Healing Healthcare By Meg Gaines
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[Audience Applauding]

I'm actually really glad to be here. Relieved and that last presentation of Jessica's was a perfect example. The work I do allows me to abide with many people as they turn to face their death and even as they breathe their last breath. Although this is always nothing short of the sacred experience, I don't often get a chance to talk about it. You see, I run a non-profit, a 50133 and funders don't often wanna hear about how you help somebody die. They mostly wanna hear about how you helped somebody survived and against the odds. People like me.

When I was 38 years old, I was diagnosed with ovarian **[00:01:00]** cancer which shortly thereafter was metastatic to my liver. I was told to go home and think about the quality, not quantity of my remaining days. My chidden were then 3 and 6 months old.

By now you've probably deduced that I did not go home and think about the quality and that the quantity of my remaining days. I learned to advocate for myself and I found an experimental and risky treatment that saved my life. And now, well, see for yourselves. As you imagine, I'm a mess at my children's graduation, but I'm there [chuckles]. I realised pretty quickly that nearly every bit of privilege that's available and possible in our society I had. Every bit that can be bestowed I had, and still… the way to survival for me was harrowing **[00:02:00]**, terrifying. And it turns out that right after diagnosis, it's not the best time to learn to advocate for yourself but that's when most of us do. And whatever the outcome of that diagnosis, we all wanna have the best chance we can to live well and when it's over, to die well. It turns out that's harder than it sounds for a number of reasons, but one fundamental reason is that the core of all the risks.

It's complicated. Someone confused this for a Disney ride one time, if I'm… [Audience Chuckles] It's true that if it's true that every system is perfectly designed to get the result it gets but it's worth thinking about: what does our system design get? It certainly is not designed **[00:03:00]** to prioritise either health or caring. While there are exceptional healthcare providers, truly exceptional healthy providers bringing their whole selves to care for us every day, our healthcare system works against them.

Health and caring are not rewarded or encouraged in the business model and they often cause trouble for those who do prioritise them. So it because we don't spend enough? Oh no. We spend almost twice as much as the next highest-spending country which is Sweden and they 5600 dollars per-capita to our 9600 per-capita and they provide everything to everyone and we still have 28 million people uninsured in this country **[00:04:00]**. With an investment this enormous, soon 20% of GDP the focus is on business. Profit and non-profit organizations alike are obsessed with RVUs, Relative Value Units; what they can bill for the service provided. So procedures, scans; surgery, radiology, these are high-density RVUs and the clinicians who perform them are well rewarded financially and in terms of how they are values with these work organizations.

Time with patience is the least lucrative, so the least valued by the revenue trackers. That's why for example that we have to put up a massive fight all over the country, most recently in the state of Wisconsin where I come from to get **[00:05:00]** approval for one 30-minute consult at the End-of-Life. One 30-minute consult at the end of life, think about that. So there must be an upside, right? I mean if we spend all that much, we must have the healthiest population on

the planet, right? Not right. Unless you think being 34th on the list of healthiest countries nestled between Costa Rica and Croatia, is cause for a big end-zone celebration. We're also tied by other with other Azerbaijan for the 55 out of 56 countries for the least efficient healthcare system. You know who the least efficient is? Bulgaria. And our error rate **[00:06:00]** is abysmal. The estimates range from 200 to 400 thousand people killed a year in Healthcare. That's equivalent to crashing between one and two fully loaded jumbo jets every day. And we injure 2 to 4 million people every year. To say nothing of how much we waste in Healthcare, conservative measures are that we waste 1 out of 3 dollars. Waste 1 out of 3 dollars of that 9600 per-capita with for which we also don't cover 28 million. Some say it's high as half of what we spend is wasted. And by the way when they talk about waste it's not like it just gets dumped in the garbage it often goes through our bodies first — sometimes with significant consequences **[00:07:00]**.

Well at least the folks who work in Healthcare must be doing well, right? Oh no. We're harming and even killing our healthcare practitioners. Burnout, drug and alcohol abuse and even suicide are way too common among physicians. They have the highest rate of all three of those things than any professional. So if indeed every system is designed to get the result it gets, ours is designed to get healthcare widgets at a profit, at the expense of humans, patients and clinicians alike.

Perhaps as insidious as this is the fundamental focus on profitability keeps us from actually focusing on the real problems, the tough ones! The ones we need to **[00:08:00]** address as a nation. All the other industrialised countries have created healthcare systems designed to support health and caring but that doesn't mean they don't have problems. It just means they're focused on the right problems.

Disease prevention including developing new vaccines and treatments. Identifying and minimising environmental toxins in our food, in water, in air. The adverse health effects of poverty, racism and lack of education, this is where our money needs to be spent. These are the issues — the really tough ones— that we need to be addressing before it's too late. In order to do this, we're going to have to change the fundamental relationship between clinicians and patients from one of delivery, which describes the kind of unilateral transaction to one of co-creation where together we forge a sacred relationship dedicated to maximise in the potential **[00:09:00]** for a good healthy life and a good comfortable death.

UPS delivers and I don't even have to be home to get it. Co-creation describes the collaboration where we are mutually responsible to and for my health and where we both, clinician and patient, openly plan around my eventual death. We normalise death because, well, it's normal. But co-creation requires fundamental changes in clinicians and patients. What we used to call the sixties a paradigm shift. It requires honesty and courage to talk about what is true and to contemplate the realistic future. It requires an appropriate allocation of responsibility for my health and my **[00:10:00]** healthcare, which means partially on me! It requires an intentional levelling of the playing field of knowledge and power to create a process where patients can and must learn what we need to know to make decisions that reflect our values and our priorities. And it requires a healthcare system that prioritizes health and caring. How will we get there?

Well we can start with education of clinicians and patients and the essentials of a relationship of co-creation, partnership, shared responsibility and compassionate candor. For patients on a granular level we need useful materials to facilitate our learning what we need to know in order to partner fully in our own care **[00:11:00]** and not generic brochures. We need precision information to go with our precision medicine.

25 years ago, when I was diagnosed, I printed out reams and reams of paper from the brand new internet. Believe me, it took a lot longer then that it does now. And I researched it and researched it and researched it and brought in 250 pages about liver cancer… but I didn't have liver cancer. I had ovarian cancer metastasised to my liver, and that's completely different. How was I supposed to know they were different? This is just as likely to happen today as it was 25 years ago! The information age needs to come to healthcare in a way that benefits patients and our decision-making processes **[00:12:00]**. A simple solution would be that every cancer diagnosis, for instance, using cancer as an example, patients would receive a sheet that could be automatically generated by the electronic health record. Imagine that! Something useful coming from the electronic health record! That list our exact diagnosis, stage, the grade, the cell type, the known mutations and how about several websites that clinicians do find to be valuable resources for patients? Instead of just hearing "Don't go on the internet. It's a bunch of garbage"? We should be past the age where we warn patients away from the internet. We cannot resist its flow and we are foolish to do so. The internet is a valuable tool of co-creation and of patient-and-clinician education. And we must step into that river and figure out how to navigate its dynamic waters together. Precision **[00:13:00]** information.

For clinicians and education process that prioritizes human values and self care as highly as clinical knowledge. We could begin by requiring a course every semester addressing the role of touch, hope, honesty and compassion and abiding with patients and families' grief, fear, sadness and anger. This must become as important in the education of health professionals as more measurable skills and knowledge. Albert Einstein taught us that all that is valuable is not measurable and all that is measurable is certainly not valuable. It would also require us to acknowledge from the very start of the young person's medical education that they are human. And therefore they will make mistakes. It's not called human error by coincidence. So a course or two on how to recognise **[00:14:00]**, think through, talk about, acknowledge and apologise for mistakes would seem valuable. And protection from discipline of any kind for mistakes which are just that, things we wished we'd done differently in hindsight. We were thinking. We made irrational decisions and it turns out in hindsight we were wrong. There's so much we cannot know that isn't knowable in advance. Unexpected outcomes are a part of life including in medicine. We have to stop the fiction of excellence, meaning that there are no mistakes. And where mistakes are unwanted, our outcomes are from negligence or some other kind of human brokenness. We need to directly address the underlying causes and prioritise both patient safety and clinician well-being, we absolute can and must do both **[00:15:00]**.

Oh and clinician well-being. Clinician wellness needs to be a fundamental priority for a healthcare system. If Newton were alive today I know he'd be happy to add to his law of physics: "You can't give what you don't have." At least not for very long. If my doctor isn't happy and healthy, she isn't going to be able to co-create those things with me. Or as we say in Apalachee, "If mom ain't happy, ain't nobody happy." [Crowd Laughing] Patients won't be safe until our clinicians are. It's as simple as that. We need to place the highest priority on teaching future clinicians the primacy of self care and the science behind that practice and yes these priorities will require us to reframe, revise, and reform our healthcare system to actually become a system and to **[00:16:00]** enjoy the advantages that high-performing systems can provide. And to be focused on health and caring. That seems pretty simple. While simple, it's not easy. Profit is a fierce foe to oppose but if we have a chance, if we have a chance! It will only be possible because patients and clinicians join together in the radical recreation of healing that lies at the very foundation of our sacred relationship. Thank you.

[Crowd Appluading]

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