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Opening

Welcome to Health Hats, learning on the journey toward best health. I am Danny van Leeuwen, a two-legged, cisgender, old white man of privilege, living in a food oasis, who can afford many hats and knows a little about a lot of healthcare and a lot about very little. Most people wear hats one at a time, but I wear them all at once. I am the Rosetta Stone of healthcare. We will listen and learn about what it takes to adjust to life's realities in the awesome circus of healthcare. Let's make some sense of all this.

CEO of Your Health. What!? 00:54

I am the **CEO of my health**. Yes. This frame works! Six months into asserting myself as the boss of my company – my health, *I'm learning to be a better CEO*, feels more hopeful, respectful, energizing, challenging, entrepreneurial, and connected. I'm accountable to my company. My company, Health Hats, has purpose (vision and mission) and craves leadership and management. My past focus on 'patient-engagement' and 'patient-centeredness' fell flat, underwhelming, co-opted, paternalistic, disempowering. If something doesn't work, adjust.

Let's explore **CEO of my health** some more. I'm the CEO of a company, Health Hats, committed to best health, mine, and my communities. My company has a C-suite (executive leadership), a Board of Directors, and subcontractors and coaches. Today, I'm much of my own C-Suite - CFO (Chief Financial Officer), COO (Chief Operating Officer), and CIO (Chief Information Officer). My Board of Directors includes me as Chairperson, my wife, and my grown children. My primary care doc is my CMO (Chief Medical Officer). My company has no employees. Rather it engages subcontractors. Doctors, therapists, coaches, pharmacies, diagnostic services, community services are all subcontractors. They're independent of my company, but we hire them and have expectations of them. We could have service agreements with them.

As CEO of my company, I lead, manage, decide, and learn. As a leader, I track business and quality outcomes (personal health goals), build a leadership team (the C-Suite), and consider ROI (return on investment). I ensure an infrastructure exists to optimize operations (everyone on my team, including me, has the tools she or he needs to do their job), and support self-care for the whole team (including me). Of course, I fundraise and cheerlead, and I manage succession planning (who will lead and manage

when I can't? How will I replace members of my C-Suite and Board of Directors when they move on)? My Board of Directors holds me accountable for success of outcomes and ROI (return on investment).

Learning Together: Choices and Goals 04:00

Health Hats, the Podcast, hosted five episodes so far in the *CEO of Your Health* series. I've learned quite a bit from my guests. Let's hear from some of them now. Here, Jan Oldenburg speaks about whose goals, whose choices? The clinician or the person?

**Jan Oldenburg:** *We talk the language of choices and goals but don't process the reality. I often find myself saying, "you can't dismiss people's health choices as irrational, because they're rational to them. You don't know what context they're making them in." So, I might be somebody who prefers non-pharmaceutical options. Actually, I am. We're okay with that unless it interferes with the treatment we think you should get. We tend to frame the person's goals as our goals for them as opposed to the person's goals for him or herself.*

I'm thankful that my diagnosing neurologist, Dr. Kinkle, urged me to consider what was important to me in my life. It fit right in with the lessons I had been learning from the career coaches I follow, Seth Godin and Tim Sullivan. Following their advice, my professional mission is

**Learn on the journey toward best health**

- To make health choices and decisions
- To communicate health information
- To support each other
- To share what works

Measures of success of my personal health operations are:

1. The amount and duration of function to maintain my professional and personal life (progressing as slowly as possible);
2. The frequency of falls and near falls (personal safety);
3. The hours per week spent playing the baritone saxophone and the proportion of the day maintaining pathological optimism (proxies for function, mental and spiritual health);
4. Maintaining my podcasting and advocacy work (community contribution); and
5. Frequency of listening to my own advice (ethics and integrity).

Learning Together: Hope and Help 06:23

Barby Ingle seconded the importance of purpose in life as it relates to hope and help.

**Barby Ingle:** *Hope and help are two things that even the smallest glimmer of hope can get you through the worst situation. I guess where I find my hope and each person would find theirs in a different place. I've realized what my purpose is in life. Knowing and living and acting towards my purpose increases my hope and asking for help. It's coming up with the vocabulary to ask for help that takes practice and patience.*

Learning Together: Data Telling a Story 07:40

Jan Oldenburg told a story about her pulmonologist. She had just shared months' worth of data about her breathing, function, and medications.

**Jan Oldenburg:** *He was just like, "oh my God, you actually have data that tells a story. Most of the time when people track their data, I just get slips of paper or entries. I don't get it in any form that allows me to understand what the story is telling me." It's both the patient and the doctor that need visualization, the correlations. They need things that are suggestive of what's going on rather than that it's just data points. And most people don't know what would be useful and most doctors don't know how to describe what would be useful.*

Right now, I think my clinicians get a kick out of my stories and the spreadsheets I keep tracking exercise, weight, and time playing music. We'll need to explore the CIO (Chief Information Officer) role in future episodes.

Learning Together: Decisions and Choices 08:55

Jane Beddall, expert in Crafting Solutions to Conflict, weighed in on the permanence of decisions

**Jane Beddall:** *We can overemphasize how important the decision seems to be because we overemphasize its permanency. Maybe we're going to try this approach for a while. Certainly, in the healthcare world, the fact that this is the response that many, many people have to this treatment doesn't guarantee that's me.*

Next Jane spoke about more about the nuances of decision-making.

**Jane Beddall:** *Then it's an opportunity to say, "well, let's see how this works on this actual body and human that we're talking about - me." I think it's also very useful to stay away, generally, in thinking about decision making from the black and white decisions. There's a lot of room in the middle. So often, of well, 'let's try most of it. Let's try it for now. Let's see if we can modify it a little bit to work better for me.' And stay away from the absolutes, the ultimatums, the take it or leave it. Those invite trouble.*

*There will sometimes be a conversation about who is in the room? Who seems to be a decision-maker? Maybe not everyone who matters is at the table in the room. People are there who can't make a decision or are going to make a lousy one unless they speak to someone else,' and sometimes it's quite literally shareholders. They have an ownership interest versus stakeholders: the person who is going to have an important role in the life of the person who's making that decision. So, it's sensible to say. The other thing I think you hit on is, "Is it my emergency or is it someone else's emergency?" Is it someone else saying, "oh, I want to get this decided today? Why are you dragging your feet?" Well, because it's my health care. It's my life we're talking about here. So that's one of the things that you hit upon. I think you hit on another one which is things evolve. That's life - things change and making decisions that come across as - this is it forever. No more saying, "We make decisions one way, and we can never revisit it." That's tough.*

I love that Jane broached the subject of the variation in capacity of people making decisions whether young, old, or ill.

**Jane Beddall:** *Or you need an advocate or more than one advocate. We're all different. And some of us struggle to even think about our own medical decisions. Those folks need a lot of support. Of course, younger people are moving along that continuum of: 'I am an infant, and my parents are making decisions for me,' to 'wait a minute, I'm getting a little older. I'm getting a little older to the point of - Why can't I make the decision all on my*

*own?' For my parents at the other end of the age spectrum: 'Maybe my judgment is not as good as it once was. Maybe my eyesight is not as good as it once was, and then someone hands me something to look at to understand my options. But I can't see it very well, or they want to explain it to me in spoken words. My hearing is not that good. Maybe it's never been that good. And that's a really tough way for me to learn.'*

I have an episode coming up in a couple of weeks with friends struggling to be CEO of their dad's health as his dementia accelerates.

My multiple sclerosis is progressing very slowly, but it's progressing. My neurologist prescribed an infusion twice a year that costs \$100,000 a dose. I asked my neurologist if I needed to get it. I understood every word he said. But my brain couldn't put all the words together. Thankfully, I had my Abridge recording app turned on. I had pushed the big pink button. I went home. My wife and I listened to the transcription several times. We decided it was worth it. I'm grateful that we could take time to make an informed decision. Thank you Abridge. Abridge was created by patients, doctors, and caregivers. Check out the app at [abridge.com](https://abridge.com) or download it on the Apple App Store or Google Play Store. Record your health care conversations. Let me know how it went!"

Learning Together: Doing the Work 14:01

Matt Neil, a high school teacher, talked with me about learning to learn and what makes a good learner.

**Matt Neil:** *Education is the key here. By education, I don't just mean knowledge, although knowledge is a part of it. You said something too about not knowing that it's an option. That's how I think a lot of kids and parents approach school. They show up and exist there, as opposed to being in control. We all know that one of the differences between a good and a great student is great students ask questions. They're taking great notes. They help other members in the classroom with their learning, as well. They are reading. They're doing the work. That can apply to health care. Anytime I've had any health issues; I'm always amazed by the amount of knowledge I need to know. How do I manage this? How can I get better? How can I improve? How could I deal with it? It can be very overwhelming. I think that's how a lot of kids feel in school. Because the kids are overwhelmed, some of them throw up their hands and say why bother or they get by. Does that happen in health care, too?*

Of course, that happens in healthcare, too. Who's crazy enough to conceive of their health as a business and themselves as CEO except me and you, my dear listener?

Learning Together: Seize or Cede Control 15:40

My friend and fellow homeschooling parent, Amy Faeskorn, spoke about the Zen of leadership. Seize control or cede control?

**Amy Faeskorn:** *A lot of what you just said is very spiritual. If you're a reader of the Tao-te Ching, for example, that's the yin and yang of leadership is knowing when to act and when to observe. In my healthcare, in recent years, I have finally understood that. I've also been*

*really clear how I lead my own health like the CEO. I realize what I can get where and from whom. And I don't try to impose my needs on providers. For a long time, I used to look to Western medical doctors who are still the core of my treatment. When I seek care that doesn't involve self-care practices, right? So, I used to go to them for emotional reassurance. I need a metaphorical hug. I switched providers recently and new provider it has zero bedside manner. He's very kind, but that's not his strength. His strength is he's totally up on research. He's totally up on best practice. He gets the job done. He's very first 'do no harm.' Which with my illness, I appreciate because the impulse to intervene pharmaceutically intensely can be there, and he's more of a let's hold off. So, I realize the gifts he gives are the ones I need. He doesn't need to be my counselor or my psychologist? He can just be my Western Medical provider specialist.*

### Reflections 17:22

Whether you like it, want it, feel prepared, or understand it, let me assure you that you are already the CEO of your health. Some people lack capacity to be their own CEO due to cognitive challenges. Others have formidable barriers due to social circumstances. The role of CEO of their health does not, therefore, go away. It's a whole different set of problems for their social network and medical and neighborhood communities. And it's a topic for another day.

As I've said before in blog posts and podcasts, it's a tough system to lead and manage. It's exhausting. I'm a person of privilege and have some of the skills I need. I am Health Hats, after all. But I have nowhere near all the skills I need. There's microscopic training available for Health Team CEO, at best. Certainly, no certificate or degree. The pay stinks. There's no vacation. I can't resign. Almost no one looks at me on my health journey and says, "There goes the CEO of his health team." People, if they see me at all, say, "there goes the patient." **Patient** and **CEO** sound very different. My image of a patient is barefoot with their bare butt showing while a CEO has a suit and bling.

If you've never considered yourself as CEO of your health, I challenge you to grapple with the idea. Let it sink in for 60 seconds a day. More than that is freaky and overwhelming. Start with figuring out what your company is here to do - your purpose in life. Then build a team to help you do it. You can't be CEO alone, no matter how healthy, privileged, or lucky you think you are. If you're one of the glorious few who are already fair CEOs of your health, get better at it. Reach out to any three people close to you or near you (near like spend time with you on the same block) and help them become CEO of their health. Your lives depend on it.

I'm on a mission to learn about learning to be CEO of your health. If you have ideas or experience, let me know. Let's learn together.

See the show notes, previous podcast, and other resources or my website [www.health-hats.com/pod](http://www.health-hats.com/pod). Please subscribe or contribute. If you like it, share it. Thanks. See you around the block!