

# *Prognosis: what's it really mean*

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# Outline

1. Define Prognosis
2. Why do we need to know it
3. How good are we at making a prognosis
4. What do patients/families want
5. Prognosis for common 'terminal' diseases
6. Decision-making process
7. Pearls & Summary

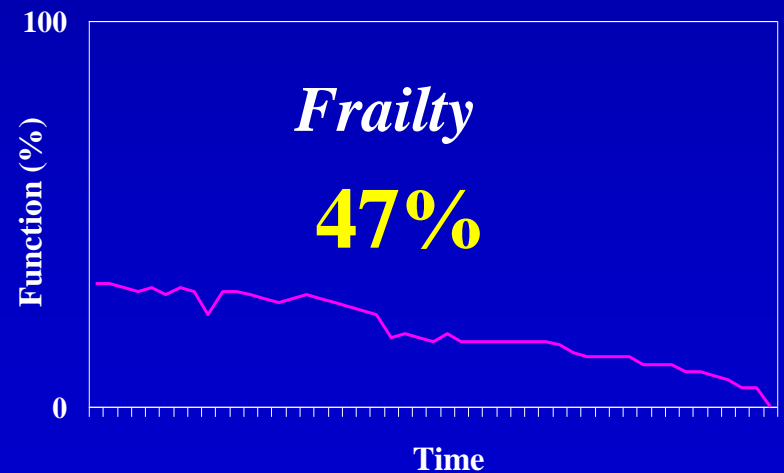
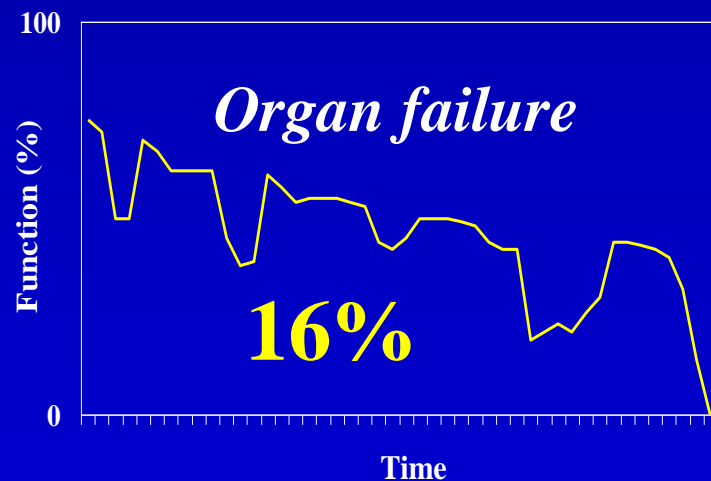
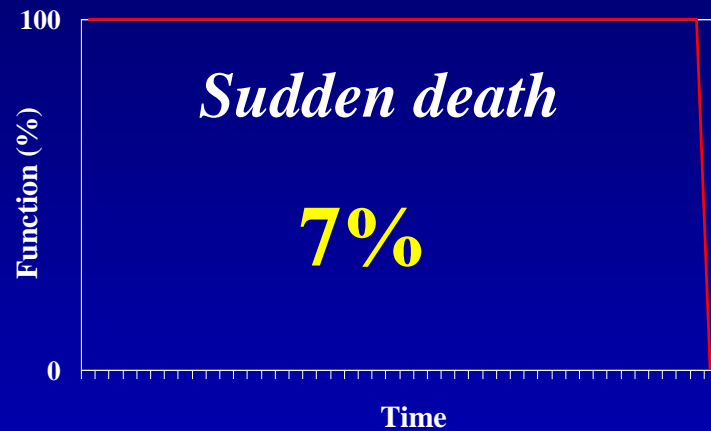
# 1. Definition of Prognosis

- a forecast of the probable course and outcome of a disorder. [*Dorlands*]
- Root word = “fortune telling” or “knowledge of the future” [*nosis*]
- Biblical reference: Psalm 39:4 “Lord, make me to know mine end, and the measure of my days; that I may know how frail I am.”

# Prognosis: When is an illness “terminal” ?

- “Terminal” = incurable + progressive + prognosis <6-12mo
- **Pattern of dying has changed over the years**
  - 1900: 90% died quickly, from infections or accidents
  - 2011: only 10% die quickly; 90% die of “chronic” diseases

# Terminal Trajectories



[Lunney JR, et. al. *J Am Geriatr Soc* 2002;50:1108-12]

# Time of Death/Prognosis Myths

- **Myth #1:** It doesn't matter what we do because people will die 'when God decides'
- **Reality:** Medical technology:
  - has created situations which keep people alive;
  - often causes suffering and prolongs dying;
  - now requires us to make decisions re medical 'interventions':
    - IV's, PEG's, Vents, abx, ICD's,
  - Are families and doctors 'playing God' by interfering?

## ...And

- **Myth #2:** doctors cannot predict death or outcome with any reasonable certainty
- **Reality:** for many patients, an educated estimate can provide helpful guidance...

## 2. Why do we need to know?

- 1) Administrative/insurance reasons
- 2) Medical decision making by physicians
- 3) Patient/family decision making
  - Avoid “abandoning”



# 1) Why: *administrative* reasons

Prognosis determines eligibility for funded services (Medicare's definition of hospice):

“an individual is considered to be terminally ill if the medical prognosis is that the individual's life expectancy is six months or less if the illness runs its normal course.”

## 2) *Why: medical* decision making

Knowing prognosis helps:

- providers determine what treatment options to offer and what advice to give.
- *change focus to ‘whole person’ – not just a diagnosis for one damaged organ*

One of the traditional duties of a doctor

- *diagnosis, etiology, treatment, prognosis*

## ...knowing prognosis may avoid Non-Beneficial or Futile Care

- 90% need some form of terminal care
- Because technology has created situations:  
Providers now face decisions of “how many and what kind of interventions are needed”
- During EOLC, we can be primary cause of suffering or, primary cause of its relief !

### 3) Why: *patient* decision making

Knowing prognosis allows for patient & family to make more informed choices, related to:

- Medical issues [such as side-effects]
- Financial concerns
- Social & cultural situations
- **Personal values**
- End-of-life planning

# Informed Decisions/choices

## Example

- 78 year old woman w/ Alzheimer's
- **Prognosis:** terminal – avg = 4.5yrs
- **Values:** dignity and comfort and knowing family as long as possible
- **Advance Directive:** no *artificial* support
  - Wanted “M&M’s” only
  - Developed pneumonia – no antibiotics !

## Personal Values: avoid futile care & abandonment?

“... they saw finally that in their attempt to help they had not helped but only complicated his disease beyond their power to help. ... Loving him, wanting to help him, they had given him over to “the best of modern medical care”—which meant, as they now saw, that they had abandoned him.”

– Wendell Berry, *Fidelity*, 1992

Choose your values & life !



### 3. How good is prognostication?

- Several prognosis/performance scales
  - Karnofsky score
  - Palliative Performance Scale
  - ECOG [Eastern Cooperative Oncology Group]
  - Disease specific scales
- Physician accuracy & judgment
  - “would you be surprised if this patient were still alive in 6-12 months?”



**PALLIATIVE PERFORMANCE SCALE (PPS)**

%	Ambulation	Activity level Evidence of disease	Self-care	Intake	Level of consciousness	Estimated median survival in days		
						(a)	(b)	(c)
100	Full	Normal <i>No disease</i>	Full	Normal	Full	NA	NA	108
90	Full	Normal <i>Some disease</i>	Full	Normal	Full			
80	Full	Normal with effort <i>Some disease</i>	Full	Normal or reduced	Full			
70	Reduced	Can't do normal job or work <i>Some disease</i>	Full	As above	Full			
60	Reduced	Can't do hobbies or housework <i>Significant disease</i>	Occasional assistance needed	As above	Full or confusion	29	4	41
50	Mainly sit/lie	Can't do any work <i>Extensive disease</i>	Considerable assistance needed	As above	Full or confusion	30	11	
40	Mainly in bed	As above	Mainly assistance	As above	Full or drowsy or confusion	18	8	
30	Bed bound	As above	Total care	Reduced	As above	8	5	
20	Bed bound	As above	As above	Minimal	As above	4	2	6
10	Bed bound	As above	As above	Mouth care only	Drowsy or coma	1	1	
0	Death							

# ECOG Staging (Cancer only)

- Metastatic [i.e. Stage IV] and failed chemoRx
- Eastern Cooperative Oncology Group
  - Stg I - ambulatory, active, mild symptoms
  - Stg II - in bed <50% of day, more symptoms
  - Stg III – in bed >50% of day [= 3-6mo. survival]
  - Stg IV – bedridden, total care [= <3wks avg survival]
- III & IV: usually have symptoms: losing wt, dysphagia, anorexia, dyspnea, dry mouth

# Prognosis Accuracy Poor

- Physicians are poor prognosticators
  - Accurate only 20% of the time
  - 63% overly optimistic

Why?

- fear of withholding hope
- death is the ‘enemy’
- lack of experience = *uncomfortable*

[Christakis. *BMJ* 2000;320][Benkendorf. *Prehosp EmCare* 1997]



*"There's no easy way I can tell you this, so I'm sending you to someone who can."*

## 4. What do people want to know?

- 80% patients want to know [from their doc]
- Many doctors won't give an estimate
- Tend to be overoptimistic [factor of 5]
- Population-based stats often not helpful when determining prognosis for individual

*Christakis NA. Death Foretold: prophecy and prognosis in medical care. 1999. Univ. Chicago Press.*

*Fine JW. The Art of Prognosis. Hospice of Michigan.*

# What do Patients & Families with Serious Illnesses Want [i.e. their goals?]

- Pain and symptom control
- *Avoid prolongation of the dying process*
- Achieve a sense of control, & Hope
- “Beat the prognosis”
- *Included in decisions & to be listened to*
- *Honest information*
  - Everyone wants adverse event info [1/100,000 - Ziegler. Arch Intern Med 2001]

\* Singer et al. JAMA 1999;281(2):163-168.

\* Tolle et al. Oregon report card.1999 [www.ohsu.edu/ethics](http://www.ohsu.edu/ethics)

## 5. Prognosis for common diseases

- General guidelines
- Cancer diagnoses
- Non-cancer diagnoses

# Factors affecting Prognosis:

## Comorbid conditions:

- Age, ADL's, CV disease, DM2, nutrition

Tempo – speed of progression

Agendas – non-acceptance, mistrust, costs

Will to live vs ‘given up’ ?

Family expectations – ‘cure’ vs ‘comfort only’

Intuition



# Cancer Prognosis <6mo if:

- Malignant hypercalcemia [S. Ca<sup>++</sup> >11]
- Extensive liver mets/failure
- Malignant pleural effusion
- Brain mets [usual = <8mo]
  - Rx steroids only = 1-2mo
  - Rx WholeBrain Rtx = 3-6mo
  - Rx Surg + RTx = 10-16mo?

# Three common cancers

## Cancer

- Lung
- 
- 
  
- Breast
- 
- 
  
- Prostate
- 
- 

## 5 year survival

- 1% (distant mets)
- 13% (overall)
- 35% (localized)
  
- 18% (distant)
- 75% (overall)
- 90% (early stage)
  
- 31% (distant)
- 73% (overall)
- 85% (localized stage)

# Examples of “Curable” Advanced Malignancies

<u>Malignancy</u>	<u>5 Year Survival</u>
• Acute myeloid leukemia	23%
• Stage IV Hodgkin's lymphoma	56-89%
• Stage IV aggressive non-Hodgkin's lymphoma	44-87%
• Testicular germ cell tumors	48-91%
• Colon cancer, resectable solitary liver metastasis	25%

# Metastatic Cancer Patient Survival with Treatment

<u>Cancer Type</u>	<u>1 Year</u>	<u>Median* (mo.)</u>
• NSCLC	33-51%	7 – 31
• Breast	~70%	23 – 26
• Prostate (Hormone refractory)	~70%	7 – 40
• Colorectal	36%-40%	18 – 24
• Pancreatic	27%	6 – 12

\*Median survival data from optimal treatment in clinical trials

# Non-Cancer Diagnoses Prognosis

(Covered in “Hospice: facts, myths, eligibility)

## Important factors for <6mo:

- ADL’s – progressive debilitation
  - Assistance for all ADL’s
- Recurring hospitalizations
- Disease-specific considerations
  - Less accurate than with cancers

## 6. How to decide what to do

- General Guidelines – Cancer ChemoRx
- Goal focused care
- How do you want to live until you die?
- Understand true risks and benefits of options
- Be informed

# General Guidelines in Decisions

- Since difficult to apply population-based prognostic statistics to individual, a guideline may help in making decisions
- Example: Cancer chemoRx questions

# General Questions when considering Chemotherapy

- Would a diagnostic procedure help?  
[E.g. a liver biopsy]
  - Can the patient tolerate the procedure?
  - Would the procedure change the treatment?
- Would the chemoRx be palliative only?
- Burden v Benefit assessment – a patient-centered v disease-centered approach [will aggressive tx of disease cause patient suffering?]



# Case example: ChemoRx Questions \*

- 43 yof w/ met. Ca colon to liver, now postop hemicolectomy, w/ ascites
- CT = thrombosis of portal vein; pleural eff.
- Labs = abn.LFT
- Oncologist consulted and recommends chemoRx

*[\* Selvaggi. AAHPM Annual Meeting 2011]*

# ...chemoRx questions

- Is the tumor a chemo-sensitive one?
  - List of cancers sensitive [chemoRx helps]
- What benefit is chemoRx in an untreated patient with metastatic colon ca to liver?
  - [could live 2+yrs; could allow liver resection]
- Will chemoRx help **relieve symptoms** [pain, SOB, n/v] ?
  - [usually – decreases liver size/ascites/effusions]

# Helpful Palliative ChemoRx

- Lung, small cell - Lung, non-small cell
- Esophageal/Gastric - Pancreatic
- Colorectal - Prostate
- Bladder - Ovarian
- Endometrial - Head & Neck
- Biliary tree/GB - Sarcoma

(Palliative ChemoRx Sensitive Tumors w/ 30-50% response)

# Unhelpful Palliative ChemoRx

- Renal Cell
- Carcinoid
- Melanoma
- Hepatocellular

(Tumors Insensitive to ChemoRx)

## ...chemoRx questions

- Will chemoRx improve quality & quantity of life?
  - [probably]
- What are potential side-effects of chemoRx? How long & can they be controlled?
  - [depends on drugs – e.g. stomatitis, n/v, diarrhea, pancytopenia x 2-3wks]

# ...chemoRx questions

- Could the chemoRx shorten her life?
  - [unlikely]
- What is her life expectancy and QOL w/o chemoRx?
  - [median survival 5-6mo; 2+yrs w/ chemoRx]

What if she was 85yr old? ...need to  
individualize goal-focused care

See website article *Treatment Options & Dilemmas: when to say stop?*  
[*Waging Peace in the War on Cancer*]

# Goal Focused Care

If the goal of medicine:

- to prevent and relieve suffering!

Knowing Prognosis can help preserve Hope  
while avoiding Futile Care

# Avoiding Futile Care - cont'd

- Should Never Hear “There’s nothing more we can do” !!!!
- Base choices on Goals
- False hope is worse than ‘no hope’ !
- Never lose HOPE – that at least good will come from decisions; that no one will be abandoned



# How do you want to live & die?

- Cancer pts who discuss EOLC wishes w/ MD have:
  - Less aggressive care/admissions to hospital
  - Improved QOL w/ more peaceful death
    - See article ----- [Zhang]
- Pts who choose hospice live ~29 days longer than those not in hospice [Connor]

# Futility – how do you want to die?





# Decisions Summary: How to Avoid Futile Care & Prevent Suffering

- 1) Clarify status of conditions and prognosis
- 2) Determine goals – longevity v comfort
- 3) **Understand all the options & risks** (read handouts & ask questions - for comfort related information go to [comfortcarechoices.com](http://comfortcarechoices.com)) – **make an informed choice...**

# Decisions: Myth of Informed Consent

What are 'goals'?

- A result or end we want to reach.

Why set goals of the medical care?

- Care goals shape expectations & priorities
- Goals may be dependent on understanding risks & benefits of options and on prognosis
- Goal-Focused care means choose only that care which will help reach a goal !

If patient and provider don't know the goal and prognosis, how can we establish an appropriate plan of care?

# Deciding:

- **Myth:** patients make informed decisions.
- **Ethical Question:** Is the “road to death” undignified and more costly because patients [and their doctors], lacking relevant information (particularly on risks & benefits), make “un-informed” decisions which often result in futile interventions?

# Communicating Risk & Informed Consent

- Some people want “Illusion of Certainty”
  - Don’t want to know!! ??
- Illusion of Certainty: the belief that an event is absolutely certain although may not be ! Examples:
  - Treatments have only benefits but no harm
  - There’s only one best treatment
  - A diagnostic test is absolutely certain

# But, in reality...

- “In this life, nothing is certain but death & taxes”- **Franklin’s Law**
- All real world events are uncertain
- Every healthcare decision is one between two risks, not between a certainty and a risk
  - *All attempts to do good, also generate unwelcome side-effects !!*



# Communicating Risk ...

- “**Risk**” [*the possibility of harm*] is an uncertainty that can be expressed numerically (via probabilities & frequencies)
- **Forms of Risk Communication:**
  - Probabilities [confusing]
    - Single event probability
    - Conditional Probabilities
  - Frequencies [less confusing]

# Communicating Risk ...poorly

“The bad presentation of medical statistics such as the risk associated with a particular intervention can lead to patients making poor decisions on treatment.”

– leads to misinterpretations

\* G.Gigerenzer. Simple tools for understanding risks. BMJ 2003;3:621

whatever  
happened to  
our sexual  
relations?

I don't know.  
I don't even  
think we got  
a Christmas  
card from them  
this year.



# How NOT\* to represent benefits & risks...

- **Relative Risk Reduction (RRR):**  
measure (as a %) of effect of treatment relative to number people improved/saved  
[typical in journal & newspaper articles]
  - RRR amplifies small differences and makes the insignificant appear significant
  - RRR doesn't reflect the baseline risk of outcome events

[\* Henley & Edwards & Paling]

# Communicating & Common Sense:

- Public has right to clear information
- If guidelines being debated, that usually indicates *uncertainty* !! e.g. HR Therapy
- Use ‘natural frequencies’ to explain risks via
  - ARR & NNT
  - Frequency Tree
  - Population Visual aid [Paling Palette]

## ...How to represent benefits & risks

- **Absolute Risk Reduction (ARR):**  
measure of effect of treatment in terms of absolute number people improved/saved
- **Number Needed to Treat (NNT):**  
number of people who need to be treated to improve/save one

Real World Example:  
Benefits & Risks of Treatments to  
Reduce CVA Risk in A.Fib.

How much does warfarin or ASA actually reduce the risk of having a stroke or cause a major bleed from the drug used?

Data followed by different perspectives / representations (which is better?)

# Benefits of Warfarin v. ASA (in A.Fib)

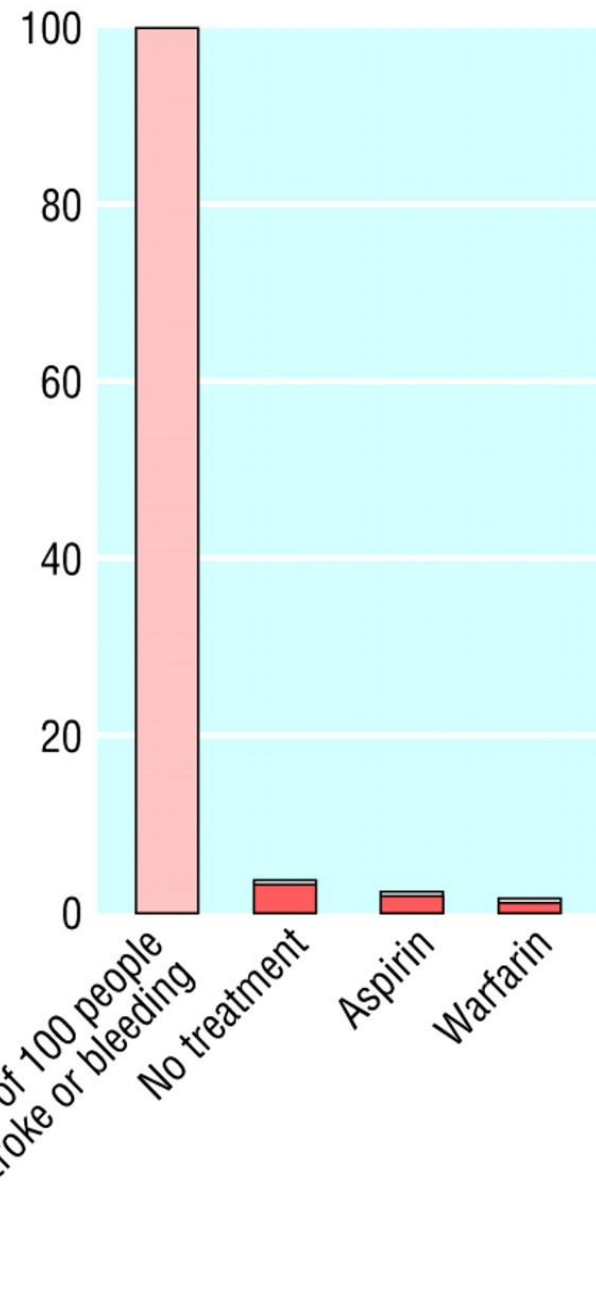
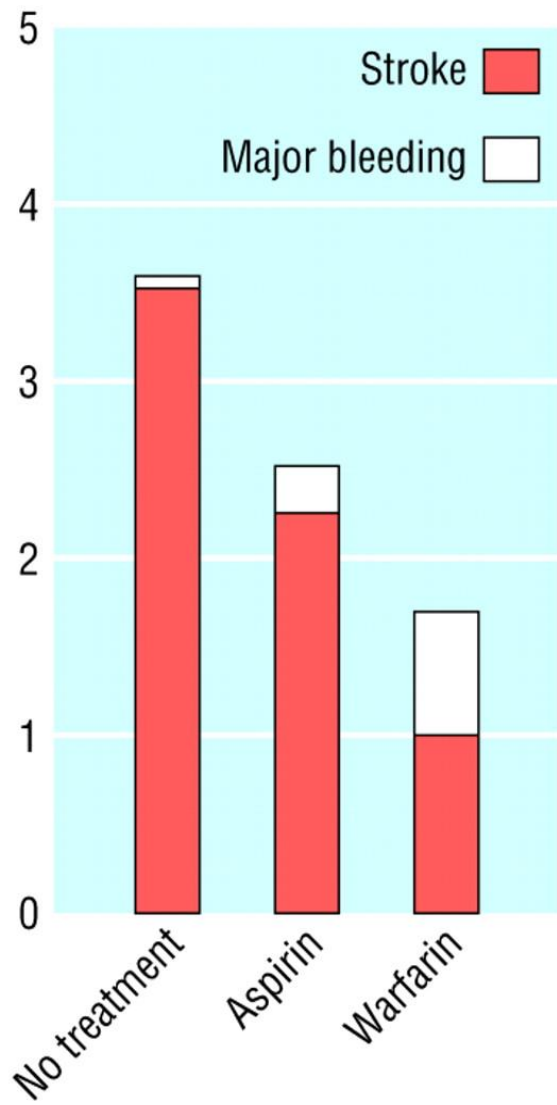
## Treatment

## Risk of CVA

- No treatment: 3.5% (1-18%: CHAD2 risk score 0-6)
- ASA:  
RRR = 37% ( $2.5/3.5 \times 100$ )  
decreases ~1% (ARR)  
NNT = 100 (100/1)
- Warfarin:  
RRR = 71% ( $1.3/3.5 \times 100$ )  
decreases ~2% (ARR)  
NNT = 50 (100/2)  
but, increases Bleeding Risk ~1%



No of people who have stroke or major bleeding  
in every 100 people with atrial fibrillation



# Risk & Benefit *Mis*-Communication

- It's how we present the information !
- “There are three kinds of lies: lies, damn lies, and statistics!”
  - Benjamin Disraeli
- Use visual aids – provide POS & NEG info
  - Paling Palettes – 1000 people
  - Dr. Chris Cates website – Visual Rx

# Be informed - Improve QOL & Dying:

- Internet information – Understand Risk
  - Cardiovascular Risk Calculator – University of Edinburgh – [cvrisk.mvm.ed.ac.uk/calculator](http://cvrisk.mvm.ed.ac.uk/calculator)
  - **Bandolier** - [www.medicine.ox.ac.uk/bandolier/](http://www.medicine.ox.ac.uk/bandolier/)
  - **Visual Rx** - [www.nntonline.net/](http://www.nntonline.net/)
- Advance Directives & Discussions
  - **OneSlideProject** – [engagewithgrace.org](http://engagewithgrace.org)
  - **Five Wishes** – [agingwithdignity.org](http://agingwithdignity.org)

# ...Avoid Futile Care: Be informed

- Other information
  - Risk Charts for Men/Women – J Nat’l Ca Inst
  - [Comfortcarechoices.com](http://Comfortcarechoices.com) – R. Webb’s website w/ info about EOLC and palliative care choices
    - These slides are on website
  - Gerd Gigerenzer. *Calculated Risks*. 2002

## 7. Summary & Pearls

- Prognosis is ‘medical meteorology’
  - ‘Fortune telling’ often inaccurate
- Knowing prognosis helps make more informed decisions and avoid futile care/suffering
- Medical technology forcing EOLC choices
- Most important factor in prognosis is ADL function – rate of decline

# Summary & Pearls...

- Make decisions based on goals and good information, not myths !
- Be assertive - it's YOUR life.
- Understand relevant risks & benefits for each treatment option
  - Ask relevant questions of doctor
  - Use ARR & NNT to evaluate risks

## ...Summary & Pearls

- “Can you live w/ your decision?” - Be comfortable with it.
- As a family member: Is your decision based on what’s best for the patient – or is ‘selfishness’ possible when having trouble ‘letting go’?

# Finally, learn from the mistakes of others

Will Rogers said...

- There are 3 kinds of men. The ones who learn by reading. The few who learn by observation. The rest of them have to pee on the electric fence for themselves.
- Never kick a cow chip on a hot day.



Thank You !

*As you slide down the banister of life,  
may all the splinters point down!*

*- Maxine*

**Enjoy yourself while you can !**