Individualism is not just about each of us playing Scrooge McDuck swimming in pools of gold coins or living as a well-armed hermit with a hundred year supply of canned corn beef or something. Sure, it might include those things. But really, for most of us who claim the label, individualism is about agency, choice and dignity for all people in respect to their equal humanity and their irreplaceable value as a person.

Despite the caricatures, individualism is profoundly humane. And to help us demonstrate this, we’ve invited Professor Lauren Hall on the show. Her latest book, The Medicalization of Birth and Death, tells the story of all the humanity lost, ground under the wheel of terrible medical bureaucracy and a system that crushes the individual in their moments of greatest tenderness and need.

So Professor Hall, I want to start by asking what exactly drew you to this topic? Because this is, at least as I’m reading this, this very much reads like a policy book to me and it’s on a set of policies, healthcare, that is frankly incredibly confusing and complex and very alien to most of us because of its intense complexity. But your treatment of it is very, very humane. So I’m interested in what exactly was the motivation behind writing this book the way that you did?

Yeah. So I actually ... I mean, in some ways, this was a long time coming, although I never ... I mean, healthcare policy was not part of my training. It was not something that I was really interested in. I did a little bit of work in biomedical technologies and things in grad school, but nothing on sort of healthcare policy proper.

At the same time, I think it was in grad school, I had the privilege of going down to Tennessee while my grandmother was dying of cancer and I was helping my mom out. She was providing a lot of the hands-on care, along with some home health aides. And for a death of cancer, it was surprisingly beautiful. I mean, it was like deaths of cancer. It was very painful. There was a lot of really difficult things that went along with it. But she died in her living room. We were actually all sitting there. I had a flight out later that day, so we were all sitting there and kind of chatting. My grandmother was on pain medication. She wasn’t responsive at the time. She stopped breathing. And it struck me that it was an incredibly peaceful way to die, notwithstanding the sort of horrors of cancer and the devastation that the cancer had brought, but we didn’t add any trauma to the experience.
So my grandfather was losing his partner for over 50 years. He himself was in frail health. And rather than being in a hospital with massive quantities of people coming in and out and bells and whistles and all sorts of other things, we were able to just sort of sit there. My mom and I, we actually got a mirror to check to see if she was still breathing. It felt very sort of 18th century. And then we called the hospice and they sent out someone to confirm and they contacted the funeral director, and my grandfather was able to sit in his living room and take in the fact that his wife and partner was dead. So it was already a traumatic experience for him, but we didn't add any trauma. And so there was something sort of meaningful to me without actually having much background in healthcare in general at that point in my life. It just seemed to me that that's how it should happen. If it can happen that way, that's how it should happen.

So I contrasted that with my first birth about a decade later when I had my first child. I was a low risk first time mother. I had a pretty non-eventful birth. First time births are always kind of crazy, but pretty non-eventful, no real medical needs. And yet the birth itself was actually fairly traumatic, and it was made traumatic by the fact that it was in a hospital. I was limited and hemmed in by all sorts of protocols and standardization that did not fit my patient profile, that didn't fit me as a human being, didn't fit my preferences. And the mind sort of boggled. And so I kept that in the back of my mind, I think, the contrast between my grandmother's death and my first birth.

And I started to sort of realize the more that I thought about it, I was working on a book on the family at the time, and so when I was casting around for things to get into once I was done with this first book, I started realizing that I wanted to know more. I wanted to know why we give birth and die the way that we do in the United States, because the reality is that my grandmother's birth is not the norm, or I'm sorry, my grandmother's death was not the norm. Most people die in hospitals or shortly after leaving hospitals. They are unnecessarily traumatized before death with massive numbers of procedures and interventions. People get much, much more care, interventions in general, chemotherapy being one of them. One of the reasons that my grandmother was able to die the way that she died is that she refused chemotherapy when it became clear that the cancer was intractable. So her experience was not the norm.

And so I started to just sort of wonder, what was it? And I actually did not anticipate writing a policy book. What I thought
I was going to write was some sort of political theory sociology book about sort of cultural attitudes toward birth and death and how we've changed our understandings. And then as a political scientist, when I actually started digging in, I realized, "Oh no, this is absolutely a political problem. The sort of tail of culture is being wagged by the dog of politics." But all of this is completely predictable given the incentives that various policies have put into place. So I actually ended up writing a very, very different book than I started.

Anthony Comegna: 06:52 Your story of your grandmother reminds me of this wonderful little book by Simone de Beauvoir, the existentialist philosopher, called A Very Easy Death, where she's writing about her mother's death. It's a reflection on everything that makes life worth living and everything that rushes into your understanding in these incredibly important moments.

Anthony Comegna: 07:22 So I was reading through your book and I was continually struck by these stories of people trying to essentially maximize their humanity in these incredibly powerful and important and meaningful moments, and then being constantly fought every step of the way through by this nameless, faceless, nonhuman entity, the medical bureaucracy, and it is almost as though it's an impersonal force, although of course, your stories throughout confirmed that no, there are very real people behind these terrible policies that we have. And now I do want to dig though a little bit more before we return to the more philosophical conversation, as a policy work, what sorts of research questions are guiding this book?

Lauren Hall: 08:22 Yeah. So knowing almost nothing about healthcare when I started other than my own experiences, I went in with enormous humility. And so the first thing that I did was I actually just started interviewing providers. I started interviewing doctors, I started interviewing ... I had a pretty good handle on the patient side just because I had talked to a lot of friends giving birth. I talked to friends about their grandparents and parents dying. So I actually felt like that part was fairly clear to me, the things that people were frustrated about.

Lauren Hall: 08:53 But I think, especially coming from as a new mother, I spent a lot of time on birth blogs and stuff, birth, motherhood, Facebook groups and stuff. And there's a lot of demonization of providers in those groups. And I actually don't think providers are intentionally harming people. That's just not what's going on. So I wanted to see what providers thought was going on, because it can't be that you go into medicine to help people and
then end up just violating their rights in all of these really foundational ways as just a sort of side effect somehow.

Lauren Hall: 09:27 And the providers were as frustrated as the patients. So when I started interviewing, I started with a couple of palliative care doctors. I started with a couple obstetrician gynecologists. And everybody sort of went down through the ways in which their practices are restricted by various kinds of forces that are outside their control. And it really is a sort of medical bureaucracy with quotes around it. In a recent blog post that I did about the book, I refer to it as sort of the mind flayer from Stranger Things, because it takes on a kind of life of its own.

Lauren Hall: 10:05 So for me, I use those interviews as a way to try to clarify my research questions. So I started actually picking out ... I actually was very unfamiliar with certificate of need laws until I interviewed a gynecologist, an obstetrician gynecologist in a state that has almost no birth centers. And she said, "Oh. Well, the reason is that it costs $500,000 in fees to get through the certificate of need process." That doesn't include what you need to actually rent the space. That doesn't include what you need to do any of these other things. And so I just sort of started making a list of all of these things that providers were mentioning to me. So certificate of need policies came up, obviously. Insurance barriers came up, obviously. And we can talk more about the specific sort of policies in more detail later. But for me it was really sort of, it was pulling from providers where they felt the primary barriers were.

Lauren Hall: 11:02 And so once I had a sort of working list, then I started to really dig into the secondary literature and start looking at, okay, well, what's the actual evidence on certificate of need? Mercatus has some wonderful resources on that. And I just started looking, so are the providers wrong? Are these policies actually doing something that we don't understand, and so they're good and defensible policies even if they have these side effects, or are they policies that are in fact either outdated or cronyist, meaning that they serve an interest group at the expense of the rest of the population. And what I found of course, in many, if not all of the cases that I lay out in the book, the vast majority of these policies are either outdated or cronyist or both. And they do not fulfill any positive purpose in the broader healthcare ecosystem that I sort of laid out. But in fact they do serve to sort of provide a monopoly and restrict patients in certain very targeted kinds of ways.

Anthony Comegna: 12:10 Yeah. One thing that leapt out to me over and over and over again was that you had spent a few pages talking about some
horrible policy and its outcomes and then, but you asked the question, "Well then why would we have this awful thing in place?" And more often than not, it seems lurking in the background is the AMA and some sort of lobbying effort from 20, 30 50 years ago that we're stuck with still.

Lauren Hall: 12:37 Yeah. And that was another thing that surprised me. I mean, again, I went in with pretty open eyes. I was kind of willing to take everything as it came. I did not expect to find what I found about the medical lobbying. I mean, actually, it surprised me how pervasive the AMA had been in really trying to limit competition from alternative providers in driving out midwives in this really clearly systematic way throughout the 20th century.

Lauren Hall: 13:14 And so a big piece of the puzzle for medicalization and why we give birth and die in these uniquely medicalized ways is that persistent lobbying on the part of physicians has kept other providers out. So we have to go to the most medicalized providers, and I think birth is the clearest example of that. I mean, in the United States, 90% of women give birth with a trained surgeon. That is absolutely insane. There's no other country, no other developed country that does that. And we know of systems that exist in the UK and Europe that triage birth, like we triage every other kind of medical event, right? You get the flu, you don't go to an ear, nose and throat doctor, right? You don't go to a specialist. You go to a general practitioner who can assess your risk and then scale you up the risk ladder if necessary.

Lauren Hall: 14:13 But we start birth out as though it's a five alarm fire. And the reality is that that frequently makes it a five alarm fire once you put women in these really unnatural kinds of situations and give them all sorts of interventions that are actually unnecessary and in fact, often harmful. And the same thing is true of death. So you can see the same kinds of patterns. The research on oncology is very clear on this. So patients get way more chemotherapy than they need. The chemotherapy causes side effects that requires other kinds of interventions. And so patients die in hospitals instead of the way that my grandmother died, which was peacefully at home. I mean, let's be clear. She was in a lot of pain. She had terminal cancer. There's no way to make this better. But in her situation, medical care would have made it worse.

Anthony Comegna: 15:02 But now it seems that you're running up against not only bureaucracies, but also there's an element of the Hippocratic oath that seems to run contrary to your argument here, that
these special moments of birth and death should not be fully medicalized events where we're always trying to intervene and interfere and prolong life and things like that. But yet that is kind of what medicine is all about.

Lauren Hall: 15:31 Yeah, and I think too, I mean, one of the themes that kept coming up as I was doing this research was the fact that we've just become as a society much more risk averse than we used to be. And some of that I think comes from the power of medicine itself where there's always the possibility of a cure right around the corner, so why wouldn't you take that opportunity? Why wouldn't you jump on that? Well, you don't want to jump on it because it might have really serious side effects and you have to take into account quality of life versus quantity of life at some point.

Lauren Hall: 16:02 And the same thing is true in birth, right? There was an OB who I interviewed for the book and he said, "At some point you do have to wonder, how many infant deaths can you prevent by cutting open every woman, right, just giving everyone an automatic C-section?" And he said, "I don't know the answer to that kind of calculus, right, how many C-sections is worth avoiding one dead baby." I don't think that's a question that we can answer using policy, using policy kinds of tools. I think that's an answer that women have to answer for themselves in terms of their own risk aversion. So I do think that there is an element of culture that I think is driving the bus in important kinds of ways, but we feed into that culture of risk with the hospital environment itself. So when I talk to hospital providers versus community-based or home providers, hospital providers have just a really skewed understanding of risk, so every birth is a potential emergency. If you talk to EMTs about home birth, they think they're all wildly dangerous and it's irresponsible and should ever, ever do it.

Lauren Hall: 17:16 Well, that's because they only see the negative home births. They never see the 95% of home births that don't require any kind of intervention at all, that happen seamlessly at home and mother and baby are happy. And in fact, most transfers that even ambulance drivers see or EMTs are not in themselves emergencies, right? They're women that are going to the hospital for extra pain relief or something like that. I mean, the sort of weird media representation we have of birth as being like just everyone's always on the precipice of death at any given point is just not accurate.
So I do think that providers get sucked into that environment of risk. And so if you talk to providers who operate in the hospital, they just have a very different sort of attitude. That's not true of all hospital providers. I mean, I actually did a fair amount of interviewing docs with more sort of demedicalized practices who work in the hospital. And one of the interesting patterns, and this is not a scientific ... it's just a sort of observation ... is that many of those doctors get out as soon as they can because they find fighting against the hospital framework, the medicalized hospital framework, to be so difficult.

So I do think that there's some sorting that happens and the people who are more in favor of demedicalized options tend to avoid hospitals. They tend to avoid working in hospitals, and then providers who are much more in favor of medicalized options land in hospitals. And that makes sense that culturally, that's why that would happen. I don't know if that addresses your sort of point.

Yeah. Yeah, I think so. So one thing also throughout the book is this metaphor of comparing America's healthcare system to a river's sort of catchment zone or watershed and that everything sort of funnels into this one central stream. And it reminded me a lot of this ... I'm a historian by trade and there's this bit of new deal propaganda of film by director Perry Lorens called The River. It's propaganda for the Tennessee Valley Authority, which is the one true blue socialist program from the new deal, and it's all about showing the immense importance of the Mississippi River and how many products flow into it and all the millions of men labor hours that go into products going down the Mississippi.

It's full of lines like, "From the frozen wastes of upper Minnesota down 3000 miles to the Gulf, from the steel mills of Pittsburgh down 2000 miles to New Orleans and from New Orleans out to Birmingham and Buenos Aires, clothing the world," things like that. And everything, everything in America just somehow funnels into the Mississippi River and the government needs to get control of it and keep a handle on things, because it also floods and causes a great deal of destruction from time to time. And so I found this metaphor of the river watershed very, very compelling. And I wonder if you could talk us through why you used that metaphor and what importance it takes throughout your book.

Yeah. That metaphor actually came from a suggestion made by one of the Institute for Humane Studies workshop participants, because IHS kindly hosted and funded a workshop on the book
maybe six months before the book was due. So at that point, I had the structure, I had the bones, I had a rough draft, but I knew that there were all of these pieces. And this had really actually been sort of bedeviling me from the very beginning is that there were so many pieces and trying to understand how they fit together was really difficult in my own mind and I knew that it was hamstringing readers too, because it's one thing to say all of these variables compound on each other, right? I mean, and that's what we're talking about here. We're talking about a variety of policies that interact with each other in sort of compounding ways to limit people's choices sort of at the end, right? It's sort of a process. I'm picturing like a PowerPoint process tool or something like that. But I didn't have a way to think about it that really I thought captured how powerful these forces could be.

Lauren Hall: 21:48 And so one of the participants actually said, "It would really help," and he actually referenced another book that I can't remember what ... You might actually know, but he's like, "This person had this really powerful metaphor of a fortress and it sort of framed the rest of the book or a castle versus something else." I'm sure you'll know the book later, but so he said that metaphor really helped him understand. And so I thought, "Okay, all right, that's what I need. I need some kind of metaphor for thinking about this that can help me put it together and demonstrate the effects that it has on individuals, because ultimately I'm an individualist by sort of training and by disposition, and so I'm less concerned about writing a policy book that tells us how expensive healthcare is. That to me is not the major sort of point of interest. Obviously the economic costs are really devastating, but I really, really wanted to investigate the way that these policies affect individuals as they navigate the system.

Lauren Hall: 22:51 So I was driving home from the workshop and talking to my husband and I was like, "Well, maybe ... The word navigate keeps coming up," and then we were talking about this cascade of interventions that happens at the beginning and end of life, which is you make one intervention and then that causes side effects that need to be treated with something else, and then all of a sudden you are hooked up to every machine possible in a hospital and you can't move and all these other horrible things happen.

Lauren Hall: 23:17 So the cascade of interventions is a pretty clear descriptor in the medical literature. And I thought, well, so what pushes people over that cascade? If I'm thinking about that cascade as an actual, literal waterfall, what is it that pushes people there if
they don't want to be there? Well, it's the strength of the current. It's the speed of the current. It's the fact that there's no place to land. You can't get out of the current even if you wanted to. And so over the course of that drive home, we actually sort of worked together to build out this concept of, well, here's what we have. We have three main tributaries that from my research seemed to be the most important policies that influence healthcare outcomes. That's insurance policies starting with Medicare and Medicaid, but leading into the private insurance industry. So you have reimbursement on the one hand. You have liability, so insurance risk and malpractice in that other area. And then that third regulation, or the third tributary is regulations.

Lauren Hall: 24:25 So how do these three tributaries, thinking about it like sort of the Mississippi, how do these three tributaries ... like upstream, they may start out fairly small or in isolation. Each one might not have as much of an impact. But what happens when you thrust them together? Well, what happens when they come together is what happens in a watershed is the volume of water increases over time. And so as you move down in a watershed, the volume of the water increases, you have fewer options, the speed of the water frequently increases, and all of a sudden people who are on that river have fewer options, right? They are swept along by forces that they don't understand and very often are not even aware of because those forces happened so far up river that they're not even aware of them.

Lauren Hall: 25:13 So that I thought was a really nice way of capturing how these different sort of policy structures fit together into this what I ended up calling the healthcare watershed. And so if you picture sort of a person, I'm a kayaker on this watershed, on one of the top tributaries, they might be doing okay, they can sort of paddle, they can kind of keep up. But once you add another force of water into that stream, all of a sudden things get a lot more scary. They can't make decisions as quickly or as thoughtfully because the time constraints have become so clear and all these other kinds of things.

Lauren Hall: 25:54 So that's sort of how the healthcare watershed metaphor developed. And I've found that the more I used it, the more useful I found it because it really does demonstrate the way in which these policies put pressure on people downstream, on the human beings that are living and working in these kinds of environments. And they're pressures that you almost cannot escape from. So in each of my births I worked very, very hard to achieve reasonably non-medicalized births that were consistent with my safety, the safety of the baby and my preferences. And
I would say that in each of those cases my preferences were violated in pretty important ways, not by my providers. My providers were universally awesome, but by just the hospital system itself. So that I think is where the sort of metaphor of watching this water rush from various tributaries into a central channel of healthcare decision making can help understand how those regulations really affect individual people on the ground.

Anthony Comegna: 27:07

Now, I think to sort of close this out here, it might be worth pointing out to people that all of your personal medical decisions are completely within your own control. At least properly speaking, that is how it’s supposed to be. We all have complete and absolute medical choice if you will, protected. But unfortunately, not all providers are like the ones that you seem to have had. And the worst stories in this book for me at least, are the ones that just scream Nazi doctors, where they are forcing treatments on people against their will or without their consent. There are stories of doctors who perform invasive procedures on women when they are unconscious in front of groups of students just because they have an opportunity while she’s passed out for this procedure to go ahead and show the students something else. It’s just full of these terrible kinds of stories of doctors violating patients’ consent or not even bothering with it in the first place. And again, I think the focus on these kinds of stories reflect the humane concerns that go into this whole subject.

Lauren Hall: 28:35

Yeah. And I’ll just add, I think one of the things that I’ve decided to move forward with now that the book is published is highlighting the way in which we really do have a serious informed consent crisis in medicine. We claim all the time that we care about informed consent. You’ll sign consent documents that are meaningless and don’t actually tell you anything. So consent has become this rubber stamp and because it’s become a kind of bureaucratic rubber stamp, it has no meaning at all anymore in the actual sort of way in which doctors solicit your preferences, right, what you want to happen to your body. And that’s exacerbated by the fact that patients often don’t know very much about their specific situation and they don’t know very much about whatever condition they have.

Lauren Hall: 29:26

But informed consent, and I’ve talked to other people who do work in bioethics and other people who do work in medicine, and it’s a much, much bigger crisis than people are talking about. So we tend to focus on bad actor doctors, right? So the doctors who are sexually assaulting patients or performing surgeries for profit over and above what’s necessary or whatever. But we have systematic violations of informed
consent every single day in almost every single interaction that patients have with their providers. And that is what nobody I think is talking about.

Anthony Comegna: 30:02 Yeah. Again, just adding onto that, the portions about racial disparities in healthcare were again, very, very troubling, and the fact that oftentimes African American women in particular are simply not listened to or not believed about their own symptoms or their consent is not solicited.

Lauren Hall: 30:27 Yeah. That I think is an area that is just now starting to gain more traction. Most providers will say that they provide culturally competent, sort of racially sensitive care. But if you actually look at the data and you talk to you black patients, it's a crisis. If you look at the way in which we interpret pain, for example, in African American patients versus white patients, black patients are much less likely to have their pain adequately controlled in both birth and at the end of life. So there's all of these really serious problems and I think the most vulnerable populations, and particularly racial and ethnic minorities are sort of at the ... they're even more on the margins when it comes to the harms. As I think I put it in the book, they have the fewest benefits from medicalization and they received the worst harm.

Anthony Comegna: 31:32 Our greatest thanks to professor Lauren Hall for her time this week and for writing such a wonderful book. Yes, it is pretty horrifying sometimes, but that's only because the dangers here are so bad. If you or anyone you know is entering a period of birth or death in their lives soon, it's worth learning the risks they'll face from this system. And hopefully we can all take some of this knowledge and turn it toward truly helping people when life leaves them the most vulnerable.