Only in America No One Dies

Road map to dealing with a serious usually fatal disease

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Amazing time in medicine

- Better understanding of the biology
- Better management for a range of diseases
BIOLOGY
Crick and Watson discover the “secret of life” in 1953
DNA and double helix
DNA is the structure of chromosomes
Human genome is mapped in 2003
Human Genome: Many reactions
THERAPEUTICS
Development of antibiotics as an example

- Sir Alexander Fleming discovers penicillin in 1928, now over 160 antibiotics
Now many therapeutics

- Estimate over 6,000 different drugs
- Extensive range
  - Cardiac
  - Pulmonary
  - Gastrointestinal
  - Diabetes
  - Oncology
DEVICES

MANY EXAMPLES
A complication of heart attacks: ventricular fibrillation

Normal sinus rhythm

Ventricular fibrillation
Implantable defibrillator
Patient with an implantable defibrillator
BETTER DIAGNOSTICS
Beatles and CAT scan technology
PET Scan: Evaluation of physiology
Magnetic Resonance Imaging (MRI)

- Use radio frequency
- Does not use radiation
- Enclosed and noisy
MRI of the breast: an improvement over mammography for select circumstances
CANCER MEDICINE

- Earlier diagnosis
- Better therapeutics
Breast Cancer

- Better Outcomes
- Early diagnosis
  - Mammograms
  - Breast MRI
- Better therapeutics
  - Local management
  - Systemic management
Discovery of HER2 biology and breast cancer management

- Taking a poor prognosis breast cancer situation to now potentially curable situation
Human Epidermal Receptor 2 (HER2)

Inside of the cell
HER Family Proliferation and Survival Signaling Pathways

HER2 Gene Amplification

- Normal cell
- Tumor cell
- Centromeric probe for chromosome 17 (CEP17)
- Probe for HER2 gene
Breast Cancer Subsets

Trastuzumab binds to HER2

- Continually suppresses HER2 activity
So when we are diagnosed with a serious potentially fatal disease, so why should we not be able to beat it and do well?

- We have all these medical advances in diagnosis and therapies
- We are a “can do” nation
- And yes we are stubborn
Cultural ethos in the United States

“That it’s hard to believe that a disease can get the better of us with such great technologies available”

Lowell E. Schnipper, MD
Harvard Medical School
Lance Armstrong Phenomena: who did it, so why can’t I?
“Do not go gentle into that good night
Rage, rage against the dying in the light”

Dylan Thomas
Cancer Statistics in US 2009

- 1,479,350 new cancer cases
- Age of patients
  - Median age 67
  - 25% ages 65-74
  - 22% ages 75-84
  - 7.5% 85 and older
- 562,340 cancer deaths
- Gender
  - One of two men will die from cancer
  - One of three women will die from cancer
Road Map

How to deal with the diagnosis of a FATAL disease
Initial phase

- **Diagnosis**
  - What is it?
  - Confirm and verify
  - Start a personal medical folder/note book

- **Prognosis**
  - Is it fatal?
  - What is the expected survival: weeks, months, years?
Your role

- Identify your medical team
- Identify your support team
- Develop ownership of the treatment plan
- Expect a “roller coaster” ride of emotions ranging from disbelief to anger to fight to acceptance
Putting your teams together

- Multidisciplinary medical team
- Supportive team
Criteria for your medical team

- Knowledge
- Skills
- Communication
- Collaboration
- Compassion
Multidisciplinary medical team

- Get your docs in order
- Make sure they work well together
- Identify a team captain (may have co-captains)
Patient Doctor Relationships

- Paternalistic
- Autonomous
- Shared Decision Making
Identify your support team

- You need a chief advocate usually your spouse/significant other/family member/close friend
- Family
- Friends
- Other support groups
  - Support groups (e.g. Life with Cancer program)
  - Faith related support
Treatment options

● Benefits
  – Response rate
  – Progression free survival
  – Overall survival

● Side Effects
  – Short term
  – Long term

● Goal: quality of life and prolongation of life
Clinical Trials

- Is there something better than standard therapy
- Hopeful
- Benefits/side effects are not well defined
- Types
  - Phase I: identifying side effects of new therapy
  - Phase II: evaluating benefit of new therapy
  - Phase III: comparing new therapy with standard therapy
Second Opinion

- Good idea for rare or complicated diagnosis
- Treatment options vary
- Just not sure about your team
Doctor appointments

- Plan for these meetings
- Develop a list
- Most initial appointments are one hour
- Most f/u appointments are 15 minutes
- If you need more time, ask for it but ahead of time
Check list

- Treatment details
- Tests for monitoring
- Medical costs
- Nutrition
- Sex
- Travel
- Is this genetic?
- Complimentary care
- Advanced directives
Last night, my husband and I were sitting in the living room and I said to him, "I never want to live in a vegetative state, dependent on some machine and fluids from a bottle. If that ever happens, just pull the plug."

He got up, unplugged the Computer, and threw out my wine.
Treatment phases

- Initial phase
  - Benefits/risks
- Second line phase
  - Benefits/risks
- Beyond second line
  - Benefits/risks
- Each major treatment decision is a “fork in the road” with a change in the benefits/risk ratio and needs a re-evaluation
White knight syndrome

Make things better
Solve the problem
Be the “good guy”
HOPE versus TRUTH

- Not mutually exclusive
- Patients do better with the truth
- Avoid false hope
Terminal phase

- Am I there yet?
- Palliative care
- Hospice
- Exercise control over this process
CONCLUSION

It ain’t over till it’s over.

Yogi Berra
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