

KLS Foundation 2015 International Conference

July 19, 2015

Atlanta

A decorative graphic consisting of a solid teal horizontal bar, followed by a white horizontal bar, and then three thin, parallel white horizontal lines.

Managing Your KLS Care;

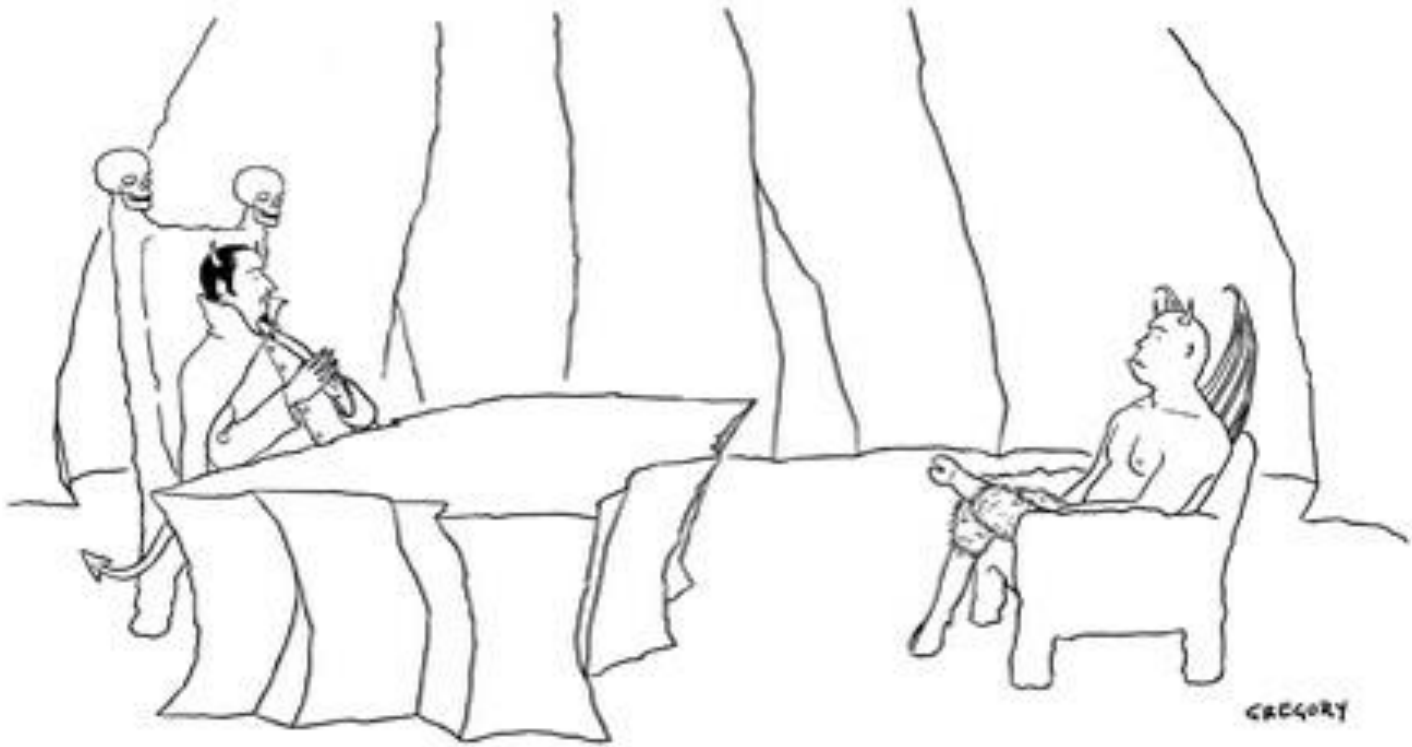
Collaborative Provider Relationships & Supportive care

Gaylene Grossman, RN BSN CNOR
KLS Foundation Advisory Board

Topics

- Our Health Care System
Good news for the KLS patient
- How to insure a great patient experience
- Tips on finding a doctor you can work with
- Supportive care
- Discussion

Power Point...a necessary evil...



"I need someone well versed in the art of torture—do you know PowerPoint?"

Shifting landscape of healthcare



Why the Patient Experience Matters



Empathy and Connection

- A new business model has emerged to address the need for healthcare providers to learn about the patient experience and how to build their awareness and skills
- Empathy is now being taught to doctors and staff at hospitals across the country.
- Language of Caring, The Beryl Institute and The Advisory Board are a few.

What are the CAHPS?

- CAHPS stands for Consumer Assessment of Healthcare Providers and Systems; refers to a family of standardized and scientifically sound surveys that ask consumers and patients to report on their experiences with health care services in different settings.

***If you receive one of these surveys please
let your voice be heard***

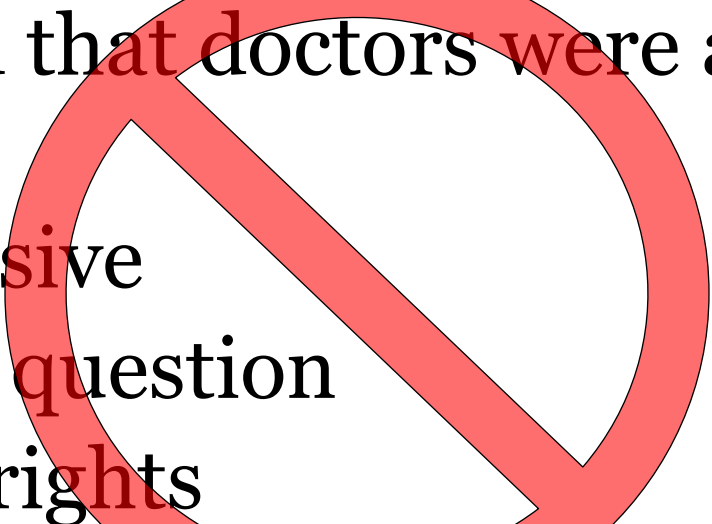
The Patient Experience is focus:



The Good News for KLS Patients

- Patient-centered care is replacing the historic physician centered system with one that revolves around the patient.
- Need for supportive care aligns with new focus on empathic care and providing a quality experience where patients and families feel heard.
- Metrics for reimbursement include collaboration with other providers as necessary

The patient of the past...

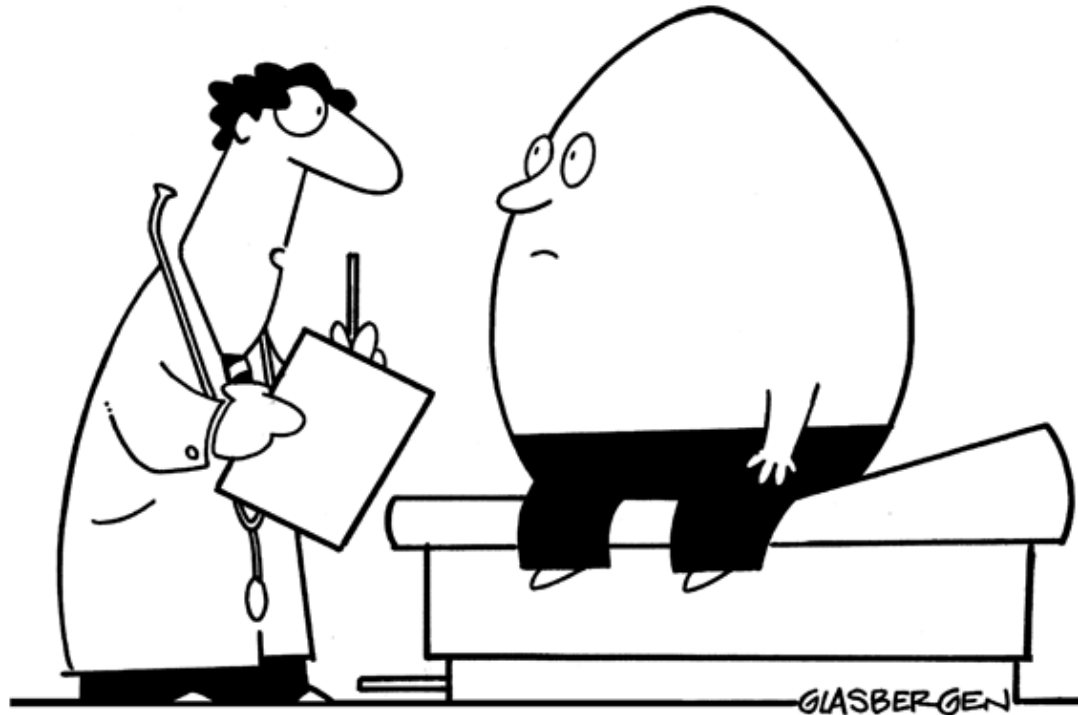
- Believed that doctors were all-knowing experts
 - Was passive
 - Did not question
 - Had no rights
- 

Being a great patient

- Predetermine your visit goals
 - Diagnosis
 - Symptom management
 - Documentation
- Be a partner with your doctor to manage your care
- Question anything that does not seem safe or appropriate

Be willing to point out the obvious to the doctor

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“I’d like to order some tests, Mr. Dumpty. You look pale.”

Going from Good to Great

- Time is limited with the doctor, be prepared
 - Fill out paperwork ahead of time
 - Prepare list of medications with dosages/timing
 - Send doctor any reading material you want to discuss before the appointment
 - Bring lab or image results with you
 - Bring copies of any and all pertinent consultations
 - Arrive on time if not early

Be courteous to staff

Finding a doctor

Do's

- Refer to list on the KLS website
- Network with other in the KLS community to ask for recommendations
- Utilize search engines like healthgrades.com and rateMDs.com
- Check with your insurance company
- Screen potentials on yelp

Don'ts

- Pick from the yellow pages
- Expect him or her to know about KLS
- Continue to see a doctor who is unwilling to learn about a rare disorder
- Think you have to stay with a doctor who is not collaborative despite your best efforts

Your Role as KLS Educator

- Reference material
 - KLS Foundation
 - YouTube
 - Facebook

KLS on YouTube

Mat Sherman



My Life with KLS

Tannis and Alanna



Living with KLS & Alanna Wong Life

ABC's of supportive care

- In the absence of a treatment or a cure, the best we can do is provide a safe and caring environment
- Consider collaborating with your healthcare provider to try medications for symptom management

“If you want results you have never had before you have to be willing to do something you have never done before.”

Mat Sherman

KLS Revealed

- Alanna & Diane Wong have developed a survival guide with a wealth of information such as:
 - Caregiver strategies
 - Coping Mechanisms
 - How does one heal?
 - What you can do to help
 - Explaining KLS to others
 - Finding emotional support

ABC's of supportive care

Tips from our collective experience

- Create a physical environment that is safe, secure and comforting
- Decrease noise and light
- Allow the person with KLS to sleep as much as they need to and offer healthy foods when awake (cookie dough, in-and-out and mac n'cheese count)
- Be patient, calm, loving, and a good listener
- Consider limiting visitors
- Take custody of cell phone, computer and car keys
- If over 18, Consider Durable Power of Attorney

KLS Revealed

Available for download

Net profits go to the KLS Foundation.

To order go to:

<http://alannawonglife.com/shop/klsguidebook/>

Hope

“Hope is the belief that our children will find the meaning and purpose in their lives and through the adversity of their suffering, the greatest opportunities will be revealed.”

Alanna & Diane Wong

Thank you and god bless

Discussion / Questions