

Patient Engagement Through Empowerment

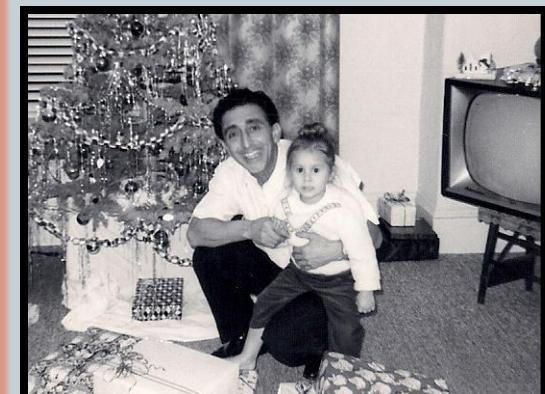
Julia Hallisy, D.D.S.

**Putting Patients and Caregivers
in the Driver's Seat**

October 10, 2013

About Me

- Wife and mother
- Practicing dentist
- Patient advocate
- Author
- Former hospital volunteer
- Advocate for my late daughter, sister, and father



The Empowered Patient Coalition

The Empowered Patient Coalition

A consumer and advocate- led non-profit organization that works to inform, engage, and empower patients, family members, and providers.



**The Empowered
Patient Coalition**



The Empowered Patient Coalition is a 501(c)(3) charitable organization created by a patient advocate devoted to helping the public improve the quality and the safety of their healthcare. The coalition feels strongly that the first crucial steps in both patient empowerment and patient safety efforts are information and education. The public is increasingly aware that they must assume a greater role in health care issues but they need tools, strategies and support to assist them in becoming informed and engaged medical consumers who are able to make a positive impact on health care safety.

Promoting Patient Safety

Patient Safety Resources

As one of our first projects, the coalition has developed a detailed and comprehensive patient guide to hospital care which will give consumers a blue print for interacting with the health care system in ways that are safe, successful and empowering. Patients will understand how the system works and be able to identify key staff members, learn how to ask the right questions at the appropriate time, build invaluable communication and collaboration skills, and both recognize quality health care and feel comfortable speaking up if their health care needs improvement. The consumer and the patient advocate will learn how to reduce the odds of experiencing medical error and hospital-acquired infection and understand the tremendous impact they can have on patient safety and health care quality.

Supporting the Consumer and the Patient Advocate

Informing Patients
Building Partnerships

Create Your Own Patient Safety Video

Have you, or someone you love had an adverse medical experience with a product, procedure, or medication?

Learn How Reporting Events Can Help Others

Click Here

View Reporting Data

***Our website is now optimized
for mobile devices***



The Empowered Patient Coalition

My Inspiration



Katherine "Kate" Hallisy 1989-2000

A Life-Threatening Hospital Infection



- A “routine” 30-minute biopsy
- 48 hours later – rash, fever, lethargy, kidneys failing
- Told infection is not the cause of Kate’s illness
- PICU on life support for 7 weeks
- Sepsis, ARDS, C-diff, bed sore, ICU psychosis, PTSD
- Permanent heart and lung damage
- Delay in limb-sparing procedure leads to amputation
- Post-amputation wound infection
- Months of physical therapy
- Financial cost = \$396,000 in 1997 dollars



Patients and Providers – Shared Challenges



- Patient education , engagement, and self-management
- Establishing relationships and building trust
- Effective and efficient communication
- Speaking up, moving up the chain of command - and feeling comfortable and supported doing so
- Making our voices heard in health care delivery, safety, and quality



What We Do – Tools, Resources, and Support

Empowered Patient®

Your 1-3-6-12 Month Plan

To Be An Empowered Patient

Dr. Julia A. Hallisy
An Empowered Patient® Publication

Empowered Patient®

Hospital Guide
For Patients and Families

Updated by Dr. Julia A. Hallisy
An Empowered Patient® Publication

Empowered Patient®

The Patient Journal
Your Hospital Diary

An Empowered Patient® Publication

EMPOWERED PATIENT®

OUTPATIENT VISIT SUMMARY

Patient Name: _____ Date: _____ Doctor: _____

Reason for visit: Routine "well" check Illness/injury – minor Illness/injury – major Immunization Follow-up

Main concern (One sentence each, if possible)

1. _____
2. _____
3. _____

List symptoms, if any: _____

Vital signs: Blood pressure: _____ Temp: _____ Weight: _____

List vaccinations given: _____

When is next dose/booster due? _____

List tests or procedures ordered:
List reason(s) test or procedure is needed:
How and when will results be communicated?
Referrals to other providers: _____

Changes in dosages of current medications? Yes No List changes: _____

New medications ordered? List name(s): _____ What condition is it treating? _____

When to start and stop new medication? _____

Is the writing on the prescription readable? Yes No If no, stop and confer with provider.
Understandable directions? I have repeated the directions back to the provider.

Is a follow-up appointment needed? Yes No If yes, when? _____ or date scheduled.

Things to ask my provider: _____

I should learn about or research the following: _____

Good sources of information: _____

Wellness recommendations: _____

Goals before next visit: _____

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Empowered Patient Decision Support Guide®

A communication and collaboration tool for patients, caregivers, and providers

THREE QUESTIONS TO ASK FOR THE DOCTOR IN A QUESTIONING & CHECKLIST DOPPLER THAT APPEARS TO YOUR INFORMATION. A PDF REPORT OF YOUR UNIQUE DECISION SUPPORT GUIDE WILL BE GENERATED AFTER YOU COMPLETE THE QUESTIONNAIRE.

THE DECISION I NEED TO MAKE IS:

Time frame for making this decision:

Now
2 days
Later / month end
Upcoming year
12 months

 **The Empowered Patient Coalition**

SEARCH

Home About Us Fact Sheets & Checklists Resources Advocate Directory Report A Medical Event Publications Training

Free Online Training Patient Safety Courses

The coalition feels strongly that one of the first crucial steps in both patient empowerment and patient safety efforts are information and education. To this end, we developed online patient education training modules to help patients, family members, and caregivers learn the fundamentals of important patient safety and advocacy issues.

About Our Free Online Training Courses

PATIENT SAFETY COURSES

Introduction to Patient Safety

[Lesson 1](#)
[Lesson 2](#)
[Lesson 3](#)

The Hospital Staff

[Lesson 1](#)
[Lesson 2](#)



2012 Study of Low-Income Patients in CA*



- Patients want a “closer connection” with their providers.
- 80% said it is important to have a provider who “knows you pretty well,” but *only 38% report such a connection*.
- 67% of those who feel informed about their condition feel comfortable asking questions. Only 33% of those who do not feel informed are comfortable asking questions.
- 33% of respondents who reported not following a provider’s advice said they did not understand what they were supposed to do.

* 2012 Survey conducted by Langer Research and funded by the Blue Shield of California Foundation. 1024 respondents.

Note: “Low income” defined as an income of \$46,000 or less for a family of four or more people.



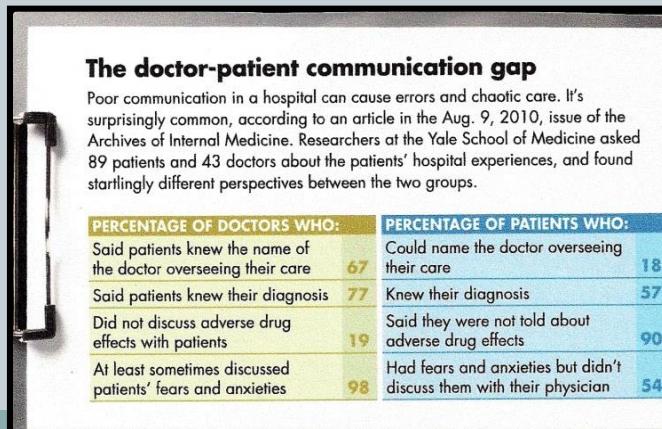
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Challenge # 1 - Communication



- Patients struggle to ask any questions at all
- Patients are not focused, organized, or concise
- Patients may have a long list of vague complaints
- Patients ask the “wrong” kind of questions
- Patients worry about being labeled “difficult”
- Patients bring up concerns at the very end of the visit



Source: Consumer Reports

A Solution -Empowered Patient® SBAR Forms

Give patients tools to help them organize their thoughts, observations, and questions.

EMPOWERED PATIENT®
OUTPATIENT COMMUNICATION GUIDE
SBAR Technique

Situation
• MY NAME IS: _____
• I AM THE: _____ (relative, advocate, friend, Medical Power of Attorney) for _____ (state patient's name)
• I AM CALLING BECAUSE I HAVE CONCERNs OR QUESTIONS ABOUT: _____

Background
• THE PATIENT'S CURRENT MEDICAL CONDITION IS: _____
(Examples: pneumonia, heart failure, infection)
• THE PATIENT ALSO HAS THESE ISSUES: _____
(Examples: dementia, difficulty walking, unable to communicate, bedridden)
• THE PATIENT IS: _____
(Examples: taking new medications, recovering from surgery, waiting for test results)

Asessment
• NEW SYMPTOMS I notice are: _____
(Examples: more pain, change in mental status, difficulty breathing, lack of appetite)
• THE PATIENT SEEMS TO: _____
(Examples: have a fever, be in pain, have less energy than usual)

Request
• I WOULD LIKE TO TALK ABOUT: _____
(Examples: coming in for an office visit, a home health nurse, having a test)
• HOW AND WHEN SHOULD I CONTACT YOU IF THE PROBLEM CONTINUES?

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Concept and form based on the Kaiser Permanente SBAR Technique for Communication: A Situational Briefing Model

**SBAR COMMUNICATION TECHNIQUE
FOR PATIENTS & ADVOCATES**

Situation
I AM _____ (state your name).
I AM THE _____ (relative, advocate, friend, Medical Power of Attorney) for _____ (state patient's name).
I AM CONCERNED ABOUT _____.

Background
THE PATIENT CAME TO THE HOSPITAL BECAUSE _____.
THE PATIENT'S DIAGNOSIS IS _____ or is unknown at this time.
THE PATIENT'S PHYSICAL OR MENTAL LIMITATIONS ARE _____.
(Examples: dementia, hearing loss, difficulty walking, unable to communicate, language barriers)
THE PATIENT IS _____.
(Examples: on oxygen, receiving new medications, having procedures or surgery, awaiting test results)

Asessment
NEW SYMPTOMS I have noticed are _____.
WHAT HAS CHANGED in the patient's condition is _____.
(Examples: pain level, vital signs (blood pressure, temperature, pulse), breathing, mental status, color of skin, sweating, agitation, dizziness, lack of energy)
THE PATIENT SEEKS TO BE _____.
(Examples: stable, unstable, declining or deteriorating, in serious trouble)

Request
I WOULD LIKE TO DISCUSS THE FOLLOWING POSSIBLE ACTIONS: _____.
(Examples: consultation/evaluation, a second opinion, calling the Attending Physician, scheduling a family meeting, additional tests or monitoring, transfer to another unit or facility)
IF A CHANGE IS ORDERED, how and when should I contact you if there is no improvement? _____

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Easy to use
Patients acquire skills
Builds confidence
Organized and concise
Saves time
Reduces stress
Improves communication



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Challenge #2 –Engagement (Even for a physician!)



“I felt trapped in an alternate reality.”

“Seeing all those errors serially occur was really shocking.”

“How difficult it was to give feedback.”

“I Felt Lost and Powerless.”

Dr. Jonathan Welch, *Health Affairs December 2012 31:2817-2820; doi:10.1377/hlthaff.2012.0833*

A Solution - Engaging Patients in the Hospital

- Patient and family rounding
- No restrictions on family visiting hours
- Use of whiteboards
- Patient and family advisory councils, committees, board memberships
- Involve patients in root cause analysis
- Offer a written or electronic patient journal
- Encourage the use of a patient progress sheet
- And many more...



EMPOWERED PATIENT®

INPATIENT DAILY PROGRESS SHEET

Patient Name: _____ Date: _____

Care Team members:

Doctors: _____

Nurses: _____ Nursing assistants: _____

Therapist: _____ Social worker: _____ Other: _____

Current diagnosis: _____

New symptoms observed: _____

Patient's overall condition seems: the same better worse

Changes in medications? No changes

Meds added (list): _____

Meds stopped (list): _____

Blood work, tests, or procedures ordered? Yes No

Name: _____ Why needed? _____

Name: _____ Why needed? _____

Name: _____ Why needed? _____

Received blood work, test, or procedure results? Yes No

Findings: _____

Patient's physical activity level: _____

Vital signs are: in normal range out of normal range

List patient's normal range here (ask providers): _____

List vital signs that are out of range: _____

Patient's treatment goals for today: _____

Goals attained today: _____

Questions for the Care Team: _____

Back of this form left blank to add additional notes, questions or concerns.

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Challenge # 3 -Speaking Up, Being Prepared and Patient Involvement

First, you need a *relationship* followed by trust,
information, skills, support, and confidence

Afraid to Speak Up at the Doctor's Office

By PAULINE W. CHEN, M.D.



The doctor-patient communication gap

Poor communication in a hospital can cause errors and chaotic care. It's surprisingly common, according to an article in the Aug. 9, 2010, issue of the Archives of Internal Medicine. Researchers at the Yale School of Medicine asked 89 patients and 43 doctors about the patients' hospital experiences, and found startlingly different perspectives between the two groups.

PERCENTAGE OF DOCTORS WHO:
Said patients knew the name of the doctor overseeing their care
67
Said patients knew their diagnosis
77
Did not discuss adverse drug effects with patients
19
At least sometimes discussed patients' fears and anxieties
98

PERCENTAGE OF PATIENTS WHO:
Could name the doctor overseeing their care
18
Knew their diagnosis
57
Said they were not told about adverse drug effects
90
Had fears and anxieties but didn't discuss them with their physician
54



U.S. National Library of Medicine
NIH National Institutes of Health

Patients Balk at Asking Health Care Workers to Wash Hands

Study found only 14 percent of hospital patients have actually spoken up

Sources: New York Times, Consumer Reports, Medline Plus, Joint Commission



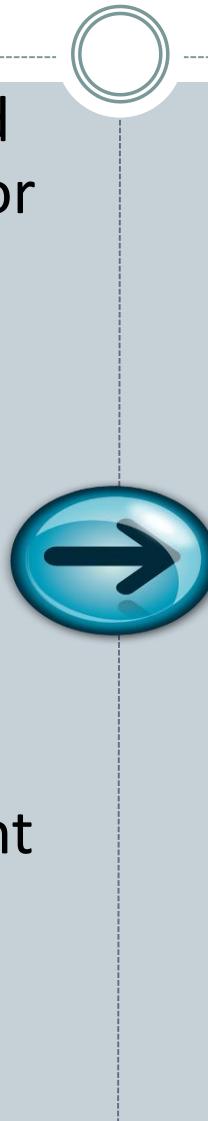
Speak Up:

PREVENT ERRORS IN YOUR CARE



A Solution- Preparing for Visits

- Stress the importance and value of being prepared for visits.
- Ask patients to use a structured form including three main questions.
- If there are more than three concerns, ask patient to alert the staff to schedule more time.



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PREPARING FOR A HEALTH CARE VISIT

Date: _____

Reason for my visit: _____

Main questions and concerns (try to limit to one sentence, if possible):

- _____
- _____
- _____

Symptoms I am having:

- _____
- _____
- _____

When my symptoms started: _____

Other health care providers I have seen recently:

- _____
- _____
- _____

New medications I am using (include over-the-counter and herbal):

- _____
- _____
- _____
- _____

5. List additional medications on the back of this form.

Anything else my provider should know:

- _____
- _____
- _____
- _____

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A Solution – Interactive Visit Summaries

- Inform patients that it is helpful to write down questions and goals
- Patient goals are listed on the visit summary
- Start with one or two simple, achievable, and *measurable* goals
- Consider having patients fill in parts (or all!) of the visit summary



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OUTPATIENT VISIT SUMMARY

Patient Name: _____ Date: _____ Doctor: _____

Reason for visit Routine "well" check Illness/injury – minor
Illness/injury – major Immunization Follow-up

Main concerns (One sentence each, if possible)

1. _____
2. _____
3. _____

List symptoms, if any: _____

Vital signs: Blood pressure: _____ Temp: _____ Weight: _____

List vaccinations given: _____
When is next dose/booster due? _____

List tests or procedures ordered: _____
List reason(s) test or procedure is needed: _____
How and when will results be communicated? _____
Referrals to other providers: _____

Changes in dosages of current medications? Yes No List changes _____
New medications ordered? List names: _____
Why is medication needed? _____ What condition is it treating? _____
When to start and stop new medication? _____
Is the writing on the prescription readable? Yes No If no, stop and confirm with provider.
I understand the directions I have repeated the directions back to the provider
Is a follow up appointment needed? Yes No If yes, when? _____ or date scheduled _____

Things to ask my provider:
I should learn about or research the following: _____
Good sources of information: _____
Wellness recommendations: _____
Goals before next visit: _____

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Challenge # 4 – Preparing for Surgery and Recovery

The many important considerations can be overwhelming:

- Diagnosis and decision-making
- Choosing a surgeon & hospital
- Questions to ask/consent
- Anesthesia
- Preparing for surgery
- The day of surgery and having an advocate present
- Post-surgical issues, pain control, and the plan for assistance during recovery



A Solution – Patient Fact Sheet & Checklist

EMPOWERED PATIENT®

"Ten Things Patients Should Know" Series

SURGICAL PATIENT CHECKLIST

1. I know why my surgery is needed, the risks and benefits and how often it is successful for my condition: Yes No
2. I know what is involved in my recovery and how long it may take: Yes No
3. I know who will be doing the surgery, if they are board-certified in this specialty, and how many times they have done this procedure: Yes No
4. I consent to have other doctors assist during my surgery: Yes No
List other surgeon's names here:

5. The surgeon will personally sign the surgical site: Yes No
6. The patient will be included in signing the surgical site: Yes No
7. A surgical checklist will be used and a "time out" will be taken before surgery begins: Yes No
8. Antibiotics are needed prior to the start of surgery: Yes No
9. I know when antibiotics should be stopped after surgery: Yes No
10. I know how my surgeon can be reached if there is a complication: Yes No

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EMPOWERED PATIENT®

"Ten Things Patients Should Know" Series

BE PREPARED FOR YOUR SURGERY

1. DECIDING ON SURGERY: Why is the surgery needed? How successful is the surgery in correcting the problem and what are the potential short and long term risks? What will the recovery process be like?
2. CHOOSING A SURGEON: Ask about the surgeon's experience with this particular surgery and check his or her credentials online. Is the surgeon board-certified in the specialty you require?
3. WHERE TO HAVE YOUR SURGERY: Check your hospital online at www.QualityCheck.org or www.HospitalCompare.hhs.gov. Does the hospital have an Intensive Care Unit(ICU) and a Rapid Response Team(RRT) to respond to emergencies?
4. SCHEDULING YOUR SURGERY: If possible, schedule your surgery for early in the day and early in the week. Try to avoid having procedures on major holidays, nights or weekends.
5. SURGERY AND RECOVERY: Who will actually perform the surgery? Will assistants or residents be participating, and if so, to what degree? Will the surgeon be in town and available in the days after surgery?
6. ANESTHESIA: Will your anesthesia be handled by a board-certified anesthesiologist or a certified nurse anesthetist? Who will be assisting them?
7. PREPARING FOR SURGERY: Patients should not shave surgical site for 2-3 days before surgery to prevent small cuts in skin where bacteria can enter. Patients must not eat or drink for 6 to 8 hours before surgery.
8. THE DAY OF SURGERY: Be sure all information on the patient's ID band is accurate. Have all pre-operative medications, including antibiotics, been ordered and given? Be sure the surgeon signs the surgical site before the patient is sedated.
9. ONCE SURGERY IS OVER: Have an advocate present to discuss details and ask if there were any complications with the surgeon after the surgery is over. Be sure the patient is kept warm and ask if the patient needs specific treatments to prevent blood clots.
10. PAIN CONTROL: If the patient is using a PCA (patient controlled analgesia) pump, be aware that malfunctions can occur and watch for signs of an overdose, including shallow breathing, extreme sleepiness and small pupils. Be aware that pain medications can cause severe constipation so ask about precautions.

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Empowered Patient Decision Support App



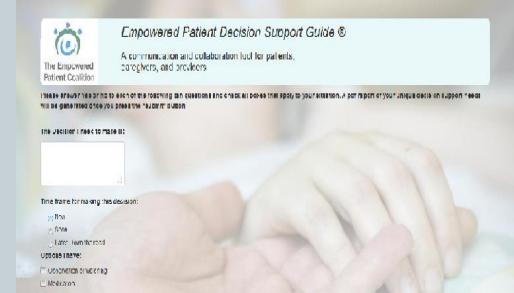
1. I feel I have the basic facts I need to make this decision:

Yes →

- I know if my diagnosis is confirmed
- I know the average length of treatment and recovery time
- I know if having this treatment may prevent me from having other treatments later

No →

- I need more time/information from my doctor or nurse
- I want a second opinion/information from a different doctor or nurse
- I need help understanding and learning about my condition
- I want to look up standard tests and treatments
- I want to know about the success rate of the suggested treatment
- I want to talk to other patients who have what I have (online communities, in- person support groups, or other patients suggested by my providers)



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Challenge # 5 – Discharge, Home Care, and Preventing Readmissions



- Discharge instructions, access to Discharge Summary, medication list, complications to watch for, and a phone number to call
- Teaching patients how to care for any wound, dressing, or surgical site. Do they know the signs of infection or other complications and what action to take?
- Improving the healing environment – nutrition, stress, sleep, support...
- Patients know when to return for post-discharge visit, which doctor they need to see, the appointment is scheduled, confirmed, and there is follow-up
- Home visit for medication reconciliation and assessing environment, progress, and caregiving and any other needs.

A Solution – Discharge and Home Care Fact Sheets



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PREPARING FOR DISCHARGE

- DISCHARGE INSTRUCTIONS:** Does the patient have a clear, readable copy of the discharge instructions and the discharge medications?
- NEW MEDICATIONS:** If new medications have been added to the treatment plan, have they been checked for drug interactions? Do you understand all instructions and especially the dosing schedule?
- "RESCUE ME" NUMBER:** Do the discharge documents contain a phone number to call if there are questions or concerns?
- FOLLOW-UP APPOINTMENT:** Has a follow-up appointment been scheduled with the patient's physician?
- HELP AT HOME:** If the patient will need help at home, are family or friends available to help and have they been contacted?
- VISITING NURSE:** Will a visiting nurse be needed and has the doctor signed the order?
- SKILLED NURSING FACILITY:** If the patient is being discharged to a skilled nursing facility, do you know how long she is authorized to stay? Is there a plan for her subsequent care?
- WOUND CARE:** Does the patient or advocate have clear instructions for caring for any wound or surgical site? (This should include how to change bandages or dressings, when bandages should be removed, and when the patient can shower or bathe.)
- PHYSICAL THERAPY:** If the patient needs physical or occupational therapy, when should therapy start and who will schedule it?
- MEDICAL EQUIPMENT:** If the patient needs new medical equipment (e.g., oxygen, wheelchair, hospital bed, commode, walker) has the order been placed, and filed with insurance if covered? When will the medical equipment arrive?
- DISABILITY/ WORKER'S COMPENSATION:** If the patient is applying for disability benefits or worker's compensation coverage, does the hospital or doctor need to submit documentation? Who can the patient contact if more information is requested?

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HOME CARE AFTER SURGERY

- Be sure you have a **NUMBER TO CALL** if the patient has any serious complications, or other problems such as loss of appetite, depression, anxiety, or insomnia.
- Ask if the patient needs to monitor any **VITAL SIGNS** at home such as blood pressure or temperature.
- Know the **SIGNS OF BLOOD CLOTS (DVT OR PE)**: swelling, redness or breathing difficulties. Be certain that you have a way to reach the doctor – even after hours.
- Know the basic **SIGNS OF WOUND, BLOOD OR URINARY TRACT INFECTION**: fever, redness, rashes, pain, swelling around the incision, drainage from the incision, painful urination.
- Know the **SIGNS OF INTERNAL BLEEDING**: low blood pressure, sweating, confusion, shallow breathing, weak pulse, and pale skin.
- If the patient has a **DRAIN** in place, learn how to empty it and what the fluid from the drain should look like. What changes warrant calling the doctor?
- Use a **MEDICATION LOG** to keep track of dosages and side effects of multiple medications. Consider using a **PILL ORGANIZER** to organize your drugs and a **PILL SPLITTER** if tablets need to be cut in half.
- Be aware that **NARCOTIC PAIN MEDICATIONS** such as morphine, hydrocodone, or oxycotin can cause dizziness, loss of appetite, constipation and hallucinations. Do not drink **ALCOHOL** when taking pain medications.
- Be aware that **ACETAMINOPHEN** – the ingredient in Tylenol – is present in many over-the-counter medications as well as prescription pain medications. Adding extra doses of Tylenol to your prescription medications can cause serious liver damage.
- Does the patient have any **DIETARY RESTRICTIONS** or need any nutritional supplements? Will they need medications to prevent **CONSTIPATION**? What does the doctor recommend?
- Ask how much **ACTIVITY OR EXERCISE** is appropriate. Should the patient be up and walking to prevent blood clots? When can the patient drive?

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Our Barriers



Being a small, grassroots organization



Getting the word out to the public about our resources

Reaching people before they experience a challenge

Health care institutions recognizing the need for patient education and recommending our materials

Things Can Be Different



- Patients have skills and confidence to be part of the team
- Patients communicate effectively with SBAR scripts and coaching
- Patients prepare for visits in advance and help with visit summaries
- Patient and family keep their own progress sheet
- We “make the case for why” and patients engage and self-manage

HealthCare.gov
Take health care into
your own hands

Learn How



Pathways

The Rise of the Empowered Patient

Once marginalized, consumers are taking more control over their own treatments.

The degree of broad and inclusive consumer activism has increased exponentially in recent years. Consumers are no longer satisfied with the products offered, the complexity of the transaction, and, ultimately, the pricing. They are demanding transparency, accountability, and a sense of justice. Given the recent global financial crisis, which many traditional financial institutions have survived through intervention, the fact that many personal investors are turning to alternative investment management—including individual finance advisors and portfolio managers, many others encouraged consumers’ expectation of unbiased and sound guidance. This shift has led to a new era of greater accountability in the sector, skepticism about care and peripheral constituencies, and a reevaluation



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My Validation



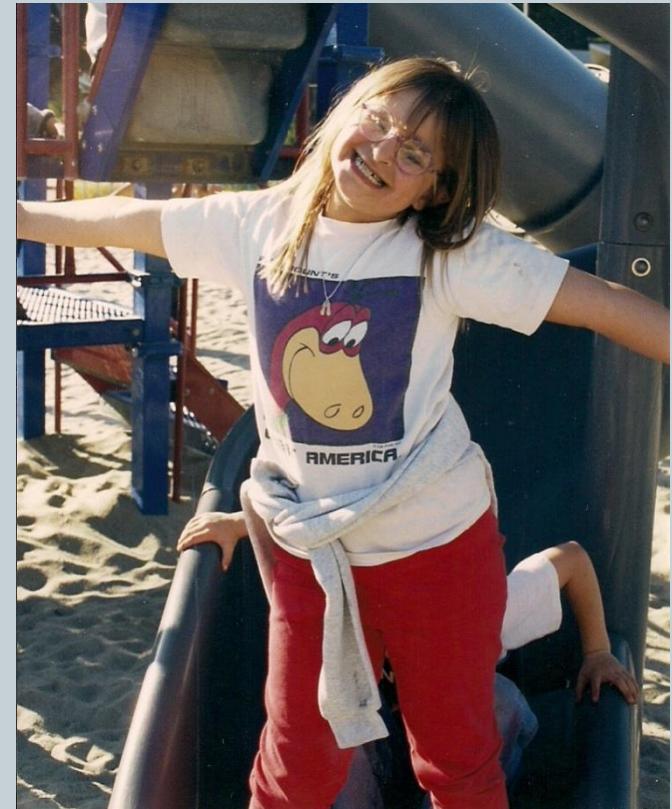
- Why must I leave the room when you talk about my child?
- Why isn't everyone up to speed and on the same page?
- Why is it so difficult to have my questions answered?
- Why does the staff seem so overwhelmed and rushed?
- Why are chemo and other meds delayed for hours on end?
- Why isn't there a pharmacist on the team all the time?
- Why don't you want to know what parents think?
- Why didn't I know that I could have asked others for help?



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What Would Katherine Say?

- We are at a fork in the road
- There is no middle ground
- People are suffering and dying
- We can, and must, do more
- Why is it taking so long?
- **You** can make it better



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The Empowered Patient Coalition

Informing Patients Building Partnerships



- Free Hospital Guide
- Factsheets and Checklists
- Free Patient Journal
- Apps
- Patient Safety Training
- Sign up for our Newsletter

www.EmpoweredPatientCoalition.org

Contact



Julia@EmpoweredPatientCoalition.org

Tel. 415-681-1011

Twitter@EPCoalition

Facebook –The Empowered Patient Coalition

LinkedIn – Julia Hallisy

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