DISRUPTIVE
WOMEN
IN HEALTH CARE™

Patient Advocacy: How to be an Empowered, Engaged, Equipped and Enabled Patient

Perspectives from Disruptive Women in Health Care
October 2010

www.disruptivewomen.net

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Patient Advocacy: eBook Introduction and Resources

There is a revolution going on. Patients are leading the charge. And they are armed with data and outfitted with technology. Not to mention a healthy dose of chutzpah. But there is much work to be done.

Many patients today recognize the need to speak up and track and share information – with researchers, health providers, payers, and loved ones. How best to do this? Well, the folks at the Department of Health and Human Services (HHS) recognize the value of the data on which they sit. Todd Park, the HHS Chief Technology Officer, has undertaken the ***Data Liberacion!*** project, the purpose of which is to free the data, which have been virtually locked in government safes, so that people - providers, payers and researchers can access it, learn from it, and apply it to improve health outcomes.

Here are two absolute knock 'em out of the ball park examples of the power of data:

Hear Disruptive Woman Indu Subaiya interview Josh, an incredible young man with a rare, life threatening disease and then Patrick, a dynamite medical pioneer. These guys were part of a panel at the first ever Washington DC Health 2.0 conference. Both stories will amaze and inspire you..really.

Despite the excitement and potential, many people are unfortunately still trapped in what Gilles Frydman, affectionately referred to by Disruptive Woman Jane Sarasohn-Kahn, as the founding father of ACOR, calls the ***Tyranny of Data***.

While well-intentioned folks are trying to figure out who has the right to what data, how privacy factors in to these discussions, who owns what data, how researchers can best use patient data while maintaining a high degree of scientific and statistical rigor, many patients, impatient with the status quo, are moving at warp speed. These patient advocates, activists even, are firing up their computers, mobile devices, and their paint brushes (hat tip to Disruptive Woman Regina Holliday—patient advocate/artist) to help spread the word and bring about better health, and better health care.

Make the data count - Put the bling in research!

Robin Strongin
Founder, Disruptive Women in Health Care;
President & CEO, Amplify Public Affairs

Robin Strongin is an accomplished public affairs expert with almost 30 years of experience working in Washington, DC. Her areas of specialization include health care, science, technology and innovation. Robin has worked with and for federal and state governments, regulatory agencies, Congress, think tanks, nonprofit organizations, corporations, coalitions and trade associations. Robin is currently serving on the AcademyHealth Translation and Communications Interest Group as well as the boards of the Juvenile Diabetes Research Foundation (JDRF) Capital Chapter and Physician-Parent Caregivers. Robin is a member of the Women Business Leaders of the U.S. Health Care Industry Foundation.

I’ve said this before, and I’ll say it again — when it comes to data, while Double Blind Randomized Controlled Clinical Trials (RCT) are considered by many to be the Gold Standard, as someone who just loves jewelry (and I am proud to admit it), **gold is good but platinum is better.**

My challenge to the research community: seize this pivotal moment in time and develop that Platinum Standard — a standard that maintains the rigor of a clinical trial (the gold standard) while incorporating the valuable patient information and data that technology allows. (Just a thought: as patients with chronic illnesses live longer, and are therefore on treatments longer, what about patient data informing post-market surveillance as just one example?)

Ultimately of course, data and technology in and of themselves are not enough.

As you can see in the following blog posts, to be an effective advocate for your health, patients and caregivers need to understand basic math and statistics to learn how to understand treatment options, learn how to proactively work with insurance companies, learn how to talk about and prepare for end-of-life decisions, learn how to be responsible for their safety, learn how to question and push back and speak up (Act Up?).

One of the benefits of being an engaged patient is you don’t have to go it alone. We have assembled a brief list of resources to help get you started.

Patient Advocacy Resources

- About.com Patient Empowerment: http://patients.about.com

- AdvoConnection: www.AdvoConnection.com Helps find an advocate when you or a loved one needs assistance for medical/navigation issues, billing or insurance claims, getting permission for insurance payment rejections, birthing, geriatric home health and more. It’s a free service that lets you search by zip code and service needed.

- Association of Cancer Online Resources (ACOR): http://www.acor.org/ offers access to 159 mailing lists that provide support, information, and community to everyone affected by cancer and related disorders.

- Center for Advancing Health (CFAH): http://www.cfah.org. CFAH conducts research, communicates findings and advocates for policies that support everyone’s ability to benefit from advances in health science.

- Center for Medical Consumers: http://medicalconsumers.org/. Is committed to broadening public awareness about the safety and quality problems that pervade America’s medical care. The Center is active in both nationwide and statewide efforts to reduce medical errors, report disclosure of physician conflicts of interest, improve the quality of medical care, and encourage public access to information about the comparative performance of doctors and hospitals.

- CNN's Empowered Patient: http://www.cnn.com/SPECIALS/empowered.patient/. Elizabeth Cohen presents her weekly stories about patients who stepped up in unusual ways to get the medical help they needed.

- Coalition for Patients Rights: http://www.patientsrightscoalition.org/. The Coalition for Patients' Rights consists of more than 35 organizations representing a variety of licensed health care professionals who provide a diverse array of safe, effective, and affordable health care services to millions of patients each year.

- Consumers Advancing Patient Safety (CAPS): http://www.patientsafety.org/. Is a consumer-led nonprofit organization formed to be a collective voice for individuals, families and healers who wish to prevent harm in healthcare encounters through partnership and collaboration.

- The Empowered Patient Coalition: http://www.empoweredpatientcoalition.org/. The Empowered Patient Coalition is dedicated to providing an unprecedented level of information, resources and educational support to the public. The Coalition is committed to promoting a culture of transparency, meaningful interaction and active participation that will allow patients and their advocates to assume a greater role in improving the safety and the quality of their health care.

- EmpowHer: http://www.empowher.com/. EmpowHer is a website that seeks to provide information for women dealing with health problems and enables women to connect with others in a large peer-to-peer community. There also is information dealing with diet and general well-being.

- E-patient Dave: http://patientdave.blogspot.com/ is the blog of Dave deBronkart, who was diagnosed with Stage IV Leukemia in 2007 but defied the odds and beat the disease. He blogs about the need for patients to be informed and empowered in dealing with the health care system. His blog documents issues he feels important as well as his doings.

- Every Patients Advocate: Every Patient's Advocate has one important purpose-to help patients learn everything they can about advocating for good health and medical care for themselves or their loved ones. http://www.everypatientsadvocate.com/index.htm

- Hospice Patients Alliance has ten key questions for patient advocacy: http://www.hospicepatients.org/10-essentials-pt-advocacy.html

- The Informed Patient Institute: http://www.informedpatientinstitute.org/. The Informed Patient Institute (IPI) is an independent nonprofit organization that provides credible online information about health care quality and patient safety for consumers.

- National Patient Advocate Foundation: Dedicated to improving access to health care through policy reform at the state and federal government levels. http://www.npaf.org/

- Patient Advocate Foundation: http://www.patientadvocate.org/ to provide effective mediation and arbitration services to patients to remove obstacles to healthcare including medical debt crisis, insurance access issues and employment issues for patients with chronic, debilitating and life-threatening illnesses.

- Regina Holliday: http://reginaholliday.blogspot.com/ is a patients' advocate who paints murals to enhance patient empowerment as well as other changes to the health care system. Her blog deals with portraying her murals and furthering her advocacy.

- Revolution Health: http://www.revolutionhealth.com/pages/nonprofit-organizations Oftentimes, Patient Advocates are associated with particular diseases, such as the American Cancer Society or American Heart Association. A master list is found within the website of Revolution Health.

- Society for Participatory Medicine: http://participatorymedicine.org/. Is devoted to promoting the concept of participatory medicine by and among patients, caregivers and their medical teams and to promote clinical transparency among patients and their physicians through the exchange of information, via conferences, as well through the distribution of correspondence and other written materials

Getting What You Need From The System: Tips For Advocating

When my husband, Paul Berger suffered his stroke, we were both in our 30s, established in our careers, and planning for the future. We wanted to continue our active lifestyle, which meant overcoming Paul’s disabilities and pulling services out of many different organizations, each with their own roadblocks. I became Paul’s advocate. Here are my tips for successful advocacy to get what your survivor needs from the system.

There are three types of advocacy: (1) personal advocacy by individuals, family members, friends or others to obtain benefits and services from public or private service providers; (2) legal advocacy by a lawyer to navigate legal processes; and (3) political or policy advocacy by lobbyists and concerned citizens to change government systems.

Personal Advocacy

Most caregivers learn to be personal advocates by “on-the-job” training, usually starting with hospital, medical, and therapy providers, then health insurance. Here are some tips to help you improve your personal advocacy:

- Make a written list of your needs and questions, and go after the most important first.
- Research as much as possible from insurance policies, medical brochures, treatment plans, and other sources.
- Talk to other caregivers and ask for advice, especially for the names and phone numbers and emails of people who were helpful to them.
- Call and ask for the person or department that specifically handles the services or questions you need answered. Ask for the exact spelling of that person’s name.
- Write down the date, time, person’s name, and topic discussed in any phone calls. Keep this in a file with your other materials and research.
- Be persistent. This may mean calling every day. This may also mean asking another family member or friend to call on your behalf.

Stephanie Mensh
Senior Associate, New Editions’ Consulting

Stephanie Mensh found herself thrust into the role of personal caregiver and patient advocate in the same shocking instant that her husband, Paul Berger, suffered a severe stroke. Stephanie was only 31, Paul 36, when their middle class, career-oriented lives lurched suddenly off track. That was over 20 years ago. Since then, they have both thrived due to teamwork and Stephanie’s caregiving mantra: push the survivor to be as independent as possible; do what you (the caregivers) do best; and communicate. Stephanie works with Paul in their publishing company, Positive Power Publishing, and contributes to their website on stroke recovery www.strokesurvivor.com.

- If you feel that your questions are not being answered, or you are not getting the appropriate services, find an outside professional, agency or organization that can intervene on your behalf.

Legal Advocacy

Sometimes the only way to get the services or resources you need is by taking legal action with the help of a lawyer. Legal advocacy does not necessarily mean going to court. Most often, a lawyer can advocate for you through telephone calls and correspondence. Most legal actions relate to contract or financial problems, such as insurance companies paying claims, enforcing federal protections regarding employer's sick leave/family leave policies, or negotiating with creditors to prevent foreclosure or bankruptcy. If you have been denied social security disability or other benefits, an attorney can file an appeal.

When Paul had his stroke, we decided to refinance the mortgage on our house. Our lawyer prepared a specific "power of attorney" so I could attend settlement alone, since Paul was too ill to leave the hospital. Attorneys specialize in different areas. Look for one who specializes in your particular problem. Ask your family lawyer to refer you to a specialist, or contact the local bar association, or local legal aid organization. The American Bar Association has online referral links.

Don't wait for a family crisis. It is never too early to have a will, a power of attorney for financial/business affairs, and a power for health matters, as well as a living will that will provide instructions on life support if you become critically ill.

Political Advocacy

Finding services for stroke survivors can be challenging, especially once the "acute" phase – the immediate hospitalization – has passed, since the types and costs of available services vary so much from one area to another. Speech and physical therapy are often limited, and vocational rehabilitation services and related case management may have waiting lists.

When you need services that are not provided in your area, you may need to change the system — by translating your personal advocacy skills and passion into political or policy advocacy.

You can start by writing letters or emails, and visiting your elected officials or their staff. Your local city, county and state officials want your vote in November — so do your US Congressmen and Senators. They want to hear your concerns and find ways to help. You can do this on your own, with your survivor/family member, and/or with other caregivers and survivors.

The first step is to learn about your elected officials — who they are, where their offices are located, how to contact them, and details of their policy interests. For example, learn what committees they serve on, and what bills they have drafted, supported, and voted for. Most have web sites with this information, and their offices will answer questions and mail you additional material. For the US Congress, visit this link.

My volunteer efforts led me to an appointed position on the local citizen advisory committee that oversees the county's human services programs. I have a voice to support programs for people with disabilities, which has become crucial during these times of state and local government cut-backs.

On the state and national level, Paul and I participate in the American Heart-American Stroke Association's Lobby Day in Washington, DC, and continue our advocacy from home as part of the AHA/ASA's "You're the Cure" grassroots network — an easy way to stay informed on state and national issues. To join, visit.

Life In The Trenches Of Health Insurance Business: How To Make Sure Your Surgery Is Covered

This month's health insurance issue: Linda is having surgery in the morning, but at 4 p.m. the afternoon before, she gets a call from her HMO requiring her to post a $400 advance deposit — or the surgery is off. What should she do?

The situation: Our client Linda was scheduled to have surgery using a surgical group that had negotiated fees with her HMO carrier. Besides being told to post $400 in advance, she was told she needed to sign a form stating she would pay whatever fees the carrier would not pay to the doctor.

This came despite the fact that the surgeon was in her HMO network and Linda had gotten the proper referral and authorization from the carrier. In fact, her policy dictates that when a provider has signed a contract with an insurance carrier, the patient is held harmless from all fees associated and cannot be asked for additional payments other than applicable copays, deductibles, and coinsurance. In this case, the policy had a $20 doctor copayment and 100% coverage, with no hospital copayment.

Linda called us in a panic, and we immediately phoned our contact at her HMO. Due to the late hour, our contact couldn't do anything until the following morning, when she would have a representative from provider relations step in. And after a long discussion with the insurance company, Linda did not have to post the deposit and did have a successful surgery.

The solution: Don't assume anything before having surgery. Get on the phone and make sure you are covered.

1. **Contact the insurance provider and verify all benefits**. Always get the name of the representative you talk to, as well as the department name and number. Try to speak with a supervisor. Also, note the date and time you had the discussion, since all calls are recorded and can be pulled to make sure accurate information was given.

2. **Get all pre-authorization agreements in writing**. Typically, the doctor's

Stephanie Cohen
CEO, NFP Golden & Cohen

Since co-founding the health care benefits firm NFP Golden & Cohen, in 1992, Stephanie has helped it grow into one of the largest female-owned companies in the Washington metropolitan region. With more than two decades of experience in small group health insurance, disability programs and life insurance, she was a finalist for the Ernst & Young Entrepreneur of the Year Award, serves on the prestigious United HealthCare, Coventry, Aetna and Kaiser Broker Council and is a member of the Womens' President Organization, the District of Colombia Insurance Commissioner Advisory Council and The Greater Washington Health Underwriters.

office will call, but you should insist on getting it in writing, too, so you can be sure everyone involved in the surgery — the surgical center, hospital, anesthesiologist, doctors, etc. — is covered by your health insurance plan.

3. **Understand your policy and be clear about the items that you may be required to pay for**. Many hospitals, surgical centers, radiological providers, and labs will send you a bill in addition to submitting it to the insurance company. Remember: Never pay a bill unless the insurance company has received it first and re-priced it (including applicable discounts) and until you have received evidence of benefits that match the bill.

The painful truth: Unfortunately, the system is broken. Insurance carriers, doctors, and patients will continue to eek out whatever they can from the health-care and insurance system until new policies are in place that make it clear exactly what the contract is that they are entering into. If anything is unclear in your agreement, a new one needs to be worked out that will include cost, payment, and what insurance covers.

If I were the Health Insurance Ambassador: I would require that all doctors notify the patient about the exact cost of the surgery before the procedure. The patient would then have a full understanding of the costs associated with the surgery and the doctor would receive the appropriate payment.

In defense of doctors, I would also change how they take payments. Doctors do not ask for money upfront. They provide a service and hope that they will receive payment afterward. Perhaps they should swipe a credit card before the procedure or at the time of an office visit.

E-Patient Dave: One Patient Advocate's Survival Story And What We Can Learn From Him—How To Be An Empowered, Engaged, Equipped And Enabled Patient

Interview by Robin Strongin

Richard Davies deBronkart Jr, known by many as e-Patient Dave, is a cancer patient and blogger who, in 2009, became a noted activist for health care transformation through participatory medicine and personal health data rights.

In 2010, he became a published author and Disruptive Women in Health Care's August Man of the Month.

"I was a middle-aged guy going through life, as involved with my own health care as I was with my car's carburetor, which is to say, virtually not at all. And then I found out I was almost dead."

That's how my interview with Dave started.

Dave was diagnosed in January 2007 with Stage IV, Grade 4 renal cell carcinoma (kidney cancer) at a very late stage. His median survival time at diagnosis was just 24 weeks; with tumors in his lungs, bones, and muscle tissue, his prognosis was dire. Now, almost four years later, e-Patient Dave has emerged as a patient advocate, with a self-described calling to connect, engage, and empower patients.

e-Patient Dave
August 2010 Disruptive Women
Man of the Month

Dave had been proactive for years when it came to choosing providers he liked, so when it came to crunch time, he was fortunate on several levels: he received excellent treatment at Boston's Beth Israel Deaconess Medical Center; his physician, Dr. Danny Sands, who in addition to serving as Dave's primary care doc since 2003, also serves as the Senior Medical Informatics Director at Cisco and as such is on the bleeding edge of online communications and health information technology; and, the Biologic Therapy program helped Dave participate in a clinical trial for the powerful High Dosage Interleukin-2 (HDIL-2). His last treatment was July 23, 2007, and by September it was clear he'd beaten the disease. His remaining lesions have continued to shrink.

Technology and Patient Advocacy: An Author is Born

Dave observed that many patient advocates come to patient advocacy because they were injured, or had a negative experience with the health care system. This was not the case for Dave. He had a life altering experience; a near fatal disease that rather than kill him, turned his life in a different direction.

Before his diagnosis, Dave was a savvy online guy. “I’ve been online since 1989, heck I even met my wife online. So it’s no surprise that I ended up with a cutting edge academic medical center and physician.”

While the health professionals, life saving medicines and medical technologies were key to his survival, so too was the Internet—it became another of Dave’s lifelines:

- Dave was able to communicate with his primary care physician by email and his hospital was committed to making information available electronically;
- Dave used the web to access information about his disease;
- He joined the Association of Cancer Online Resources, an expert patient community; and
- A participant in online communities before his illness, Dave quickly figured out that using online technology to update his friends and family not only provided an efficient means to communicate what was happening and how he was doing, but it connected him to a great number of people who cared about him, supported him, were there for him. He started an online journal and support community on CaringBridge.

Many people suggested to Dave that he write a book about his incredible journey. But one man, Dave’s friend George Alexander, presented Dave with a tremendous gift: he took Dave’s online journal and blogs, the essence of everything Dave had been through as well as the lessons learned, and through his Changing Outlook Press, worked with Dave to publish Laugh, Sing, and Eat Like a Pig: How an Empowered Patient Beat Stage IV Cancer (and What Healthcare Can Learn From It).

The book, available on Amazon, pulls you in. I couldn't stop reading it. Dave and I are Facebook friends, he follows Disruptive Women on Twitter, and I was very aware of his contributions to patient advocacy. But it wasn't until I sat down with the book and started at the beginning that I realized the phenomenal power of Dave and his work.

The book is not only a page turning chronology of Dave's story, but it contains very useful information: lessons in patient empowerment, thoughts on statistics and medical evidence, e-Patient white paper chapter summaries, and finding online support groups. Not to mention it has introductory essays by two previous Disruptive Women in Health Care Men of the Month: Matthew Holt and Paul Levy.

E-Patients and Participatory Medicine: An Advocate is Born

As Dave was no stranger to the online world and blogging prior to falling ill, he was invited by his primary care physician, (one year after his diagnosis) to join the annual retreat of the e-Patient Scholars Working Group, founded by the late Tom Ferguson MD (to whom Dave's book is dedicated). "My mind just exploded. That was January 2008, one year after my diagnosis. I couldn't stop reading everything on the epatients.net site – how e-patients can help us 'heal' health care – and I renamed my blog. Good-bye Patient Dave, Hello e-Patient Dave."

e-Patients: How They Can Help Us Heal Healthcare
Since that time, e-Patient Dave has been very involved with the e-Patient and Participatory Medicine movement and is currently on the Board (a founding co-chair) of the Society for Participatory Medicine, a 501(c)3 public charity, which "aims to advance the understanding of physicians and other professionals in the importance of well-informed, empowered and engaged patients making informed decisions about their care and treatment."

As the Society's website says: *Participatory Medicine is a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners.*

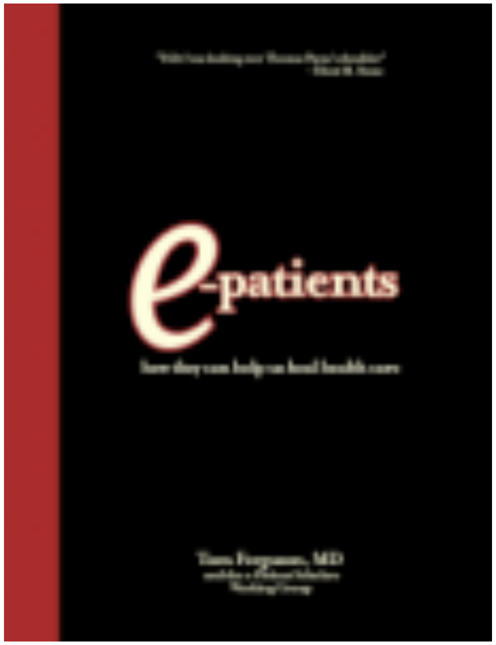
Today he's applying his previous career experience, in marketing and public speaking, to evangelizing patient engagement. A keynote speaker who often leaves jaws dropping, he received an audience rating of 4.9 out of 5 at this year's ICSI / IHI Colloquium. His busy fall schedule is at www.ePatientDave.com/schedule and videos of past talks can be seen at www.ePatientDave.com/speaking.

Dave reiterated to me that on-line access gets him access to information but doesn't make him an oncologist. But it does help him be an active participant in his care.

I asked him what advice he would like to share with other patients. Here are some highlights:

- Empowerment is not just about using the Internet—speak up for what you want
- Trust Yourself – you can help far more than you might imagine—get engaged
- It's absolutely vital for people to actively check and follow up with their health care professionals—to obtain lab results and other critical information

"Some day our medical system might be absolutely reliable to do everything right – until then, it behooves us all to be actively involved in our care….Patients can help—more than they realize."



The Art Of Advocacy: A Perspective From A Physician-Parent Of A Young Adult With A Childhood-Onset Chronic Condition

We all know how hard it is to advocate for ourselves, our spouses and our parents. But can you imagine having to advocate for your child day in and day out for the rest of your life? This is the harsh reality faced by many parents of children with childhood-onset health conditions and disabilities. And believe me, it is hard! When my perfectly healthy child became critically ill at the age of 8 years, I went from being a medical fellow to a life-long, full-time parent advocate.

I learned everything I didn't want to know about the health care system, but I eventually realized that the knowledge I acquired as an advocate is equally critical to health care practitioners if they are to provide quality health care, i.e., the right care the right way at the right time. Adding the dimension of patient-centered care means care is delivered the way patients need and want it.

Right now, we are still learning how to advocate for the right care the right way at the right time. It looks like we'll have to wait a while to get care the way we need and want it.

As a parent and a physician, I had to be extra careful in the pediatric health care world. If I came across as too demanding, I would have been dismissed as a neurotic or helicopter parent. (I know a couple of physician-parents who were erroneously said to have Munchausen's Syndrome by proxy.) If I didn't advocate, I risked danger. In every situation, I had to find the fine line between objectivity and subjectivity, to assure myself that I truly was balanced in my approach.

The problem is that even though most of us know what to advocate for, we are still dealing with human beings in the health care system. They have pressures and barriers, they have egos,

Santi KM Bhagat, MD
Founder, Physician-Parent Caregivers

When Dr. Bhagat's daughter became critically ill at the age of 8, she had to withdraw from a medical fellowship at the Armed Forces Institutes of Pathology not to care for her child, but to manage her child's health care. In spite of having preferential care from her pediatric group, prime health insurance, and medical training, she went on to experience a health care nightmare. Dr. Bhagat felt she needed to understand the health care system from the outside, so she decided to study health policy and pursued a Masters in Public Health at the George Washington University School of Public Health and Health Services. Dr. Bhagat received her medical degree from the University of Bangalore and completed her residency in pathology and laboratory medicine at the Georgetown University Medical Center. She is the Founder and President of Physician-Parent Caregivers (PPC).

they have feelings – and they have the knowledge.

The art of advocacy is getting health care providers to do the following:

- Provide the best care so the patient achieves and maintains optimal health, and
- Empower patients with the knowledge needed to make informed -decisions and self-manage their health and health care.

The art of advocacy should empower health care providers to practice the art of medicine.

Parent advocates have another equally complex system to tackle: the education system. After learning about all the various laws, e.g., Americans with Disabilities Act, Individuals with Disabilities Education Act and Section 504 of the Rehabilitation Act, parents have to learn about the culture of their child's school as well as the county and state educational systems. Then, parents have to advocate with human beings in the educational system to practice the art of education.

When our children grow up and enter adulthood, all the rules change and we are back at square one again. The only consistency is that the systems are devoid of supports, and as parents, it is up to us to start over and learn from scratch on how to advocate for young adults with childhood-onset conditions and disabilities.

How Math May Save Your Life And Recommend Treatments: Relative vs. Absolute Risk Reduction

When I was in college, I would ask my math professors how I could apply what I had learned in my math courses to the real world of problems that I would encounter. I didn't get much of an answer. However, if they had said math may save your life and help you make good health decisions, I would have said show me what you mean. Well, here is how understanding a couple of math principles can make a huge difference in our health care decision-making.

Most likely you will know someone who has been diagnosed with cancer: family, friend or yourself. It can be a daunting task to understand recommended treatments and what those treatments may mean in terms of preventing a recurrence of cancer or a cure.

For example, the media reports a 50% increase in survivorship. Pretty impressive and sounds like the latest miracle drug. However, when evaluating a treatment you should ask if the percentages you are being provided are the relative risk reduction or the absolute risk reduction percentages so that a fully informed decision can be made.

In one study, 56.8% of patients chose the medication whose benefit was presented in relative terms and 14.7% chose the medication whose benefit was in absolute terms.* The patients in this study thought that the true benefit was much greater than it actually was when relying on the relative risk.

Here is an example of relative versus absolute risk reduction:
100 women took ABC pill and 100 women took a placebo, which is not an actual medication. Of the 100 women who took ABC pill, 2 developed cancer and of the 100 women in the placebo group, 4 got cancer. It is reported that this clinical trial showed a 50% reduction in cancer and another report states that the same clinical trial showed a 2% decrease in cancer. Both percentages are accurate and that is because the data are being reported in two different ways.

Lisa Martinez, JD, RN
Consultant and Educator

Lisa Martinez is a consultant and educator in women's health and founded The Women's Sexual Health Foundation (TWSHF). As a registered nurse and an attorney, she led TWSHF to provide up to date resources on sexual health information for women and health care professionals. She recently co-authored a Medscape CME program, completed a women's health brochure on FSD, and assisted editing *The Breast Cancer Treatment Handbook* by Judy Kneece. Ms. Martinez has spoken to multiple national and international audiences. She has appeared on *ABC* and *CBS News LA*, and has been interviewed on NPR programs. She has served as a source for media outlets including T*he Wall Street Journal, Washington Post, More Magazine*, and *Discovery Health*.

The 50% reduction was reported using relative risk reduction. The 2% decrease was reported using absolute risk reduction. It is extremely important that you understand the difference between the two when making decisions about your care.

In the relative risk reduction report, 2 women who took the ABC pill out of 100 developed cancer and 4 women out of 100 who took the placebo got cancer. Two cancers in the ABC group are half as many as the four in the placebo group. Thus the 50% increase in survivorship or calculate 2%/4% = 50%.

To calculate the absolute risk percentage, do the following calculation: 4% (placebo) – 2% (ABC pill) = 2% absolute difference.

Here are some other examples that should make the difference between absolute versus relative risk reduction even more clear.

Group 1	Group 2	Absolute Difference (Group 1 - Group 2)	Relative Difference (Group 2/Group 1)
40% (4/10)	20% (2/10)	20%	50%
4% (4/100)	2% (2/100	2%	50%
0.4% (4/1000)	0.2% (2/1000)	0.2%	50%

<u>So when presented with options for chemotherapy or any treatment, make sure you ask your health care provider to give you the relative and the absolute risk reduction percentages.</u> For the absolute risk reduction number, just ask your health care provider, "What is the actual number of patients out of 100 who benefited from the treatment?"

If your provider cannot answer that question, then ask that she or he find out for you.

To be a savvy health advocate you must become statistically literate, and understanding the difference between relative risk versus absolute risk reduction moves you towards the head of the class.

To learn more about health statistics consider reading Know Your Chances: Understanding Health Statistics by Steven Woloshin M.D.M.S.,Lisa M. Schwartz M.D.M.S., and H. Gilbert Welch M.D. M.P.H.

*Malenka DJ, Baron JA, Johansen S, Wahrenberger JW, Ross JM. The Framing Effect of Relative and Absolute Risk. J Gen Intern Med. 1993 Oct;8(10):543-8.

Give Us Our Dammed Data

On Thursday night in an office space in Georgetown a crowd was forming. It was an after-hours crowd. The room was filling with advocates, artists, professors, and students. There were doctors, IT professionals, authors, and members of the community. There were mothers, fathers, grandparents and children. They had all come to see an exhibit of art.

This office was the shared space for Clinovations and Ozmosis. The wonderful folks at Clinovations had suggested placing one of my paintings in their space to brighten up the blank white walls. Perhaps one of my paintings would support an even greater awareness of the need for patient-centered care. I thought, why stop with one painting why not many? Why not have an entire show and invite people from every facet of health care and beyond? I wanted to create a space for conversation and networking. I wanted people to get together and have some face time surrounded by art.

I envisioned a crowd of people thinking of ways to provide better care for patients everywhere. As I thought about this, I realized that this concept would be the focal piece of the show. Give Us Our Dammed Data is my first crowd-sourced painting, and it features quite a crowd. I wanted to paint a citizen army of patient advocate authors. I knew quite a few from Facebook and Twitter and had read their work. So I asked for suggestions from Dave DeBronkart, Trisha Torrey, Lisa Lindell and Helen Haskell. Between the five us we created a list of potential authors. Helen suggested I contact all of them and ask their permission to include them in the painting.

Regina Holliday
Artist and Advocate

Regina Holliday is a DC-based patient rights arts advocate. She is currently working on a series of paintings depicting the need for clarity and transparency in medical records. She placed her first mural in the series in May of 2009. After the death of her husband, Fred Holliday II, on June 17th 2009, she began a large mural titled “73 cents.” This piece depicts Holliday family’s nightmare journey through the medical system during Fred’s cancer care. The painting became part of the national health care debate and was covered by the *BBC, CNN, CBS, AOL,VOA, NPR, The Washington Post* and the *BMJ*.

With her help I found their addresses. I really enjoyed the give and take of emailing each author. I explained I wanted to paint them and their books.

And so another crowd gathered in Georgetown on Thursday night. They did not move or laugh. They did not drink wine or nibble the delicate appetizers. Instead, they stared down upon us with sorrowful smiles. In a room usually filled with laptop computers and hushed conversation hung a large painting picturing a crowd of authors. These authors' books span 15 years, and all of them are telling a very similar tale.

17 authors with weapons in hand stare down upon the viewer. The three panel painting measures 60 inches by 144 inches. It is a very large painting, and yet it is crowded with many who have been hurt and many who have suffered. Every one of them is an author. Most of the authors in the painting took the hurt and outrage they felt about a dysfunctional medical system and channeled that into a book. That book is their shield and their pen is a spear.

These are people who have taken up arms in a battle they had never intended to fight. Note they are dressed only loose robes or hospital gowns. Their feet are bare. They dress as the supplicant or the pilgrim. They are on a mission. For some of the citizen soldiers it has been a very long path.

Journalist Michael Millenson's Demanding Medical Excellence was published in 1997, and as you read it it is hard to comprehend it was written 13 years ago. It reads like it was written yesterday. So in the far left panel Michael's back faces the viewer in the piece. The public has not been listening. He is turned toward a fellow advocate who will spread the word. He is speaking to Julia A. Hallisy who looks concerned. And so she should.

This is Julia A. Hallisy, whose daughter, Kate, fought a losing battle with cancer in her short life. In 1997, Julia was well aware of the failings in our health system as she desperately tried to get an oxygen machine so her ten-year-old would be able to breathe as cancer was attacking her brain.

On the right side of Michael stands Janet Lynn Mitchell. In her book Taking a Stand she recounts her battle to walk after enduring 10 knee surgeries. Her many surgeries were due to a mistake during her original surgery. This was covered up and parts of the medical record were altered and "lost."

Below Janet sits Martine Ehrenclou, author of Critical Conditions. Martine spent over a year guiding both her mother and godmother through medical wilderness. She saw so many hazards and “never events.” She was determined to create a book to help others survive their hospital stay.

To Martine’s left sits Evelyn V. McKnight, author of A Never Event. Evelyn contracted hepatitis along with 857 other cancer patients due to reused contaminated syringes.

Beside Evelyn sits Elizabeth Cohen, Senior Medical Correspondent with CNN. She will soon publish The Empowered Patient: How to Get the Right Diagnosis, Buy the Cheapest Drugs, Beat Your Insurance Company, and Get the Best Medical Care Every Time. She has used her years as a patient and a patient advocate for her family members to help others. Informed by years of reporting medical tragedies as a reporter, she too felt she must write a book.

In the far right panel on the lower right side sits Sorrel King. Hers is one of the sadder stories in this piece. She alone stares out of the frame and seems to make eye contact with someone who must be quite small…. Sorrel lost her daughter Josie. Josie was only 18 months old. Josie was recovering from a bad burn when she died from severe dehydration and an unfortunate dose of narcotics. Sorrel knows intimately the importance of patient and caregiver access to medical records. Being able to read the orders in a record can save a life.

Seated behind Sorrel to the left is Lisa Lindell. Lisa wrote 108 Days. In her book she tells a day-to-day account of her successful campaign to keep her husband alive. She was astounded when she read her husband’s medical record. The nurse’s notes specified that she had an “unreasonable” belief that her husband should live. Beside Lisa sits Patrick Malone a malpractice attorney and patient rights activist, who wrote The Life You Save. Patrick lists nine necessary steps to getting the most out of the current medical system. The number one step is: Get a copy of your medical record.

Behind Patrick to his left stands Jari Holland Buck. She wrote Hospital Stay Handbook. She would understand the frustration of Lisa Lindell, as she too, kept her husband alive during his hospital stay.

Beside Jari stands Margo Corbett, the author of The Savvy Patient Toolkit. She became inspired to advocate after she was told her husband may not survive the night. She used all of her talent and past job experiences to create a handy checklist for patient care.

To Margo's Left stands Carolyn Oliver,MD, who wrote Cautious Care: A Guide to Patients. This was the first patient empowerment book I ever read. Fred Trotter gave me a copy after I asked an access question before the crowd at Connect 2009 in DC. I loved it its simple and clear instructions.

Next in line is Sanjaya Kumar, MD author of Fatal Care. Dr. Kumar is dedicated to the improvement of patient safety and real time collection of data.

In the center panel to left stands John James. He lost his son Alex at the age of 19. John was astounded when he read Alex's medical record. He saw so many mistakes and examples of miscommunication that led to Alex's death.

To John's right stands Sandra Gilbert author of Wrongful Death. Her husband died during routine surgery. Her story recounts her efforts to grieve while trying to find out what exactly had happened.

In the center stand the ones who lived. Dave Debronkart author of Laugh, Sing and Eat Like a Pig and Trisha Torrey author of You bet your life, The 10 Mistakes Every Patient Makes complete our 17. They had a very different experience. They got access to their medical records; they fought the system and won. The title of the piece is a play on the words Dave spoke: “Gimme my damned data.” His phrase described the anger and frustration of all of us who have suffered so in a system where a patient sees a record only as an afterthought. I decided to expand on his comment and add an actual dam.

So in the middle of this painting stands a version of Hoover Dam labeled Meaningful Use, HITECH. The data may still be dammed, but now it has begun to flow and it is pouring right into a laptop computer. We may have to wait three days, but due to government action, we will get access to our records.

This has been a long post. I may have lost some of you in listing all of the advocate authors. I hope you are still reading for there are two others in this picture.

To the far left stands Clay Shirky author of Cognitive Surplus, and to the right is Melinda Blau, author of Consequential Strangers. They are feeding the pack mules.

Every army must have pack mules. They supply the troops; they carry the supplies and are sure-footed on the mountainous path. If you haven't read the books I would recommend them to be read together. Melinda reminds us of the power of all the people in our life. It is the friend's friend who often gets us the job or finds us the right doctor. Clay Shirky informs us of the inherent potential in a world where thousands of people log on and data crunch with no other goal than doing good for others. He sees the future of medicine when it combines with the data aggregation of sites such as Patients Like Me.

So this is the story of Give Us Our Dammed Data. It is a painting that had 17 advocate authors. I could have painted more. I could have covered every wall in the Clinovations office space with advocates who are fighting for us. I stopped with 17.

Why? There are 17 people in 73 Cents. There are 17 pills in another piece at this exhibit, Sutent in a Shadow Box. And I took up my shield and sword on June 17th 2009. My shield is a canvas and my sword is a paintbrush. I am so glad my art can create a space where these authors can look upon us as the mighty army they are. I am in awe of the work they have done. I hope you will feel the same.

End-Of-Life: Starting The Conversation Before You’re A Patient

This Is A Story About The Power Of Ideas To Go Viral

Alexandra Drane
President and Co-founder, Eliza Corporation;
Co-founder, Engage with Grace

Alexandra is currently president and co-founder of Eliza Corporation, a leading provider of integrated health care communication strategies and one of Entrepreneur magazine’s “100 Brilliant Companies” (2009). Alexandra is also a co-founder of Engage with Grace, a not-for-profit movement launched in October 2008 aimed at helping people understand, communicate and have honored their end-of-life wishes. She has devoted her career to inspiring people to lead healthier, happier and more engaged lives through the use of innovative technology.

About a year ago, as key elements of the health reform bill were in debate, some savvy political strategists coined the term “Death Panels.”

It was both brilliant and damning – positioning end-of-life care as an incredibly personal decision put in the hands of a big government. And it was catchy – to the point of scoring a cameo appearance on *Saturday Night Live* …even proving worthy of parody by Bill Maher. What those savvy politicians forgot was that sometimes even the best laid plans can be put to rest (pun absolutely intended). Because as frustrating as it was to see end-of-life issues exploited for political purposes, in the end, the Death Panel fiasco actually served to breathe life into the very opposite movement. It did those of us telling our story about the importance of really understanding, sharing, and having honored our end-of-life wishes – whatever those wishes might be – a favor. It got people talking and thinking about this one issue that affects absolutely every one of us – ending our lives with the same grace and intent with which we live them.

And today, one year later, we have a huge, respectable body of work around end-of-life planning in response to what was intended as a damning political catch-phrase. Articles like Atul Gawande’s in *The New Yorker*; an *Associated Press* article on how Americans are overtreated; a multi-part segment on *National Public Radio*; debate over the topic in the *Boston Globe* …and so many more.

We couldn’t have imagined when we went live with **Engage with Grace** in 2008 (you can watch a video of the launch here) that our movement would spread so far – but having seen the outpouring of support from people just eager to tell their story, we shouldn’t have been surprised by the backlash Death Panels created.

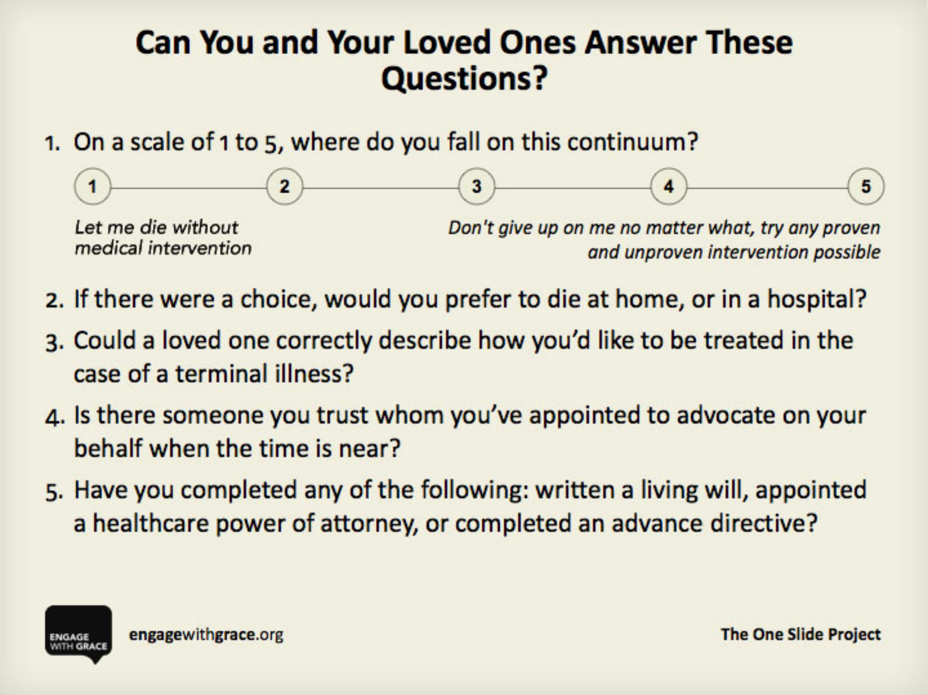
The idea behind **Engage with Grace** is simple – we as a nation need a tool to help get these conversations started. Something that can be shared easily with family, friends, colleagues – anyone really.

So we came up with **The One Slide** — just five questions about our end of life preferences each of us should be able to answer for ourselves, and for our loved ones, before it is too late to decide. Preferences we should then commit to supporting – no matter what the opposition. And we asked a whole lot of people to answer the questions for themselves, and then spread the word.

Now, thanks to an annual Thanksgiving blog rally as well as countless supporters spreading the word through their teaching, their business presentations, and their after-hours conversations with friends and family – **The One Slide** is spreading, and the five questions are getting answered. **Engage With Grace** was even named to the 2009 health care lexicon by HealthLeaders magazine. So now, to celebrate the great honor it is to be in the company of Disruptive Women, we humbly ask that you help us keep the movement alive.

Oh yeah – and one more thing – to all you fear-mongers out there who coined and perpetuated the Death Panel mania – we want to thank you. Looks like your best laid plans just might be finding their final resting place.

Pass it on.



Can You and Your Loved Ones Answer These Questions?

1. On a scale of 1 to 5, where do you fall on this continuum?

1 — 2 — 3 — 4 — 5

Let me die without medical intervention

Don't give up on me no matter what, try any proven and unproven intervention possible

2. If there were a choice, would you prefer to die at home, or in a hospital?
3. Could a loved one correctly describe how you'd like to be treated in the case of a terminal illness?
4. Is there someone you trust whom you've appointed to advocate on your behalf when the time is near?
5. Have you completed any of the following: written a living will, appointed a healthcare power of attorney, or completed an advance directive?

ENGAGE WITH GRACE

engagewithgrace.org

The One Slide Project

Making Decisions About Health Care: Is Your Brain Turned On?

When we listen to experts, our brains turn off. This is the finding from a study conducted by Greg Berns, a neuroscientist at Emory University. Here's what he did. He asked 24 college students to solve a personal financial problem. He watched their brain activity using a functional MRI and observed a lot of thinking going on.

Next, the students listened to a financial expert who told them what they should do. A second brain scan showed that the students' brain activity had virtually ceased. The lesson? When we listen to experts, our brains shut down.

When I heard about this study, I couldn't resist applying the findings to how people make decisions about their health care. Advertisements on television urge viewers, "Ask your doctor." In other words, don't think for yourself.

Suspend your own thought process and do what someone advises you to do, even if it means you will be exposed to significant risks that are often glossed over.

For optimal health, we can't delegate the management of our health, or our health care, to someone else. We need to own it. This requires a shift from the notion of consent to informed choice.

Here are 10 questions to help re-engage our brains in health care decisions. Call it a **Checklist Manifesto for Informed Choice**:

- What is the procedure or test?
- What is the purpose of it?
- What happens if I don't have it or do "watchful waiting?"
- What are treatment options for the condition I have?
- What are the risks and benefits of these options?
- What do the risks and benefits mean for me and my life?

Rosemary Gibson
Writer, Strategist

Rosemary Gibson is a writer, strategist, and thought leader in U.S. health care. Her new book, *The Treatment Trap*, puts a human face on overuse of unnecessary medical treatment. Rosemary has made her mark as a national leader in patient safety. She is the author of the critically acclaimed, *Wall of Silence*, a book of narratives of patient experiences with medical errors. At the Robert Wood Johnson Foundation in Princeton, New Jersey, Rosemary led national initiatives to improve health care quality for sixteen years. Rosemary is a frequently invited speaker on patient safety and health care quality for physicians, nurses, hospital administrators, trustees, health care ethicists and policy makers.

- Do the risks exceed the benefits?
- If surgery is being considered, how many of the surgeries has the doctor performed?
- Who will perform the surgery? Will residents, or doctors-in-training, be involved?
- How many of these procedures have been done at the hospital where it will be performed?

There’s an added bonus to being fully informed. Research shows that when people have their brains turned on and are engaged in making decisions about their health and health care, they use less intensive and costly approaches to treating their condition.

That can only be good for one’s health – and pocketbook.

The Ethics Of Patient Advocacy

As a registered nurse, I feel great pride in my profession. The list of reasons is long. One factor enjoys external validation, nurses have topped Gallup's Honesty and Ethics ranking of different occupational groups every year but one since they were added in 1999. The exception is 2001, when firefighters were included on the list on a one-time basis, shortly after the September 11th terrorist attacks. I consider it an understandable outlier. Apparently citizens think we are ethical and honest.

This amazing achievement is no accident. The ethos of nursing, since Nightingale, has gone well beyond the familiar "Do No Harm." Ours has been an ethos of patient advocacy. We teach and enforce it with the same intensity of focus we give to medication administration. I think of it as a hybrid ethos, merging the principle-based ethics of Lawrence Kohlberg (read masculine) with the relationship-based ethics of Carol Gilligan (read feminine). Early on, as we became increasingly adept at articulating our "Code of Ethics," the Hastings Center fretted with our fixation on patient advocacy. We insisted and persisted. I am proud of that.

This persistence about patient advocacy shapes the daily lives of practicing nurses. It is achieved in health care settings where hierarchic structures are designed to protect the hegemonic power of physicians and health care administrators. It is perpetuated in civic discourse. It is rarely visible, often only made public in whistleblower lawsuits where a nurse was fired for being a patient advocate, i.e., challenging a practice or person that puts the patient at risk. It is complex work, behind the scenes, often made exceedingly difficult and even career threatening.

When I was a very young nurse, a nurse leader advised me as follows: "If you haven't been fired by the time you reach the age of 30, you probably have been co-opted." At the time I found this advice disturbing. Over time, through a number of experiences that pivoted on professional integrity and the cost of protecting it, I have learned the wisdom of her message. I agree with her.

Phyllis Kritek, PhD, RN, FAAN
Consultant

Phyllis Kritek has deep roots in health care, beginning with her clinical career in mental health nursing and extending to several academic leadership roles, including dean, department chairperson, director of research, and creator and director of two doctoral programs. Long recognized for her leadership in the national nursing community, Dr. Kritek is a Fellow of the American Academy of Nursing (FAAN), and a member of several professional organizations, where she has served in a variety of leadership roles. Dr. Kritek has published extensively in peer-reviewed journals and books. She has served on the editorial board of several nursing journals and was the Editor of Nursing Forum from 1989 to 1992.

The media exacerbate the challenge. It may surprise the sponsors of “Nurse Jackie” to discover that thousands of nurses every day take on the challenges she faces and do so without becoming addicted to drugs. Finally, a nurse that is a patient advocate, but apparently only able to do so while abusing drugs and having affairs. The distortion of nurses and nursing by the media is as troublesome as their willingness to render us invisible or their naïveté about who we are, what we do, and how we do it.

But indeed, we persist. We advocate for our patients with a fierceness unknown to most patients and families. We view it as a matter of ethics. As with other fields of endeavor, we have a normal curve distribution of effectiveness in our efforts, courage in our convictions, and success in our outcomes. Nonetheless, I will give here the advice I give to anyone facing an important health event.

Find the best nurse you can. Tell that nurse that you have selected him or her as your personal advocate. These advocates should be taken to appointments, charged with asking important questions, protective as needed. These advocates should be at bedsides before, during, and after surgeries and other important medical procedures. These advocates should be encouraged to question whatever needs questioning on the behalf of their patients. Most nurses understand this role: they have been doing it for family and friends their entire careers. It would also be nice if you would acknowledge the gift they give in doing this important work.

Patient advocacy, for nurses, is an issue of professional ethics. Count on it!

Patient Advocacy: When Disruption Creates A Win Win Win

Trisha Torrey
Writer and Advocate

Trisha is known as Every Patient's Advocate. She is a newspaper columnist, radio talk show host, About.com's expert in patient empowerment, and a national speaker who teaches patients how to navigate the unwieldy and dysfunctional health care system. She has been quoted by the *Wall Street Journal, CNN, NPR, USA Today, Fox News, O Magazine, US News and World Report* and other media. Trisha's first book, entitled Y*ou Bet Your Life! The 10 Mistakes Every Patient Makes (How to Fix Them to Get the Health Care You Deserve)* was published in 2010. She also founded AdvoConnection.com, a website that supports the work of private patient advocates and connects them to the patients who need their services.

Once upon a time when we experienced strange symptoms, we went to the doctor, the doctor listened and asked questions, we got the medical tests we needed, were correctly diagnosed and successfully treated, and we could afford all that great care.

I say "once upon a time" because today, that scenario is mostly a fantasy. And sadly, today's story doesn't always end with happily-ever-after – for anyone.

Providers went to medical school to learn to heal and help. Instead they carry excessive patient loads amidst decreasing reimbursements, spend a small fortune on malpractice insurance, and reject some patients who don't have the right kinds of payers, or who take up too much time with difficult diseases or comorbidities. They are frustrated with their inability to deliver the care they prefer to deliver, but they must protect themselves or they will lose their practices.

Since the passage of reform, insurers have been forced to realign their requirements and services so they can continue to suck money from employers, patients, providers and the government. They spend billions on lobbying efforts, and reduce their provider reimbursements – at the expense of patients who are continually denied the care they need. A million families go bankrupt each year because they erroneously believed their insurance would cover their care when they needed it.

Those patients, accustomed to provider paternalism and decent payment coverage, find themselves blindsided to this devolved system that no longer provides the care they need and deserve. They get sicker. They die from medical errors. They lose their homes. No one has ever even suggested, much less taught them how to stick up for themselves or take responsibility for their own medical decision-making.

Patient Advocates to the rescue! Patient advocates are the only participants in the health care equation who may deliver improved outcomes for everyone – providers, payers and most of all – patients.

When an advocate accompanies a patient to an appointment, less time may be required because the advocate will facilitate communication and the process. In a hospital setting, a bedside advocate will double check drug dosing and insist on hand washing, keeping the patient safe and providers out of hot water.

Payers benefit from the efforts of patient advocates, too. Advocates help patients understand, or question a diagnosis before the wrong treatment is dispensed or performed, and therefore must be reimbursed. A billing or claims advocate knows how to file paperwork correctly, reduce a hospital bill, saving time and expense for payers and patients.

Of course, advocates provide the biggest benefits to us patients. We can rely on our advocates to be focused on our improved outcomes and well-being. Just like – once upon a time — we relied on our doctors.

Talk about disruptive! Rare is the case that an extra person in any relationship can improve the outcomes for everyone involved.

But this is no fantasy. Patient advocates are skilled and ready to help. Including an advocate in the medical care delivery equation can help us refocus on the possibilities of the good care that providers wish to deliver, payers are willing to pay for, and patients deserve to get.

Patient Safety Is All About You

Whether you are having an outpatient procedure, being admitted to a hospital or having a prescription filled, there are basic patient safety tips you should be aware of and act upon when necessary. Do not assume anything about your care.

If the staff places an identification bracelet on your wrist, take a look at it and verify that all of the information on the bracelet is correct. Although the staff should review the information on the bracelet before the procedure, this may not always happen. I knew of a health care professional who was having a minor diagnostic procedure performed, and after the procedure, she noticed that she was wearing the identification bracelet of a male patient.

Use the call light. If the staff instructs you to use the call light before getting out of bed, do it. You should not be concerned that you are bothering them. They want you to call for assistance so that you will not fall.

Speak up if you have questions or if you are unclear about the instructions you have been given. Also, if the staff has not provided written discharge instructions to you, request that they do.

If you are given a medication that you do not recognize, ask what it is and what it is for, and inform the nurse that the medication does not look like a medication you normally would take. If they respond with, “the doctor ordered this,” that is not an adequate answer to your questions.

No news is not good news. Don’t breath a sigh of relief because you have not heard from your physician’s office regarding the results of a test. Call the office for the results and you may want to request a paper copy of the results too. In a study published in the June 22, 2009 issue of *Archives of Internal Medicine* there was found to be more than a seven percent failure rate in communicating abnormal test results.

Lisa Martinez, JD, RN
Consultant and Educator

Lisa Martinez is a consultant and educator in women’s health and founded The Women’s Sexual Health Foundation (TWSHF). As a registered nurse and an attorney, she led TWSHF to provide up to date resources on sexual health information for women and health care professionals. She recently co-authored a Medscape CME program, completed a women’s health brochure on FSD, and assisted editing *The Breast Cancer Treatment Handbook* by Judy Kneece. Ms. Martinez has spoken to multiple national and international audiences. She has appeared on *ABC* and *CBS News LA*, and has been interviewed on NPR programs. She has served as a source for media outlets including *The Wall Street Journal, Washington Post, More Magazine*, and *Discovery Health*.

Use a hospital or surgery center that is accredited. Ask if the facility is accredited either by The Joint Commission or another recognized accrediting body.

Patient safety is all about you.

Learning To Be Your Own Best Advocate

Everyone needs to be his or her own health care advocate. I realized this when I noticed my mother struggling to manage the numerous medications she was taking. With so many prescriptions and over-the counter medications to keep track of, I was concerned about her taking the correct dosages at the correct times and following all the various instructions.

So I decided to create a medication chart that allowed her to track her medications more easily and ensure she was taking them correctly. We then showed the chart to each of her physicians and pharmacist. The result was a dramatic change in my mother's medication regimen. The chart enabled her physicians to view what they and all her other doctors were prescribing. They soon realized just how many medications she was on and that some medications were actually counteracting others. Many prescriptions were changed or stopped and over time she went from taking 16 medications to 9.

Adverse events related to medications are the fourth leading cause of death in U.S. for patients over the age of 65. This startling statistic led me into the patient-advocate role. Since that time, my own experiences have continued to reinforce my belief that individuals need to take control of their health and work to make sure all their health care providers, caregivers, and/or family members are working together as a team.

After being faced with several health scares in 2008, I decided to have an MRI breast scan for peace of mind. I had learned that the scan was the best diagnostic and screening tool for women with large, dense breasts and a family history of breast cancer. Since I had a mammogram six months earlier, which was normal, my physician did not think the MRI was necessary. However, I decided to have one to be certain I was breast-cancer free. To everyone's surprise, the scan revealed three spots that biopsies confirmed to be multifocal breast cancer. Since I knew my own body and had educated myself about available screenings, I may have saved my life because I was told a mammogram might have taken years to pick up the spots. This may not be the right course for every woman, but everyone should know that this tool exists.

Grace Bender
Owner, infinisity, inc.

Grace Bender has more than thirty years experience in public relations, government relations, management, and community volunteer work for organizations ranging from inner-city nonprofits to major cultural institutions. Her work has included program development, fundraising, financial management, special events, as well as chairing galas and balls. In the business world, Mrs. Bender was vice president of a consulting firm that represented companies seeking new business in emerging markets. Her previous experience included working as a government relations consultant to a law firm representing corporate and institutional clients. Over the years Mrs. Bender has also worked on numerous national and local political campaigns in various capacities.

I made the decision to undergo a double mastectomy and because it was caught early, I did not need chemotherapy or radiation. However, I was prescribed Tamoxifen, which is a drug that can help prevent cancer from reoccurring. Like many medications, you must be careful about what other medications you are taking. I discovered that the anti-depressant I was on counteracted the benefits of Tamoxifen. Again, I acted as my own advocate. Remember: Medications can save your life. However, you must take them correctly and be very careful about what else you are taking, eating, or drinking in combination with your prescription.

Medical errors by physicians and hospitals are still prevalent and a staggering number of patients are misdiagnosed every year. Compounding the problem is the fact that numerous prescriptions prescribed by various physicians are not being reviewed on a regular basis and patients self-medicate.

Patients should not just depend on a physician's files of their medical information but take it upon themselves to create their own permanent medical records. Before going into a medical appointment, everyone should be prepared with the following information:

- List of current medications and dosage
- List of ailments
- Medical history (if seeing a new physician)

A patient should also be prepared to explain to the doctor exactly what his or her problem is and offer an overall view of his or her health. If a serious condition exists, perhaps he or she should bring someone else to the appointment. In many cases a friend or loved one can interpret the information the doctor provides more objectively and be ready with questions that someone in an emotional state might have difficulty asking.

Ultimately, it is the responsibility of the individual to be their own advocate, know their own body, ask questions, and make sure everyone that is part of their healthcare "team" is communicating and basing decisions on the current, accurate medical information.

A Short Story About Dumping My Doctor

It was 1998 and I was new in town. By town, I mean a Midwest city on a big river with well over two million residents and two academic medical centers. Having been diagnosed with a rare heart disorder many years before, finding a good cardiologist in town was one of my first priorities.

I checked my health plan, researched the local paper, called the university medical centers and settled on a highly regarded, mid-50s, white-haired cardiologist in private practice with an affiliation at one of the medical centers in the area.

Our relationship lasted six months. Well, maybe one year, but that would be a stretch.

As a former physician's assistant, I handled the paperwork and repetitive tests that come with seeing a new doctor without concern. But the first few months of my move I was miserable and an emotional wreck. My mother died four days after I moved; her mother the next month. The job I was hired to do was canceled and I missed passing the bar exam by one point. I was exhausted and trembling at night from the weight of all the changes and uncertainty in my life.

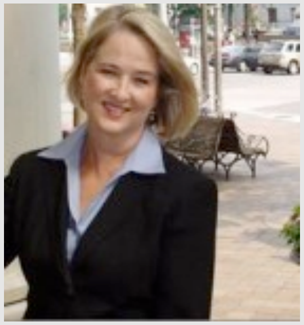
When the palpitations started, I knew the stress was too much.

"I think I'm depressed," I said with a lump in my throat to the Midwest cardiologist a bit shocked that I could utter the word. It was our third visit. I went on. "I'm not sleeping well, all I do is cry, and I'm just a bundle of nerves." Without looking up from the note he was scribbling in my chart he said, "Have you thought about looking for help on the internet?"

It was all I could do to sit upright on the examining table. I was shocked and disappointed that this was his best suggestion.

"The Internet?" I thought to myself. "Who is going to hold my hand or hug me on the Internet?"

Gwen Mayes, JD
Writer



Gwen Mayes has devoted her 30-year career to the responsible development of health policies that balance the interests of patients, regulators and health providers. While working in women's health, Mayes launched Writing With Insight®, and was the monthly health columnist for Today's Woman magazine for 4 years. Writing with Insight® brings together her unique experience as a patient advocate, lawyer, government relations expert, health policy official, medical communicator and story teller to improve the health of individuals and society at large. She consults with medical device companies and reimbursement firms on distinct medical delivery systems and patient rights established with health reform legislation.

At that moment I realized I needed a different doctor. I walked out of his office and never returned.

What I had overlooked was the importance of finding a doctor I meshed with personally. Not just one who had a prominent title, several clinical trials to his name, and a prestigious academic center standing behind him, but one that could simply look me in the eyes and tell that something wasn't right. Someone with empathy and a gentle touch. Someone I could build a relationship with.

The doctor-patient relationship is delicate; for patients living with chronic conditions or illnesses it means balancing personal rapport with clinical knowledge. Sometimes all you want are the facts from your doctor. But sometimes, you want a hug and some encouragement and the personal connection is as healing as any pill. Keep looking until you find the best of both.

Medical Gift Registry For Patients

Diem Brown was battling ovarian cancer when wedding and baby registry invitations begin flooding her mailbox. While her friends were asking for blenders and dishware, all she wanted was a wig and some help covering her medical bills. But there were no resources for her to orchestrate these needs, and flat-out asking was awkward.

Fast-forward four years, and Diem is now making this resource possible for anyone in the hospital. Since entering remission a little over 4 years ago, she has been working on a medical gift registry– amply called MedGift.com– which launched this week.

I met with Diem at Health 2.0 in San Francisco. She is beautiful and confident, and radiates genuine enthusiasm and compassion for this venture. From Real World / Road Rules contestant to ovarian cancer patient to her new role as entrepreneur and executive, Diem faces adversity with grace and resilience.

Check out our interview here.

Halle Tecco
Founder and Executive Director, Yoga Bear

Halle Tecco is a San Francisco resident and social entrepreneur passionate about technology, service and healthy living. She is the founder and executive director of Yoga Bear, a non-profit providing more opportunities of health and wellness to cancer patients through the practice of yoga. Halle has worked as a product manager at various consumer-internet startups, including Enternships.com and Kiva.org. She also serves as an advisor to GreatNonprofits.org. Halle was a 2009 L'Oreal Women of Worth Honoree. She is pursuing her MBA at the Harvard School of Business and will graduate in 2011.

Disruptive Women In Health Care Cosponsors Two Patient Advocacy Blog Talk Radio Shows On Real Women on Health!

How Health 2.0 is Evolving and Why You Should Care
Original Air Date: August 03, 2010
Featured guests, all Disruptive Women, included **Robin Strongin**, founder, Disruptive Women in Health Care; **Indu Subaiya**, co-founder of Health 2.0; and **Jane Sarasohn-Kahn**, health economist, principal of THINK-Health and founder of one of the most influential health blogs, Health Populi.

Indu Subaiya, MD, MBA
Co-founder, Health 2.0

Indu Subaiya, MD, MBA is co-founder of Health 2.0: User Generated Healthcare, a first-of-its-kind forum showcasing leading edge digital media, web and mobile technologies in health care.

Jane Sarasohn-Kahn
Health Economist; Principal, THINK-Health;
Founder, Health Populi

Jane Sarasohn-Kahn is a health economist and management consultant who has worked with health care stakeholders in the U.S. and Europe for over two decades. Jane founded THINK-Health, a strategic health consultancy, in 1992.

Patient Empowerment: How to be Your Own Best Advocate
Original Air Date: August 05, 2010
Featured guests, **Robin Strongin**, founder, Disruptive Women in Health Care; **Trisha Torrey**, Guide to Patent Empowerment, About.com and quoted in August's "O" Magazine; and **Regina Holliday**, medical advocate and muralist, painter of "73 cents," a depiction of challenges she faced to acquire her late husband's medical records as he struggled with cancer ("73 Cents" also cover of *British Medical Journal* 9/09).

Trisha Torrey
Writer and Advocate

Trisha is known as Every Patient's Advocate. She is a newspaper columnist, radio talk show host, About.com's expert in patient empowerment, and a national speaker who teaches patients how to navigate the unwieldy and dysfunctional health care system. She has been quoted by the *Wall Street Journal, CNN, NPR, USA Today, Fox News, O Magazine, US News and World Report* and other media. Trisha's first book, entitled *You Bet Your Life! The 10 Mistakes Every Patient Makes (How to Fix Them to Get the Health Care You Deserve)* was published in 2010. She also founded AdvoConnection.com, a website that supports the work of private patient advocates and connects them to the patients who need their services.

Regina Holliday
Artist and Advocate

Regina Holliday is a DC-based patient rights arts advocate. She is currently working on a series of paintings depicting the need for clarity and transparency in medical records. She placed her first mural in the series in May of 2009. After the death of her husband, Fred Holliday II, on June 17th 2009, she began a large mural titled "73 cents." This piece depicts Holliday family's nightmare journey through the medical system during Fred's cancer care. The painting became part of the national health care debate and was covered by the *BBC, CNN, CBS, AOL, VOA, NPR, The Washington Post* and the *BMJ*.

On The Meaning Of Patient Advocacy: A Personal Reflection

Kelley Connors
President and Founder, Real Women on Health! and Wellness Coach

Patient advocacy has a new meaning for me – for years I was only looking at one piece of the advocacy puzzle. Today, I see the whole picture from the patient as well as organizational standpoint. One's view certainly intensifies as your passion rises when your own family member or friend needs help navigating the health care system to receive the right care.

For years, I've been behind the scenes of educational campaigns that benefited from with pharmaceutical industry support; think Go Red for heart disease awareness among women, and Susan G Komen's grassroots efforts to increase public awareness about the importance of self-breast exams and mammograms.

But, things change when it's your dad who has chronic myelogenous leukemia (CML). And, you start to dig in to find out as much as you can about the condition, how to pay for a drug that costs $8,000 a month, and how to coordinate care when oncologists – as valued as they are – may miss concomitant conditions that impact how a patient feels and responds to CML treatment.

Here's what I've learned:

Being an advocate is about being curious, passionate and a seeker of information. For example, patient medical records are full of data that will help you close the gaps in care, should you or your family member need hospitalization. Can you access your medical records quickly should you need to make a life or death decision? The federal Health Insurance Portability and Accountability Act, which governs access to medical records, gives hospitals and doctors 30 days to respond to a request for medical records, although some state laws provide for a shorter time frame, and in urgent situations, such as a transfer to another hospital, it's customary for hospitals to move more quickly.

Be prepared to make your request in writing and, to shorten the time frame, ask your physician's office (the new physician in the case of patient transfer) to request them. Remember, medical records are yours and they contain the doctor's notes and instructions as well as diagnoses that often are communicated but likely not "heard" or "understood" by the patient or family.

One way to get your medical records more quickly is to seek out providers who use electronic medical records so the records can be e-mailed to you. Some providers even have an electronic portal so you can read your records anytime you want on a secure Internet site.

In summary, it’s one thing to work in health care PR, creating the patient advocacy programs for large companies but when it’s your family member who needs help, the word patient advocacy fills in with passion and purpose which is important but never enough. You need to understand the system and how it’s broken to identify the gaps.

To receive invitations to events, announcements of special series, and other news from the Disruptive Women in Health Care blog, please sign up on the site.

Disruptive Women in Health Care is a blog dedicated to serving as a platform for provocative ideas, thoughts, and solutions in the health sphere. We recognize that to accomplish this, we need to call on experts outside of the health industry.

The Disruptive Women have audacious hopes for our blog:

DISRUPTIVE
WOMEN
IN HEALTH CARE

- We're driving change
- We're creating chaos
- We're finding cures

…We're disrupting the health care status quo.

Disruptive Women is a project conceived of and owned by Amplify Public Affairs.

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