Who By Very Slow Decay

Posted on July 17, 2013 by Scott Alexander

Trigger warning: *Death, pain, suffering, sadness.*

I

Some people, having completed the traditional forms of empty speculation – "What do you want to be when you grow up?", "If you could bang any celebrity who would it be?" – turn to "What will you say as your last words?"

Sounds like a valid question. You can go out with a wisecrack, like Oscar Wilde ("Either this wallpaper goes or I do"). Or with piety and humility, like Jesus ("Into thy hands, o Father, I commend my spirit.") Or burning with defiance, like Karl Marx ("Last words are for fools who haven't said enough.")

Well, this is an atheist/skeptic blog, so let me do my job of puncturing all your pleasant dreams. You'll probably never become an astronaut. You're not going to bang Emma Watson. And your last words will probably be something like "mmmrrrgggg graaaaaaaaaaaHAAACK!"

I guess I always pictured dying as – unless you got hit by a truck or something – a bittersweet and strangely beautiful process. You'd grow older and weaker and gradually get some disease and feel your time was upon you. You'd be in a nice big bed at home with all your friends and family gathered around. You'd gradually feel the darkness closing in. You'd tell them all how much you loved them, there would be tears, you would say something witty or pious or defiant, and then you would close your eyes and drift away into a dreamless sleep.

And I think this happens sometimes. For all I know, maybe it happens quite a lot. If it does, I never see these people. They very wisely stay far away from hospitals and the medical system in general. I see the other kind of people.

If you are like the patients I see dying, then here is how you will go.

You will grow old. When you were young, you would go to institutions and gradually gather letters after your name: BA, MD, PhD. Now that you are old, you do the same thing, but they are different institutions and different letters. Your doctors will introduce you to their colleagues as "Mary Smith, COPD, PVD, ESRD, IDDM". With each set of letters comes another decrease in quality of life.

At first these sacrifices will be minor. The COPD means you have to breathe from an oxygen tank you carry around wherever you go. The PVD will prevent you from walking more than a few feet at a time. The ESRD will require three hours dialysis in a hospital or

outpatient dialysis center three times a week. The IDDM will require insulin shots after every meal. Not fun, but hardly inconsistent with a life worth living.

Eventually these will add up beyond your ability to manage them on your own, and you will be sent off to a nursing home. This will seem like a reasonable enough idea, and sometimes it goes well. Other times it gives you freedom to develop a completely new set of morbidities totally unconstrained by what a person in any other situation could possibly be expected to survive.

You will become bedridden, unable to walk or even to turn yourself over. You will become completely dependent on nurse assistants to intermittently shift your position to avoid pressure ulcers. When they inevitably slip up, your skin develops huge incurable sores that can sometimes erode all the way to the bone, and which are perpetually infected with foul-smelling bacteria. Your limbs will become practically vestigial organs, like the appendix, and when your vascular disease gets too bad, one or more will be amputated, sacrifices to save the host. Urinary and fecal continence disappear somewhere in the process, so you're either connected to catheters or else spend a while every day lying in a puddle of your own wastes until the nurses can help you out. The digestive system isn't too happy either by this point, so you can either have a tube plugged directly into your stomach or just skip the middleman and have an IV line feeding nutrients into your bloodstream.

Somewhere in the process your mind very quietly and without fanfare gives up the ghost. It starts with forgetting a couple of little

things, and progresses until you have no idea what's going on ever. In medical jargon, healthy people are "alert and oriented x 3", which means oriented to person (you know your name), oriented to time (you know what day/month/year it is), and oriented to place (you know you're in a hospital). My patients who have the sorts of issues I mentioned in the last paragraph are generally alert and oriented x0. They don't remember their own names, they don't know where they are or what they're doing there, and they think it's the 1930s or the 1950s or don't even have a concept of years at all. When you're alert and oriented x0, the world becomes this terrifying place where you are stuck in some kind of bed and can't move and people are sticking you with very large needles and forcing tubes down your throat and you have no idea why or what's going on.

So of course you start screaming and trying to attack people and trying to pull the tubes and IV lines out. Every morning when I come in to work I have to check the nurses' notes for what happened the previous night, and every morning a couple of my patients have tried to pull all of their tubes and lines out. If it's especially bad they try to attack the staff, and although the extremely elderly are *really* bad at attacking people this is nevertheless Unacceptable Behavior and they have to be restrained ie tied down to the bed. A presumably more humane alternative sometimes used instead or in addition is to just drug you up on all of those oldtimey psychiatric medications that actual psychiatrists don't use anymore because of their bad reputation.

After a while of this, your doctors will call a meeting with your family and very gingerly raise the possibility of going to "comfort care only", which means they disconnect the machines and stop the treatments and put you on painkillers so that you die peacefully. Your family will start yelling at the doctors, asking how the hell these quacks were ever allowed to practice when for God's sake they're trying to kill off Grandma just so they can avoid doing a tiny bit of work. They will demand the doctors find some kind of complicated surgery that will fix all your problems, add on new pills to the thirteen you're already being force-fed every day, call in the most expensive consultants from Europe, figure out some extraordinary effort that can keep you living another few days.

(then these people will go home and log onto the Internet and yell at cryonics advocates for being selfish for wanting to live longer. Don't those stupid cryonicists realize all that money could be spent on charity, instead of chasing after fantastically unlikely chances?)

Robin Hanson sometimes writes about how health care is a form of signaling, trying to spend money to show you care about someone else. I think he's wrong in the general case – most people pay their own health insurance – but I think he's spot on in the case of families caring for their elderly relatives. The hospital lawyer mentioned during orientation that it never fails that the family members who live in the area and have spent lots of time with their mother/father/grandparent over the past few years are willing to let them go, but someone from 2000 miles away flies in at the last

second and makes ostentatious demands that EVERYTHING POSSIBLE must be done for the patient.

Your doctors will nod their heads and tell your family they respect their wishes. It will be a lie. Oh, sure, they will *carry out* the family's wishes, in terms of continuing to provide the care. But *respect* ? In the cafeteria at lunch, they will – despite medical confidentiality laws that totally prohibit this – compare stories of the most ridiculous families. "I have a blind 90 year old patient with stage 4 lung cancer with brain mets and no kidney function, and the family is *demanding* I enroll her in a clinical trial from Sri Lanka." "Oh, that's nothing. *I* have a patient who can't walk or speak who's breathing from a ventilator and has anoxic brain injury, and the family is insisting I try to get him a liver transplant."

Every day, your doctors will meet with your family another time, and eventually, as your condition worsens and your family has more time to be hit on the head with a big club marked 'REALITY', they will start to relent. Finally, they will allow your doctors to take you off of the machines, and you will be transferred to Palliative Care, whose job I do not envy even though *every single palliative care doctor I have ever met is relentlessly cheerful and upbeat and this is a total mystery to me*.

And you will die, but not quickly. It takes time for the heart to give up, for the lungs to fill with water and stop breathing, for the toxic wastes to build up. It is generally considered wise for the patient to be on epic doses of morphine throughout the process, both to

spare them the inevitable pain as their disease takes their course and to spare their family from having to watch them.

…not that they always do. It can take anywhere from a day to several weeks for someone to die. Sometimes your family wants to wait at the bedside for a week. But a lot of the time they have work and things to do. Maybe they live thousands of miles away. You haven't recognized them in years, you haven't spoken a coherent word in months, and even if for some reason your brain chose this moment to recover lucidity you're on enough morphine to be *well* inside the borders of la-la-land. A lot of families, faced with the prospect of missing work and school to sit by what's basically a living corpse day in and day out for weeks just to watch it turn into a non-living corpse, politely decline. I absolutely 100% cannot blame them.

There is a national volunteer program called No One Dies Alone. Nice people from the community go into hospitals to spend time with dying people who don't have anyone else there for them. It makes me happy that this program exists.

Nevertheless, this is the way many of my patients die. Old, limbless, bedridden, ulcerated, in a puddle of waste, gasping for breath, loopy on morphine, hopelessly demented, in a sterile hospital room with someone from a volunteer program who just met them sitting by their bed.

And let me just emphasize again, not everyone dies this way. I am hugely selection biased by my position in a hospital. But enough

people die this way. I'm in a small community. There can't be too many deaths here. Of the ones there are, I see a lot of them. And they're not pretty.

EDIT: *Just looked up statistics. Only about a quarter of old people die at home. The rest are split between hospitals (disproportionately ICUs), nursing homes, and hospices.*

II

Hospital poetry is notoriously bad.

I mean, practically all modern poetry is bad. Modern poetry by complete amateurs could be expected to be even worse. But hospital poetry is in a league all of its own as far as badness goes.

When I search "hospital poetry", Google brings up examples like the following:

> Pain… searing
> Belly… throbbing
> There is no baby.
> There will be no baby.
> Endometriosis.

I feel bad making fun of it, because it is clearly heartfelt. This is part of the problem with hospital poetry. It is very heartfelt, where-

as I think most popular poetry comes from people who have strong emotions but also some distance from them and a little bit of post-processing. And unfortunately doctors, who are on this decades-long quest to prove they are actual people with real feelings and not just arrogant robot-like people in white coats who know a very large number of facts about thyroiditis, just eat this sort of thing up.

But I'm not really complaining about those sorts of endometriosis poems. The ones I'm really complaining about are worse. The epitome of the genre I can't find on Google, because it was presented as some kind of event at the hospital where I trained in Ireland. I don't remember it, but let me just make up some doggerel approximately faithful to the spirit of the original:

> When my doctor told me that I had cancer
> I knew that despair was not the answer
> It felt like the darkness was closing in
> But to give up would have been a sin
> Everyone here helped me so much
> And nothing is like a helping hand's touch
> Thanks, Dr. Connell, and everyone in Cork
> I really appreciate all your hard work

Doctors and nurses eat this kind of thing up and put it on shiny plaques that go on the walls of the hospital. (I suggest a wall near the gastroenterology unit, to expedite care for people who start vomiting.)

Wittgenstein said that “if anyone ever wrote a book of ethics, that really was a book of ethics, it would destroy all the other books in the world with a bang.” I’m not really sure what he meant. But if anyone ever wrote a book of hospital poetry, that really was a book of hospital poetry… well, I don’t know what would happen, but I bet it would be loud and angry, and that it wouldn’t be put on shiny plaques on anybody’s walls, except maybe the same people who hang Hieronymous Bosch paintings on their walls.

Wait, am I calling hospitals hellish? Sure am. It has nothing to do with the decor, which has actually gotten much nicer in your newer hospitals until it’s hard to tell them apart from a stylish office building. It’s nothing to do with the staff, either – most doctors and some nurses seem pretty happy and trade banter around the water coolers like everyone else. It’s mostly the screams.

The screams are coming about 33% from the confused demented old people I mentioned, 33% from people having minor procedures performed without anaesthetics for one or another good reason, and 33% from people who just have very painful diseases (plus 1% from me sitting in the break room looking up examples of hospital poetry for this post). They run the gamut of human screams. There are wordless shrieks. There are some angry screams, like “$#%! YOU GET ME OUT OF HERE!”. There are a lot of people screaming “SOMEBODY HELP ME!” And there are some religious screams, like “OH GOD!” or “JESUS HELP ME!” or “CHRIST NO!”.

When I first started working in hospitals, I would not only inevitably run over to these screams, but I would feel contempt and anger at

the rest of the hospital staff who would just continue their daily routine. I soon learned better. Not only would I be unable to do anything – I can't single-handedly cure their painful illness, or make their procedure go any faster, or explain to them that the year is 2013 and they're no longer on their childhood farm in Oklahoma – but as soon as they saw me I would be the one they started screaming at and expecting to save them. The bystander effect, my last defense, disappeared. Sometimes I would make a stand by asking the nurse to increase their pain medication or something, and be politely told all the reasons why that was a bad idea from a medical perspective (pain medication has lots of side effects which doctors monitor carefully). In the end I would just slink out of the room, wishing I had never come in.

So the constant screams being completely ignored by a bunch of happy people going through their day is pretty hellish. But there's also the bodies. Usually we are able to avoid thinking about people as bodies except to briefly note that certain people like Emma Watson are really hot. In a hospital, this filter disappears. Some people have gigantic swollen legs the size of your waist. Others have huge ulcerated sores all over. Still others have skin covered with the sorts of bacterial colonies you usually only see on a petri dish. And body sizes range from so thin that you can see their organs bulging out of their skin and use them as a grisly impromptu anatomy lesson, to so morbidly obese that you have to search through the fat folds to find body part you're looking for.

The senses are under constant assault. Smell is the worst. There are some people who can identify different infections by smell.

Pseudomonas aeruginosa is supposed to smell fruity. *Gardnerella* is supposed to smell fishy. *Clostridium* is supposed to smell like the worst thing you can possibly imagine, if it were then covered in feces and left to rot on a warm summer day.

But the other senses get their time too. The sight is vexed by flashing call lights. And the hearing is battered with incessant beeping from IV lines which have hard-coded alarms to alert doctors of critically important events such as "Look at me! I am an IV line!" The end result is something it would take a first-rate poet to describe. I'm tempted to nominate Oscar Wilde. He did a good job on prisons in *Ballad of Reading Gaol*, and I feel like the skill would transfer:

> He does not rise in piteous haste
> To put on convict-clothes,
> While some coarse-mouthed doctor gloats,
> and notes each new and nerve-twitched pose,
> Fingering a watch whose little ticks
> Are like horrible hammer-blows […]
>
> He does not stare upon the air
> Through a little roof of glass;
> He does not pray with lips of clay
> For his agony to pass;
> Nor feel upon his shuddering cheek
> The kiss of Caiaphas.

But after some more thought, I think I'm going to go with Wilfred Owen:

> If in some smothering dreams you too could pace
> Behind the wagon that we flung him in,
> And watch the white eyes writhing in his face,
> His hanging face, like a devil's sack of sin;
> If you could hear, at every jolt, the blood
> Come gargling from the froth-corrupted lungs,
> Obscene as cancer, bitter as the cud
> Of vile, incurable sores on innocent tongues [...]

Or better yet, if Oscar Wilde's muse when he was writing *Reading Gaol* were to bear Wilfred Owen's children, then those kids would be competent to write hospital poetry that was actually hospital poetry.

Dante would also be an acceptable choice.

III

You may have read the excellent article How Doctors Die. If you haven't, do it now. It says that most doctors, knowing everything I've just mentioned above, choose to die quickly and with very limited engagement with the health system.

I (and the doctors in my family whom I've asked) am pretty much like the doctors in the article. If I get a terminal disease, I want to wring what I can out of the few months of life I have left and totally avoid any surgery, chemotherapy, amputations, ventilators, and the like. It would be a clean death. It would be okay.

My big fear, though, is that I *won't* get a terminal disease.

If I just start accumulating damage, growing more and more bedridden and demented and pain-riddling until I want out – well, there won't *be* a way out. If there's not some very specific life-saving treatment that can be withdrawn, I'm stuck above ground, not just in the "unless I want to risk the danger and shame of suicide" way I am now, but – if I'm too debilitated to access means of suicide on my own – in an absolute way.

Even if my doctors and nurses and caretakers are sympathetic, my only legal option, without exposing *them* to jail time, is to starve myself to death – something both painful and difficult, and itself not really the way I want to go.

I was sitting in an ICU room yesterday where a patient's body had just been brought out after their death. My attending was taking care of the paperwork in the other room, and I was sitting there reflecting, and I started thinking about what it would be like to die in that room. There was a big window, and it was a sunny day, and although I mostly had a spectacular view of the hospital parking lot, a bit further in the distance I could see a park full of really big

trees. And I knew that if I were dying in that room my last thought would be that I wanted to be outside.

I think if I were very debilitated and knew I would die soon, I would want to go to that park or one like it on a very sunny day, surround myself with my friends and family, say some last words, and give myself an injection of potassium chloride.

(this originally read “morphine”, but just today the palliative care doctor at my hospital gave an impassioned lecture about how people need to stop auto-associating morphine with euthanasia, because it makes it really hard for him to offer morphine painkillers to patients who need them without them freaking out. So potassium chloride it is.)

This will never happen. Or if it did, it would be some kind of huge scandal, and whoever gave me the potassium chloride would be fired or something. But the people dying demented and hopeless connected to half a dozen tubes in ICU rooms aren’t considered scandals by anybody. That’s just “the natural way of things”.

I work in a Catholic hospital. People here say the phrase “culture of life” a lot, as in “we need to cultivate a culture of life.” They say it almost as often as they say “patient-centered”. At my hospital orientation, a whole bunch of nuns and executives and people like that got up and told us how we had to do our part to “cultivate a culture of life.”

And now every time I hear that phrase I want to scream. 21st century American hospitals do not need to “cultivate a culture of life”. We have enough life. We have life up the wazoo. We have more life than we know what to do with. We have life far beyond the point where it becomes a sick caricature of itself. We prolong life until it becomes a sickness, an abomination, a miserable and pathetic flight from death that saps out and mocks everything that made life desirable in the first place. 21st century American hospitals need to cultivate a culture of life the same way that Newcastle needs to cultivate a culture of coal, the same way a man who is burning to death needs to cultivate a culture of fire.

And so every time I hear that phrase I want to scream, or if I cannot scream, to find some book of hospital poetry that really is a book of hospital poetry and shove it at them, make them read it until they understand.

There is no such book, so I hope it will be acceptable if I just rip off of Wilfred Owen directly:

> If in some smothering dreams you too could pace
> Behind the gurney that we flung him in,
> And watch the white eyes writhing in his face,
> His hanging face, like a devil’s sack of sin;
> If you could hear, at every jolt, the blood
> Come gargling from the froth-corrupted lungs,
> Obscene with cancer, bitter with the cud
> Of vile, incurable sores on innocent tongues
> My friend, you would not so pontificate

> To reasoners beset by moral strife
> The old lie: we must try to cultivate
> A culture of life.