

## NOTES from Presentation by Gae DelCampo – Pinschmidt at January 2013 AARP Meeting

My husband Bill and I are members of **LIFE PRESERVERS**, which is an adjunct of the **Unitarian Universalist Fellowship** here in Fredericksburg. Bill came up with the name, which well suits our concerns, having to do with care giving, end-of-life issues and situations germane to the elderly.

We're here today to share some specifics concerning us all, having to do with hospitals and corporate medicine's intrusion into hospitalization. How many here are familiar with the word *hospitalist*? Patients at Mary Washington know it well. A *hospitalist* is a doctor who is a paid employee, much as a nurse is a paid employee of the system.

When Bill was hospitalized at Mary Washington, not long ago, his family doctor did not come in every day to discuss and monitor his care. Under a *hospitalist* system, family doctors no longer do that -- no longer make rounds, no longer have those hospital privileges formerly allocated to professional visits and patient interaction. Those of you who have been patients under this new system know that such care is now superseded by a *hospitalist*; which is to say - in Bill's case - a doctor who was a stranger to him, knowing very little of his history beyond notes on a chart. He first walked into Bill's room reviewing that chart, acquainting himself with particulars as he did so. His introduction was cordial, examination was swift, conversation consisted of orders relayed to a nurse. Following which, he left, leaving us to mull over questions unasked and prognoses all but unaddressed.

Bill's stay was all too typical. Patients these days too often feel themselves adrift in a system ostensibly geared to their care, but where holistic medicine once had a family doctor keeping us apprised of our progress, no one much seems to coordinate patient information these days, beyond what is noted on a board at the foot of the bed. That is considered sufficient. But, it's very far from that.

Realistically, corporate medicine's takeover of healthcare is rapidly becoming nationwide. BOTTOM LINE: *hospitalists* in one form or another are here to stay. Disbursements and Accounting Departments love the idea, we all understand that, as do many physicians, since it offers regular hours to overworked professionals who - under the old system - all but lacked private lives.

We, as patients, are less enthusiastic. Our care is on the line ... which is why it's doubtless time for us to listen to what the medical community has long been telling us, and that is that we need to make ourselves responsible; an interactive part of the process beyond just taking to our beds. That is where Patient Advocacy comes in. What we're talking about are patient journals or logs, making the patient and his/her advocate an interactive part of the system. When we talk with former patients about this, most are very receptive. Among those who have been assigned to the care of *hospitalists* - complaints are pretty much the same. *"Who do I ask for information now? Once holistic medicine goes out the window, with no family doctor to refer to, who can tell me what's going on?"*

Conceding care to some stranger, unfamiliar with our history except what appears on a chart, is not re-assuring. Somehow, a kind of fragmentation sets in. Why? Because fragmentation is pervasive when it invades the care process; it too often compromises patient access to information, promoting serial disconnects that haunt a hospital stay. Mounting frustrations result. In patient terms, this is significant; a flaw in corporate hospitalization, and one of the chief reasons why Patient Logs are, indeed, an idea whose time has come. Not all admissions are people with a ready grasp of their own situations, which is why logs offer better reinforcement than fleeting conversations with busy and elusive staff.

So, here comes the good news! Mary Washington Hospital is getting on board with a forthcoming Patient Guide. Now in the works, soon it will be a part of their Admissions Process. Which is to say that we - as incoming patients - will receive a journal or log, explaining various aspects of care, hospital routines, and assorted pro-active means of keeping us informed through a system of advocacy, in which we or assigned family, friend or volunteer, are kept abreast of information relative to all our ongoing therapies, tests, medications, nurse and hospitalist visits - enhancing our personal enlistment in the care process.

Let's narrow the focus and put ourselves in this picture: as patients either we function as our own advocates or someone fills that function for us. In either case, we want to know as much about our own situation as can be understood without some kind of medical degree. Family doctors used to do that for us; *hospitalists* do not. A family doctor used to know our history, knew the family, knew a lot about us that a hospitalist does not. Know. This is where Patient Logs come in, creating a permanent record, journaling our hospital stay in terms of easy reference. All those questions we never thought to ask, we can now ask and record. Information we never seem to remember, we will also record, plus requests and suggestions kept right at bedside, close at hand for review and for taking notes. Procedures and treatments will be logged, visits by hospitalists and nurses, plus lab and test results, making us all, as earlier noted, interactive parts of the process focused upon our care.

And why shouldn't that be? We certainly have a vested interest in it, beyond which a freely circulating advocacy can very well impact our needs. As Patient Advocates, most of us would welcome a relative or friend in this role, but volunteers trained in process and empathetic skills could also introduce the system as soon as it's helpful to do so; that's a judgment call. Suffice it to say, if connectedness is integral to therapy - (we are assured it is) - then stemming that gnawing sense of futility attached to anxious feelings of being adrift should be central to outcome as worthwhile patient goals. Translation: *"Why are they doing these tests and what are they supposed to tell us?" "Who is this other doctor and why are they calling him in?" "Why have they got me hooked up to this monitor? What's it been telling them?"*

Here's an example: some months ago Bill was hospitalized. I as wife and advocate, asked for specifics on some blood tests but found myself politely turned away. "Sorry, but I'm not permitted to give that information." "But I'm his wife! Not some stranger!" "I'm sorry but those are the rules..." The follow-up was that only if his circumstances were deteriorating did they then have permission to tell.

How about that! To someone fluent in legalese this may make some kind of sense, but our feeling was and is that the advocate needs to be drawn INTO the loop, not excised FROM it. Fear of the unknown is a *bugbear*. Who here hasn't experienced that? Not knowing has a capacity to eat away at us - often more so than knowing. With changing hospital shifts, random identities, personnel coming and going night and day - informational fragments were all that Bill and I had to go on, and trying to piece them together produced at best a patchwork of information with more questions than answers. We were never sure what all those tests were for, or how they related to diagnostic procedure, so being better apprised really could've been helpful to us.

Conceding that those of us along in years have pretty much come to accept long waits as measures of the hospitalization process, in which regard a lot of extensive testing comes to seem grimly routine. Feeling exposed to the world, stared at by strangers, rolled on gurneys into elevators, down long halls, into, onto and under formidable machines ... minutes morphing into hours stretched out in some obscure corner of the building. Over which time, to patients often unattended, a little solid information can help dispel growing anxieties when we're feeling vulnerable, ill and alone. So we had ample reason for concern, but efforts to address much of this were pretty much blown off to staff ostensibly in attendance, but nowhere in sight. Small wonder that under such conditions fear and anxiety compound. Patients and caregivers of all ages have discussed this with us, and all agree that pervasive fragmentation invading the care process does, in effect, consign patients to something like a kind of "Limbo".

Concerns about this lack of holistic oversight, prompted lengthy discussion among Life Preservers and a letter went out to Mary Washington Hospital suggesting a Patient Log or, at least, a brief DAILY SUMMARY as a means of helping to bring advocate and patient up to speed, explaining why's and wherefores in terms of expectation. Such information provides focal points for discussion when the *hospitalist* visits the scene. Given which - Summary, Journal or Guide, most patients and advocates could and would maintain such a reference in their own best interests. Relative to which, is our need just to Speak Up. Registered nurses interviewed make the point "... *that patients and their loved ones are often intimidated by doctors and nurses.*" Martine Ehrenclou, in her groundbreaking book **Critical Conditions** insists upon this: ASK QUESTIONS! "...*if you're confused about something...you have a right to ask...and to feel comfortable about the medical care provided. You, as patient, want to be comfortable - you want your loved one to be comfortable. If your loved one is confused, talk to the primary nurse (NO OTHER NURSE WILL DO), or hospitalist, and make sure your questions are answered.*"

My darling little Auntie said, to the contrary, "*I don't know what all those tests are for! He's the doctor - let him do his job!*" Which, if we're talking faith, builds churches, but not effective doctor/patient relations. Not at this point in time. Not with annual U.S. patient deaths well into the thousands, ascribed to faulty hospital care. As Ehrenclou points out, "*The number of patient emergencies can make hospitals...frantic places, so much so that it's possible that (a patient) could be forgotten or overlooked. (When in doubt) find the primary nurse on the floor and ask. If a procedure was ordered that hasn't been done, or surgery has been delayed, ASK! A firm and respectful manner will get you more of what you want for the patient, bearing in mind that belligerence usually backfires.*"

What it comes down to is this: each admission is a duality. Patient and advocate are halves of an interactive duo. Staff should be cognizant of this. Bearing in mind that advocacy must not be intrusive, is not a mechanism for intimidation, nor may it presume upon staff. One doctor interview in **Critical Conditions** makes the valid point that each family or patient should inform the Admissions clerk who has been designated to represent them. To expect a doctor to discuss treatments/ decisions with everyone in the family is not reasonable, citing as a *nightmare family* the one "...*where everyone wants to share their experiences and opinions about medical care with the doctor.*" Sensitivity is requisite to advocacy and making it work. As it turns out, however, that's not too hard to pull off. As one MD insists, "*Don't allow your loved one to go into the hospital and just let things happen....*"

Two models of journals we find particularly instructive are:

1. **The Josie King Foundation Log**, broadly in use throughout Pennsylvania's hospitals. They like it up there. They say it makes them more efficient and promotes better in-house relationships.
2. **Critical Conditions**: Martine Ehrenclou's "*Essential Hospital Guide...*" which also includes a detailed step-by-step log replete with useful information on "*taking the hell out of health care,*" according to one reviewer. This recommended read was brought to our attention by nurse, Bonny Weber, a member of Life Preservers, whose enthusiasm for it made us all light up.

Mary Washington, to its credit, has in effect followed an outline of **Critical Conditions** which in its opening chapter explores in detail 15 steps comprising the basics of advocacy. Issues such as pain management and diet are discussed. Allergies and treatment plan. Sample questions:

1. **What is that for?**
2. **What medication is that?**
3. **Would you please re-check the name of that medication?**
4. **Do you know that (name) has an allergic reaction to that kind of medication?**
5. **Bill has (name of illness, injury or problem). Or, Gae had cataract surgery and wears replacement lenses. I just wanted to make sure you were aware.**
6. **My mother is in considerable pain. Do you think she could have some medication as soon as possible?**

All making the point that "...the goal of the advocate is to support the best possible medical care for your loved one," and certainly - as your own advocate - the best possible care for yourself. All of which is covered extensively under such headings as:

- a. **Health Directive Documents** offering space for listing: Advance Directive, Living Will, Durable Power of Atty and DNR orders.
- b. **What I Can Do to Help With Patient Care**
- c. **Procedures and treatments**
- d. **Lab and Test Results**
- e. **Medication Information**
- f. **Sample Questions for Doctors and Primary Nurses....**when we can't quite think of what to ask, after the doctor has left, or in the car on the way home.

Ehrenclou's book becomes its own log in a section with blank pages for notes, and - at the back - an annotated Reference Guide, starting with:

**Patient Diagnosis and the doctor who made it**  
**Treatment Plan and the doctor who created that**  
**New Medications and dosages - cost and generics**  
**Patient prognosis**  
**Expected length of stay**  
**Planned surgery and date**  
**Pre-op appointment date**  
**Notes on possible referrals for second opinion**  
**Notes on conversations with primary physician/hospitalists, referral physicians, and primary nurses**

Sample questions include:

- "What is the diagnosis of this illness/injury? Can you explain this to me?"** Take notes.
- "Can you please explain the treatment? Are there risks?"** Take notes.
- "New medications? What are those for? What are the costs likely to be? Can generics be used? Will Medicare cover it?"** Take notes!

Bear in mind, as earlier noted, under the old holistic system, answers to such questions were supplied by a family physician whose knowledge of the situation pretty much encompassed it all. Whereas, corporate medicine's approach now makes note taking and record keeping on the part of patient or advocate, a highly useful, even necessary procedure in navigating the system. Ample space for Progress Notes offers blanks for questions of primary physician/hospitalist, ancillary people, daily conversations with them all, and patient observations throughout the length of the stay, now around three or four days. A handy Glossary of medical titles and terms de-codes much hospital vocabulary, making discussions comprehensible which otherwise might not be, and an Index sends us directly to pages most pertinent to our specifics.

So struck by the comprehensiveness of this research were our Life Preservers members, that most of us now feel a combination of Mary Washington's forthcoming **Patient Guide** plus **Critical Conditions** will be ideal accompaniments for any hospital stay. The latter can be ordered on Amazon or locally. Such logs and journals constitute empowerment in situations where our well-being is at stake. Think of them as the pro-active difference between navigating the system with confidence or feeling adrift in it. What it comes down to is this: the choice is now ours, and the ball is in our court.