

***About Health TV with Jeanne Blake***  
**Bedside Advocates**  
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JEANNE BLAKE: Welcome to *About Health TV*, I'm Jeanne Blake. If you, a parent or another loved one has ever been hospitalized, you know how overwhelming the experience can be. Time and again patients complain about a lack of communication between them and their healthcare provider. Many hospitals are taking bold steps to enhance doctor/patient communication but it's agreed that there's still a great need for bedside advocates. We're joined today on this edition of *About Health TV* by Dr. Jonathan Fine, a retired physician who has started such an organization, Bedside Advocates. Dr. Fine thanks so much for coming in.

DR. FINE: Great to be here.

JEANNE BLAKE: Now the miscommunication between healthcare providers and patients creates a potential for medical errors, that's something that's firmly established. The Institute of Medicine reports that medical errors cause nearly 100,000 deaths every year but you started your organization not driven by data, but a very personal experience, explain to us?

DR. FINE: Well, I just stumbled into this in retirement you might say, not that I was totally idle. But I had a very good friend who, I can mention his name because he's part of this story in a bigger way, Sumner Kaplan, who served in the state legislature, was a Judge in Massachusetts, a General in the Army Reserves, a really great guy. But he's at the age of 85, he had a series of serious chronic conditions and I went to the hospital to visit him on one of these occasions in 2004 and found him at death's door and I decided I'd spend the night. He had wonderful family support but they couldn't spend the night, they had small children and that got to be a habit of mine as long as he was hospitalized. Well we went through about five or six hospitalizations like this and he would turn to me when the doctor left the room and say "what did he say?" Part of his, his anxiety overflowed, he later confided in me that what he was thinking is "am I dying?"

JEANNE BLAKE: So his, his inability to understand what the doctor was saying was it because he was 85, was it because he was overwhelmed as I said can be when you're fearful and you're taking in a lot of information. Or, what do you think, what was the, why was he needing you to help interpret?

DR. FINE: You know, and, of course, I've been hospitalized myself and so I have both the point of view of the patient and people I've helped and having been a practicing physician. Those perspectives are all uniquely different and if you have all three of these, maybe you can do a better job at it. But I think when you're a patient in the hospital; the whole world is foreign to you. Everything that's done is hard for you to grasp, besides you're sick, you're on some kind of medication, sometimes for pain, you don't get a good night's sleep, you're confused who these people are who keep parading through your room and the doctor is very busy, he comes, if you're lucky, he'll take your hand and he's gone after a few words, you don't know the score. You really don't know what's going on. So it's more than miscommunication, it's lack of a sense of security that people have. I think being in a hospital is an experience of maximum insecurity and one thing we try to do and what developed into this organization is to give people what's come to be missing in healthcare today, whether at bedside or in their own homes or in the doctor's office.

JEANNE BLAKE: Right.

DR. FINE: And that is the sense that there is someone with you who always will be with you who is within reach of the telephone and they are going to provide reassurance, they are going to look out for medical error as you point out which is still very prevalent and they are going to help you with your medications, they are going to help you stay as healthy as possible.

JEANNE BLAKE: So after your experience with Mr. Kaplan for five or six hospitalizations, you had this idea of actually formalizing the relationship that you had so that others could benefit?

DR. FINE: Well he and I did together. We talked about this. We said this thing really works. Not that family members don't do this to the nth degree for their own

loved ones, but the public at large, even those that have family support, don't have this. When I've been in the hospital, I've been alone. It's the aloneness as much as anything else against this huge what can I say landscape of machines and needles and IV's and people rushing you around from one place to another sometimes you don't even know the destination you know. And understanding almost none of it even if you're a well-educated, well-informed person. So Kaplan and I said maybe we can do something for others and we began planning in the fall of 2005. We have a non-profit organization that's tax exempt and now we have two small teams of volunteers that are trying this out in Eastern Massachusetts.

JEANNE BLAKE:                   And they're not all physicians?

DR. FINE:                    No, what we've done though, because they're not all physicians, is we have some nurses who are retired and lay people who know the score because they've been through this with their own parents, they know the grief, the heartache and the confusion and they're very empathetic for others in society whether young or old, we do this for the elderly but we also have some younger clients. Now I want to emphasize we don't practice medicine even though some of us are medically trained.

JEANNE BLAKE:                   Exactly, right, right.

DR. FINE:                    But we know the medical labyrinth and we know how to get prompter appointments and to look out for error and to help people with their medications and how to communicate effectively on their behalf when they ask us with their doctors.

JEANNE BLAKE:                   You have been a doctor for many, many years and how have you seen healthcare change in the work that you are doing now compared to the years that you were taking care of patients?

DR. FINE:                    I know it echoes I don't know whether everybody feels this way but I think the system has broken down. Healthcare is broken. Why is it broken? It's too fragmented. I always rush to the hospital if I have a serious enough problem but I do it with a certain sense of dread because there are so many discontinuities. I talked to a

woman in the waiting room of an intensive care unit at one of our great hospitals who told me she was the only person that knew her husband well enough and she was twice kicked out of the emergency room when she brought him in with a stroke. And nobody else knew him and his record was that thick and, and so there is that kind of problem as well. So we're trying to personalize care by getting retired health professionals to take this up on a one-on-one basis for people who need this kind of help.

JEANNE BLAKE:                   And you'd like more physicians?

DR. FINE:                   We'd love to get more. The Mass Medical Society has tried to help but we don't quite have the right key to unlock that door as yet. Now we have, we have one other physician in this pilot project; Douglas Fiero is his name who is a wonderful, well-informed doctor in semi-retirement who is also advising but the key to what we're doing is our volunteers are in small groups of five and six and so whether they have a background in nursing or as a physician or as lay people, we all consult together and support each other and although our, our information is kept confidential, we discuss cases and how we can improve our role.

JEANNE BLAKE:                   Now how are you welcomed in the hospitals? And by the doctors?

DR. FINE:                   Well that's key. This is a very interesting point you're making. We're welcomed by different people in different ways. I think some full-time hospital doctors they're referred to often as hospitalists, are a little dicey about having another retired physician looking over their shoulder so we have to be both diplomatic and explain we're not there to practice medicine, we're there more as an informed friend of the patient. And when we do that, we can establish a pretty fair relationship. I want to emphasize though that most of what we do is not during hospitalization, because even the sickest people usually don't spend most of their time in the hospital.

JEANNE BLAKE:                   Right, right.

DR. FINE:                   So it's relationships with doctors over the phone, or when they go to the doctors' office or specialist.

JEANNE BLAKE:                   Interesting.

DR. FINE:                    Yeah, and I find that specialist are much more forthcoming, this is anecdotal information, but most specialist see the need because they see people every ten to fifteen minutes at most, they know very little often about the people referred to them and when there's an informed person who comes along and can give them a concise explanation of the problem and the history,

JEANNE BLAKE:                   Sure.

DR. FINE:                    Often it's much better than they can what they can get from the referral note even if they've read it or from the patient herself or himself.

JEANNE BLAKE:                   It's interesting because when I produced a program called "When Breast Cancer Comes Back," I interviewed women with metastasic cancer so of course they had been in the healthcare system for a number of years by the time I interviewed them and they, of course, have learned to be their own best advocate and it's not to say, I mean my friend Liz who narrates this segment that I'm going to show you, always had someone go with her to the hospital because she needed somebody else there that could hear the information because she, because I think that I read in you know, somewhere, that you can have three people in the room and you leave the room and three people will have heard three different things and so she always had an advocate even though she had really learned to be a very strong advocate for herself so let's just take a look at this segment called "Picking the Right Doctor" and then I'd like to get your thoughts?

VIDOE CLIP:

"Breast cancer takes a huge toll on us. The treatment can be really tough. Last summer as I lay in the hospital weak as could be waiting for a stem cell transplant, I though about how much faith I had in my doctors and nurses. Thank God I trusted them but that's not the case for everyone. If you don't trust your doctor, it's really important that you follow your instincts."

“If you have any doubts about whether that’s the right person to hear you and to be proactive on your behalf, then you need to look around and see who else might be a better fit.”

“My first oncologist was horrendous. You know, he was from the old school. I mean I went there and I was dictated what I was going to do. I was told what treatment I was going to take.”

“My first breast surgeon talked to me as if I were a bad child. I had a radiation oncologist who didn’t listen to me when I said that I had pain in my shoulder.”

“It’s your life that you’re dealing with. Who cares if you hurt someone’s feelings along the way? You’re going to hurt someone’s feelings. Get over it. You know, it’s your life that you’re taking charge of right now. Take charge of it, be responsible for it, and get what you need. The squeaky wheel gets the oil.”

“I think there is a defining moment when you know whether you chose the right doctor and I had that moment with mine on the day that he had to tell me that the cancer had spread and those words, just they sort of go right over your head. You feel numb because they’re too much to take in but what counteracted that numbness and was so wonderful is he put his arms around me and he hugged me and then he just kept his arm around me and looked right at me and said, “I will be with you every step of the way.” And even talking about it, I feel it now, my biggest fear as a woman living alone, who will be there? Will I be abandoned? And I love this man. He’s been my partner, my ally, he respects my values, he listens to me, he cares and I know he will not stop caring and he will not stop being there until the very last minute.””

DR. FINE: It’s poignant and what you have in that segment if you don’t mind my saying which has a touch of genius the way it’s all brought together are people who were totally frustrated by the failure of communication, by their experience of the doctor being distant or impersonal which is more and more, by the way, the case, and someone who found a loving, warm doctor who was also highly competent. That shows you the whole spectrum that’s out there. Let me, can I talk for a second about a couple of stories very briefly? I was recently worked up for double vision and after seeing a series

of physicians starting with my primary care doctor I was sent to a super specialist called a neuroophthamologist who studies the relationship of the brain to the problem with vision and he knew I was a retired physician but when he took me into the examining room, he said now I'm going to put drops in your eyes and I put my head back and then I said to him what kinds of drops are those? I thought I was entitled to know. And his reply was "those are eye drops." Now that tells you something about one of the problems in medical communication today and the people in the video which I looked at, they also had unnecessary hardship that we have become so professionalized in a way. I've had nurses from leading hospitals come to me and say that they have so many tasks now that they cannot provide tender loving bedside care to patients and we miss it, we need it.

JEANNE BLAKE:                    We do need it.

DR. FINE:                        It's curative.

JEANNE BLAKE:                    Of course it is. For some reason your story is reminding me of an experience that I had at a well-known Boston hospital. I had, my two closest friends had died within six months, one from ovarian cancer, one from breast cancer and I had a terrible allergic reaction that required me to go to a dermatologist. And he didn't ask, really ask any questions, he just looked at, you know, it was a reaction that I had on my scalp and he looked at it and he just was very brusque and he got a needle that I think was like 30,000 feet long and just started, you know, injecting me with whatever it was, cortisone, something I imagine and then on his way out he turned around and he, I had a little green pin like the breast cancer pin but it was green and it was for ovarian cancer and he said "what's that for?" And I said, and I was really like looking it had been two days maybe since my friend died and I said it's for ovarian cancer, you know, I've lost these two friends and I became emotional and the look on his face was why did I ask? And he was so transparent, he was trying in a way to be gracious and oh I forgot to be nice to the patient and then but then when I wanted to explain he was like ugh, I don't have time for this and he was like "sorry to hear that" and he flew out the door. I will never forget that interchange, ever and I'm really lucky though I actually must say maybe because I was a medical reporter for so long in this City, I've got the greatest doctors and so I, and I also know how to advocate for myself.

DR. FINE: Well I'm going to have to say that although I gave an illustration of a doctor who was let's say not really tuned into the emotions that I was feeling.

JEANNE BLAKE: To say the least.

DR. FINE: Overall, I think people in the healthcare system where I spent much of my life, try to do the best they can. The time pressures are tremendous.

JEANNE BLAKE: That's right.

DR. FINE: They're always several people in the waiting room or somewhere else in the hospital that you've got to see. You want to get home by 7:00 or 8:00 at night if you can. I understand. That's why I say the system's broken.

JEANNE BLAKE: I agree. I agree.

DR. FINE: I don't fault the nurses who can't give tender loving care. I don't fault the doctor necessarily who has a mask-like face and doesn't really communicate or empathize with you. I fault the way the system is and that's why we're in business. We don't charge by the way, anybody for our services.

JEANNE BLAKE: Right. I assumed that.

DR. FINE: I thought I'd mention another case and how meaningful it can be. I was myself hospitalized with a severe migraine and they weren't sure whether I was having a stroke or not and the guy in the next bed was far worse off than me and he was moaning and there was a curtain between us and I just decided because the nurse was too busy, to pull the curtain back and see if I could help this poor soul and it turned out he was a 52-year old construction worker from New Bedford actually and I live in Cambridge, Massachusetts and when I was discharged from the hospital after a very brief period I followed him every day. I met his family. I went to New Bedford to see how he was doing. Last week I visited him again in his hometown and he gave me a 7 lb. lobster to take back.

JEANNE BLAKE: Wow.

DR. FINE: He calls me up to see how I am.

JEANNE BLAKE: Oh, that's wonderful.

DR. FINE: And this has been going on for two years. And I found him a Harvard Medical graduate who speaks his language which is Portuguese and I found him the best practitioners for his other problems, a severely degenerated hip and other specialists and neurosurgeon who would pay attention to him and speak to him in his own language. And this means everything to this man and finally he was financially very badly off and I said well why don't I try to see if I can help him because he'd had two cerebral hemorrhages and all these other conditions and high blood pressure and so I called up the Disability Commission where he had crudely filed an application that would have gone nowhere, and the wonderful woman on the other end of the phone said if I had known he'd had two cerebral bleeds this puts a totally different slant on the picture and within months he was awarded I think very justifiably disability because he was in construction and at risk by very heavy lifting and he was able for the first time in seven years to go back to the Cape Verde Islands and visit his mother.

JEANNE BLAKE: How wonderful.

DR. FINE: And that, we're friends for life.

JEANNE BLAKE: The power, and so you as a volunteer to the organization, the founder and volunteer, it goes both ways.

DR. FINE: So now the Veteran's Administration, rather the members of Congress responsible for the care of Veterans want us to try to do this on a larger scale for both the newly returning veterans and for the older veterans in Massachusetts who were putting together a pilot project in the Boston health system on the Veteran's Administration has a marvelous leader that wants to partner with us and see what we can do for Massachusetts veterans.

JEANNE BLAKE: And you're getting calls from other parts of the country as well?

DR. FINE: And we are. And the idea is out there.

JEANNE BLAKE: This is a national model.

DR. FINE: It's a national model. It's newly being developed. It was two years massaging the idea and now we have ten volunteers and the way we're beginning to do it is the volunteers don't want to take on 24/7 – 365 on their own shoulders even though each has only one client who needs their help but they, we're in some cases partnering so there are two of them together with two clients and that makes it a lot easier for one individual to do this.

JEANNE BLAKE: Dr. Fine is there, I mean you are working with retired healthcare professionals but is there a training that they have to go through?

DR. FINE: Yes, we've improvised a training program. We started off with a 6 ½ hour training program. I'd like to put a plug in for the law firm that gives us pro bono services.

JEANNE BLAKE: Go ahead.

DR. FINE: Because it would cost a fortune. We'd never have gotten off the ground without them, it's McDermott Will & Emery which is a national law firm. And they have offices in Boston that are just splendid and they let us meet there with our people and it's a wonderful dimension that so many others in society are responding and helping us in this venture.

JEANNE BLAKE: Well the need is only going to get greater as the population ages and as you mentioned, if you're working with soldiers that are coming home there's going to be a greater need there unfortunately.

DR. FINE: Down the road we have to do more elaborate training and if this model succeeds as I feel confident it will, there is going to have to be a training program leading to a certificate or a degree so that we will have people in this broken healthcare system with who provide the continuity in the personalized care that the public yearns for and which is largely lost.

JEANNE BLAKE: What I'd like to do with the amount of time that we've got left, and I don't know how much time that is, Mary, if you can find out. Oh great, we only have four minutes.

DR. FINE: My fault!

JEANNE BLAKE: No, I'd like to just ask no, the time flies all the time. I just want to ask a couple of, make a couple of points. I actually pulled these out of a publication that I read that was listing things that you need to do if you're a patient and I just, I think that you'll just be able to respond to these. One of them is to know your rights when you go into the hospital. How can that help you as a patient?

DR. FINE: Well I, to know your rights when you go into the hospital, personally I don't think can help you much when you go, when you're a patient because you're sick, your obtunded, meaning you're under the weather, and most people, and I mean, I'm talking about almost everybody, are intimidated by the atmosphere, the doctor in the white coat and don't assert their rights.

JEANNE BLAKE: That actually brings up a really important, I've heard from so many people and in a way you know I can understand this, that if you are feeling that you're life is in their hands and you've already maybe, you, you are more hesitant to speak up.

DR. FINE: If you speak up, you, I don't want to say people are cynical, but they're skeptical at the very least. What you speak up about that things will change. If the doctor's not explaining to you something clearly that you can understand what are you going to do? Ask him to say it again? And then

JEANNE BLAKE: Well, what did you say when he said “they’re eye drops?”

DR. FINE: I asked “what kind of eye drops?”

JEANNE BLAKE: And did you get your answer?

DR. FINE: I made a little progress he said they’re anesthetic eye drops. But then I said to myself shall I ask him what kind of anesthetic eye drops? But the average person would not have gone that far.

JEANNE BLAKE: No, of course not, I would be intimidated.

DR. FINE: Exactly right and so you have these rights.

JEANNE BLAKE: Well, one of the things is ask questions but I guess we’re moving right on beyond that one. But go ahead doctor.

DR. FINE: You should ask questions.

JEANNE BLAKE: Of course.

DR. FINE: Donald Berwick is one of the most distinguished, charismatic physicians in America. Queen Elizabeth made him Knight Commander of the British Realm last year or was it 2005 which is only Steven Spielberg and a few others and he heads the Institute for Healthcare Improvement he and he, he’s very much taken with what we’re trying to do and one of his comments is when you go to the hospital, take someone with you.

JEANNE BLAKE: Exactly.

DR. FINE: Because it’s the someone who’s going to have to play this role of paying attention to your rights.

JEANNE BLAKE: There you go.

DR. FINE: And getting the answers for you, and so on.

JEANNE BLAKE: That's right. And also, bring an advocate's on the list so.

DR. FINE: Yeah, but answer this one. If you're hospitalized, okay, you're there as I think, 24 hours a day, right, and sometimes for several days, and you're person who's supposed to be with you isn't there most of that time, so you're alone.

JEANNE BLAKE: Right.

DR. FINE: And that shouldn't be, we've got to work on this problem. But I'd like to emphasize again it isn't just the hospital experience, it's what happens in between and preventing people from deteriorating seriously because they've been neglected in their own homes.

JEANNE BLAKE: Exactly, many important points. We could talk for an hour but we're out of time.

DR. FINE: We're not going to talk for another hour?

JEANNE BLAKE: No but you can come back with more stories and we will come back.

DR. FINE: Shucks.

JEANNE BLAKE: But let's give your website because it's really important.  
Okay Bedside

DR. FINE: advocates is one word .org.

JEANNE BLAKE: [www.Bedsideadvocates.org](http://www.Bedsideadvocates.org) and we'll have this on our website with the transcript of this program as well on Abouthealth.com.

DR. FINE: Great, can I put in [Jonathanfine@mac.com](mailto:Jonathanfine@mac.com) if you want to write to me personally an email.

JEANNE BLAKE: You just did and we'll put that on our website as well.

DR. FINE: That's very kind of you.

JEANNE BLAKE: Okay Dr. Fine. Thank you for coming in and God bless you for the work that you're doing.

DR. FINE: You're great.

JEANNE BLAKE: Thank you very much and we thank you for joining us on *About Health TV* and we look forward to seeing you next time. I'm Jeanne Blake.