I’m gonna live, live, live, live, live till I die

“e-Patient Dave” deBronkart
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LinkedIn.com/in/ePatientDave
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How I came to be here

- High tech marketing
- Data geek; tech trends; automation
- 2007: Cancer discovery & recovery

- 2008: E-Patient blogger
- 2009: Participatory Medicine, Public Speaker
- 2010: full time
- 2011: international
“It can be argued that the largest yet most neglected health care resource, worldwide, is the patient...”
Richard Alpert  Ram Dass

Tapes – 1980s
• Conscious Aging
• Approaching Death
From Ram Dass I heard:

“As I am now, so you will be
Prepare yourself to follow me”

“Being born
is like setting sail on a ship
whose purpose
is to go out in the ocean and sink.”
“Health Online” – in 1996!
“You are already your own doctor.”
Tom Ferguson, M.D., 1985

Our interactions with the healthcare system are only the tip of the iceberg.

Self-care is and has always been our predominant form of health care.

Doc Tom said, “e-Patients are equipped, engaged, empowered, enabled.”
Physicians suggest. Patients ignore. Technology alone won't bring them together. But a new relationship just might.
Me? An indicator of the future??

• Who’s getting online:
  – 1989: Me (CompuServe sysop)
  – 2009: 76% of US adults online

• Who’s romancing online:
  – 1999: I met my wife (Match.com)
  – 2009: One in eight weddings in the U.S. met online
  – 2011: One in five couples met online
Shifting Paradigm?

- Information asymmetry
  - Physician as oracle
  - Comfortable
  - A burden?

- Information symmetry
  - Physician as partner
  - Threatening vs. liberating
  - Physician as healer
The Engaged Patient, 2006

12 items in my pre-appointment “agenda” email

Ophthalmic migraine?

- Shape of the disturbance is exactly as shown at right (from http://www.richmondeye.com:simulation.asp=migraine).
- But the interior is dazzling, not the pattern shown here.
- Behavior is as described at that site and others (see log below).
- The shape may point left or right.

<table>
<thead>
<tr>
<th>#</th>
<th>Date</th>
<th>start (approx)</th>
<th>gone by</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>30-Oct</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>4-Nov</td>
<td>8:58</td>
<td>9:22</td>
<td>Wife’s birthday</td>
</tr>
<tr>
<td>3</td>
<td>21-Nov</td>
<td>12:35</td>
<td>12:50+</td>
<td>Long gone by 1:30. Different shape this time - almost a mirror of the other, right of center, below center. Note - Thanksgiving was 11/23. The usual Nike-like chevron. Note: with both eyes closed it's like yellow &amp; black stripes.</td>
</tr>
<tr>
<td>4</td>
<td>25-Nov</td>
<td>19:40</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>6-Dec</td>
<td>12:05</td>
<td>before 12:50</td>
<td>Start: non-specific sense of dazzle;</td>
</tr>
</tbody>
</table>

Shoulder

- Range of motion complaint: “right shoulder is having range of motion trouble. No discomfort, but it just doesn't seem to work right: I find myself lifting my shoulder instead of the arm.”
- Made a Jan 2 appointment w/ Dr Zilberfarb
The Incidental Finding

Routine shoulder x-ray, Jan. 2, 2007

"Your shoulder will be fine ... but there’s something in your lung"
Multiple tumors in both lungs
E-Patient Activity 1: Researching my condition

Renal Cell Cancer Treatment (PDQ®)

Stage IV and Recurrent Renal Cell Cancer

Stage IV renal cell cancer is defined by the following stage groupings:
- T4, N0, M0
- T4, N1, M0
- Any T, N2, M0
- Any T, any N, M1

The prognosis for any treated renal cell cancer patient with progressing, recurring, or relapsing disease is poor, regardless of cell type or stage. Almost all patients with stage IV renal cell cancer are incurable.
Classic Stage IV, Grade 4 Renal Cell Carcinoma

Illustration on the drug company's web site

Median Survival: 24 weeks
Facing the Reaper
My mother
My daughter
After the shock you’re left with the question:
What are my options?
What can I do?
Get engaged.
Get it in gear.
Do everything you can.
Reality is what it is

Whether we know it or not

And regardless of what we think
The basic theme of this book is that every person must accept a certain measure of responsibility for his or her own recovery from disease or disability.
Laugh
Sing
Eat Like a Pig

“LAUGH, SING, AND EAT LIKE A PIG
Prescription
Customer
take daily as needed
Unlimited refills
Dr. Sands, McDermott, Wagner, Anderson

How an empowered patient beat Stage IV cancer (and what healthcare can learn from it)
Introductory essays by Dr. Danny Sands, Paul F. Levy, and Matthew Holt

“In my list of greatest personal reads”
— James B. Conway, Institute for Healthcare Improvement

“A recognized online champion of participatory medicine” — Boston Globe

deBronkart
"e-Patient Dave"
E-Patient Activity 2: “My doctor prescribed ACOR” (Now mostly moved to SmartPatients.com)
My patient peers told me:

• “Welcome to the club…”

• “If you don’t want to die of kidney cancer…”

• “This is an uncommon disease – get to a hospital that does a lot of cases”
My patient peers told me:

• There’s no cure, but HDIL-2 sometimes works.
  – When it does, about half the time it’s permanent
  – The side effects are severe.

• Don’t let them give you anything else first

• Here are four doctors in your area who do it
  – And one of them was at my hospital
You have no idea what you’re capable of.
Surgery & Interleukin worked.

Target Lesion 1 – Left Upper Lobe

Baseline: 39x43 mm

50 weeks: 20x12 mm
How the e-patient community helped save my life: an essay by Dave deBronkart

BMJ 2013; 346 doi: http://dx.doi.org/10.1136/bmj.f1990 (Published 2 April 2013)
Cite this as: BMJ 2013;346:f1990

Dave deBronkart, policy adviser on patient engagement
ACOR’s practical information may have saved my life

As a responsible engaged patient, knowing that IL-2’s side effects might kill me, I sought to prepare myself. First I sought authoritative sources; there I found dry facts: “Side effects are often severe and rarely fatal, and include . . .” I thought, “What am I supposed to do with that?” and turned to my peers on ACOR. I asked, “You who’ve done this—what was it like? What do I need to know?” From them I received 17 firsthand stories—a wide range of experiences. I felt prepared—and today Dr McDermott says, “You were really sick. I don’t know if you could have tolerated enough medicine if you hadn’t been so well prepared.” In this case valuable—as in potentially lifesaving—information came from outside the establishment.
Concurrent macro trends

• The evolution of certainty (and authority)
  – A telling sign: “data parasites”

• Trend 2: March of culture change:
  – 2012: Institute of Medicine, NLM
  – 2014: BMJ
  – 2015: Mayo

• Trend 3: Beehive etc

• Trend 4: Escape velocity
Bottom line:

An unprecedented population that needs and deserves to know about the palliative option in addition to the “curative track.”
Outreach:

Culturally it starts with listening to the ultimate stakeholder.

“I don’t know what I said until I know what you heard”
The evolution of scientific certainty and thus authority
Clinical trials - where to get involved?

Clinical question/problem → current patient involvement

Clinical trial design

Patient recruitment
  e.g. providing information on clinical trials, advertising trials

Impact on patients
  doing the right thing

Trial management,
  e.g. consent, patient information leaflets, trial adherence

doing things right
Scientists regularly sign up patients in clinical trials to test new treatments. Now, they are seeking patients to help them design some of those trials.

Patients and researchers can bring different perspectives to treating disease. In a trial of a potential prostate-cancer drug getting underway at the Icahn School of Medicine at Mount Sinai in New York, doctors had planned to ask patients periodically about side effects such as nausea. But patient input convinced them to ask additional questions, including how many days patients felt well enough to go to work.

Patients have also helped design a trial at the University of Wisconsin, where researchers are testing a new strategy to help children with diabetes monitor their disease, and another trial comparing epilepsy drugs in children at Emory University School of Medicine.
Adoption of new practices years after discovery
The “17 years” thing

From A. Balas, Institute of Medicine, in Yearbook of Medical Informatics 2000

<table>
<thead>
<tr>
<th>Clinical Procedure</th>
<th>Landmark Trial</th>
<th>Current Rate of Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fecal occult blood test</td>
<td>1986 [16]</td>
<td>17% [17]</td>
</tr>
<tr>
<td>Diabetic foot care</td>
<td>1993 [18]</td>
<td>20% [19]</td>
</tr>
</tbody>
</table>

Flu vaccine, year 32: 55% doing it, 45% still not

Beta blockers, year 18: 62% doing it, 38% still not

Cholesterol, year 16: 65% doing it, 35% still not

Diabetic foot care, year 7: 20% doing it, 80% still not

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Scurvy

264 years!
IN PRIMARY school Babbage learned that there were nine planets in the solar system. None were known to exist outside it. Since then, astronomers have spotted over 800 planets around other stars (and thousands more "candidates") and demoted Pluto to a mere "dwarf planet". Even a cursory glance at other fields reveals similar patterns.

Samuel Arbesman, a mathematician at Harvard, calls this "The Half-life of Facts", the title of his new book. In it he explains that this chum of knowledge is like radioactive decay: you cannot predict which individual fact is going to succumb to it, but you can know how long it takes for half the facts in a discipline to become obsolete. Such quantitative analysis of science has become known as...
After 30 years of practicing peer review and 15 years of studying it experimentally, I’m unconvinced of its value.

Evidence on the upside of peer review is sparse, whereas evidence on the downside is abundant.

Most of what appears in peer reviewed journals is scientifically weak.

Richard Smith, 25 year editor of the British Medical Journal, 2009
“It is simply no longer possible to believe much of the clinical research that is published, or to rely on the judgment of trusted physicians or authoritative medical guidelines. I take no pleasure in this conclusion, which I reached slowly and reluctantly over my two decades as an editor of the New England Journal of Medicine.”
...much of the scientific literature, perhaps half, may simply be untrue. The apparent endemicity of bad research behavior is alarming. Afflicted by studies with small sample sizes, tiny effects, invalid exploratory analyses, and flagrant conflicts of interest, together with an obsession for pursuing fashionable trends of dubious importance, science has taken a turn towards darkness. As one participant put it, “poor methods get results.”
The segment is about a report released Tuesday by the National Academies of Science on errors in diagnosis. NBC Nightly News anchor Lester Holt calls it “a staggering new report about a dangerous blind spot in our healthcare system”: wrong diagnoses. The report says

- 1 out of 10 patient deaths are affected by a missed diagnosis. (If the diagnosis is wrong, how can the treatment possibly be right??)

- Every year about 5% of patients get misdiagnosed

Think about that next time you see a waiting room full of 20 patients.

The segment says the report has these recommendations:

- Changing the pay structure for doctors, to emphasize the time spent with the patient
Predictably, the empire starts to strike back. It can look ludicrous.
Please Do Not Confuse Your Google Search With My Medical Degree &
Belgian Government on healthinfo: "don't Google it!"
Belgian Government on healthinfo: "don't Google it!"
Post on LinkedIn:
dave.pt/belgiangoogle2

The ad videos:
dave.pt/belgiangoogle3
dave.pt/belgiangoogle4

Belgian Government on healthinfo: "don't Google it!"
Meanwhile, evidence grows that the current paradigm is collapsing.
Doctors Apologize For Telling 19-Year-Old Cancer Patient To ‘Stop Googling’ Symptoms,
Doctors Apologize For Telling 19-Year-Old Cancer Patient To ‘Stop Googling’ Symptoms, Admit Fault In Her Death

Jun 18, 2015 07:02 PM  By Ed Cara
The coming BOOM in “market” for palliative care
I’m 65! That’s *really* old (you’ll be amused) – and I love it.

By e-Patient Dave

Some people moan about adding years. I love ’em. Today I’m 65, and I want lots more! I wanna get old!

We the old and many are coming for you!

Did you know more than half the humans who’ve ever been 65 are alive today? That’s partly because medicine keeps saving people like me, who tried to die in middle age. Thanks, medicine; now get ready for lots of us getting older, happily, with chronic conditions. (I myself have slightly elevated blood pressure, and I’m just emerging from “obese.”)

Like my classmate Jay Pollack, who posted on Facebook that he’s getting a pacemaker because medicine saved him twice in ten years.

Have you thought about my question last September about *taking care of all the old people?* Or how about Pew Research’s new book Next America, which *depicts among other things* how America’s classic “age pyramid” is becoming rectangular? Each band in the graphic is a five year age group. We used to have very few 80+, and now it’s commonplace: *(Graphic modified 10pm ET)*
Half of everyone who’s ever been 65 is alive today

Population today: ~7.0 billion
End of World War II: ~2.3 billion

By Jon C. White, MD

I read a statistic the other day that I thought must surely be a misprint. It claimed that two-thirds (approximately 65%) of all people who have ever lived to the age of 65 are alive today. I did some research with the intent of exposing the obvious exaggeration, but instead came up with more disturbing statistics: The number of people who have ever lived on the earth since man first appeared 50,000 years ago can be estimated by mathematical modeling; the total is thought to be 106 billion.

Currently, there are 7 billion people living or about 7% of all who have ever drawn a breath. These extraordinary numbers are a consequence of the exponential nature of population growth. I also confirmed that an estimated 50% to 70% of people who have lived to age 65 are indeed alive today! The fact that 65% of the planet’s 65-year-olds are living now suggests that there is more than just the growth of the population at work. There is also a dramatic increase in life expectancy. In short, population growth is in a very sharp incline and these multitudes are living far beyond what they did
My classmate Jay
The demographic imperative
The demographic imperative
The demographic imperative
WHO IS OLDER AND YOUNGER GIVEN YOUR AGE

dave.pt/olderyounger
“Longevity escape velocity”
(Wikipedia)
“Longevity escape velocity”
(Wikipedia)
“Longevity escape velocity”
(Wikipedia)
“Longevity escape velocity” (Wikipedia)
“But culture change is HAAAAARRRD”
MARRIED?—No reason to neglect stockings!

Husbands admire wives who keep their stockings perfect

Lovely stockings add so much to your appearance. Don’t risk constant runs, snaky seams and wrinkles.

SAVE ELASTICITY—Cut down on runs and wrinkles with Lux! Write to Lever Brothers Co., Dept. 16, Cambridge, Mass., for a free box of Lux. (Offer good in U.S. and Canada only.) Lux saves the elasticity that makes stockings fit and wear. Cake-soap rubbing and soaps with harmful alkali weaken elasticity!

for stockings—LUX

CONSTANT RUNS are unsightly and expensive—cut them down with LUX
show her it's a man's world

Van Heusen
man's world
It's nice to have a girl around the house.

Though she was a big baby, our house didn't have to hire a dog to keep her off. After one pair of her Mrg. Leggs pants, she was ready to have him walk all over her. That made staying home and off the savagery from the savage beast! If you'd like your own feet to feel warm, buy a pair of these handsome Mr. Leggs pants. Such up our new automatic-enhanced fleece of 60% "Dacron" and 30% nylon — incomparably wrinkle-resistant, about $25.00 at most department stores.

Dacron in the air!

The comfort of Leggs.
Vote **NO** on Woman Suffrage

**BECAUSE 90%** of the women either do not want it, or do not care.

**BECAUSE 80%** of the women eligible to vote are married and can only double or annul their husbands’ votes.

**BECAUSE** it is unwise to risk the good we already have for the evil which may occur.

Votes of Women can accomplish no more than votes of Men. Why waste time, energy and money, without result?
Women are soft and gentle, but they hit things.

If your wife hits something in a Volkswagen, it doesn't hurt you very much.

The parts are easy to replace. And cheap. A fender comes off without dismantling half the car. A new one goes on with just ten bolts. For $198.40, plus labor.
2.8 e-Patient Years in Pictures
"I'm gonna live 'til I die" barbershop
I’m gonna live, live, live, live, live till I die

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