Lessons Learned from Brushes with ~~Death~~ Serious Illness – mine and others

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Objectives & Disclosures

- Objective: make the illness experience easier for all concerned

- Disclosures:
  - Editor, Up to Date (<$5000/year)
  - ABIM, test writer for Hospice & Palliative Medicine
  - Member, ASCO Guideline Committee, *Initial Management of Androgen-Sensitive Prostate Cancer (since 2000); Cachexia; Palliative Care, co-chair; Neuropathic pain; Value; co-chair, CSF guidelines; Lung cancer; Choosing Wisely*
  - Johns Hopkins received gifts of 2 Scrambler Therapy machines, value $120,000 for research

- Research Funding: PCORI, NIH, NINR, Lerner Foundation

My situation

1. Medical oncologist since 1987
2. Doggedly attuned to finding and fixing symptoms
3. Concurrent palliative care since early 1990's
4. Known for being a "truth teller" – being open and honest to those who wanted a forecast of the future

Communication is key

1. How do you like to get medical information?
2. What is your understanding of your situation?
3. What is important to you?
4. What are you hoping for?
5. Have you thought about a time when you could be sicker…Living Will or advance directive?

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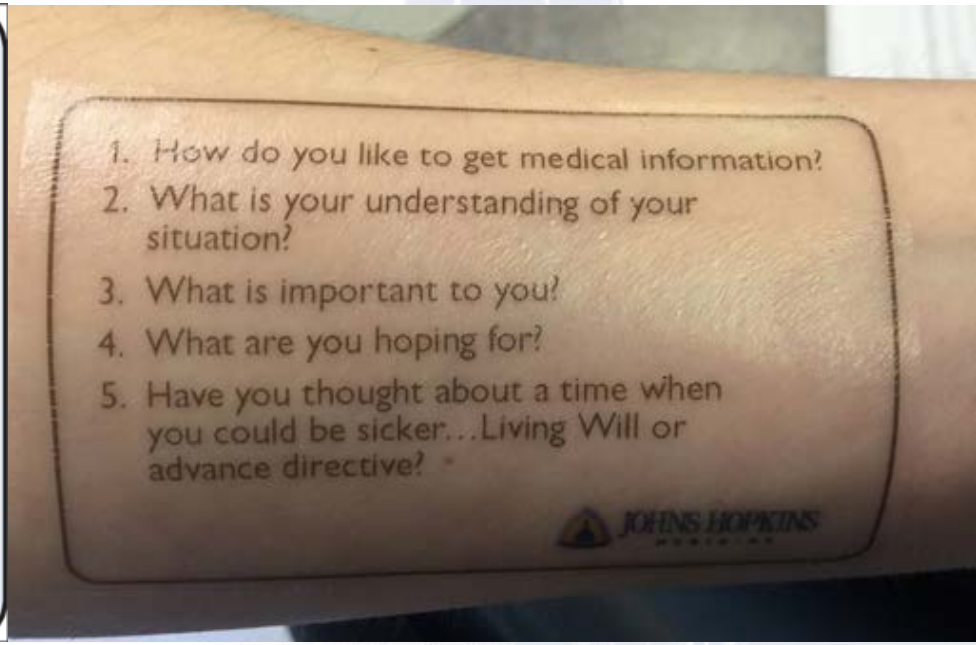

Inspired by Morris DA, Johnson KS, Ammarell N, Arnold RM, Tulsky JA, Steinhauser KE. What is your understanding of your illness? A communication tool to explore patients' perspectives of living with advanced illness. J Gen Intern Med. 2012 Nov;27(11):1460-6. doi: 10.1007/s11606-012-2109-2. Epub 2012 May 26.

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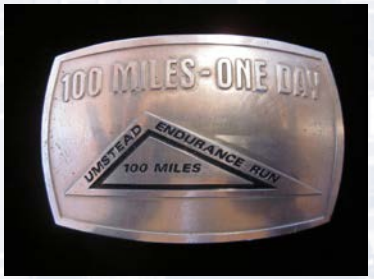
My situation

1. Serious depression requiring hospitalization in 1983 – then not again till 2018 when I was treated with anti-androgen therapy and testosterone hit zero
2. Bicuspid aortic valve discovered serendipitously after Umstead 100 mile Endurance Run (Stable)
3. Prostate cancer
   - Prostatectomy April 2016
   - Recurrence by PSA September 2017
   - Treatment with anti-androgen therapy and “salvage” radiation October 2017 – February 2018



My situation

Side effects

- Muscle weakness almost immediately
- Incessant hot flashes and insomnia in 2 weeks
- Transient Ischemic Attack (TIA) March 2018
- Pneumonitis – lung inflammation due to bicalutamide (Casodex™) – dropped my lung function to 65%, March 2018 to present – could not run
- Severe suicidal depression June 2018 requiring admission

4. Recurrence, with rising PSA September 2019, which at some point will worsen and likely take my life (or, my heart or depression or lungs….)

5. Waiting for the other shoe(s) to drop.

Oxybutynin (Ditropan®) for hot flashes

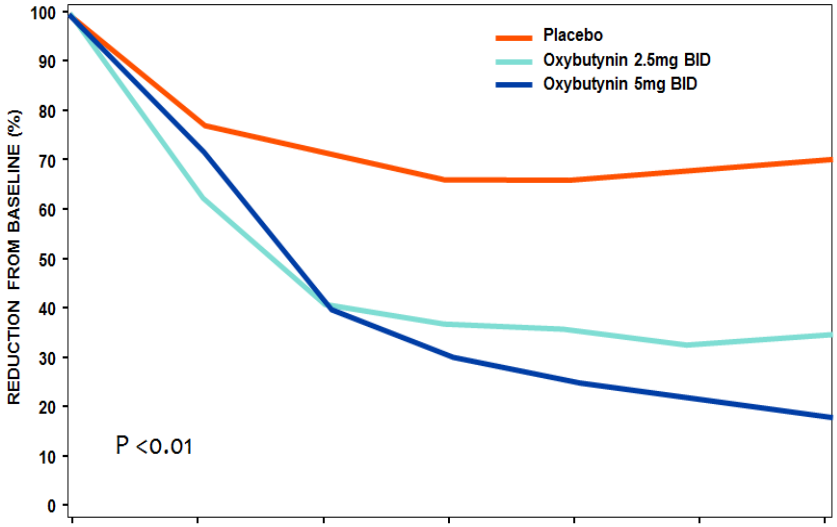
Nothing worked for me until

Oxybutynin for Hot Flashes Due to Androgen Deprivat in Men

TO THE EDITOR: Nonhormonal treatments used for menopausal hot flashes in women have generally been found to have limited efficacy against hot flashes induced by androgen deprivation for the treatment of prostate cancer in men. Gabapentin and venlafaxine have been found to have limited efficacy.[1] Megestrol acetate, although modestly effective,[2] can have hormonal side effects; it has also been associated with in levels of prostate-specific antigen (withdrawal that suggest stimulation growth by the drug[3] and, when the dr to treat cachexia, it has been associ rapid growth of metastatic prostat Oxybutynin is effective for refractory h in women; in one randomized tria

N ENGL J MED 378;18 NEJM.ORG MAY 3, 2018

Smith TJ, Loprinzi CL. NEJM 2018



WEEKS	Baseline	1	2	3	4	5	6
Placebo	38	38	38	37	35	35	35
Oxybutynin 2.5 mg BID	40	40	38	36	35	35	34
Oxybutynin 5mg BID	35	35	34	32	32	31	31

Leon Ferre, R, et al. JNCI Cancer Spectrum 2019

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Take Home Messages: Patients and families

1. Partner with a health care professional who will listen to you and work with you over time.
2. Figure out a communication strategy. If you need more time, request it in advance.
3. If you want numbers, like “best case, usual, worst case” – ask for them.
4. Get the best care you can. Clinical trials.
5. Watch for depression and/or demoralization.
6. Do mindfulness or meditation. Or yoga.
7. Exercise!

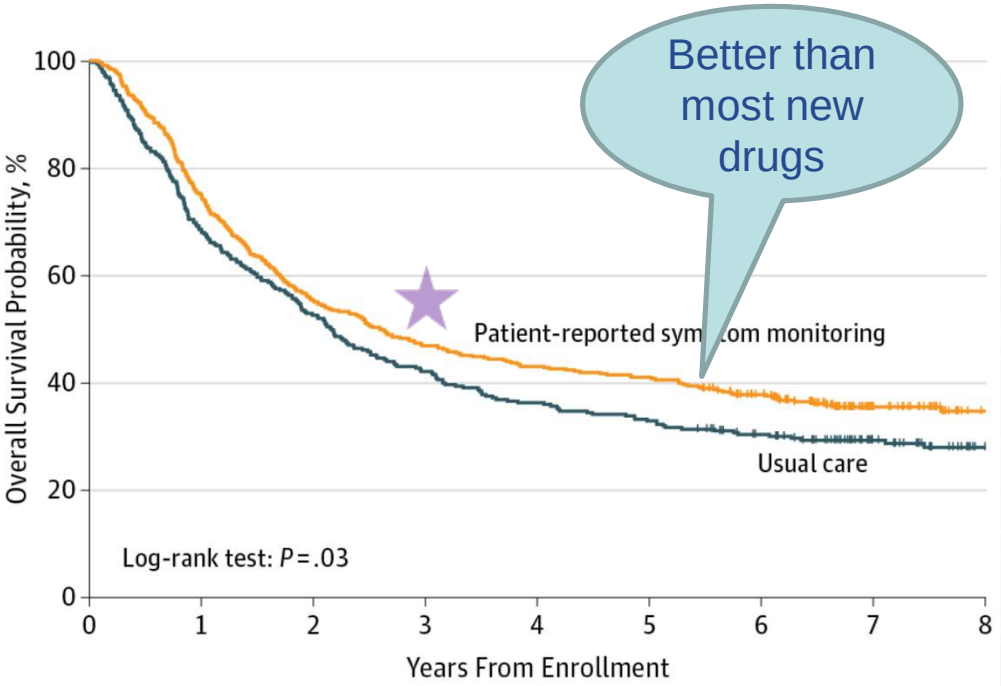
Take Home Messages: Health Care Providers

1. Get palliative care involved early and often. Improves symptoms, care and caring.
2. Don't be afraid to bring things up. There is *NOTHING* you can broach we have not lain awake at night thinking about.
3. You cannot take away hope.
4. At each visit, ask: "How are you coping?" And ask the family, "How are ***you*** coping?"
5. Do mindfulness or meditation. Or yoga.
6. Exercise!

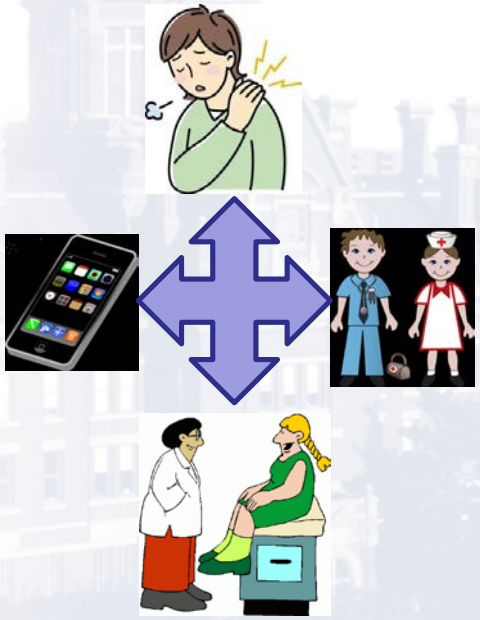
Pain and symptoms are really important!
HCPS – ASK! Patients/families – REPORT!

Overall Survival Among Patients With Metastatic Cancer Assigned to Electronic Patient-Reported Symptom Monitoring During Routine Chemotherapy vs Usual Care.

Reporting symptoms weekly, and acting on them, improved survival by 6 month average, or 6 out of 100 people.



No. at risk									
Patient-reported symptom monitoring	441	331	244	207	190	181	148	65	33
Usual care	325	223	171	137	118	107	89	50	27



JAMA. 2017;318(2):197-198. doi:10.1001/jama.2017.7156

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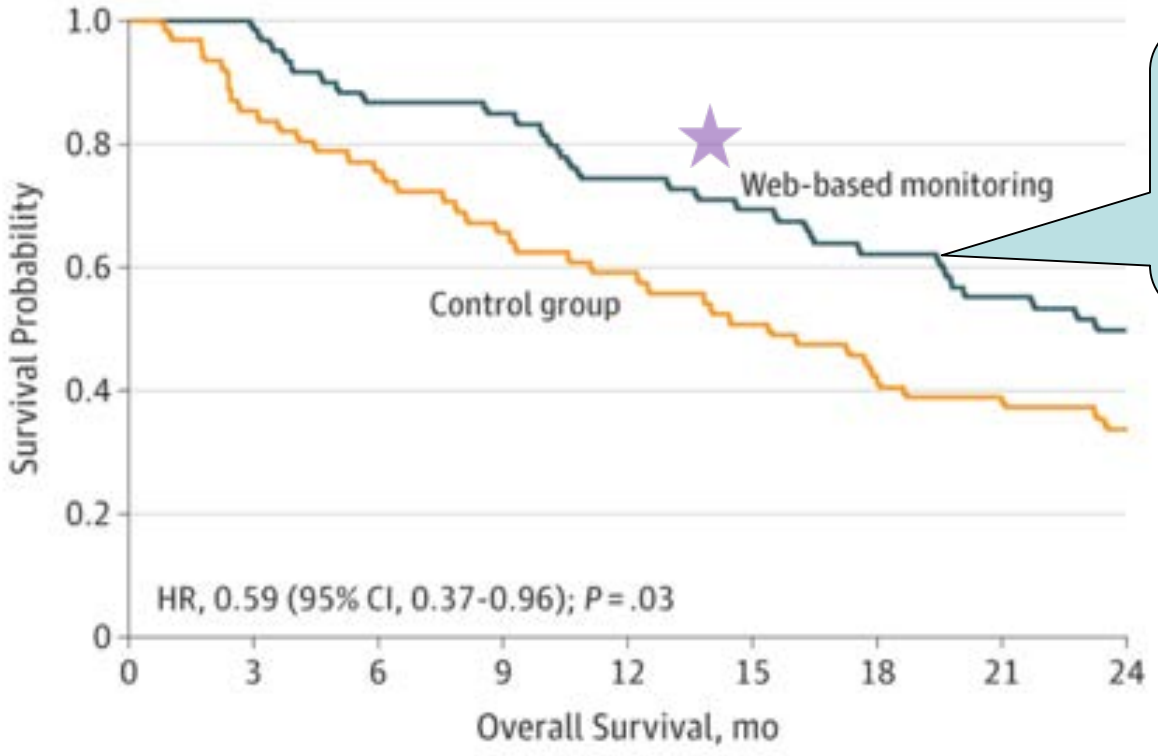
Reporting and acting upon symptoms leads to *better survival*

From: **Two-Year Survival Comparing Web-Based Symptom Monitoring vs Routine Surveillance Following Treatment for Lung Cancer**



Ask about symptoms and encourage people to report – it could save a life

JAMA. 2019;321(3):306-307. doi:10.1001/jama.2018.18085

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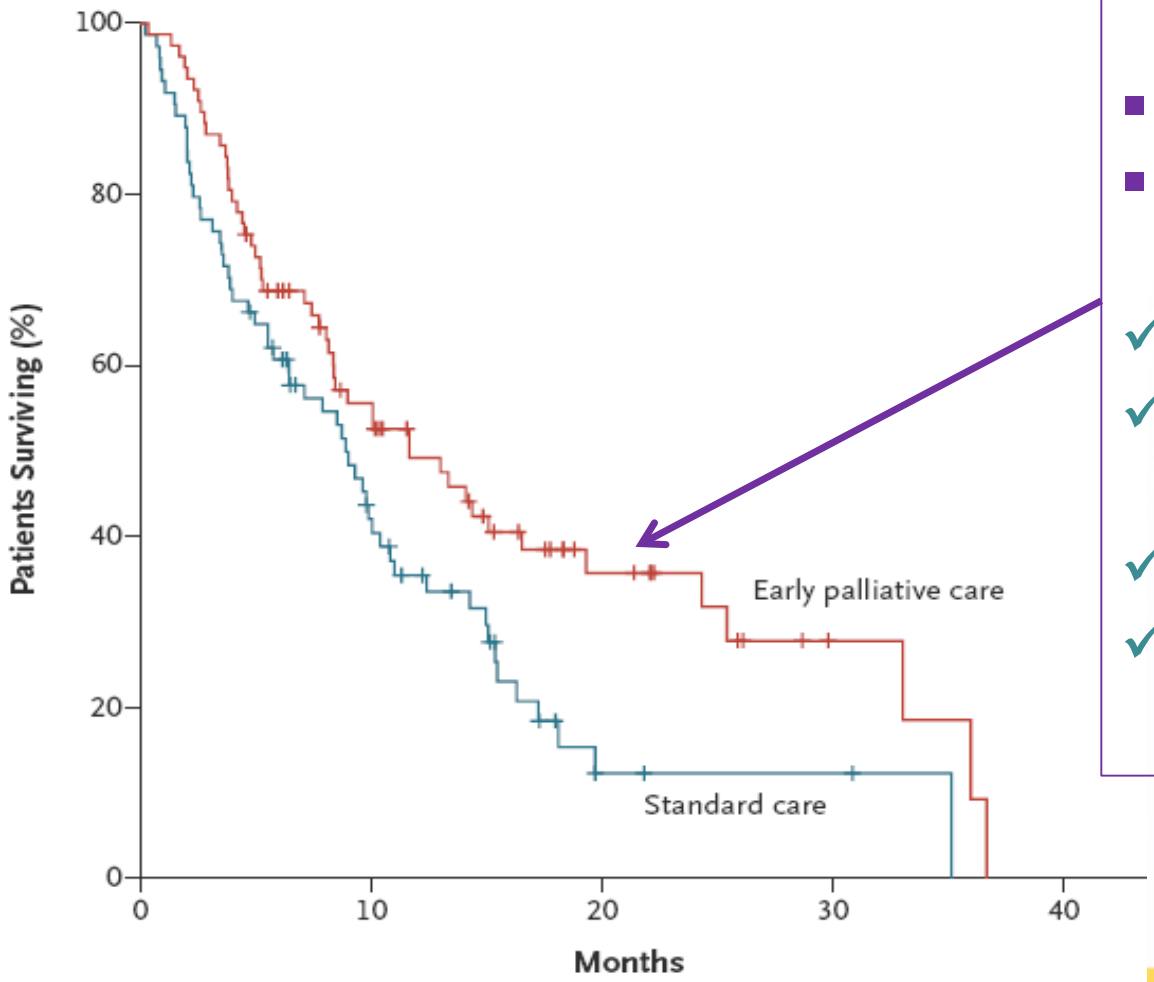
Lung cancer patients lived almost 3 months longer if they got concurrent palliative care in addition to usual oncology care

Temel J, et al. NEJM 2010; Temel J, et al, JCO 2011



- 20 minutes on symptoms
- 15 minutes on coping
- 10 minutes on illness understanding

✓ Better QOL

✓ Better understanding of prognosis

✓ Less depression, anxiety

✓ 2.7 months longer survival

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Take Home Messages that I have learned from my brushes with death

- The diagnosis of ANY SERIOUS ILLNESS is an existential slap, to quote Nessa Coyle. Your patient may not be able to focus on much. For a while. Even medical people. Write the important parts down.
- Some recognition that this can be upsetting is really welcomed. “Your world has really been turned upside down with the cancer. And now this _____.”
- Ask: “Would you like to discuss what this means, in terms of prognosis? I am worried about you, and what this means….”
- **Ask: “How are you coping?”**
- **Ask the family: “How are you coping?”**

Thank you

- **My health care providers.**
- **My colleagues and friends, especially the late Terry Langbaum.**
- **My family.**

- Joann N. Bodurtha MD MPH, geneticist and pediatrician
- Anna Jo Bodurtha Smith MD MPH MSc, GYN ONC Fellow, UPenn
- Daisy, RIP

Ref: Langbaum T, **Smith TJ**. Time to Study Metastatic-Cancer Survivorship. N Engl J Med. 2019 Apr 4;380(14):1300-1302. doi: 10.1056/NEJMp1901103.