know how to begin to defend myself. Something was stirring my brain like porridge, all the while threatening awful things under its breath, just below the surface of my awareness, safe from my grasp.

(continued on page 3)

Nayda Cole is an engineer and a technical writer. She is currently on long-term disability from her job at a Calgary oil company.

## Resource allocation and age

"In a recent study by two Swedish professors at the Stockholm School of Economics, Magnus Johannesson and Per-Olov Johansson, a random sample of Swedes were asked about their preferences for allocating scarce medical resources. To save the life of one 30-year-old, they were willing, on average, to trade the lives of five 50-year-olds or 35 70-year-olds. All age groups responded in much the same way. The professors also asked another sample of Swedes how much they would be willing to pay for a hypothetical programme to extend their life by one year beyond 75. On average, the respondents said they would pay no more than SKr10,000 (about \$1,520). In a country where provision for old people is particularly generous, that response gives pause for thought."

(*Economist*, 27 January 1996)

## Without comment

"Few press accounts have framed the Medicare controversy in terms of the need for health coverage for all Americans, the need for cost containment in all sectors of health care and the need for a broad-based, progressive tax that would once and for all fix the chronic deficits in the Hospital Insurance [Medicare] Trust Fund and finally bring some 41 million people into the health insurance system."

(Trudy Lieberman, *Nation*, 6 November 1995)

## Religion and medicine in journalism

Speaking at a recent conference sponsored by Harvard Divinity School's Center for the Study of Values in Public Life, Peter Jennings, senior anchor and editor of ABC's *World News Tonight*, argued that "increasingly, medical reporting needs to include a religious component, whether it has to do with the ethics of genetic engineering or how we deal with the end of life now that we have created so much technology to extend it. . . . We cannot cover education without having a greater understanding of how people's religious beliefs affect their thinking on everything from school

choice to the curriculum. Coverage of family and social issues would be wholly inadequate without understanding people's religious views of abortion and divorce, teenage pregnancy, and sex education."

(*Harvard Divinity School Bulletin*, 1995)

## Health care and the media

Commenting on James Fallows's new book about the media, *Breaking the News*, Jonathan Alter writes, "It is the coverage of health care that Fallows views as 'the press's Vietnam.' Whatever your view of the Clinton plan, the misreporting was astonishing. Elizabeth McCaughey wrote a highly influential piece in the *New Republic* saying that the Clinton plan did not allow people to buy their own health care outside the system. George Will passed on to millions the claim that doing so could land patients in jail. The McCaughey article eventually won a National Magazine Award and catapulted the author to the lieutenant governorship of New York. The only problem with it, as Fallows establishes, was that it wasn't true. No matter. It was 'hot' and 'talked about.' That was enough."

(*Newsweek*, 29 January 1996)

## Subsidizing natural medicine

The King County Council of the greater Seattle area has unanimously voted to establish the nation's first government-subsidized naturopathic health clinic. In a *New York Times* article about the decision, Timothy Egan reports that "natural medicine, long considered to be on the fringe of health care, is reaching the mainstream, and to no greater extent than in this state [Washington]. The new clinic will put the alternative treatments, which have been the province of better-educated and more affluent Americans, within reach of the poor. And as of Jan. 1, the state of Washington began requiring health insurance to cover treatments like acupuncture, massage therapy and other forms of licensed natural health care."

(*New York Times*, 3 January 1996)

## Class divisions and the safety net

Different classes will be differently affected by the political decisions about public health that are now being debated. If, as some have estimated, an additional 1.2 million children may enter the poverty category under impending changes in the welfare system, what role has sensitivity—or insensitivity—to these social divisions played in the political decision-making process? And do the political parties really differ in their approaches to these divisions? One Democratic legislator's rueful answer to these questions, quoted in a lead editorial in the *Nation*: "They attack the poor; we defend the middle class."

(*Nation*, 11 December 1995)

## Mostly unintended

A recent Institute of Medicine report recommended a major public educational initiative and measures to reduce unintended—either unwanted or mistimed—pregnancies, which account for almost 60 percent of all pregnancies in the United States. Noting that children resulting from the unwanted pregnancies are more likely than others to have low birth weight, to die in their first year, to be abused, and to lack sufficient resources for healthy development, the report advocates "(1) improving knowledge about contraception, unintended pregnancy, and reproductive health; (2) increasing access to contraception; (3) explicitly addressing the major roles that feelings, attitudes, and motivation play in using contraception and avoiding unintended pregnancy; (4) developing and evaluating a variety of local programs to reduce unintended pregnancy; and (5) stimulating research to develop new contraceptive methods for both women and men, answer important questions about how best to organize contraceptive services, and understand more fully the determinants and antecedents of unintended pregnancy."

(*Journal of the American Medical Association*, 1 November 1995)

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*Making the Rounds in Health, Faith, and Ethics* (ISSN #1082-1015) is published semimonthly, except monthly in July and August, for \$29.95 per year (\$40.00 for institutions) by the Park Ridge Center for the Study of Health, Faith, and Ethics, 211 E. Ontario, Suite 800, Chicago, Illinois 60611. Application to mail at second class is pending in Chicago, Illinois, and additional entry. POSTMASTER: Send address changes to *Making the Rounds*, The Park Ridge Center, 211 E. Ontario, Suite 800, Chicago, Illinois 60611, attention subscription fulfillment. © 1996 The Park Ridge Center, an affiliate of Advocate Health Care. Printed on recycled paper. Letters to the editor should be sent to *Making the Rounds*, 211 E. Ontario, Suite 800, Chicago, Illinois 60611; or faxed to 312/266-6086; or e-mailed to mtr@prchfe.org. TO SUBSCRIBE: send a check for \$29.95 per subscription (\$40.00 for institutions) per year (payable to the Park Ridge Center; please add \$20.00 per year for non-U.S. subscriptions) to the above address or call 312/266-2222 to order with Visa or MasterCard. Back issues are available for \$2.00 each (includes postage and handling). Articles are indexed in the following: *Bibliography of Bioethics*; BIOETHICSLINE; *Cumulative Index to Nursing and Allied Health Literature*; EBSCO Publishing; Information Access Company; UnCover.

(continued from page 1)

Thoroughly “stirred” and utterly terrified, I teetered at the edge of the abyss, knowing only that “that way madness lies.”<sup>1</sup> The fear of madness has remained my jailer for many years, but never did the chains hold me so cruelly as at the beginning. I felt great anger at the unfairness of being tortured from within; it would be some time before I learned how to fashion an effective weapon of defense from this anger. After several desperate months of trying to keep working, I underwent the confusion and embarrassment of having abruptly to abandon my career (as an oil industry engineer in Calgary) to go on long-term disability—for who knew how long—because of an illness not yet definitively named. The losses were piling up fast.

Essential to my survival during this harrowing time was the experience and wisdom of my now-longtime counselor, Leigh. Unbeknownst to me, 15 years before this she also had experienced panic disorder. She immediately recognized what was happening and mitigated much of the confusion—and shame—I felt over the conflicting, unhelpful, and at times even punitive opinions of others, especially members of the health care community. Somehow Leigh gave my mind, trapped in a maelstrom of terror, some small but vital sense of order and security.

Adding to my bewilderment and shame (the latter from suddenly having a problem supposedly “all in my head”) were the attitudes of a number of people around me who, while doing their best to cope with my sudden desperate state of illness, changing needs, and rapidly shrinking horizons and capabilities, nonetheless gave me the distinct impression they thought I had become weak and thus of little value. This is a heavy burden to ask a person so terribly ill to bear, and it hurts me still.

I all too frequently encountered people’s tendency to proffer facile solutions to serious illness: “If you’d just take such-and-such a pill for a few weeks [or a few months, or the rest of your life], you’d be fine and you could get right back to work.” How easy it would have been had that been true. I was enraged by comments that equated my disability leave with a vacation: “You’re so lucky you don’t have to get up at 6 A.M. anymore like I do to go to work.” Such remarks ignored the fact that I was not sleeping much anyway: I was fighting for my sanity 24 hours a day. “Stop being so selfish. Get out and do something for someone else, and you’ll be fine” was also popular—and me with years of volunteer work under my belt, trying to cope with being unable even to care for myself all of a sudden. Probably the most destructive, downright unfair judgment came, regrettably, from a therapist considerably out of her depth who asked, “Are you sure you’re trying hard enough?”

The lack of basic human compassion and support these comments revealed intensified my fear that I might not succeed in reclaiming my mind and my life from the enemy within me. In addition, they raised the specter of emotional and perhaps physical abandonment at a time when I badly needed others to shore up my battered belief in my own strength and worth. I was not so sick that I could not still be hurt.

I struggled with the uninformed judgments of others for a good five years before I gained the confidence and perspective necessary to accept the truth: contrary to the medical wisdom of the

time, panic attacks do indeed vary—significantly—from person to person. My attacks, for example, seem never to have read their own definition in the textbooks. Lacking this formal education, they don’t realize they’re not supposed to last longer than 30 minutes *maximum*, that they should respond favorably to techniques such as distraction thinking, deep breathing, exposure therapy, or relaxation exercises, and that they should cease and desist when certain drugs are prescribed and taken. Irrespective of psychiatric and pharmaceutical postulates, my attacks blithely go their own way, in their own time. What they lack in education they make up in tenacity.

Years ago, one of the characters on the television program *Laugh-In* used to say, “I feel sure the outcome will be one way or the other.” During those first few years I wasn’t so sure. It seemed I would very probably live the rest of my life in a terrifying limbo, unable to do the most ordinary things—go to the grocery store, eat in a restaurant, have company to stay, or simply be in a room with the door shut. It was unthinkable that I should ever get on a bus or airplane, survive in an elevator, be able to get to the hospital if I were hurt or to the veterinarian if my cats were sick,

or travel outside my own part of the city, much less ever work again.

Accepting long-term illness seemed a new concept to me, but I began to recognize I had been coming to terms with it, unawares, over the previous 12 years, since a spine injury at the age of 16 had left me with substantial back and neck pain and ever-present severe headaches unrelieved by the strongest of prescription drugs. I was able to understand and accept the extremely restricted life I led because the pain was due to a physical condition, albeit one with no cure and only the prospect of steady deterioration. Accepting that disability due to a mental or emotional condition such as panic disorder is real and doesn’t constitute “giving up” or being weak was much more difficult for me and for others around me. Our society tends to validate physical problems with measurable symptoms and invalidate nonphysical ones; I worked hard for six or seven years to come to terms with the critics, both without and within.

The only decent choice I saw was to go forward along the path of trying to understand the cause, message, and mechanism of my illness, striving for resolution and healing. I slowly learned that the information and answers I needed were inside me but in a language I didn’t understand clearly. I loathed having to accept a significant and unknown period of illness and intense suffering while I learned this new language, but it was the best option I had.

I often wish I had a picture of Leigh’s face during this time and a medal for patience to give her. She sat across the desk, week after week, exhibiting neither impatience nor frustration at my inability to grasp what is essentially a simple concept: the difference between acceptance and giving up. She looked at me with such a humorous mixture of caring for my struggle, wonder at my being so obtuse, and faith that in the end I would get the point that I had to laugh with her many a time.

After four years of struggle and terror, I experienced a further severe collapse, triggered by an incident in our neighborhood, which was, by chance, similar to trauma I had experienced as a child. Suddenly I was in a worse state, overall, than I had been at the onset of panic disorder. Several new and vicious symptoms appeared from nowhere, causing me to feel completely overrun, with no hope of ever regaining my former ground. In particular,

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the unrelenting sensation of being about to choke to death was hard to get used to. In the several years it stayed with me, I at least progressed to believing I probably always *would* be able to swallow and breathe, if never with ease or confidence. These days, when this symptom pays me only a short visit, I wonder how I stood it all those years, with no rest breaks except sleep.

For a month or so following the incident, I had to have friends stay overnight whenever my husband was away. Leigh, bless her, came to my house for counseling sessions that entire summer, for I could no longer leave my neighborhood. Accepting that I *had* to ask other people for such basic support forced me to learn the hard lesson of humility, but it brought some of my friends and me closer together and deepened my faith in human beings in general. In a culture so physically secure yet socially fragmented as ours, the opportunity to give something absolutely essential to another human being (one not normally dependent on you, as is a child) seems to me a rare and precious gift. I am more often on the "giving" side these days, and what I learned from asking helps me to give. I feel a sense of honor at being able to be there for another person whose path is steep or rocky, as was mine.

During that long summer of collapse, I read the same three books over and over and watched taped reruns of a few sitcoms, as anything else from my large collection of favorite—and innocuous—books and videotapes was too frightening. Everything had to be carefully censored so as not to provoke panic. Depression and insomnia were, for the first time in my life, ongoing problems (they and panic are often fellow travelers). To avoid waking my husband or whichever friend was in the house with me, I used to put a *M\*A\*S\*H* tape in the VCR, ready to press "play" in the middle of a sleepless night. The television characters provided welcome companionship as I walked with terror and gave my mind fleeting moments of distraction during what seemed an inexorable descent into the abyss.

The source of my will to fight and my heart to go on was Masou, my beloved feline friend of many years. He knew and loved the essence of me, whether I was sick or well, sane or not. With him I had no expectations to meet, no judgments of how I handled my illness to deal with, no messages of being worthless if I was no longer "productive" to resist. Masou's unconditional love and acceptance was a crucial place of rest and joy for my beleaguered soul; he was truly a blessing.

With my sanity in constant peril, feeling hopeless and defenseless, I was heartened and grateful to realize I still had control over *something*: I categorically refused to be hindered in caring for Masou. The year before, he had become diabetic, requiring a strict regimen of diet and twice-daily insulin injections. Panic or not, Masou got his food and his shots, had his symptoms monitored, and was, as always, my anchor. Beyond caring for him, however, a nightmarish state of limbo prevailed; realistic hope of improvement seemed absurd.

It was well into the following year, in 1989, before I improved enough to be out of this desperate state. Interestingly, I felt stronger than ever spiritually, having triumphed repeatedly, surviving many more trips "to hell and back," as I call panic's sieges.

At this point, as the result of five years of hard work in counseling, I had finally figured out what purpose my illness served,

what it was trying to tell me—a topic for another time. Having long been a student of Eastern philosophies, I based this assessment of purpose on my core belief that this life is a "script," which I wrote for myself, to learn certain lessons. I trust my experiences are meant for my good, to foster my progress as a soul toward the ultimate goal of enlightenment, or God-consciousness. By no means do I always like what I get, both panic disorder and my spine injury being prime examples, but I believe that this life is what I chose, so I try to learn from it the best I can and be grateful for the chance to grow.

Often interpreted as encouraging self-blame, this philosophy of life is rather one of self-responsibility and constant openness to growth, both spiritual and personal (if the two can be separated). Learning, not punishment, is the point of our "bad karma," as the trials of life are popularly called these days in Western society. While it in no way invalidates natural human feelings of sadness, fear, and loss during difficult times, the life-script concept leaves little room for self-pity, victimhood, and the bitter question "Why me?" Trying to "live the teachings," as it's called, has enabled me to be certain that panic disorder, among

other challenges in my life, does indeed hold meaning and worth, and to believe that I am not suffering randomly. This perspective is of inestimable value to me, every day of my life.

Without this illness I might never have been driven to make grace a cornerstone of my life. I feel blessed, knowing that God is an active, interested, and reliable participant in every aspect of every minute of my existence; this certainty is the source of my strength and my peace, whether I am ill or not.

Grace comes to me in many guises, and I like to look for the humor in its choices. For example, a new symptom that appeared during my 1988 collapse was an uncontrollable shaking of my arms and legs that I came to call "flopping." Frequent and prolonged spells of such flopping continued for months, and I grew used to it. It wasn't painful, and I much preferred it to the aforementioned relentless sensation of choking.

Although desperately ill at this point, I found I was able to rejoice, wonder, and even laugh at the fact that the flopping had ceased to upset me. This small manifestation of grace in the midst of overwhelming illness was a *great* comfort to me. One of my most indelible memories from that awful period was of lying in bed night after night, terrified and unable to sleep, flopping away, but somehow finding humor and a measure of power in this lone oasis in the desert of suffering, confusion, and despair that was my life.

In learning that acceptance does not equal giving up, I unknowingly cleared the way for grace to bless my life. Unfortunately, the measure of serenity I have gained from this and the lack of resentment with which I am able (most days) to accept my state of chronic illness has been erroneously interpreted by others to mean that I have given up my efforts to recover and thus admitted failure, or that I must *like* being ill, or that I'm opting out of so-called real life, or even that I'm lazy and no longer want to work. Given the prevalence in our society of the idea that "non-productive" people are disposable, the notion that a person who is ill may have experience and insights useful to others and can indeed still make a valuable contribution to the world is rank heresy to many.

**I was enraged by comments that equated my disability leave with a vacation: "You're so lucky you don't have to get up at 6 A.M. anymore like I do to go to work."**

I continue to make progress, but I am still far from recovered. Although I am still painfully and frustratingly disabled, my faith in the process of life is firm. To live in harmony—and health—for me means accepting my true nature and purpose, living and growing as I am meant to. I like to call it living with “attention and intention,” not taking life or health for granted. This has become much easier for me since I have been ill and have been brought repeatedly to a place where it seemed I could never have either again.

Acceptance helps me to acknowledge that, for today at least, I am operating under numerous restrictions, and my short-term challenges and abilities are not what I would prefer. What I do not

accept, however, is that illness can stop me from valuing my place in the world or prevent me from walking my life's path. It has merely made me more creative in finding ways to do so.

*Someday I'd like to get my hands on that K-T boundary clay, the stuff that makes up the "thin black line." I'd like to have some on my desk, as a memento of my own cataclysmic struggle to achieve acceptance and a celebration of what a difference this has made to my life.* □

#### NOTE

1. Shakespeare, *King Lear* 3.4.21.

## A Parallel Case Story: Light among the Shadows

W. Andrew Achenbaum

LIKE NAYDA COLE, I GREET THE MORNING LIGHT WITH FEAR: Am I going crazy? Will I have to go back to that psychiatric center? Who will tell me the time has come once again to seek aggressive intervention? Can I trust my family, friends, and colleagues to act in my best interest—or will they satisfy their own needs? How will I know when I no longer can be my own principal mental-health-care manager, as I have been for nearly a decade?

The pain of addressing these questions—a liturgy I perform each day immediately upon rising—blessedly is transformed into rejoicing that my premonitions are baseless . . . at least for today. By the time I have shaved and showered, I usually manage to have warded off the anger, confusion, and shame that I feel about the demons and creative highs associated with the form of mental illness that has altered the way that I think about myself and interact with others. But I cannot deny what I must never deny even for a single moment—even though I remember few details: two psychiatrists once judged me psychotic; bad chemistry in the brain put a seemingly normal person in institutions I once blithely considered peripheral to my world.

Nayda Cole has struggled for more than a decade with panic attacks. I cannot wholly identify with her particular chronic illness. Nor can I pretend that I have suffered to the extent that she has. I still have my job. Many people who have known me most of my life do not know that I, like Cole, “teetered at the edge of the abyss” and await, with dread, a recurrence.

Like Nayda I was caught unawares, even though I suspected things were not quite right. In a six-month period nearly a decade ago, my brother, a good friend, and a mentor had died. I lost a major grant. My wife and I were going through a rough time. I had little interest in anything at work. The combination of all of these distressing circumstances was sufficient reason for my depression. Indeed, had I not been depressed, then I would have had to have been insentient—hardly a desirable alternative. In any event,

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although I had been trained to keep on smiling, I had had the blues before. They usually lifted in a day or so. This time, however, the depression persisted. It deepened over an eight-month period, paralyzing me. Day after day I would go to the office and stare blankly at the computer, sweating profusely but producing nothing. When thoughts of suicide seemed a sensible solution to my woes and the troubles I was causing others, I sought help.

The nurses, psychologists, and psychiatrists I spoke to were competent. They were true professionals. No tale of recent aberrant behavior I told them seemed to faze them. Great care was taken to

protect my privacy. It was finally decided that I was eligible to become a subject in a young physician's research project—my fancy degrees and ability to turn a phrase made me a good guinea pig. Although all of the protocols were duly observed, I had no idea what the researcher hoped to determine by adding me to her pool of subjects. My conversations with the principal investigator rarely lasted more than a minute. Even though I did not feel like working, she would remind me, she was busy. I was given nortriptyline and told to take it twice daily and come back to the clinic

every three weeks. I dutifully followed the regimen. And it worked: I remember the day a teaching assistant yelled at me for daring to whistle loudly down a hallway. I did not care: I was feeling better.

Indeed, my mood was improving every day. In early December, my family and I went to London, where I gave four major lectures in two days. Back in the States, Christmastide was a time of real euphoria. I was energized. I functioned at peak efficiency on three hours of sleep. My consciousness expanded beyond my wildest dreams. I found myself reciting passages from the *Aeneid* and *Iliad* that I did not remember memorizing. I was eager to tell my friends at the depression clinic how well I was doing.

But I never got back to the clinic. Because of the trip to London I had missed a few sessions. Now the place was closed for two weeks for the holidays. By the time I did finally get examined by someone, I was really flying, seeing things in new lights. Some of the events on that fateful Epiphany remain vivid. I, who am quick with words, was making extraordinary leaps with anagrams. I ran into a secretary I had not seen for 15 years and asked her about her

W. Andrew Achenbaum is professor of history and deputy director, Institute of Gerontology, University of Michigan, Ann Arbor.

adolescent son, whom I called by name (an amazing feat since I invariably forget neighbors' names). Several hours before I entered the hospital, I decided that I must have died, but I took consolation in the fact that if this were death I truly could look forward to the communion of saints.

Now, years later, usually when tempers flare, I am periodically told other details about my full-blown mania. I am not disbelieving, but I am appalled that I behaved so inappropriately. I am embarrassed. I feel degraded. I still feel as if I should be punished for my misdeeds, but I also know that in some ways I literally was out of control. No one knew I was bipolar. If they had known, they never would have given me nortriptyline. Nothing personal: just one of those things. Off to a private hospital I went, to be detoxed. And there I was given a new set of drugs, which everyone assured me might or might not work. New shadows darkened my path.

So far I have been lucky. Lithium, weekly therapy, and daily exercise work for me. But there are no guarantees. Even assiduous effort is not foolproof. Sometimes the blood levels change, making adjustments necessary, which in turn cause undesired side effects. Having been spared extreme highs and lows for eight years, I am assured and reassured that the odds of a major reoccurrence are minimal. I guess that I believe the professionals, sort of.

But the larger truth is that I who was raised to be a man and trained to protect himself now realize that vulnerability is not just the stuff of John Berryman's love poems. I see myself in a new light, not wholly comforting. I have become an "other." That "dark side," like it or not, is integral to my identity. I was always a pretty sensitive fellow; now I have more compassion when I deal with colleagues, students, and strangers. Recognizing my own brokenness

fundamentally affects any advice I presume to offer. The limits to my well-being impress me as much as the possibilities.

I reluctantly have had to give up my sense that dualisms structure the world. I have come to realize that there usually are third and fourth (or more) options to consider. Furthermore, few boundaries are timeless. What seems *fixed* in the abstract usually dissolves over the course of daily living. Inherited values, senses of self take on unexpected, malleable forms as people (re)construct

their views to make sense of a world that they cannot utterly fathom. Not everybody discovers this in the same way. Some people are lucky: they are taught or discover through little mishaps that the world order is more complicated than they once thought. The rest of us are not so fortunate. We learn at great cost, often rudely, about the fragility of the human condition, the contingency of finding light in shadows.

Perhaps sooner or later, nearly all of us will have to face an event that transforms our lives. The manner, timing,

and extent of the illness or disaster cannot be predicted. In her courageous narrative, Nayda Cole helps us to identify some of the mystery, the shadows in which she wrestles with such events. Her passage toward madness and then back toward acceptance is heroic, for she has endured nothing less than the collapse of an identity that had served her very well.

Nayda Cole has a new sense of self, but her acceptance is by no means totally comfortable. Nor is the process of accommodation yet complete. Nonetheless, in recounting her pains and her triumphs, Cole tells us something very profound: we are granted, even under horrific odds, the grace to mold our lives as best we can. Facing our own shadows opens us to grace, which amazingly prepares us for self-renewal. □

**Perhaps sooner or later,  
nearly all of us will have to face  
an event that transforms our lives.  
The manner, timing, and extent  
of the illness or disaster  
cannot be predicted.**

## Commentary: Seeking the Good of the Patient

*Daniel Anzia*

WHEN UNEXPECTED FRIGHTENING THINGS HAPPEN TO US, our bodies usually quickly prepare themselves for defense or escape. Our hearts beat faster, our breathing quickens, blood flow to our muscles increases, our attention and alertness is heightened. Emotionally, we experience fear, although we may not be immediately aware that we are afraid. This response, often called the "flight-fight response," occurs automatically, without our having to think it over. When there is real danger, this biological response helps us to function.

Imagine suddenly experiencing a similar intense and distressing emotional, mental, and physical state in the absence of any apparent danger. Your heart beats rapidly, you sweat and feel short of breath, you feel pain in your chest and tingling sensations in your arms, you feel dizzy or faint. When this occurs in the presence of danger, we recognize its cause. When it occurs out of the blue,

with no outside cause, we wonder if we're about to die or if we're losing our mind.

This group of symptoms has become known as a panic attack. When such attacks are repetitive and there is no other medical explanation, this is called panic disorder. It is like having an alarm system that goes off on its own. These symptoms are so distressing and so similar to those of a heart attack, that people suffering them frequently go to emergency rooms. When test results are in and there is no evidence of heart damage or dysfunction, it is not unusual for patients to be told, "Nothing is wrong, you're fine," and sent home. This can be a puzzling message for someone who has just experienced such symptoms and who hopes doctors will identify the problem, provide reassurance, and recommend treatment.

If repeated panic attacks are not identified and treated, people suffering from them often become continuously apprehensive about when the next attack is going to occur. They may look for the causes of the attacks in what they happened to be doing at the time—even if they were simply going about the usual rounds of daily life, such as being at the grocery store, driving to work, being

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with people, or being alone. They then try to avoid the situation in which the attack occurred, or they try to have someone always with them, or they try to have a quick means of escape. This pattern of behavior is called agoraphobia, and it can interfere greatly with daily life.

There is good evidence that vulnerability to panic disorder is inherited. A growing number of effective and safe drug treatments have been identified that can usually control or eliminate the spontaneous attacks and reduce anxiety. Effective psychotherapies contribute to reduction of symptoms, to enabling patients to cope with the symptoms until they are lessened, and to the prevention and treatment of complications such as agoraphobia.

Cole's story describes symptoms like these and others as well. Although Achenbaum suffers from a different mental illness, he reflects on similarities of the experience: uncertainty about diagnosis and treatment, fear of recurrence, the search for help, dealing with self-blame and stigma from others, and, especially, the need to come to terms with a new sense of self. Their stories and reflections can help us learn several important things about the diagnosis and treatment of such conditions and of persistent and recurring illnesses in general.

First, the criteria clinicians use to diagnose such conditions do not always fit the experiences of patients as well as we would like. People differ, their bodies differ, the way they experience things differs. The clinical practitioner must determine which diagnosis fits the best, not which fits perfectly. Psychiatry is no different from other areas of medicine in this regard. The fact that a patient doesn't have the "classic" symptoms does not mean that the diagnosis is wrong, and it certainly doesn't mean that the patient is wrong! Life is not simple. It is important for both physicians and patients to avoid misunderstandings and oversimplifications about diagnosis. This would diminish the likelihood of the patient's feeling blamed by the doctor for not getting better or of the doctor's feeling blamed by the patient when symptoms cannot be quickly and completely relieved.

Second, diagnostic criteria are a scientific tool to identify treatments more or less likely to work for particular conditions, to help physicians match treatments to patients. The best diagnosis increases the likelihood of identifying a successful treatment but does not guarantee it. When treatment does not go smoothly or

benefit is slow in coming, patients and caregivers should talk openly about it and keep working together for better outcome.

Third, there is much more to treatment than diagnosis and prescription. There is a relationship between physician and patient, a relationship which should be oriented toward the patient's good. Defining and working toward this good involves serious and ongoing communication in trust between doctor and patient, since the good of the patient as the patient sees it will not automatically be identical with the good of the patient as the professional sees it. Working toward a shared view of the good of the patient regarding health is a mutual obligation of doctors and patients that Pellegrino and Thomasma call "beneficence-in-trust" (1988:54).

It is not clear that Nayda Cole found such a relationship with a physician, but the development of trust in her counselor enabled that relationship to help sustain and support her despite the continuation of symptoms. Psychiatry and its related professions have historically emphasized the importance, even the indispensability, of such a relationship in therapy. Therapists should also aim to bolster the role of patients' other relationships in providing support during

time of illness. For most people, the worst suffering is suffering alone.

Finally, both Cole and Achenbaum highlight a deeply personal task for people with serious illness, especially mental illness, a task which any professional or therapist can at best assist or not obstruct, a task which no professional can do for patients. This task is to try to make sense of and understand what they experience, to find or define what it will mean to them, to incorporate it into their vision of themselves and their "world order." For many people this means incorporating the experience of illness into the perspective of their religious faith, for others into the worldviews they find most meaningful. If the sufferer (especially of any chronic illness) does not recognize this task, he or she may experience the added pain of suffering without meaning.

Cole and Achenbaum help us recognize how the experience of illness can become a source of transformation and growth. □

#### REFERENCE

Pellegrino, Edmund, and David Thomasma. 1988. *For the Patient's Good: The Restoration of Beneficence in Health Care*. New York: Oxford University Press.

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Responses from our readers are cordially invited. Comments, suggestions, and letters to the editor are welcome. We are also glad to consider manuscripts for publication (length: 1,200–6,000 words); please call or write to request guidelines for authors.

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