

## Transcript

Matters of Engagement podcast

Episode: "Caregiving and Work"

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## SPEAKERS

Jennifer Johannesen, Emily Nicholas Angl

### **Jennifer 00:00**

Hi, I'm Jennifer Johannesen. And you're listening to Matters of Engagement, a podcast examining issues at the intersection of health, healthcare and society.

### **Jennifer 00:09**

So today we're doing something a little bit different. We're giving a shot at making video along with the podcast! So you can watch on our YouTube channel, or as always, you can listen in your favorite podcast app.

### **Jennifer 00:20**

This episode has two parts. We're first going to feature a short talk I gave at the Canadian Caregiving Summit in Ottawa a few weeks ago. I'll put a link in the show notes so you can see what that was all about. My talk was specifically focused on caregiving and work - so my experiences as an extreme caregiver, also trying to earn a living. So after that short recording - it's about 10 minutes - we'll then showcase the conversation that Emily and I had afterwards. It's an informal and unscripted discussion, where we debrief on some of the things that I talked about, and some of Emily's responses to it.

### **Jennifer 00:53**

And it was actually really interesting for me to reflect on my presentation, and also talk with Emily about it, because we've become such good friends over the course of making this podcast. So what you'll hear is the same kind of conversation we have in coffee shops, as opposed to our heavily scripted usual episodes. So first up is the recording of my talk. And then please join Emily and I for our candid conversation afterwards.

### **Jennifer 01:18**

[start of talk given at the Canadian Caregiving Summit] Hi, my name is Jennifer. Thanks so much for having me here today. My son Owen had cerebral palsy. He was also deaf, nonambulatory G tube fed, incontinent, fully dependent for all aspects of daily living. For his complex care needs, he required "extreme caregiving" all his life. I borrow that term from my old friend Donna Thompson! Owen required 24 hour extreme caregiving until his death in 2010, at the age of 12. After Owen died, I embarked on a few projects, kind of to process everything that had happened.

**Jennifer 01:56**

Now one of those projects was to write my book, No Ordinary Boy. If you visit noordinaryboy.com, you can actually download the PDF of the book for free. And I'm mentioning that because it tells a much fuller version of our story than what I'm going to share now. And another project of mine was to earn a master's degree in bioethics.

**Jennifer 02:16**

Now the study of bioethics includes a number of things, like looking at the clinical encounters between doctors and patients, as well as evaluating health and health care policy. And a big focus of bioethics in both of those realms is thinking about scarce resource allocation, like who gets organs or emergency beds, and on what basis. So we're concerned with conceptions of fairness and justice.

**Jennifer 02:40**

But another aspect of bioethics that we consider is the ways that health and healthcare impact our common societal project of supporting human flourishing. So how do our health and health care experiences impact our ability, as individuals and together, to feel fulfilled, and to support our families to build community and to pursue our own goals?

**Jennifer 03:04**

Our topic today is "Caregiving and Work". And there are many ways to think about this from a bioethics perspective. And the one I want to highlight is this: that work is, in our society, one of the very important ways that we as humans build our social networks. It's one of the ways we form our identities, and how we contribute to society. It's how we earn money to enable us to do the things we want to do. And all of these things contribute to this idea of human flourishing.

**Jennifer 03:34**

Okay, so that's work. Now, except for the money part, which is a big one... one might imagine that caregiving, even the extreme kind, offers the same thing. Ask any of us at this Summit, and you'll find that we build strong social networks with fellow caregivers. And indeed, our identities become shaped by our experiences. But in addition to the money part, there's still one more really big difference between work and extreme caregiving. And that is choice.

**Jennifer 04:04**

I was a longtime round the clock caregiver to a child who was born with multiple severe disabilities. And I performed that role out of a profound sense of love and duty. And I think as a result, Owen had a pretty wonderful go of things. But there was something I could never really confess until now. And it's that being an extreme caregiver was never what I had envisioned for my own life. And to be completely honest, for most of the time, it's really not what I wanted. And it also maybe didn't have to be that way.

**Jennifer 04:38**

After Owen was born, I learned pretty quickly that our circumstances were seen by everyone around us, including the healthcare profession, as a personal tragedy, and that what we were grappling with was my

family's problem and ours alone. I can see it now, that I felt stuck in my role, and, frankly, in my life. And while we did muddle through, my caregiving responsibilities took an immense toll on my own opportunity to flourish in the way I would have wanted. I abandoned my own personal priorities and ambitions, in order to keep my son alive. And not only did he of course depend on me to do that, the health care system did too.

**Jennifer 05:18**

For me to access anything available to us through community or systemic supports required an absurd amount of effort. I was endlessly having to prove that he was disabled enough to receive services. I even had to find my own (funding) flow-through agencies to manage money that Owen was entitled to, I had to find creative ways to cobble together a paid support network so I could just somehow grab moments of sleep. And to paint a picture of how vital this was: for his entire 12 years, Owen could only fall asleep and stay asleep if he was being actively held and rocked. My very survival depended on having paid support. And all of that work doesn't even begin to account for the time and energy spent on his therapies, his interventions, his schooling, or managing his many, many illnesses and surgeries.

**Jennifer 06:09**

In my case, my extreme caregiving era had a beginning and an end. I was 28 when Owen was born and 40 when he died - which, frankly, were the years I had been thinking I would be able to build my career while raising my children. The career part had to fall away. And I did indeed grieve that for a long time. It also left me in a position of complete financial dependency. I was reliant on both my partner and the state to not only provide a safety net for Owen, but also for me. I was in the prime of my potential working life and had no means of supporting myself, or investing in my own future.

**Jennifer 06:51**

Now, I do have to say that for sure, my partner - the boy's dad - also faced challenges as a father of a child like Owen. But his career plans weren't thrown off course. And his ability to work was never impacted. And as our relationship was breaking down and we were splitting up - the boys were around six and eight at the time - their dad didn't have the same financial concerns I did, especially when it came to self sufficiency and earning an income.

**Jennifer 07:19**

I am now 53 years old. I had about four years of salaried employment before I had kids. I was a full time extreme caregiver for 12 years and have been self employed since. Now, these days, I also look after the affairs of my elderly mother and support my other son who is about to enter university. So even as I've been building a career finally, the financial pressures haven't let up and I do have to keep working at a high intensity. But I see that many of my peers are starting to think about retirement, or at least contemplate how they can end their careers on a high note. Some are making plans to enjoy their empty nests. But those of us with extreme caregiving responsibilities, either currently or in our history, we're on shaky footing in terms of career finances, or both.

**Jennifer 08:09**

So let's circle back to this conception of human flourishing and our society's expectation of a right to pursue fulfillment and happiness. There are some things we collectively deem fit to support in this regard, right?

Especially when it comes to nurturing families. Things like maternity leave, subsidized daycare, family tax breaks and benefits. But this level of extreme caregiving that I've been talking about doesn't even register at that level. What we do is just seen as an extension of unpaid domestic work and family responsibility, with the cost felt predominantly, but of course, not exclusively by the female in heteronormative pairings.

**Jennifer 08:50**

The requirements of this unpaid work are so all consuming that employment is often impossible, which essentially keeps us the caregivers in permanent financial dependency to a partner, to family members, to the state. And if and when the caregiving responsibilities end, we're basically no further ahead than when we started. In fact, we're often quite behind.

**Jennifer 09:14**

So you might ask, what do we do? Well, from a workplace perspective, we can consider ways of perhaps adjusting how we think about qualifications or education equivalency, and think about employer expectations, and maybe how we can translate our caregiving experiences to mean something in the workplace. Excellent ideas, of course, but I think this would require shifting some pretty deeply held embedded cultural norms. So while super important, I do think that's more of a long game. But we can also approach this from a policy level and decide that we want to live in a society that sees extreme caregiving as a shared responsibility. Not just a terrible bit of personal bad luck.

**Jennifer 10:01**

As part of this push for a national caregiving strategy, there are lots of interesting policy ideas being tabled, including mandatory CPP contributions for caregivers, universal basic income (one of my favourites), paid caregiver leave and caregiver health benefits. And these are some of the ways that society can help ensure that caregivers get the support they need. And I wanted to end on this note, because while stories are powerful, they can also shift focus to pity when what is really needed is systemic change.

**Jennifer 10:34**

So I'd like to conclude this session on caregiving and work by saying that caregiving, especially the extreme kind, is work. It's unpaid, and relentless, and it has an immense opportunity cost. It leaves us with few options for income, investment and careers and future financial stability. I hope these discussions at this Summit can spark some new thinking about how to enable caregivers to participate in society and working life in the ways that we choose to. In other words, to give all people a chance to flourish. [end of talk]

**Jennifer 11:11**

We're doing something a little bit different with this so that we can have some or we can have some visuals with our little podcast production. And we're gonna see how it goes with an experiment.

**Emily 11:20**

It feels like an experiment. It's kind of fun.

**Jennifer 11:27**

Does it feel weird? Because usually we're so scripted

**Emily 11:29**

It feels weird. It feels a little. I don't love cameras in general. But I will do it for this. And for you. I will do it.

**Jennifer 11:39**

I feel a little untethered. Because you know, me, I like my like my script.

**Emily 11:42**

You like to be scripted.

**Jennifer 11:43**

I do like to be scripted! But we'll see how this goes. So why don't I just described what we're talking about today? So last month, or maybe it was... yah, I guess it was last month at this point - I was invited to speak at a conference called... or it was hosted by the Canadian Caregiving Center of Excellence, which is a funded entity, funded by private money, the Azrieli Foundation, and they're advocating for the development of a national strategy for caregiving. So a way to support people who have to take time off work, or who maybe are under employed in a traditional fashion who are needing to look after a family member or a loved one could be a child, a parent or sibling. They're advocating for things like health care for caregivers, CPP contributions, perhaps insurance, or some other types of insurance of some kind, maybe even income, other types of supports. So that was the conference and the stream of topic that I was involved in was called Caregiving and Work. So it was specific to parents of young adults who have severe disabilities and the extent to which we've been impacted in our ability to work and earn a living.

**Emily 13:02**

Yeah. And it's a little different for you, because you know, you're talking, I feel like especially of late, you've more been talking about, you know, your ideas about whether it's patient engagement or different health care concepts, broadly, but not delving so much into your own experience. So directly maybe as a caregiver? I think you're always referring to it, or you might allude to it, but this was much more asking you to reflect on your experience. As opposed to come up with like a thesis. So yeah, that must have felt a little different.

**Jennifer 13:39**

It did. And it's something that I'm very conscious about, you know, in the early days of my engagement experiences, I guess, as many people I started out as someone who would sort of testify, I suppose, and give my personal story and talk about my experiences. And it just felt it started to feel exploitive, and kind of draining. And like I was performing my story for people or performing my experiences to elicit some kind of emotional response. And I felt like a kind of supporting actor in something that I wasn't quite clear on. And so that's partially why I wrote the book that I did and why, since then, I've refrained from being involved in a lot of storytelling.

**Jennifer 14:24**

And, yeah, I'm not sure what shifted for me in this one. I think it's a combination of things. One was my friend Christa Haanstra asked me to, so I gave it serious consideration - more so than I perhaps would have had if it had been more of a cold call. And I also feel like this topic of caregiving and work is something I just had never really thought about before. It seems obvious to me now that of course my life trajectory has changed quite a bit based on the fact that I've been what I call an extreme caregiver for 12 years. But the fact that it continues to ripple through my life or have an impact now... it hadn't really occurred to me. And so it was interesting to dissect my own life and experiences and try to package it up in a 10 minute talk.

**Emily 15:18**

It certainly sounds like, you know, it's hardly as if they were saying come and like, tell us your experience. And just tell us a story. Like, that doesn't feel that sounds. You know, you're more in line with what you what you do in the sense that there was a specific topic. And there was a specific, kind of like an academic frame or like something that you were going to use as a structure to what you were talking about. And there was a purpose to this event, which was to have some sort of change happen within the system, as opposed to come talk to this group and hopefully, you will just move them [crosstalk]

**Jennifer 16:02**

That was a key piece - there was an agenda for the conference for the session. We talked a lot in our prep sessions around what our objectives are, what do we want to convey? And what is the purpose of the conference. And it felt like much more of an advocacy effort than other conferences I've been involved in. And I think that's something you and I've talked about a lot with the podcast in general, that these kinds of community-based, needs-based messages feel like for me, they feel more worth supporting than institutional objectives. I mean, I guess one could argue that or, I guess, one could assess this from a number of angles. But for me, I could really feel the kind of lobbyist activist vibe in the conference. And that was kind of nice, actually. It was refreshing.

**Jennifer 16:59**

I'll just say this off the top - is one thing, I feel like this was a really nice opportunity to look at some of these ... usually talk about caregiving focuses on how fulfilling it is, and how it's this act of love, and that we love our people we look after, and we just want a bit more support. And I think those are all valid and important things to say, and certainly things I've felt. But the cost of it, and the opportunity cost and the toll it takes I think there's not often a lot of room to think through those things, or to talk about those things. So this, and particularly around the question of choice - most people would not opt to do this and don't sign up for it.

**Emily 17:51**

I think that was a really key differentiating factor when I was reading this, because given the sort of work we both do, I actually sort of feel somewhat different from what you said. Which is I feel like I talk and think a lot about the difficulty with caregiving because I'm around the engaged caregivers and concepts around, you know, changes to paid leave. Just because of the spaces that I go in around engaged patients and engaged caregivers. However, I think broadly, you're correct from like, you take a step back, or you read about stories in the news or

things like that. I do think there has been a shift in the last few years and particularly with the pandemic to realize the necessity particularly what happened with older adults in care homes and this unpaid caregiving.

**Emily 18:47**

But I think that choice part really was interesting. That was sort of the crux of the whole thing for me because it distinguished even concepts that are different from choosing to have a child or choosing to take on paid caregiving work, things like that. Because we do lump in terms of policy and in terms of concepts around... when we talk about caregiving, often when you look at government... it says paid and unpaid and all of these things... kind of get lumped together. So this idea about honing in on extreme caregiving, and in particular, this talk, of children, it doesn't mean it can't apply otherwise - but this idea of choice - and I wondered, you know how much you think those sort of differentiating factors are important when we think about policy, in terms of differences in policy for, for someone like a person in your situation where you have a child who was born with the type of needs that there's no way you can work. Versus paternity leave and maternity leave and I suppose also what we might expect is that for aged parents, we might say, you know, that's just an expected thing. It's not something that you have choice over. It's just the way that our society works. This idea of choice. So how it would affect or how we should think about it in the policy realm?

**Jennifer 20:18**

You're right. It's seen on a continuum of family obligations and family responsibility. I'm not sure if that's what you said, But that's what I'm picking up on. It feels like it's part of a continuum of expectations on parents and families to manage the people in their family, like the people that they've either bred themselves or their own parents or whatever. It just seems to be as part of our responsibilities to our family. Where I think we would do better is to compare the responsibilities of the extreme caregiver to the experience of somebody who suddenly finds himself with a severe or chronic illness themselves or incapacitated in some way because of an accident. You know, there are many more supports for people who find themselves in dire straits physically, or from a health perspective, as opposed to the caregivers themselves, who are seen as obliged, perhaps, to look after their charges. So I anyway, I guess I'm just thinking that it's no more a choice for most caregivers than it was for somebody to experience a fall off a ladder or something like that. It really does sometimes feel the same way, that it's this external force that happened to you through no choice of your own. And, and the degree to which society steps up to support some of that is I think really lacking for caregivers.

**Emily 21:53**

Do you think that has anything to do with this sort of non binary? Like, if you have a child versus you don't have a child? That's pretty obvious. Versus where would you draw the line at what's extreme caregiving? Or what warrants being, you know, fully subsidized, or subsidized, versus what is just considered you having a child at home who has some needs? And I sometimes wonder if when, you know, policies or government shy away from those things, it's this idea of, like, a slippery slope, or a non clarity of where that would be? Or who would get it and who would not?

**Jennifer 22:32**

Yeah, it's hard to pinpoint because, you know, you can argue that every child is special, every child needs... you know, there I know of many I'll just say in air quotes, you know, normal families where the parent, typically the

mother decides, at some point that they're needed at home to manage as their child starts school, or they need to have a flexible work schedule because they want to volunteer at the school or because the child needs extra help with homework or, you the other partner is traveling a lot. And so they want to be home to make lunches and these are all obligations that creep into one's life, and you start to refactor and rethink your own priorities or set aside your goals in order to fulfill expectations for the family.

**Jennifer 23:25**

So yeah, all of that is a bit murky as to where extreme caregiving starts and stops. I mean, I don't know where the line is. But I will say that for most people who identify with this term of extreme caregiving, usually there's some degree of medical intervention and skill that's required to manage the life of somebody to manage their survival, frankly. Often there's a complete lack of sleep. There's a lack of social connection, there's very little time for nurturing relationships, friendships, personal health, and wellness. So it's an all encompassing, give up everything, or else the person you're looking after dies. That's kind of what I mean by extreme caregiving. So I can see why it can get conflated with this continuum of family care, and where, like I said, where that bright line is. Like, where this is this and this is this. I don't know where one would draw that line. But I do know what extreme caregiving looks like and I think anybody who has experienced it would know what to call it. And what that looks like.

**Jennifer 24:39**

It was floated at the conference that if somebody, if the person you're caring for qualifies for disability supports, through our normal kind of gatekeeping processes of you know... if you're on disability for tax reasons, or if your child is considered a dependent well past the age of what a dependent usually is, then that's one way to signal that there's probably an extreme caregiver involved. And that, you know, if you can tie a person who is known to have a disability with a caregiver, you can kind of paint a picture. That's a little different than just a normal family constellation, or situation.

**Emily 25:30**

It makes absolute sense. And I think sometimes the arguments about like... but how would we know? Well, sometimes it's actually just like, well, of course, we would know, at least when you know exactly where the line is, maybe not. But there are certain things that I think would absolutely qualify. After reading a little bit about it, you know, one of the things that seems to be... in the past what would be done is offering more services, versus... so the payment or the support and recognition is not for the person who's caregiving, but it's for the services that the person needs, and then those become outsourced, or that's what the health system pays for. And I feel like through the pandemic, maybe that shifted in terms of... even from a scientific basis, like the recognition of the limits, the particular type of needs that are met by family caregivers... that even if it's the same type of care being given by somebody else, it doesn't have the same effects or there's other repercussions. And also the amount that was going unnoticed that you think like well, I provide a personal support worker, but maybe I liken it to the concepts around or like emotional labour and, and the amount that it takes to just manage those things. Do you feel... previously that's been more of where, where answers have gone? is getting more services versus supporting the caregivers?



**Jennifer 27:06**

Well, there's a couple of things. One is, you're right the services that are provided to the person who needs it, whether it's developmental, or around access, or social supports and things like that, it takes a lot to apply for them, to continue to qualify for them, to administer them, to bring the person to their activities. And to also open up your home to workers that come and go. And they're under their own kinds of employment contracts and are allowed or not allowed to do certain things. And so managing all of that requires a significant amount of work. You can't just let it unfold, nobody's managing it for you. And nobody's doing all the paperwork and the tax returns and all the qualifying documentation and things like that. And so yeah, there's all of that.

**Jennifer 28:00**

And then in the case of a child, and possibly even an adult, you have to constantly prove the need. It's not as though somebody's going to grow their leg back or that a child, like my son, was going to suddenly develop skills that allowed him to be independent, or more independent. So I suppose it's possible. In other cases, certainly, that would be the case. But the fact that there was no way for me to just say, Listen, Owen is who he is. And he's the same as he was last year. And the same he was two years ago, can we just carry on with what was... like the funding or the services? Every year was a new application and a new argument to be had. And there's a strong sense of having to really fight for the maximum services. So there was there was always a degree of having to convince your caseworker that you need as much as you're saying you need. So yeah, the work is extreme, no matter what, even if you access the services that that are provided.

**Jennifer 29:04**

...the kind of appropriateness of what's been offered as well and the professionalization of a lot of services that don't need to be professional. Well, I mean, maybe they do for other reasons, but for the sake of quality of delivery of care. It's kind of nonsensical, frankly, like all these constraints on who I could hire, who I could have supporting my family. They always needed to have certain training or be an RN, or be a PSW, have a credential of some kind when typically, for our needs... I learned how to change his G Tube. I don't see why I couldn't train somebody to do that. You know, so it was, um, I guess I'm veering into maybe dangerous territory.....

**Emily 29:54**

Well, I was only going to call you out a little bit there because I was like, that's literally something you have said previously when we've talked about engaged patients informing the system and directing policy and stuff is, you know, how much does your knowledge or your caregiving experience should we extrapolate to broader policy or concepts around what should be done....

**Jennifer 30:18**

Oh I'm not talking about training people to deliver care to other people, I'm talking about hiring people to look after my son, where some of the funding was attached to hiring someone with a particular background.

**Emily 30:34**

How do you get around that in terms of safety mechanisms, or ensuring that there's some sort of standard or that the person isn't putting themselves and their child at risk? I'm, of course not saying in your situation, but like...

**Jennifer 30:56**

Well, there was nobody double checking that I was doing things right. Yeah. And, you know, to be fair to it's not as though I'm talking about changing a trach, or something, you know, or giving injections of some kind, or, you know, these were more like...

**Emily 31:14**

Yeah like if I hired a babysitter, yeah, like, and I'm not suggesting my son has the same sort of needs... I just mean, nobody has any problem with me hiring, I literally have hired like, 13 year old kids to come, and they took a babysitting course or whatever. And I'm just cognizant, as you're talking, though, of kind of this layered aspect that there seems to be. Because you're talking about the exhaustion of the doing of it. But then there's this, what you're just talking about the exhaustion of getting somebody else to do it, potentially, if you were not to do it. So booking the people having them in your home negotiating with them. It's kind of like being a manager. I mean, even when I've done it for my own health, I used to say it was like having a second job. And then the kind of lack of what I'll call flourishing, you kind of use that term, but literally, every need that might fundamentally keep you stable to do that kind of work, by definition kind of can't be met. Because of the type of work it is.

**Emily 32:22**

So you're in this absolute cycle and kind of catch-22 where because there's not really support for you on any of those levels.... I mean, I might liken it to the kind of support workplaces tried to do where we're like, don't worry, we have a yoga room. It's like, don't worry, you get one day a week where somebody comes and does a da-da-da, or like don't worry, there's a care place around the corner, and you can drop them off for an hour. Lucky you. Or like, they're probably offering you like a free massage. Like all of the things that we sort of assume would help are not the structural issues at play. And so, I mean, I've always been aware that it's basically like we're creating this new group of ill, overworked people. And, yeah, it's more of an observation just as you're talking and a bewilderment I suppose, that that is what happens to people and I've seen people and you've shared your experienc.... And anyways, I'll let you respond to that.

**Jennifer 33:24**

I mean, it's imperfect. You know, I don't have answers for that. And I think that there's a kind of an umbrella of sometimes life sucks category that this falls under - you can't fix it all through policy, or you can't fix it all through provision of services and things like that. But I think, you know, what becomes clear is that where, particularly in the context of caregiving and work or employment is that money can go a long way to helping with putting back some choice into the obligation and removing some of that financial precarity that a lot of caregivers experience because of their work or their caregiving commitments and requirements. And there is nowhere to put your disabled child safely and still be able to pursue the same kind of life your neighbor down the street does. At least that was my experience.

**Jennifer 34:26**

And so I think if at least some of that can be alleviated through payment through healthcare, like through health support for the caregiver, maybe some self direction of funds or autonomy in terms of how you want to spend the money, that it's not all just through programs, and hours and facilities, that you can choose to create a life

for the person you're looking after, but through self directed funding. And for some people, that also doesn't work because it puts all the responsibility on them. It's like here have some money, and maybe the problem will go away. So it comes back to perhaps some degree of choice. Like, what sort of level of support do you want? And what sort of need do you have? And would you prefer money or people or perhaps a case manager who knows all the ins and outs of all the systems and can walk you through everything. That doesn't exist, either. So a hybrid approach maybe would be a good answer.

**Emily 35:35**

And also maybe it comes down to the fundamental conceptualization of what we're doing it for. And I think that's something that, as I was trying to look into a bit more about this, this idea that by funding caregiving or supporting caregivers, there could be one moral argument for it. Because everyone has the right to flourish, or everyone has the right to feel well or have work or function on their own, to have autonomy or whatever we want to frame it as - it's hardly my area of expertise. But we could also frame it (and people do, sorry) as this is to the benefit of all society, and even economically speaking for the government, to be supporting people to look after, in the best way possible, the people who are in their family. As family caregivers, us funding that societally is at every level kind of a investment.

**Jennifer 36:33**

Nobody is immune to the possibility that either you or your family member is going to be faced with the same thing. And so it's not just collectively we're all aging - but you're aging, I'm aging, our children will be aging,

**Emily 36:51**

We all have a personal stake in it.

**Jennifer 36:53**

We all have a personal stake, there's personal risk at every corner. Your husband, your child, you - you know, anybody could need something from a family member. And so to be looking at caregivers as like, Oh, those people over there, they need our help. It's not a complete kind of story. It's not about charity, or about being nice to the people who are less fortunate than us, I don't think. I don't think that's a comprehensive enough view. I think we also need to acknowledge that we are all vulnerable and all precarious, in different ways.

**Emily 37:33**

Do you think there's a distinction between like... for instance, when I think of my son, I feel like I would say like, oh, I'm a parent to my one son.

**Jennifer 37:41**

Yeah, not as a caregiver.

**Emily 37:42**

But I feel like if my son had a disability, or needed to be... like I would say, I'm, you know, I, I'm a stay at home caregiver to my son. Yeah, I would make that distinction, which is interesting, isn't it? Like, even though policy wise, we might lump everyone who does caregiving, there is this distinction between - if my parents even were

getting a bit older and they just needed some help, I probably wouldn't call it caregiving until they got to a certain point. And what that point is, would probably be very interesting to a policymaker - like where is the point where that person needs support to be a caregiver? But I even think just semantically, there'd probably be a point where I would flip over to saying I'm a caregiver to my parent. And I wonder too, if like, just to pivot slightly to a really key theme within your piece, but I also wonder how that would be gendered in terms of people calling themselves a caregiver? Like if my son was home, and both my husband and I did a lot, but I sort of did more, would I be the caregiver? And he would also help but he was still working, so he technically wasn't a caregiver? Do you know what I mean?

**Jennifer 38:56**

Well, I think we're accustomed to identifying who is the child's primary caregiver. We use that term, I think, right, in everyday life? You have to say who? You know, so that they don't say "parent" because sometimes...

**Emily 39:14**

Yeah. Backup emergency person.

**Jennifer 39:17**

But you know, you raise an interesting point. I mean, it would be interesting to ask Michael, the boys' dad, if he ever identified as a caregiver. Probably not.

**Emily 39:30**

If you are still working even. Even if you had still been working, like do you identify as a caregiver until that is what you do?

**Jennifer 39:38**

Your primary role.

**Emily 39:40**

Yeah, I probably do more with older adults than maybe with a child. But anyways, I think it's really interesting. And I do think there must be a gendered thing there too, in terms of how easy it is to allow yourself to be termed that or to think of yourself in that way. And I knew, I mean, you brought up concepts, obviously, that are borne out in the data that you know, women tend to be in these roles significantly more than men, and probably particularly for something like a young child. Like, I also wonder about the choice part with gender. Like, if it feels you had no choice but to become... whereas maybe a male might feel more that it's their choice whether or not to take that on or to keep working or not...

**Jennifer 40:29**

There's definitely a negotiation. It's not like "I choose, you choose, we're each choosing". As a couple, if that's your configuration, you know, we definitely had to make some decisions together about what made sense. And I knew for me as a new parent and as Owen being my first child, I was all in. I was like, there's no way in hell you're gonna stay home, I'm staying! I'm managing this! Because it was just how I felt and there was no discussion. Not "there was no discussion" but that WAS the discussion. This is my role. And my partner was

making far more money than I was. So you know, the question of gender starts long before the moment of "who's going to stay home?" You know, it's not like a coin toss. There's all kinds of social and financial things that predate that moment, that dictate what makes sense. And so of course, it makes sense, because Michael made more money. And I had just undergone a whole bunch of trauma, essentially, from the diagnosis to surgery in utero, early delivery, all the trauma of the NICU and all of that. So I was invested, you know, this was my project. So yeah, it's hard to comment on it in isolation, because I think all the rest of society is still set up really in this way to uh, yeah, I guess it pre-determines that usually it's the woman who's going to stay home and do all this.

**Emily 42:15**

And I guess that brings to mind what fundamental other changes need to shift to support even good caregiving policies? What cultural shifts, whether it's from policy to just like, broadly, the way that society sort of functions need to shift so that even if we do institute new policies, these things are more equitable, or these things are, like you said, like, if we change the policies, and we support people, but there's no pay equity, and women are not as represented in certain fields, and women are over represented in caregiving anyways. And there's some things that in terms of bearing the child and things like that won't change. But yeah, I think when we start to narrow in on specific policies like things around caregiving, it does start to question what shifts would need to happen to support the implementation of that being equitable and also sustainable to function well?

**Jennifer 43:30**

And I think it's also not just limited, of course, to just gender questions. But to expand on that, too. It's questions about ableism and what is it we're asking of... so in my case, what we're asking of parents to fix or to act upon the child and to try to normalize or mainstream your child even in the face of extreme unlikelihood or adversity? What are the expectations on parents to go above and beyond?

**Emily 44:10**

It's almost like it comes back to choice again, a little bit. It's like, now here, you don't have choice again. It's like, here is what it looks like to take care of your kid. Here's what it looks like to have a "functioning to the best of their ability" child with this diagnosis, or we should always be optimizing x y z. And that's not your choice. That's like we'll only fund it if it's this or will only support you if you try to do this. And that's so... I can't even fathom Jen. Like all of the feelings you must have. Like where do you put all those feelings?

**Jennifer 44:49**

I wrote a wrote a book!

**Jennifer 44:53**

I remember at one point there was an occupational therapist, who we had who I really liked. She was very keen on these tracking sheets when Owen was... we were doing these interventions around communication and hitting the switch to signal a light. So that it was like a yes or no and doing activities around communication using assistive devices. And she was really keen on me filling out these tracking sheets. I was like... do I have to? And she's like, Well, the truth of the matter is if I don't show progress, I cannot keep coming. So we need to. She was basically winking at me, like, show that he's getting better. However minute the changes are, and it means I can continue to come for under your program that you've signed up for. And there was a little bit too of... there

was a bit of an edge of performance review for her to show that she was making an impact. So that she wasn't just coming to the same child's house for four years and there not being improvement.

**Jennifer 46:02**

And it was very subtle the messaging there, but she was keen to demonstrate that she was actually having an impact. And for my benefit, making sure that she could keep coming, to engage with Owen and give him the best chance to keep learning and things like that. But he had to show improvement. And that also felt like this really backwards kind of pressure on me to perform as a good parent, and to make sure he was performing as a good little disabled child, and continuing to improve so that everybody's narrative, could, you know, could be happy and fit in.

**Emily 46:39**

How much do you think that that could be shifted with maybe methods that we currently go to like: well, that's why we need patient reported outcome measures that are like, this is what the goal should be from the framing of the patient. Or this is why we have to do shared decision making in terms of goals, or this is why no patient should lead the... versus we need some sort of fundamental restructuring of things. Like, do you feel like it would have benefited you if if those goals or the things that she was trying to show, were more in line with things that you felt like actually mattered?

**Jennifer 47:16**

I mean, it's not that those tasks weren't aligned. I recall saying things like, you know, I would love for Owen to be able to express a preference to be able to tell me which shirt he would like to wear, or what activity he would like to do next. I would love to get that kind of feedback, I don't know how to draw it out of him. And so the OTs, particularly in the communication realm, had tools. They had ways of trying to train or teach skills. It's very slow and there's many approaches. And there's different things you can harness in a person, whether it's a movement, or eye blink, or the way they breathe, or the thing they look at - you can try to turn those into communications skills, in a way.

**Jennifer 48:09**

So it's not that it wasn't aligned that way. And I just felt really trapped by how long everything took. And and nobody ever said to me: What if? What if the priority was more about enjoyment? Or what if we look at all of the things in your family's kind of boundary. You know, like your other child, and your need to work, and your need to sleep, and Owen's need for quiet time? What if we looked at everything instead of just "Oh, what do you want? Oh, I want him to communicate! Okay, let's just plow through with that, full steam ahead, and then spend all your waking hours doing that. There just wasn't a more robust conversation. So I think to your point, something slightly more holistic. Not slightly, a much more holistic view on it that did not prioritize this kind of almost impossible, performance metric.

**Emily 49:18**

I don't know where we want to take this conversation to but I do want to say how much I appreciate this conversation because like, as usual, I get very resonant with people and I'll get compassionate, but then I get

excited and talk a lot. But I also am aware that this is probably more that we've ever talked about Owen. I mean, we talked a bit about the book and there's been times on his birthday or something. We've talked a bit like...

**Jennifer 49:45**

That's true, isn't it?

**Emily 49:45**

I don't think we've ever talked for like an hour and something just about your experience as a caregiver and that's pretty significant. Like, I think. It's significant to me, because I love you. You can take that out if you want but....

**Jennifer 49:59**

Yeah it's a rare moment that I actually put myself back in that time to think about how it felt and what I did and all of that. So it's nice to occasionally dip back in. Sometimes it's harder than others emotionally, and some of the emotional difficulty is in me being, in our typical meta fashion, me being aware that I'm not as connected to it anymore, that so much time has passed. That it's, in fact, an entire lifetime of Owen's that has passed since he died. And so going back even further than that, I sometimes... I forget. Like, I'll have to look at pictures to remind myself or read some of my old writing or flip through my book to kind of remember what my experience was at the time. So I definitely have recollections and ways I process things now. But putting myself back in those moments can be difficult, partly because I'm aware of how long ago it was. And that there's something like... it should feel more present somehow, or it should, it should be more.... I don't know, I, I sort of feel like...

**Jennifer 51:14**

I guess one thing I'll just sort of conclude with to an extent is, um, you know, we were talking like, as, as I'm sort of moving through all the different phases of my life.... and we were talking the other day about work and income and salary and all of that. And I realized that, you know, when I compare myself or look at other people who are still looking after their adult children or their young adult children, or people who have been making efforts to get into the workforce and have been really struggling.... I know that I've been fortunate in that. First of all, I had developed some employable skills before I had Owen - so I was a web developer before, and I returned to web development after. And certainly, as I was managing, going through his life, I learned a lot of project management skills, a lot of ways of advocating for him and for myself and for my family that have served me well since then.

**Emily 51:14**

I've heard that a lot from people who've had children die, or to say, like, you know, you have a day where you don't think about it, or you have a moment or when you think about it, it doesn't have that absolute penetrating feeling for one hour of the day. And that there's this guilt of. like, I'm supposed to feel a certain way, about things...

**Jennifer 52:46**

So I think I've managed to carry on with my life, collecting up skills and abilities and being able to apply them now. And not everybody's in that position. We're all across the spectrum of socio economic status and capacities

and mental health and our abilities. You know, all of that. And I know some people whose children maybe didn't live as long and whose caregiving experiences were much longer ago - and it lives with them every minute of every day. And, you know, the fact that I sometimes forget or I have trouble going back to that spot - there's a bit of compartmentalization there that allows me to carry on and still be a motivated and ambitious and to be thinking about my future. Whereas I think in some other context, that's a lot harder to do.

**Emily** 53:43

But I think it's relevant and I think it's an important thing to point out that we weren't trying to comprehensively go over the experiences of caregivers today or solutions to caregiving. We are exploring your talk and your experience, and it would have kind of been - unfair is the wrong word - but like, a bit presumptuous - if I had started to delve into ideas too much about the experiences of what.... I wonder, what about the experience of these sorts of people in a different socio economic bracket or who have a non heteronormative household or who ... I want to make sure that, you know, we were talking about your experience and not expecting... and you would never advocate for this by all of the things that you've ever said!... that we extrapolate from you to inform, more broadly, anything. But I do think it's, you know, it's an important perspective, it's important to hear the difficulties that people can go through and I certainly think that it's informative in the sense that it's shown me an experience that I hadn't heard before. But I do think it's relevant for you to have said what you said and that we make it clear that that isn't the purpose of what we're doing today.

**Jennifer** 55:08

Yeah. Okay, let's leave all this in.

**Jennifer** 55:13

This episode was written and produced by Jennifer Johannesen and Emily Nicholas Angl. If you'd like more information about our podcast, please get in touch through our website at [mattersofengagement.com](http://mattersofengagement.com)