

# CITIZEN VOICES

## in HEALTH ETHICS



A Newsletter of the New York Citizens' Committee on Health Care Decisions Inc.

Spring 2005

### THE COMPLEXITIES OF MEDICAL ERRORS

The Institute of Medicine defines an error as the failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim. Unfortunately, errors in medicine are common, and the increasing complexity of medical care makes errors even more likely. Medical treatment is a highly intricate and coordinated activity involving often a team of professionals juggling physiologic, anatomic, pharmacologic, environmental, and psychosociologic concerns within large and often complicated institutional systems.

It is important to note the relationship between errors, mal-outcomes and negligence. Mal-outcomes are untoward, yet not unanticipated, events that may result from correctly prescribed and instituted treatment. Mal-outcomes are often evident to patients. Errors, in contrast, may or may not cause a bad outcome, may or may not be evident to patients, and may or may not be due to negligence. Negligent acts involve carelessness or role-specific ignorant behavior.

Since patients are biologic entities, not arithmetic ones, responses to treatments often vary from anticipated ones. One disease and one treatment often do not equal one cure. Each patient presents with subtle variations in symptoms and signs of illness and each patient has a particular medical and social history that influences treatment choices and often affects responses to treatment. Few patients present to the hospital with diseases as if they had "read the textbook". Therefore, physicians necessarily need some latitude in individualizing treatment plans.

One difficulty is assessing when a physician's individualized treatment plan is so particular as to be medically dubious or even erroneous, particularly when the patient's eventual outcome is not favorable. Another challenge is assessing the use of increasingly technologically complex procedures for which success rates are unlikely to be 100%. Are all failures errors?

Yet another challenge is parsing out appropriate responsibility and remedy for errors. Take for example a simple medication error. A hospital physician writes, in partially legible handwriting, an order for doxepin 25 mg. (a sedative, appropriately dosed) that the nurse interprets

as doxazosin 25 mg. (blood pressure medication, maximum accepted dose 16mg.). The nurse sends the order to the pharmacist who dispense the medication. The nurse administers the medication and the patient suffers an adverse event. There are numerous points and levels of accountability. The physician should have written more legibly. The nurse should have been aware of accepted uses of the medication and recognized that the patient did not have hypertension. The pharmacist should have noted that the order was for an excessive dose. The patient should have self-advocated and asked the nurse to identify each medication and its purpose. The institution could have had a computerized entry system for medication ordering to eliminate errors due to illegibility. Some hospitals require, as do as nursing homes, that next to every medication order a diagnosis or medical indication is written to correlate the medication with its intended purpose. The institution should have also monitored their physician staff for legible charting and counseled repeat offenders. Did the institution "float" a pediatric nurse to an adult medical floor where medications were unfamiliar? Had the institution engaged in appropriate nursing retention and recruitment activities to avoid a shortage of appropriately qualified nurses? Did the institution appropriately verify the pharmacist's credentials before hiring and appropriately monitor his performance?

What are appropriate responses to errors by clinicians and institutions? Errors often occur due to one or more breakdowns in the system. Good systems build in a series of error protection steps so that an error is detected as it moves through the system and corrected before causing any harm. Institutions should analyze errors for individual-personnel components and, more importantly, for system problems. This system oriented response to errors is called root cause analysis and until recently was not a common activity in the health industry.

When clinicians are involved in errors, patients may be completely unaware of the error, suspicious that an error occurred, or clearly cognizant of the error. In the latter situation the clinicians should always directly address the error, take responsibility to the extent it is appropriate, and assure the patient that the institution will investigate and remediate the contributing factors to the error.

*(continued on page 2)*

*(continued from page 1)*

Should physicians always disclose errors to patients who may not be aware of the error? As a rule physicians should disclose errors, even those of no significant medical consequence to the patient. This is respectful of the patient, supports the patient's autonomy, mitigates any loss of trust by the patient in the health team, and is consistent with societal and health care norms in which patients are educated and empowered consumers of health care.

There are, however rare exceptions to this rule. One exception is therapeutic nondisclosure, also known as therapeutic exception or therapeutic privilege, which is the withholding of important health information from a patient for the patient's benefit. Physicians' use of therapeutic nondisclosure often creates potential conflict between physicians' obligations to protect patients from undue harms and to be honest and open with patients. Council on Ethical and Judicial Affairs of the American Medical Association notes that therapeutic nondisclosure may be permitted when "disclosure poses such a serious psychological threat of detriment to the patient as to be medically contraindicated."

Although therapeutic nondisclosure is intended to limit harms to patients, nondisclosure may cause harms such as suspicion and distress from being incompletely informed and therefore disadvantaged in advocating for one's self. Nondisclosure may exacerbate fears of the unknown. Nondisclosure risks damage to the patients' trust of physicians and nurses, and damage to the patients' perception of respect by these professionals. Furthermore, many patients ultimately become aware of attempts at nondisclosure. A physician may reasonably engage in minor and temporary nondisclosure for the patient's benefit, as long nondisclosure causes no material impairment of decisional autonomy. For example, a physician may briefly wait to discuss a minor error with the patient until information about the incident (e.g. what occurred, why, and the institution's response to it) in order to have a more meaningful and productive discussion with the patient.

In the final analysis, minimizing errors in medical care is really a collaborative endeavor that includes health professionals, health administrators, as well as patients. Patients need to be well informed about their health, illnesses, and medications. Patients should be inquisitive about the treatment plans their physicians' have developed for them, and a clear understanding of all the interventions they receive in the hospital. Health professionals and administrators must continue to honestly appraise the systems in which they work to safeguard patients. The health industry has recently adopted many of the safety-ensuring processes of the aviation industry, long a standard in public safety. Greater use of medical informatics computer technology to improve accuracy in documentation and information sharing will also undoubtedly result in greater error prevention.

Medical care is increasingly complex, and often involves an ever increasing number of health professionals working within larger organizational systems. The key word for us all is vigilance.

#### References

1. To Err is Human: Building a Safer Health System. Washington DC: Institute of Medicine, National Academy Press; 1999.
2. American Medical Association, Council on Ethical and Judicial Affairs. Code of Medical Ethics. Chicago IL. 1997, section 8.12:125
3. Wu AW, et al. To Tell the Truth: Ethical and Practical Issues in Disclosing Medical Mistakes to Patients. *Journal of General Internal Medicine.* 1997;12:770-775.
4. Bates DW et al. Effect of Computerized Physician Order Entry and a Team Intervention on Prevention of Serious Medication Errors. *Journal of the American Medical Association.* 1998;280:1311-1316.
5. Meisel, A. The Exceptions to the Informed Consent Doctrine: Striking a Balance between Competing Values in Medical Decisionmaking. *Wisconsin Law Review* 1979,413-488.

*Jeffrey T. Berger, MD, FACP is Director of Clinical Ethics, Department of Medicine, Winthrop University Hospital and Associate Professor of Medicine, SUNY Stony Brook School of Medicine.*

## OUR MISSION

**The New York Citizens' Committee on Health Care Decisions is a non-profit, non-partisan grassroots initiative providing an impartial forum for public discussion of critical health care issues.**

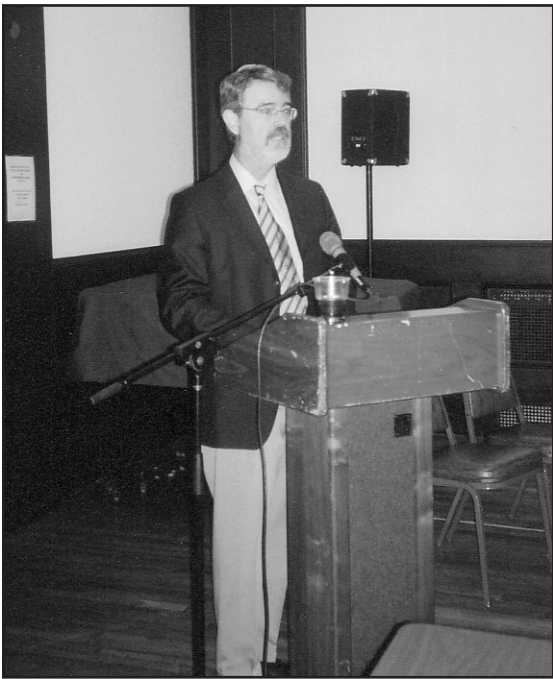
## **FITZUGH MULLAN, MD FEATURED AT ANNUAL MEMBERS' RECEPTION**

“Big Doctoring” – the resurgence of the primary care movement – was the subject at hand in Dr. Mullan’s presentation at the June 3rd Annual Members’ Reception held at the Ethical Culture Society.

Following a long career in public health – beginning as a practicing physician with the National Health Service in New Mexico and working his way up to Assistant Surgeon General (Rear Admiral) – Dr. Mullan found time to continue publishing, teach public health and practice public health in Washington, D.C.

With this background Dr. Mullan shared with us a lively presentation on the evolution of primary care -- its initial dominance, the rise of the subspecialty movement, the introduction of managed care, and now the ever more importance of the general practitioner in the landscape of often a vast and impersonal system.

The latter part of the presentation focused on the lives of the independent physicians who are portrayed in his book “Big Doctoring”. His detailed, personalized accounts of the doctors that he interviewed held everyone’s attention. All shared his admiration for their independence and dedication and were left on a note of optimism.



*Members Reception 2004 speaker Dr. Fitzhugh Mullan.*



*Members Reception 2004*



*Marsha Hurst of Sara Lawrence College and NYCCHCD Chairperson Beatrice Greenbaum.*



*NYCCHCD Chairperson Beatrice Greenbaum, Fall Let's Talk 2004 speaker, Paulette Gabel, and NYCCHCD Board Member Judith Lauterstein.*

## GREETINGS FROM THE CHAIR ...

Dear Friends,

November is National Hospice Month commemorating its unique philosophy of care for the dying with special events nationwide. Those among us who have sown the seeds for hospice care, nurtured them as they grew and blossomed, proudly acknowledged its emergence as the primary model of medical care for those on life's final journey. A path paved with compassionate comfort palliative care, strewn with love, spirituality, peace and respect for one's dignity when "living with dying".

A cause for celebration! But one might conceivably ask, why this special tribute on the pages of NYCCHCD's newsletter? A reasonable question – a straight-forward answer. Why not? How could we side-step the obvious – the meaningful synergy between the philosophy of hospice care "doing something more", and the ethical principles guiding our significant role in "promoting choice" for end-of-life patient-centered "Care Trumping Cure" – steeped in equating the importance of the quality of life with the length of life.

Before we become enmeshed in the what, where, when and why of the Joys and Hopes of Hospice, neither an oxymoron, nor a contradiction in concepts as we know them, a look at history reveals hospice as not just another modern day phenomenon. With its name derived from the Latin root Host-Guest, shared by hostel, hospital and hospitality similarly offering an expanding broad range of care and respite, we can trace its antecedents to the medieval period when religious orders provided refuge, nourishment for weary pilgrims to the Holy Land, and where the Talmud's reference to the Inn on the High Road sheltering the homeless poor, validating evidence of Saint Jerome, disciple of Abraham and Job, opening the doors of the first sick house in Rome. With the tradition of places of worship in every religion welcoming and comforting the sick and needy, their role as the earliest counterpart of Hospice in today's world is confirmed. A heritage to be savored with awe, pleasure and pride.

Fast forward to the emerging 19th century contemporary hospice movement in France, Ireland and England where the renowned state of the art St. Christopher's Hospice was established in London in 1967 by the "All-Time Mother of the Hospice Movement," Dame Cicely Saunders, whose words to her patients reflect the heart of hospice and have resonated as the hospice credo:

"You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but to live until you die."

A powerful inspirational role model for the first United States hospice, the Connecticut Hospice in Branford, Connecticut guided by Florence Wald in 1974.

Today, there are 3300 certified hospice programs nationwide, with 16 home care based and 9 in-patient facilities thriving in our own back yards on Long Island and Metropolitan New York City – with many claiming a daily patient census of 500 plus – and hospice fast-edging onto the ranks of big business as an industry. A far cry from the picket-fenced-in white clapboard houses proudly sporting a hospice sign on the front lawn visited in my travels 25 years ago, the time of my initiation into the hospice world.

Why this phenomenal growth spurt which propelled hospice onto the medical care scene with the intensity of a religious revival and the growth of a boom town? The depth and breadth of this spread into large cities and small villages did not "just happen". It speaks to compelling influences with no known boundaries be they geographic, ethnic, cultural or religious, united by an insightful vision of care for the terminally ill, drawing from public and professional life experiences and community resources to enhance the quality of life.

The confluence of social, economic, medical and legal factors, always forces for change, has further stimulated this ground swell. Paradoxically, the flip side of this self-same miracle of modern medicine, hailed for its burgeoning technology for life lengthening, had begun to back-fire in a climate nurturing consumer changing views on death and dying, fueled by a vigorous Patients' Rights Movement, endorsing self-determination for medical care decision –making via the legality of Informed Consent and Advance Directives, and still further enriched by Medicare and Medicaid entitlements for reimbursement for hospice care and third party provisions for hospice care benefits.

### **AND THERE YOU HAVE IT. HAIL TO HOSPICE CARE AS THE PRIMARY OPTION FOR END-OF-LIFE CARE!**

A windfall for decision making for the right to have and make choices within a medically, socially, financially beneficial and attractive alternative model of medical care in support of the terminally ill patient and family when curative and restorative measures have been exhausted.

And none too soon – in light of the fastest growing population 85 plus years and older with impending dire needs for compassionate comfort care within a cost-effective providers' environment in which a declining home care availability in a changing society has seen a shifting responsibility for care from an extended family to more organized medical care. Here again, Enter Hospice Care, with its different rhythm, different skills with primary emphasis on physical and emotional comfort.

*(continued on page 5)*

A quick lesson in hospice speak: where the name hospice can be parsed as both a noun or adjective. Hospice the noun refers to the site for delivery of hospice care – while traditionally and preferably the patient’s home – now more recently trending towards free-standing in-patient facilities or special units for hospice care in nursing homes and hospitals. With a final strict caveat! The hospice definition of patient’s home is wherever the patient may be.

Hospice the adjective speaks to its unique philosophy of care focusing on a long list of medical care contrasts.

***With Emphasis:***

On the Patient – *Not the Disease*

On High Touch – *Not High Tech*

On Caring – *Not Curing*

On Palliative Care – *Not Therapeutic Care*

On Symptom Control – *Not Disease Control*

On Anticipatory Continuous Pain Relief – *Not Relief on Demand Geared to Onset of Pain*

Turning to the How, By Whom and For Whom, once again the unique qualities of Hospice Care emerge. Shifting gears from PHILOSOPHY TO DELIVERY of Hands-on Hospice Care, the Patient and family comprise and are identified as the UNIT OF CARE – with the needs of both factored into the comprehensive individualized plan of care, addressed at Weekly Team Meetings for Reassessment of the patient’s condition by the 5-member inter-disciplinary care team – Nurse, Physician, Social Worker, Pastoral Care Chaplains and Volunteer — now also including the Patient’s family care giver home – uniquely placing the family in a participatory role.

Hospice care by regulation assures a 7 day/24 hour continuum of all-inclusive nursing and medical accessibility featuring four levels of care: routine patient home care and intensive crisis care when indicated; hospital in-patient acute care for co-morbidities and 5-day in-patient care allowing relief for the family member sharing the caregiving on a daily basis.

Be it noun or adjective, Hospice affirms life — concerns itself with living not dying — allowing patient to live to fullest capacity while integrating death and dying into the natural rhythm of life where the emotional, spiritual, psychological needs of both patient and family seen as symptoms – call for treatment and control!

And by respecting dying as a biographical human and social event beyond just the biological, Hospice responds to the emotional, psychological, and spiritual needs of both patient and family.

Eligibility for Hospice Care relies upon MD’s prognosis within a prescribed set of criteria:

1. MD Prognosis of Patient as having 6 months or less to live
2. Patient and family acknowledge prognosis, waive therapeutic medicine to accept palliative comprehensive medical care, pain and symptom control without the use of invasive technology
3. MD to say “I can no longer cure you – but I will continue to care for you echoing Sir William Osler who said “...we care for you sometime, we palliate often, we comfort always”.

Hospice admission originally experienced a preponderance of older patients with terminal cancer. With the gradual expansion to include patients of all ages, with progressive end-stage diagnoses such as heart and lung diseases, AIDS, Alzheimer’s, Parkinson’s, ALS and most recently, children with terminal diseases.

Now, as then, the thrust of hospice care is centered on relief of chronic terminal pain and pain control has remained the cornerstone of Hospice care.

Hospice embraces all minorities, all religions, respecting cultural diversity, race and ethnicity – thus assuring all populations with disparate views on death and dying, A Good Death on their own terms.

Concerning bereavement, in the world of hospice, ongoing counseling and pastoral care are provided to both the patient and family during the patient’s lifetime – followed by grief counseling for 13 months, extended when necessary, for the patient’s family after the death of their loved one – with special provision for the needs of children – all given by ordained clergy, certified chaplains, pastoral care specialists and trained volunteer members of the interdisciplinary care team.

Laying the groundwork for bereavement, Maimonedes said, “Be concerned with the Bereaved, not just the sick, help them during the eleven month period of mourning. In response to death provide emotional and social support, allow open expression of grief, but help to enable, to accept loss and return to a productive life. With special regard during the initial period of mourning to provide social support.”

Adhering to these time-honored precepts, on both personal and community levels, organized volunteer programs doing good deeds and “neighbor helping neighbor” by visiting the sick, bring comfort, and solace at this special time of need all emanating from our own

(continued from page 5)

houses of worship – every religion, every denomination.

Addressing terminal illness Hospice Affirms life – provides opportunity to live life to the fullest, for patient to put life in order – to remain or return to a normal place. A hospice volunteer, one assigned to each patient, as a member of the patient interdisciplinary care team, brings companionship and socialization to the patient and family by maintaining outside world connections for the patient – and opportunities for periods of respite to the family caregiver. For a hospice patient, being terminally ill does not diminish respect for either the sanctity of life or meaningfulness of life. Here again, Hospice plays a significant role in maintaining the dignity of the patient while providing an atmosphere for closure and leave-taking — “LETTING GO”

In response to the somber reality of the quote, “no one anticipated the shadow of protracted terminal agony standing behind the bright promise of longevity” Hospice leads us to understand and accept that in the finality of life when ongoing daily life becomes ever –deteriorating end-of-life, drawing on the quality of one’s own life helps to ease the experience of one’s dying.

Reflecting on the saga of hospice on its place in the ever-evolving panorama of medical care, one can not help but note while details may vary from time to time, old challenges remain, new challenges emerge to be met and overcome.

*Hospice need is never-ending! Hospice care is never-ending!*

That is the joy and hope of hospice.

*Beatrice W. Greenbaum*  
Beatrice W. Greenbaum

## IN CELEBRATION OF LIFE PLANNING WEEK

The pictured proclamation endorses the work of the ten founding members of the Caring Coalition of Metro New York. Along with our collaborating nine other celebrants, NYCCHCD gave credence to this event by utilizing the talents of the members of our professionally-trained Speakers Bureau who facilitated eight presentations to diversified groups of community organizations.

The Coalition, having completed Phase 1 of its agenda, The Planning Stage, is currently embarked on Phase 2, The Community Activities Stage, further sponsoring annual life planning events each November.

Additional local organizations with similar areas of interest will be encouraged to join as Supporting Partners hosting one or more seminars for members, clients and constituents on the importance of advance care planning for one’s own future medical care.

Potential participants are invited to contact the Coalition for further information (and in-kind assistance) by calling Mary A. Cooke at 212-995-6213 or Dan Grady at 845-561-6111. Copies of the Coalition’s guide may be downloaded from their website [www.caringcoalitionmetrony.org](http://www.caringcoalitionmetrony.org).

As an additional note to all of the above, we of the NYCCHCD can not resist remembering our neophyte role in the initial movement of advance directives upon our own founding some 15 years ago. At that time, we joined with like-minded organizations nationwide under the umbrella of American Health Decisions. At this time, we are particularly gratified to see the self-same message being spread in so many directions. We want to thank Governor Pataki for recognizing and promoting the growth of this important initiative.



### FOUNDING MEMBERS

AARP • Friends & Relatives of the Institutionalized Aged • Hospice Alliance of Downstate New York • Hospice and Palliative Care Association of New York State  
Metropolitan Funeral Directors Association • National Organization for Empowering Caregivers • New Jersey Hospice and Palliative Care Organization  
New Jersey State Funeral Directors Association • New York Citizens’ Committee on Health Care Decisions • Westchester End-of-Life Coalition

## A COMPLAINT AGAINST “COMPLAINTS”

Having just emerged, aged 82, from the Valley of the Shadow, thanks to a just-in-time-ly removal of a cancerous uterus. I am full of bright shiny ideas, most of which are probably worthless, But one, I’m convinced, is not. That is the need to expurgate the word “complaint” from the medical lexicon for defining reportage by elderly as well as other patients about their symptoms.

In this era of health maintenance organizations, with doctors even more hurried than before, and many patients even more cowed than before, the pejorative word ‘complaint’ further discourages patients from spelling out for their doctor how they feel, especially after treatment when, say, mentioning an unexpected side effect implies criticism of the doctor. This reluctance, in turn, can deprive doctors of feedback that could be helpful in patient care.

At the risk of making myself appear like the grinch and distinguished physicians at a major teaching hospital appear overly defensive, here is a case in point:

After my hysterectomy and node removal, the surgeon referred me to a radio-oncologist. I felt in no state for any further treatment, even after the standard maximum of 8 weeks of recovery. I told the surgeon that bowel and bladder were still mad as hornets, but he said that an internal exam showed my tissues to be healed.

After the first treatment, as the radio-oncologist was leaving the room, he called back, “I predict you will feel no side effects.” Half-kidding, I asked how accurate his predictions usually were. “Very,” he said.

Well, he was wrong. And now that I consider it, why wouldn’t he be? Never before in history has there been the critical mass of old people that now exist in the industrialized countries, with my generation serving as the prow of the ice-cutter in regard to how the medical profession should deal with us. Intellectually, physicians know that we may heal more slowly and respond to medication far more sensitively than before, but in practice their tendency is to rely on standard rather than minimum dosages and thus make the error of over-treating us.

The radio oncologist gave me the conventional 700 rads. Three hours later, I was felled by toxic fatigue, has developed a fiercely burning anal sphincter, got diarrhea, and found that the hot flashes I had been experiencing since hormone replacement therapy was recently denied me had become flame-like (with cheeks turning crimson and nose pulsating until I looked like Rudolph the Red-Nosed Reindeer). I phoned the radio-oncologist but he was unavailable. The next day he was also unavailable. This was the week between Christmas and New Year’s, so I talked instead to his resident, and then to his secretary. I was told that the doctor had received my messages but felt that my symptoms were not related to radiation.

What? I couldn’t believe how callous, close to unethical, the doctor was being. I therefore sent word that I would take my chances on recurrence of the cancer by skipping the rest of the treatments. The secretary begged me to reconsider. I also had a genuine complaint, one shared by elderly and other patients who undergo procedures that force them to lie unmoving on a hard table for considerable lengths of time – namely, a painful back. Mine continued to be agonizing because of a previous spinal fusion and a laminectomy. Though the radiation itself has taken 13 minutes, I had been left on the table beforehand for 25, with knees in extra high stirrups, while the professionals did the needed computations. He masseur I later turned to for help found ‘knots’ in my back, and I was forced to use a heating pad both day and night. I wrote a memo to the radio-oncologist, with a copy to the surgeon. The surgeon phoned me, and in my verbal report about the sphincter I used the phrase “burning tail feathers.” This he found so hilarious that he promised this area would be protected if I would please return for a second treatment. He also promised to speak beforehand to the radio-oncologist.

And indeed, the next treatment was much better. First, much of the computations was done while I was seated comfortably on a chair; second, I was helped onto the table as I were a cross between the Queen of Sheba and Barbara Bush, and a pillow was inserted under my lower spine. Third, the radiation was reduced from the standard 700 rads to the minimum of 500, and its duration from 13 minutes to 8. After I got home, the tail feather problem did not return. However, to a diminished degree, the toxic fatigue, diarrhea, and hot flashed did. Because I felt weird, I took my blood pressure (which I occasionally must do for hypertension). Two days earlier, it was 135/65; on radiation day, it was 175/100. I was so shocked that I asked our house sitter, a registered nurse, to take the blood pressure. Same result.

Yet, the radio-oncologist continued to insist that my responses were idiosyncratic. I therefore wrote him a second memo (which became the germ of this article).

As for your impression that my symptoms are unique, may I suggest that you or one of your residents or your secretary phone your elderly patients the day after treatment and ask whether they have any new sensations to report. Without being asked, many, if not most patients will not volunteer such information. It requires a degree of courage and medical

*continued on page 8*

*(continued from page 7)*

sophistication to stop being the “good” i.e. uncomplaining, patient and instead risk being considered a crybaby, or a neurotic who is imagining things, or a hypochondriac. Laypeople, particularly old ones, are reluctant to “bother” their doctor. They prefer to “suffer in silence.” Because they are so in awe of white coats and intricate machinery, they do not report the kind of symptoms that would actually be helpful for the white coats to know about but is termed by them a “complaint.” Nobody wants to be considered a complainer, with its implication of whining or self-pity.

In short, from the physician’s point of view, “no news” should not automatically be viewed as “good news” – and the Pentagon’s former advice about gays, “Don’t ask, don’t tell” should be turned on its head: Doctors should ask, patients should tell. A simple symbolic way to bring this about would be to substitute for the pejorative ‘complaint’ the neutral word, ‘concern’ thus retaining the traditional ‘CC’ for doctors while encouraging patients to confide what’s really bothering them.

Following my third treatment, 10 weeks after surgery, he side effects were blessedly muted. This led me to wonder whether the standard 6-8 weeks in sufficient time for the innards of an elderly patient to recover from hysterectomy plus node removal. Perhaps the fault, dear Brutus, is not in our stars but in the medical manuals still relied on by many a doctor despite their having been outdated by the Golden Oldie revolution which is about to be joined by the Boomer generation.

It’s not just manuals that need updating; so does the pharmaceutical provision of dosages for older patients. We need not just baby aspirin but also baby every-drug. 9I, for example, have to cut my lowest dosage of clonidine into quarters and take one every second night.) Most important is for more physicians to realize the unless the reported reactions by us geriatric patients stop being brushed aside, linguistically as well as otherwise, we won’t be able, as we would like, to bless them on our deathbeds. Instead we may curse them for the “harm” they promised Hippocrates to “do” but nonetheless unthinkingly did.

Originally published in the Annals of Internal Medicine, January 7, 2003.

*June Bingham, author and playwright, founded the TLC (Trained Liaison Comforter) volunteer program at New York Presbyterian Hospital in 1989. It continues to place volunteers in the intensive care waiting rooms to help the families and friends of the hospitals’ sickest patients. Anyone interested in volunteering for three hours a week should call Francis Dennison at 817-543-5018.*

---

## **NEW YORK STATE RECOGNIZES NYCCHCD CHAIRMAN BEATRICE GREENBAUM AS SENIOR CITIZEN OF THE YEAR 2004**



*Maurice Greenbaum, Beatrice Greenbaum. Assemblyman Steven Engelbright.*

Having been congratulated in our previous newsletter for receiving the Nassau County Senior Citizen of the Year, we now happily resort to the vernacular “Can you top this?”

The answer is “yes!” The Board of Directors of NYCCHCD happily congratulates Chairperson Beatrice Greenbaum for having been designated New York State Senior Citizen of the Year for 2004, celebrated by an event at the Governor’s mansion in Albany on May 5, 2004.

### **NYCCHCD’S NEW HOME**

**NYCCHCD’s new address**

**1775 Broadway, 3rd Floor, New York, NY 10019**

**Tel: 212-586-4638 • Fax: 212-586-4699 • e-mail: [nycchcd@aol.org](mailto:nycchcd@aol.org)**

## NYCCHCD “LET’S TALK” SERIES

Over the years, our Let’s Talk series has provided a forum for enlightenment and lively discussion on a myriad of topics we and you, our members, have been interested in learning about and even sounding-off on. Our Spring 2004 series “Sharing the Caring: For Patients and Families in Hospital”, introduced many of us to three important hospital resources: the discharge planner, the patient advocate and the ethics committee – patient allies one hopes to never need but now is aware of, if needed. The Fall 2004 topic “We’re on the Team -- Get to Know Us Serving Three Underserved Populations – The Deaf, The Mentally Ill, The Frail Elders” gave us a glimpse of life for many marginalized and underserved groups who are deserving of not only our tolerance and understanding, but of our active participation in providing the services seldom received from other sources.

In response to our call for your suggestions, our next Let’s Talk series “You Asked For It”, scheduled for March 9, April 13 and May 18, will cover the following topics: Hippa - The New Privacy Regulations -- Who’s Looking Over Your Shoulder And Why; DNR, CPR, DNI, IRB: Who, What, When, Where And Why - A Primer: In Whose Best Interest; and Hospitalists: The New Member of the Medical Team - What Can They Do For You And Why”.

We continue to welcome your suggestions and participation, and what you would like to be up for discussion in the next series. Come and enjoy the fruits of your suggestions!

### SPRING 2004

## SHARING THE CARING: FOR PATIENTS AND FAMILIES IN HOSPITAL WE’RE ON THE TEAM — GET TO KNOW US



*Spring Let’s Talk 2004 speaker, Eileen Zenker*

Wednesday, March 10, 2004

**“Leaving the Hospital: Discharge Planning 101”**

Esther Chachkes, D.S.W.

Director of Social Work, NYU Medical Center

Eileen Zenker, M.S.W.,

Assistant Director of Social Work, NYU Medical Center



*Spring Let’s Talk 2004 speaker, Cathleen Acres.*

Wednesday, May 12, 2004

**“Hospital Ethics Committees: A Resource for Patient and Family?”**

Cathleen A. Acres, R.N., M.A.

Administrative Director, Division of Medical Ethics

Weill Medical College of Cornell University



*Spring Let’s Talk 2004 speaker, Laura Weil*

Wednesday, April 14, 2004

**“Hospital-Based Patient Advocacy:**

**Patients’ Rights, Conflict Resolution and Truth-Telling”**

Laura Weil, M.A.

Director, Patient Representative Department, Beth Israel Medical Center

Faculty, Sarah Lawrence College Health Advocacy Program

## FALL 2004 PROGRAM: SERVING THREE UNDERSERVED POPULATIONS – THE DEAF, THE MENTALLY ILL, THE FRAIL ELDER



*Fall Let's Talk 2004 speaker, Jim Mutton*

Tuesday, December 7, 2004

**“Working with Homeless and Formerly Homeless Adults with Severe and Persistent Mental Illness”**

Jim Mutton

Director of Residential Services, Project Renewal

Tuesday, November 9, 2004  
**“Do You Know Who Your Elder Neighbors Are: Neighbors Helping Neighbors”**

Joan Mintz, MSSW

Executive Director

United Neighbors of East Midtown



*Fall Let's Talk 2004 speaker, Joan Mintz*

Tuesday, October 5, 2004

**“Hospice: Life and Death – Is There a Deaf Way?”**

Paulette Gabel

Outreach Coordinator, Deaf Hospice Program

Continuum Hospice Care Jacob Perlow Hospice/Beth Israel Medical Center

---

## MARK GOODWIN AND JUDITH LAUTERSTEIN NAMED TO BOARD

The Board of Directors is pleased to announce the addition of two new directors to the NYCCHCD Board, Mark Goodwin and Judith Lauterstein. Both Judith and Mark have been staunch supporters of the organization first through their volunteer activities as members of the Speakers Bureau and now as they sit on the Board of Directors. We welcome them both and look forward to their valuable insights and continued involvement.

Judith K. Lauterstein Ph.D, was born in Portland, Oregon and has lived in NYC for forty years where she has a private psychoanalytic practice. Currently, she is the coordinator of the Continuum Care Deaf Hospice Program/Jacob Perlow Hospice at Beth Israel Medical Center in NYC where she is responsible for the overall administration of the hospice program for the deaf, deafblind and hard of hearing at the end phase of life. She was also coordinator of the NY State Legislative Hearings on Health care access to the Deaf.

Mark D. Goodwin, J.D., MSW is a graduate of Brooklyn Law School and Boston University School of Social Work with a private practice in estate planning and elder law. He is a board member of the Latino Alzheimer's Coalition. Mark also works as a social worker in the emergency room of Montefiore Medical Center, Bronx, New York, where he leads an Alzheimer's caregiver support group. He makes many presentations to community groups on advanced directives, elder law and estate planning issues in both English and Spanish.

### BECOME A MEMBER

For only \$35 a year or \$60 per couple (*\$100 for institutions*) you can support the non-partisan community outreach work NYCCHCD performs every day of the year and receive our newsletters, mailings and invitations to our events.

Please call **212-586-4638** to become a member.

## PROCEED WITH CAUTION: HOSPITALS CAN BE HAZARDOUS TO YOUR HEALTH

On November 13 NYCCHCD joined with the Hastings Center to present a program addressing “Medical Error, Medical Ethics -- a topic of critical importance to all present and future patients and their loved ones. A group of more than 50 people attended this provocative and informative colloquium, which was held at St. Bartholomew’s Church in Manhattan under the auspices of its Center for Religious Inquiry.

Participants in this event heard from a highly distinguished group of speakers who included: Ethel Mitty, RN, EdD, clinical professor of nursing at New York University; Mark Rosenberg, MD executive director of the Task Force for Child Survival and Development at the Center for Child Well-being in Atlanta; and Virginia Ashby Sharpe, PhD, ethicist and leading expert on medical error and patient safety. Upon the conclusion of the panelists’ presentations, attendees participated in a case study discussion.

In introducing the conference, Nancy Berliner of the Hastings Center, noted that it has been nearly five years since the Institute of Medicine issued its ground breaking report entitled “To Err is Human: Building a Safer Health System.” This report broke the shocking news that nearly 100,000 Americans die each year because of medical errors. This is the cause of more deaths than those caused by motor vehicle accidents, breast cancer or AIDS. As shocking as this figure is, it does not reflect the number of people harmed by medical errors who survive. The report has generated a great deal of discussion among health care providers and in Congress. A number of pieces of legislation have been introduced in Congress to address the problems, but to date none of them have been passed.

Dr. Rosenberg opened the meeting by sharing the deeply painful story of his own family’s terrible experience with medical errors that resulted in horrible pain and suffering for his father, contributing to his death. Even though both he and his mother are physicians, they were unable to protect their father and husband from the kinds of errors that too commonly occur in our health care system because of poor communication, inadequate patient monitoring and lack of follow-up. Not only patients suffer from medical errors. His account showed clearly how -- long after the event -- families suffer from both guilt and grief, even when there was nothing they could have done to prevent the errors.

Dr. Mitty addressed the complex systems issues that contribute to medical errors. We all know that even under the best circumstances people do make mistakes. However, she described a training environment for medical professionals that is not only unsupportive, but even hostile to acknowledging and exploring mistakes, and an inefficient system for dealing with errors through litigation. Focusing on problems in the long-term care setting, she noted the failure to monitor pain systematically or, even when

monitored, a failure to provide a system that permits quick response to symptoms. Regulations can prevent nurses from using their own judgment and experience in dealing with patient emergencies, yet physicians often are not readily available in the long-term care setting. This can result in inappropriate and potentially damaging transfers to emergency rooms.

Dr. Sharpe focused on some of the issues that must be addressed in order to change the way in which health care institutions address medical errors to bring about system reforms, such as creating “no-fault” systems of error reporting. This would encourage health care providers to report errors that occur, even those that do not harm patients, without fear of reprisal, thus permitting an examination of the factors that may have contributed to the error.

Some steps that we as health care consumers can take to be alert to possible errors were also explored. As our health care system becomes more fragmented, the possibilities of error increase tremendously. It is extremely important that someone be with the patient as much as possible. It may be up to the family members to supply the information and communication about the patients’ condition to new health care providers, to remind them of the tests that have already been preformed, or medication allergies that may be overlooked. It may be the family member, who might be more sensitive to changes in the patient’s immediate condition, who must alert the health care providers, and, if necessary, insist they pay attention to the patient’s symptoms. It is important that family members and patients be alert for errors, bringing them to the attention of the health care administration and asking what is being done to improve their systems of care to prevent future errors from occurring.

A few hospitals are making efforts to systematically address medical errors. A recent news article describes the efforts of the Virginia Mason Medical Center in Seattle, Washington, to handle mistakes in a new way. In response to a mistake that killed a patient, the hospital told the family what had happened and publicly apologized to them. The hospital made a thorough investigation as to how the error occurred and took specific steps to ensure against such a mistake occurring again. Typically, institutions deny or attempt to cover up mistakes because of fears of litigation, which means that there is not likely to be an effort to discover the source of the error and to seek to correct it.

The conference made clear that lowering the number of medical errors that occur in our health care system is an enormous challenge. It is a challenge that we as consumers must demand be a top priority for our policy makers and health care providers. It also requires that we as consumers remain vigilant advocates for patients.

## **BOARD OF DIRECTORS**

### *Chairperson*

Beatrice W. Greenbaum, M.P.H.

### *Vice-Chair*

John W. Cornwall, M.D.

### *Secretary*

Mary L. Meyer

### *Treasurer*

Sara R. Faison

Bry Benjamin, M.D.

Carmelita Blake, Ed.D.

John Evangelista M.D., M.P.H.

Mark D. Goodwin, J.D., M.S.W.

T. Patrick Hill, Ph.D.

Jay Kantor, Ph.D.

Judith Lauterstein, Ph.D.

Sandra E. Mager

Paula Maresca, R.N.

Joel M. Roselin, M.T.S.

Mary Strong

**SAVE THESE DATES!**

### **LET'S TALK - SPRING 2005**

#### ***You Asked For It:***

"HIPPA: The New Privacy Regulations -  
Who's Looking Over Your Shoulder and Why"

***Wednesday, March 9***

#### **DNR, CPR, DNI, IRB:**

***Who, What, When, Where and Why***

"A Primer In Whose Best Interest"

***Wednesday, April 13***

#### **HOSPITALISTS: THE NEW MEMBER OF THE MEDICAL TEAM**

"What Can They Do For You and Why"

***Wednesday, May 18***

#### **MEMBERS' RECEPTION**

***Thursday, June 16, 2005***



## **NEW YORK CITIZENS' COMMITTEE ON HEALTH CARE DECISIONS**

1841 Broadway, Suite 905  
New York, New York 10023