

THE COMBUSTION CHRONICLES

Episode 102

EXPLORING THE WORLD OF PATIENT ADVOCACY

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Host

Deb Gordon
Guest

Shawn [00:00:01] Welcome to the ninth season of The Combustion Chronicles podcast. Where bold leaders combine with big ideas to make life better for all of us. I'm your host, Shawn Nason, CEO of OFFOR Health and founder of MOFI. This season is all about amplifying the voices of badass women leaders in the healthcare industry who are influencing change by thinking big, putting people first, and not being okay with the status quo. Experience matters. Culture matters, and revenue matters. That's why it's time to unite, to ignite a people-first business revolution, especially in industries that affect all of us through health care.

Deb Gordon has spent her career trying to level the healthcare playing field for consumers and now advises startups and innovators trying to make healthcare better for everyone. She is co-founder and CEO of Umbra Health Advocacy, a marketplace for patient advocacy services, and co-director of the Alliance of Professional Health Advocates, the premier membership organization for Independent Advocates. She is the author of The Health Care Consumer's Manifesto How to Get the Most for Your Money. Deb previously spent more than two decades in healthcare leadership roles, including chief marketing officer for a Massachusetts health plan and CEO of a health technology company. Deb is an Aspen Institute Health Innovators fellow Eisenhower Fellow and a Boston Business Journal, 40 under 40 Honoree. Welcome to The Combustion Chronicles Deb.

Deb [00:01:50] Thanks so much for having me. Great to be here.

Shawn [00:01:53] It is great to have you at such a background. I've been saying for so many years that health care needs to start with the consumer. I preach it all the time. I talk about it all the time. But you took the time to get in the weeds and actually write a book on it, which I have ordered. I haven't read it yet, but I have and I am. I'm going to read it because I just I love it. Can you tell us a bit about your journey from CEO to author to patient advocate extraordinaire?

Deb [00:02:26] Oh, that's very kind of you. Thank you for putting it that way. You know, I've always been motivated throughout my career by consumer insights and specifically, I've been really interested in consumer vulnerability and injustice. And I think I just identify with the underdog. Maybe I feel like I always was the underdog, too. So I relate to that. It just felt naturally for me to go from working on the inside of health care as a health insurance executive. Of course, in that role I wasn't an underdog. I don't mean it that way. But, you know, the idea of coming from the inside and bringing that knowledge out, I was just trying to help other people get that same the same kind of privilege or benefit that I felt I got on the inside of the system. And that's really one of the key values a patient advocate can offer, is helping people navigate the nooks and crannies of the health care system that are just near impossible to figure out if you don't know it from the inside.

Shawn [00:03:32] You know, Deb, last year I went on my own, had my own journey fighting and stage three colon cancer. And through that journey, being someone who had worked in the industry for years, being able to maneuver and ask for the right questions, I didn't realize how powerful it was, but I did have that aha of I'm very blessed. I understand the system. I can't imagine for someone who doesn't know what that looks like, and that's exactly what you're talking about here. So let's dig into a little bit of your research and what led you to launch Umbra Health Advocacy in your book? You posed this question Why do we pay so much for health care in America and gets a little like, I feel like we could have drinks over that for weeks to talk about that. Can you answer the question for the listeners and for myself? I would love to just know where your head is around that.

Deb [00:04:34] Yeah, and we can have drinks, we can have coffee, we can talk. For how long have you got? I mean, transmission is kind of the crux of the issue in American health care. And it's, I think, just one of the most egregious sort of unforgivable features of the U.S. health care system is just how much it costs and that so many people don't get what they need. And even if you can get what you need, like you described in your own experience, it takes such a toll. It is not easy. It is not consumer friendly, it is not consumer-oriented. And to me, that's just crazy. There are so few, if any, other market place or market or kind of industry where we as consumers

would tolerate paying so much for such questionable value. At best, it's inconsistent. Some people we you know, there's great health care in the United States and many people, you know, just get wonderful care and coverage. But many people go without. And sometimes it's the same people who, you know, at times get great care and at times do not. And, you know, there are a million reasons why health care costs so much. I keep a running list whenever I see some. And crazy. I'm like, And that's why health care costs so much. But, you know, it's just with all that spending, we still don't get enough. We still don't get enough value or quality for everyone to get the care they need.

Shawn [00:06:04] Yeah, it infuriates me. It fan. You know, it does this, it does this, it does this to me like all these things. Why does it have to be that way? And I still, you know, as I went through my journey and saw, you know, why did a chemo treatment have to cost \$29,000? But yet when it was reimbursed, it was only like 1500. Right. So just such a broken system that I don't really understand it and still don't. So you you've just focused around the shopping experience as an analogy for helping people understand what's broken in health care. Can you dig in and bring this to life for the listeners today around the shopping experience?

Deb [00:06:52] Sure. I think shopping is, you know, a sort of quintessential American pastime, if you will. Americans are very good at shopping. We understand how to shop. We understand how to consume. We are hardy capitalists in general. And we have, I think, a collective sense as a nation or a culture that when we're paying for something, it's reasonable to expect that it will work, that it will meet our needs, and that we should get what we paid for. And the idea of shopping for health care is really foreign to most people. But to me, it's a great analogy because basically in health care, we think. It's so different from anything else we shop for. We can't even put the pieces together, connect the dots that when we're when we're dealing with health care, we're spending our own money in conducting research for my book. I interviewed dozens of consumers about their health care experiences, and I specifically led with a question I thought I was just setting the scene. You know, we're going to talk about a health care purchase you've made, and people would stop me and say, wait, what's a health care purchase? And I

was like, you know, anytime you spend your own money on something to do with your health care and still some people did not understand what I was talking about, they literally could not connect to that question. And instead of beating myself up for asking a bad question, I started to realize I did that too, of course. But, you know, I started to realize that we don't even associate the money we spend on health care as our own. And I feel like when we're shopping, you know, shopping may seem frivolous. It may seem luxurious, it may seem silly. But when we're in a shopping stance or a shopping mindset, we're sort of entitled, not necessarily in a bad way, but we we, I think, think of ourselves as entitled to get value. And that just seems really far from how we approach our health care encounters, transaction spending, whatever you want to call it. I called it purchasing purchases, but imagine if we kind of understood or thought of health care spending, but those health care costs that are burdensome, What if we thought of those as our own money? Because really everyone I talked to pretty much had an experience spending their own money on health care. They either paid premiums for their insurance, they paid out of pocket costs, they paid co-payments. Some people, a lot of people get therapy and they pay the therapist cash or, you know, out of out of pocket because insurance didn't cover that particular therapist. So almost everyone had an example or many examples of spending their own money. But the construct is somehow really remote from our own. The other thing I would just say is when you get health insurance through your work, you better believe that your employer is calling it part of your compensation. You know, they're viewing those benefits, which costs a ton of money as part of compensation. So you know, what part of your own money why don't we get that that compensation is money that that is otherwise coming out of our pocket or one way or another is coming out of our pockets? So I felt like shopping is a a process, an activity, a construct that we all can understand. And if we adopted just even a little bit more of that mindset in health care, imagine what would happen and what kind of value we might expect and demand.

Shawn [00:10:41] Now, I think that's scary when you put it in those terms, like, I don't know that I've ever thought about it that way because it's just been a necessity. So I didn't look at it as shopping. But yeah, right. Like that money's getting spent and some days that value or that outfit's a really bad outfit and a really horrible experience. So

throughout your career, you've seen lots of different aspects in health care. How do you see patient advocacy now changing the healthcare landscape for the better?

Deb [00:11:16] Sure. I think I'm a realist. You might call me a pessimist, but I think of myself as a realist. And so if you think realistically, is the system going to change dramatically for the better in my lifetime, maybe an optimist would say, Of course it will. A pessimist would say it never will. And I would take a middle road, which is, you know, it may and let's work towards that. But in the meantime, let's make it better. Let's make the experience better for those of us, all of us who have to live in the system we have today. And so I just think that everyone, including insiders, even, you know, doctors, nurses, health insurance people, everyone could benefit and can benefit from an advocate. So an independent advocate works for you, the consumer. Their only allegiance is to the patient. And they are like a guide or a translator who kind of helps people navigate this complex, messy, broken system. And if you have someone by your side to show you the way, you know, I just believe you're going to get where you're trying to go more easily, more efficiently, and with less stress and sort of anguish for you. So I. I think that when someone is knowledgeable about the rules of the game, whether that's you or me or an advocate working on our behalf, I think you tend to do better in that game. So in my worldview, everyone gets an advocate, every employer, every hospital, every health plan understands that when people and patients and consumers get the care they need without as much hassle and fight, their health care is better, their mental health is better, their pocketbooks are better, and everyone benefits from that.

Shawn [00:13:12] So don't give me one thing that surprised you as you've developed and then building Umbra Health Advocacy. What is one thing that surprised you that you've discovered about the industry that you may not have known?

Deb [00:13:25] Yeah. So the first thing which I learned at the outset, I've got a few things, if I may. I'll be I'll be efficient. Let me give you three things I've learned. But the first the very first is that people don't even know this field exists. And I can say that because I didn't know the field existed. I had been in health care a long time, decades, and I had not understood that there were independent advocates who work for you, the

individual. So the first is that we exist. Number one, and many people, most people don't know that. And the second thing is that even when people discover that help is available, it can be really hard to ask for help or to feel like you need that. I think a lot of people come to us and they say, Oh, that seems great, but I think I can manage this on my own. And if I made just an analogy, I was running very regularly, which is a feat because I'm not an athlete. But so last year I was running very, very consistently and I got injured and I kept running because I felt great. But after I would run injured, I couldn't walk. So finally I said, I got to stop, I got to rest, and I thought, I may never run again. It was great while it lasted. I'm obviously not built to run. My running days are over and I was pretty bummed about it. And someone suggested that I call her physical therapist and this guy came and he I did four or six sessions with him. And it hurt. It hurt like heck. I don't know. Can I swear on this show?

Shawn [00:15:02] Totally.

Deb [00:15:05] It hurt. But after a month or so, I was back, you know, able to run again. And I've been running pretty consistently ever since, cheerfully but consistently. And that was last you know, that was a year more than a year ago. And so once I felt better and realized I could keep going on this quest for fitness that I'm always on, I thought, why did I wait so long? Why did I suffer? Why did I think I. I somehow knew what my body needed. I'm not an expert in tendons and muscles and all these things, so I just felt kind of stupid for not getting help sooner. And I had to really examine why did I not ask for help. I don't know the answer, but I think it's a phenomenon. So, you know, I think in health care it's ridiculous to think you could navigate alone, even if you know the system like I do when it's you, when it's your loved one, when it's your health, it's really hard to stay clearheaded and have the energy and the focus and the sort of motivation to fight bureaucracy. And it can be really helpful to have someone by your side. But I guess it surprises me that we have that first help is available in so much depth and breadth, and then that people sometimes think, Oh, I can do this crazy new thing, but I've never experienced before. I can manage this all on my own. And I think that what happens is people get to the point where they're in real crisis. Like I couldn't walk and I called up the physical therapist and finally got help. But if I had called him a month or two months

earlier, I probably never would have had to take that long. You know, I took a long break. I probably wouldn't have had to. And so my my co-founder always says people don't call us when they see smoke. They call us when the house is on fire. And so, you know, it surprises me still that people are kind of wait till it's a crisis to get help. But I guess that's human nature. And I promise I had three things. And the last thing is, I will say that as long as I've been in health care and as much as I've seen and done and research, I still am just shocked. Almost every day I encounter a new scenario. I learn about a new rule, a new wrinkle, a new thing. I hear about some other crazy thing that happened to someone. And I just think, my God, how could anyone? Think they could handle this on their own. I'm a veteran, I'm an insider veteran, and I am still seeing new things every day in healthcare.

Shawn [00:17:45] Yeah. Yeah. I mean, I was the same way going through my journey. Right. Should have probably hired an advocate to the point. So I love it. I love the three points. I think our listeners, those are valuable. And I'm sure there are listeners who want are going to want to pass this episode on to others in the industry.

[00:18:05] When you're a kid, waiting in a line isn't much fun, but when you're always in the back of the line, well, that totally sucks. That's where OFFOR Health comes in. Our smile and business partners, a dentist to move kids up from the back of the line by equipping dental practices for three-person in-office anesthesiology care teams who actually care about everyone they work with OFFOR Health improving the lives of the underserved and under-resourced one kid at a time. Learn more and offorhealth.com. That's O. F. F. O. R. OFFOR Health creating connections, Improving lives, and care you deserve.

Shawn [00:18:53] So we use this terminology a lot called maverick minded and leveling the health care playing field is near and dear to me, to my company, MOFI. But doing this always seems like such a flippant uphill battle. So what are the key barriers that need to be removed for the healthcare playing field to truly be leveled?

Deb [00:19:22] So it's a great question and it is such a hard question to answer, But I, I really think that the true answer is cost. And it is cost is the hardest thing to tackle in health care. You know, we're capitalists. We're a capitalist society. I've said before, I'm a capitalist. I have no objection to people who innovate and bring value to making money. I have no objection to that. So, I mean, if we could take our politics and philosophy out of it for a moment, just practically speaking, the number one barrier that I have seen in every aspect of health care, no matter what I've done, who I've talked to, what I've been working on, the number one barrier is cost. And if you have money, health care is really tough to navigate. But if you don't have money, it's it can be a matter of life and death.

Shawn [00:20:20] It could be crippling.

Deb [00:20:21] Crippling. It's exactly the right word. So, you know, I think what I would like to see again, politics aside, I'm not sure how to achieve it, but if there is, you know, I think the thing we have to face head-on is that health care in America costs too much. There are a lot of reasons for that. I told you, I keep a running list of ridiculous things that make it cost too much. But at the core, there are structural incentives locked into place. Hospitals will say insurers, insurers will say hospitals charge too much and hospitals will say insurers pay too little. And, you know, they're both right. And the problem is in that kind of battle that they're locked into. And by the way, the consumer gets stuck in the middle and often just left out altogether. So we've got to figure out the cost and it's too hard. So most of you know, a lot of innovators and policymakers are kind of tinkering on the margins. But until we kind of face head-on that we have a gross inequity or gross inequality in this country in health care, and it's financial. I don't think we'll get that far. To be honest.

Shawn [00:21:39] Yeah. I mean, you're preaching to the core here. I used to work for a major player in the company. I've said it during the season, Humana. I preach this from my soapbox many times that the healthcare system is built to play, to pay claims, not to take care of patients. And that's where that cost piece comes in. And it's really sad to me in so many ways.

Deb [00:22:02] So can I. I'm so vehemently nodding. You can hear me not, you know. Oh, no. But I just want to say, you know, if we could kind of remove some of that, you know, what is this code and what's the claim for this thing and the money for that thing? And you're on this plan. So cause that instead of that, I mean, could you imagine a system where that just sort of sat. Minutia that day to day is a grind of the claims and the line-by-line coding and all that, which is the lifeblood of of health care today. What if we could somehow lift that off, put the money in, let people get what they need, let doctors and hospitals do what they think is right and let individuals make good decisions for themselves.

Shawn [00:22:55] Wouldn't that be so easy? I would enjoy that shopping experience, Deb. Right. So we're talking about this to some may sound doom and gloom. Listen, we still have great health care for those that can access it. That's a whole other discussion. And there's still a huge lack of access there. But where do you get your motivation and energy to stay focused on supporting people through healthcare challenges? Or could we actually say healthcare nightmares? Where do you keep that motivation and energy when it can be so draining at times?

Deb [00:23:32] That's a great question. It's actually this one's easy for me to answer. You know, the common thread throughout my career and actually probably throughout my life has been my passion for consumer stories and insights. My first project out of college was working on a focus group study as a junior staffer in a public health consulting firm. And I, you know, most recently started working at journalistically writing, interviewing, doing research with consumers. And I, I just thrive on hearing people's stories and trying to make sense of those stories. And I feel like I've collected, you know, I might interview someone, I might talk to someone, I might hear what they're going through. I can still remember people in the focus group study when from when I was I think I was 21 or something like that. I literally can quote not a not every group, not every person, but there are things about people's experiences that have stayed with me literally for decades. And so all I need to do is think about or listen to a new consumer story about the challenges they're facing. It is so universal that people just want to feel. Well, to feel respected, to feel listened to, to feel taken care of. To feel safe. To feel

heard. And all I need to do is think about one person who doesn't feel that way. And it's so common that I just think, well, that's what I'm here to do. Help make sure more people feel heard, safe, cared for. And fewer people feel vulnerable, scared and alone. And also caffeine. I have to say, I feel energized. I'm a deep caffeine addict, but I'm fueled by stories of what people need and are going through.

Shawn [00:25:33] It sounds like we're very kindred in that my caffeine and the power of stories. You know, I've spent a lot of time in the state of Mississippi and back in there recently and just the lack of care and access that so many in that state face, it gives me this drive inside of me to go, We got to keep doing this. We got to keep chipping away at this. So I really appreciate that and I really appreciate the power of stories and more importantly, the power of caffeine, because it survives and keeps me going so many times. So, you know, this season for The Combustion Chronicles, Deb has been all about focusing on amazing women in leadership in health care. And we added something this season that we've never done before, and it's been so much fun doing this, but it's called her two minute drill around. How might we and, you know, my team and companies that I work with use a methodology and have a mindset around using human centered design, or some people call it design thinking. And I love this concept and we've been having so much fun with that. I'm going to set a two minute timer on my phone and I'm going to ask you this How might we statement? And we're just going to have fun with it. And I may add to some of your ideas. I may poke at him and get you to think a little bit more. But I really want this test to be an ideation time where you can take all restraints off, have your magic wand and everything to fix it. So are you ready for the step?

Deb [00:27:12] Yeah. Bring it. Awesome. Do it. All right.

Shawn [00:27:15] So here it is. How might we blow up traditional healthcare model so that patients don't even need an advocate? Go.

Deb [00:27:28] It's a great question. We, of course, should not need advocates because we shouldn't have a system so broken that you need a guide to get you through it. So,

you know, I think first I said it before we have to address like, why does health care cost so much? That's very cumbersome and probably not fun in a two minute. How might we? So what I think we should do is radically rethink how we can deal with why does it cost so much on a different podcast. But let's radically change how we finance health care. So could we? What if we put money in the hands of the consumer? So there are places in the world Singapore does this. Australia has some programs like this where money follows the person and the consumer directs their own health care spending with constraints and guardrails. So it's not like we're all going to the spa and then we have nothing left for knee surgery. But what if what if the consumer were in charge of how their health care dollars got spent and where? What if the consumer could go to whatever health care provider they wanted and when they wanted and got what they needed? So within some bounds of financial constraints so it wouldn't go berserk.

Shawn [00:28:53] So it's really blowing up even HSA user fees. And some countries, you know, Canada does put in those spa treatments and some of that, too.

Deb [00:29:03] Oh, fantastic.

Shawn [00:29:04] Right. Like, I love that idea. So what if we would say, how might we do away with just those barriers of costs and just give some control back to us as consumers? Because I feel like that's what you're saying, if we don't even have any control, right?

Deb [00:29:23] Correct. And we're you know, we're subject to half of Americans get their health insurance through an employer. So God forbid you don't like your job, you know, you may not be able to leave and expect to have the same kind of access. That's that's crazy. That's bad for the economy. That's bad for people. That's bad for innovation and entrepreneurship and all of that. So, yeah, I think that what we need to do because we're just being wild here, right? I've got my magic wand and I'm saying everyone gets catastrophic coverage somehow. You know, we take all the gazillion dollars, the trillions, literally trillions of dollars we're spending on health care. Trillion dollars and. You know, we put it towards basic universal catastrophic coverage so everyone knows they're not going bankrupt. I traveled to New Zealand in 2013 to look at their system and they didn't

understand how do people go bankrupt here because of health care. They literally could not understand it. These are smart people, but they have no equivalent. So let's protect everyone from that catastrophic financial risk. And then on top of that, employers can do more. The government can cover low income people, provide a safety net, which is necessary. Individuals can do more. But we then kind of on top of a floor of coverage could approach our health care the way we want. We still might need advocates, by the way, or want advocates because that's a lot of choice and a lot of flexibility in theory. But then your advocate is more like a coach than a fighter. You know, they're not fighting some big bad system on your behalf. They're actually working with you to understand your needs and preferences and and helping you figure out how to get optimize your health and your health care spending.

Shawn [00:31:16] I love it. I love it. I love these ideas that come out of these two minute drills. So. But it has come to a point, Deb, in our episode, every episode we do this, it's called the Combustion Questions. Three randomly selected questions from my human AI algorithm named Michael, and they were just passed to me and I have not even read them yet and will read them for the first time when I start to read them to you. So, Deb, are you ready for your combustion questions?

Deb [00:31:46] I think so. What could go wrong?

Shawn [00:31:49] All right, so here we go. Combustion question number one. If you could be any kind of bird, which kind of bird would you be and why?

Deb [00:32:01] That's a hilarious question. So I as a younger person, had like a slight fear of birds and I can't explain why. So I've not spent a lot of time examining or studying birds, and I'm not very educated about them, but I don't know. The first thing that's coming to mind is a peacock, which is probably terrible, but they are so beautiful and nobody messes with them.

Shawn [00:32:26] No, I love it because actually, as you were saying that, I thought that could be a peacock. Oh, so that's right. Beautiful.

Deb [00:32:35] I don't think they're very nice. Yeah, No, that's nice.

Shawn [00:32:38] They're nice from a distance in there. There you go. Don't mess with them.

Deb [00:32:42] So don't mess.

Shawn [00:32:43] Yeah, that's right. All right, Combustion question number two. What's your favorite candle scent?

Deb [00:32:50] Oh, easy question. Firewood. So I have a smoky, like, campfire smelling that I love.

Shawn [00:32:59] Love, love it, love it. All right, Question number three. What do you think about beach balls?

Deb [00:33:10] Hmm. I mean, they're kind of annoying. You know, I picture sort of trying to push them down in the water for fun and then popping up, and I guess that's probably fun for some people. I find that frustrating. I'd say they are fine. They're probably great for kids. They're a little lightweight for my taste. How about that?

Shawn [00:33:30] That's pretty good. I love it.

Deb [00:33:33] All right. I sound like a curmudgeon.

Shawn [00:33:35] No, I love them. So, Deb, best place for people to come and learn more about you. Obviously, Umbra Health Advocacy is connected to you on LinkedIn. Go to the website. Any other place that you would recommend, people come find you?

Deb [00:33:51] Yeah, definitely. LinkedIn. I'm sort of Twitter shy right now, but I am still there. So at Gordon Gibb on Twitter or, you know, just email me Deb at Umbra health advocacy dot com it's Umbra Umbra health advocacy dot com and I probably will be delinquent but I'll definitely try to get back to you if you reach out to me I appreciate it so well.

Shawn [00:34:15] Well thank you so much. Thank you for your time today. And Deb, I look forward to future conversations. But until then, I just say be safe and be well, my friend.

Deb [00:34:24] Thank you so much. Thanks for having me.

Shawn [00:34:27] And thanks so much for listening to this episode of The Combustion Chronicles. If you've enjoyed this episode, please take a few minutes to subscribe, rate and review. Remember that I'm always looking to meet more big-thinking mavericks. So let's keep the conversation going by connecting on LinkedIn. If you want to discover more about human-obsessed, maverick-minded leadership, go to mofi.co or go to experienceevangelist.com to learn more about my mission, to challenge leaders to blow up outdated, siloed systems and rebuild them with an aligned human-first approach. You can also learn more about OFFOR Health's commitment to reimagining outdated healthcare models at offorhealth.com. As always, stay safe, be well, and keep blowing shit up.