

“Letting people know that it’s ok to be your original self”: Talking about breast cancer & autistic community with Melanie Keiling

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Transcribed by Julie Ann Lee

(Theme song – soft piano music)

ABK: Hi everyone, and welcome to Noncompliant: The Podcast. I’m your host, Anne Borden King. Today I’m speaking with autistic advocate Melanie Keiling. Melanie is an autistic mother of autistic children. She runs the blog [Autistic Grandma](#), and campaigns for autistic human rights and works with the autistic community directly to provide emotional support for individual self-healing, self-care and personal development. Her goal is to create a strong community by providing a platform for change in the way autism is viewed by the world and to help gather autistics to gather to support one another.

Today, Melanie and I are going to talk about her blog and the supportive role of autistic communities, then we are going to dive into the topic of health care, specifically cancer care and the biases that still exist within it, especially towards women and non-binary people, and also towards neurodiverse people or neurodivergent people. And we will come up with some pathways towards changing things for the better.

Melanie, welcome to the show!

MK: Hello. I’m glad to be here. Thank you. Thank you for having me.

ABK: Thanks. Let’s start with the big news. You got your first COVID vaccine a couple weeks ago. What was that like?

MK: I did, and it was a surprise because I did not realize they had opened up the [age] 50 and above category. I’d been waiting patiently. And it was painless, I didn’t even feel the needle go in and the injection is so tiny. I mean, if you’ve ever had any bloodwork or any other kind of injection this is really an easy one. I developed a reaction at the site, a little bit of fatigue. Like, I could really feel my immune system working.

ABK: Hmm.

MK: But here I am. I’m ready to get my second dose next month.

ABK: Amazing.

MK: I hope everyone does.

ABK: Mm-hmm.

MK: Everyone that has the opportunity, just go and do it.

ABK: Mm-hmm. Through all this pandemic, autistic people have been helping each other through. How have you seen these networks of support within social media, for example on your social media pages?

MK: Well, on Autistic Grandma. I mean... I have cancer, right, I don't always feel well because of the medications I take, so sometimes I kind of back off and I'll just go a day or two without even opening Autistic Grandma, and I have this community of people that steps up and starts giving really great advice to strangers about how to support their children, just advice on different techniques on how to reach and communicate with their children and I'm really impressed with my group that I've kind of put together.

ABK: That's amazing.

MK: Yeah, and that was my whole goal – to make a really safe place for people to come and ask questions and support each other through the autistic community supporting each other, and there's been a lot of that. A lot of people stepping up. Sometimes I just go on and I'll say 'Message one of your friends and check on them. Just say hi, because you know, we're all stuck until we all get the vaccination.'

ABK: That's right. And how does being a parent impact your blog and social media and the work that you do in the neurodiversity movement?

MK: Well, for the last 22 years, all I've done is raise autistic children and I'm getting old. There's been a lot of change since I entered the autism realm, if you want to say it like that. A lot of changes. When my oldest son was first diagnosed, I googled – I don't even remember if there was google back then--but I looked it up on the internet and I got *Rain Man*. That's not the way it is anymore. Now there's lots of support out there and I want to see more. I want to see people supporting each other in each community.

[sound of children playing in the background]

ABK: Well, we were seeing so much change so quickly as people become aware of the neurodiversity movement and you're a part of that change. Like, how long have you been involved in this kind of work?

MK: Just about two years, I haven't had my blog going for very long. I was really just living, you know, as a hermit, and I reached out and I met **Amanda Seigler** first. And she kind of brought me in. I was going to therapy and my therapist suggested that I start journaling and it just kind of bloomed into a blog... trying to heal from my own childhood and heal my own wounds. Going from the journal to the blog it just naturally happened.

ABK: Right and of course with raising kids, it brings everything up from our own earlier lives as well, right?

MK: Well, yeah! You see the things you wish you would have had... 'I wish I would have had this support or that support. I wish I could have done it this way or that way'. Well now I get to do all that and give my children those things that I didn't get. And it's really kind of a beautiful thing.

ABK: It's very beautiful. It's very beautiful as well the impact of work like the blog and social media that you do. The impact that that has on families...the validation that that gives to families and the way that that's propelling such a shift, even in two years since you've started. Even in just a few years since I've started, the shift that's happened in people's consciousness is amazing.

MK: Well, they just had to have their eyes opened. ...When my oldest.. my oldest son was the one that I needed to get diagnosed because he had the most disability related to what was going on with him.

ABK: When was that?

MK: He was three, and he is seventeen now.

ABK: Okay, so that was the...in the dark ages.

MK: Yeah, it was in the dark ages. I was told 'your son will never speak and he will grow angry as he approaches puberty. He will become dangerous and he may try to kill you.' I took my Speech Language Pathologist with me, like he wanted to come and see what was going on inside this guy's office and he said this right in front of the Speech Language Pathologist. And so, I went outside and I just...I sank onto the ground and cried and the Speech Language Pathologist was telling me 'don't listen to him. He is wrong!' And I had to just walk away and come to the terms that either I believe that or I don't believe that, and so I chose not to, and I never went back. And me and the Speech Language Pathologist got him fired.

ABK: Wow.

MK: (laughter) Yeah.

ABK: Right, and none of the things that that person predicted came true....

MK: No! Oh, no, no, no, no. Because I took the time and slowed down. I pulled him out of school in third grade. I tried school with him and he's just such a big emotional guy and he's so sensitive. He has like big sensory, emotional feelings, and he was just better at home. And so I've been homeschooling him for years now and he talks just fine. He can talk. He isn't melting down. He's brilliant. And if I were to listen to that doctor, I would have set it up where it would never have happened.

ABK: Right.

MK: You know?

ABK: Right, and I think as people have pointed out, a lot of the meltdowns happen because of the environment and unfortunately it's because of the mainstream therapeutic environment that kind of triggers the meltdowns. And when we look into alternative ways of doing things...the phrase you used is perfect – just slow down, right?

MK: Slow down, yeah. Autistic children – guess what, they grow up. And any child that's going to grow up that's not being pushed into a corner; not being told constantly that what they do naturally is wrong... It's just common sense. And so, sometimes the easiest fix is...it's like the most obvious thing to do is **slow down and just enjoy your child** and **talk to your child** and **play with your child**.

But, that's not what they're told from the doctor's offices. That's not what the specialists are telling them, they're handing them the phone number to the nearest ABA therapist and I think a lot of parents want to do what's right, and so how do you tell parents 'don't listen to the doctor?'

ABK: Yeah.

MK: We're hoping that we can get them on board. And get supports in the home for parents. Like, I had to quit school. I was in college at the time; I was working at the time and I quit. And I just sat down on the floor and stayed there, and played. And maybe not every family can afford to do that. I had to change my lifestyle. But it was the most important thing; I mean it was the only thing I *could* do.

ABK: Could do – right, exactly. Especially then, but even now, a lot of times it's left to the parents to DIY if they want to do things outside of that really, ugly, awful, institutional approach which causes trauma.

MK: Oh yeah. Oh yeah, I can't imagine. I kind of keep out of a lot of the big activist stuff, because it just sickens me what parents are talked into doing, from the MMS to ABA. I mean I don't understand it.

ABK: What's interesting about activism or advocacy within the neurodiversity movement is that, yes there's the activist wing, having protests and being very involved in protests and petitions and lobbying and policy, but the other part of it, which is *crucial* is this one conversation at a time [kind of] change that happens when parents reach out and they can get support from autistic people and understanding, 'hey, why does my daughter do this?'

MK: Right.

ABK: or 'what can I do?' and that really organic, not-profit driven kind of approach, these one-to-one conversations that bring these monumental changes in the lives of families that are happening on social media and through pages like yours...

MK: Absolutely.

ABK: It's incredible!

MK: I had a parent message me on Autistic Grandma the other day and said 'my child just started banging their head out of the blue. I don't know what's going on, why are they doing this?' I'm like, do they have a headache? Do they- how old are they? Are they cutting teeth? And guess what – Four teeth coming in, all at the same time. Now... You know what I'm saying?

ABK: Right.

MK: You need someone there to say, 'it's okay, they're just cutting teeth. Give them some Tylenol; give them a popsicle and watch it. Watch it go back the other direction'. So, it's not some, you know- it's not that complicated.

ABK: Right, right. But the industry wants to complicate it because then they're the only ones that can provide the solutions, and...

MK: Because they want some money – it's a money thing.

ABK: Right, to sell... to move their product. I think it amazing the change that's happening so quickly. I think with two years from now, when we have another conversation, we're going to see just how far things have gone... how far things have moved, because of the natural instinct of most parents is to care for their kids in this way and once they realize it's possible, then it happens...

MK: Yes.

ABK: ...and that industry is kind of de-platformed, I guess you would say.

MK: I kind of let people use their own lingo on my page too. I don't correct people for saying 'my child has autism', even though I know that's not how I believe – I believe you're an autistic person. But, I'm trying to bring them in to help their children. I don't want to argue with them. I want them to calm down and **stop fighting autism like it's some kind of disease** and see that it's actually a beautiful thing if it's nurtured. We're people just like the neurotypical people. **We deserve to be nurtured.**

ABK: I'm so with you on the language thing. I think that's when the bridges really get built. When you let go of that and you see the commonality, which I see on your page, which is just great.

MK: It's hard because people do get angry. And I block some people off my page that...they're in the community. They're autistic and they were just angry and I just cannot...I can't handle

that. I don't like confrontation, it upsets me. I take two different kinds of blood pressure medicines, okay? So I literally can't handle it. And so I just don't allow it. It's working. I see a lot of parents coming in, just listening and then suddenly they'll start commenting, you know.

ABK: Well, I'm looking forward to the next part of our discussion, and I will try not to cry, because we're going to talk about having breast cancer and **navigating the cancer care system** as women and as neurodivergent people. I'm hoping we can talk about misogyny and queerphobia in the world of breast cancer care. I was living in a bubble until I was diagnosed with breast cancer. I did not realize the, like, incredible misogyny within that world. It was really, really shocking to me. And, I'm going to summarize it here, in just a couple of paragraphs for the listeners who may also not know that there's a massive problem with this.

So, when you have breast cancer, especially if you're in your 20s, or 30s or 40s or even 50s, they very often want to give you radical breast reconstruction. And that often requires multiple surgeries as kind of the norm. So, like you might think that you could go in and get a little flat enclosure without the reconstruction, but you're going to be an outlier if you want that in a lot of hospitals.

MK: Yes.

ABK: Sometimes patients are told there's no availability of options for a surgery to go flat without reconstruction. That happens in 18 percent of cases. They're told that they don't even have the option. They have to have reconstruction.

In another 5 percent of cases, women were given surgical results that they didn't even want, with the surgeons secretly leaving additional tissue instead of a flat enclosure, and that's what the researchers are calling '**intentional flat denial.**' So women's needs and wants were actually denied.

We have women with cancer who are pressured into getting reconstructed with silicone implants. Then they have pain or get sick from them or other things go wrong and they have to get explant surgery to be de-constructed ...and sometimes the insurance companies won't pay for the explant surgery. So there's a whole movement called '**going flat**' which connects women who are getting explants or who want a flat enclosure and helps them to advocate for this thing that you would think would just be normal, but it's not normal or normalized at all. The reconstruction is the norm.

Now all of this is happening *despite evidence* that women who say no to reconstruction report being happy with that decision. In fact, a research review that just came out in January 2021 in the *Annals of Surgical Oncology* showed that 75 to 90 percent of women who went flat were satisfied.

Then the same review also noted that patient knowledge about potential complications of reconstruction had been gauged to be *just 14 percent* of patients. Doctors had only advised 14

percent of the patients about the risks of reconstruction. 57 percent were told of the advantages of reconstruction...

MK: Hmm.

ABK: But a very small portion were actually told of the risks. So, it wasn't evenly presented to them. Despite this, women still do want to go flat and seek to go flat, which is kind of a testament to the fact of how much people want this, even though it's so difficult to get it provided, and the research reviewers conclude that **'implementation of uniform surgical management and improved respect for patient consent in this population would result in significantly improved patient experiences.'**

We have a consent problem in breast cancer surgery, and I guess I would like to open up the conversation to talk about how this has happened, and maybe we could talk about your experience in navigating that world.

MK: Oh, where to start?

ABK: Hmm, yeah.

MK: Everything you said. I was treated like I was a beauty queen...and I was told that I got the 'good surgeon'...

ABK: Mmm.

MK: As opposed to the 'hack'. This is like a joke that was going on in the surgeon's office. And so this guy's like 'we're going to go in and we're going to do a lumpectomy. You're going to do radiation, and reconstruction. And, everything's going to be fabulous'.

ABK: Mm-hmm.

MK: And I started looking around, because I really didn't want to do the radiation. It's not that I wouldn't, it's that I didn't want to right then because it just makes you very sick. I found out that if you just have the whole breast removed, then you really don't need radiation. And so, it took me three months to convince this man that this is what I wanted. I kept going back for consult after consult. He told me that I would never be able to look at myself in the mirror again.

ABK: (Gasp) Oh my God!

MK: He told me that *he knows* what I need; that I don't know what I need because I'm in the middle of this cancer scare and if I do not get the reconstruction, I would be back.

And so, I decided to take both the breasts.

ABK: Mm-hmm...

MK: And- again maybe it's PDA, I don't know...

ABK: (laughing)

MK: Ok, 'well then, we'll just cut them both off'. And then he got really upset. And so he sent in a Nurse Practitioner to talk to me and she's like 'Melanie, why do you want to do this?' And I told them that I have three autistic kids at home, I need to be healthy right now...

ABK: Right, right.

MK: And I don't care if I have breasts or not.

ABK: Mm-hmm.

MK: And so she walked out and told him, this is what we're doing. And we did it. And he even tried to talk me out of it at the hospital on the day of surgery! 'You only want one breast removed, right?' No, I want them both removed. Well, come to find out after the pathology, I had pre-cancerous cells in my 'good' breast.

ABK: Mm-hmm.

MK: So, I would have been back anyhow. I did do a consult with the radiologist and he told me, in front of my sister-in-law that my surgery was like 'picking dandelions with a chainsaw'.

ABK: Ugh, my God.

MK: And I left and never went back, and so him and the surgeon got into a huge fight... I started the hormone therapy which it did not work. I tried the shot I took that shut my ovaries off [which didn't work] so I scheduled [an oophorectomy] with the surgeon, and I get a phone call from their office that said I had to sign a release saying that I understood that I was being sterilized and it had to be 90 days old.

ABK: Hmm. Oh my God!

MK: And I'm like, why 90 days? 'Well, you know, you might change your mind.' I was a 40-something-year old woman with four children, with breast cancer, trying to get through hormone therapy, and [they think] I might change my mind.

ABK: [sighs].

MK: So chauvinistic! So misogynistic!

ABK: Right.

MK: That even hurt me worse than the breast.

ABK: Right.

MK: Because, I mean, like I don't... yeah. Now, I'm going. I'm sorry.

ABK: It's amazing! It's amazing! I mean, weren't you shocked? I was so shocked! I was like, I'm coming in here to get cancer taken out of my body. That's what I care about, right? And I mean I... Maybe I have the benefit of having kind of an alternative upbringing. I was raised in Madison, Wisconsin, which is like the San Francisco of the mid-west, you know?

MK: Right.

ABK: And hippy-haven, you know. You could touch the gay. You could feel the queer culture, like wall to wall carpeting, floor to ceiling in terms of... in those cultures body acceptance is the norm. And so, for me, I just never occurred to me that someone would think that I was somehow going to like *fail* socially or something if I didn't get this reconstructive surgery. It was really communicated to me that way. Like, I had one surgery, and then basically they did a really quick surgery as fast as they could, and then I had to get chemo and then I had to have another surgery. So, they didn't talk about reconstruction till the second surgery. After the first surgery – I mean they took a sizeable divot out of my breast. I didn't get it removed, but, you know, it looks different now and I accepted that. I didn't really have a problem with that. The pain that came for me was the way that I was treated, by some people in the oncology community.

It was dehumanizing. I went in to see my first surgeon, and I had this scar on my breast and whatever. I obviously wished none of this had ever happened to me, but I was kind of like, well I have a pirate boob now. It just is what it is, right?

MK: Right.

ABK: It's not going to make or break me. Right?

MK: Right, right.

ABK: So I go in and I was like well, how about the wound care? I'm trying to ask about wound care. I had this male surgeon, and he was like (briskly) 'oh well it looks fine, cover it up!' You know, right away... I just want to know, is it all healing well. He's like 'cover it up.' At that point I realized he couldn't even look at it ...and then he grabbed my robe and he covered it himself.

MK: Well, you know what? Something similar to that happened to me when I went in. I did do one consult with a plastic surgeon. And this guy comes in and I had my shirt off, and he looks over at my breast, and he turns his head away and said 'what does he expect me to do with this?'

ABK: (Gasp) Oh.

MK: And because of where my tumour was...it was in the bottom half of my right breast, , towards the inside, kind of toward the middle.

ABK: That's where mine was.

MK: And he's like 'what does he expect me to do with this? I'll have to tear your whole breast apart and move everything around and you won't know where the cancer is.' I said I thought we were removing the cancer. He's says 'you never get it all, do you?'

ABK: Oh my God.

MK: 'You never get it all. You want to know where it's at. You don't want me to move it to the other side of your breast.' I'm like, oh my God.

ABK: Oh my God.

MK: He was being honest, actually. I mean he was being brutally honest.

ABK: Mm-hmm.

MK: He couldn't even look at me, because he knew what would have to happen. And so that really was also a game-changer for me. I found the **Flat and Fabulous** on the internet and I started reading about these women who just did not do reconstruction and I don't regret it. I regret nothing.

ABK: Right. It's...the thing to me is that I thought if somebody goes into breast cancer as a career, that they're going to love breasts and they're going to love women, right? And they're going to- I don't know, I just was assuming a body-positivity about it. But what I realize is that there's actually like a real hatred of women's bodies...or almost a desire to improve upon us.

MK: Yeah!

ABK: Like we're an object. Like 'I'm going to make the best breasts I can on you' and like 'these are going to be really good ones,' or whatever. It's so unrelatable to me and you realize that it's driving people...in plastic surgery that often appears to be *the drive*. And from what we hear from the Flat and Fabulous movement and other movements of people who've had reconstructions that have gone bad is the sense that you're almost like a product. And they want to make the perfect product at the end.

I went to the surgery consult ...and it was really about just constructing this perfect 'thing'. And it's really dehumanizing, and so I went home and I laughed about it with my family because it was so absurd what they wanted to do. I had a Zoom call with my brothers that night and I told them, and they were just *laughing*. Like they couldn't believe it. And the reason my brothers couldn't believe the things that the surgeons wanted to do to me is because they're men. Like no one would ever act like it's a normal thing to do to them!

MK: No!

ABK: Right?

MK: No! No-one would ever tell a man that if you have your breasts removed – which, men do have breasts by the way. I don't think everybody realizes that. They can get breast cancer also.

ABK: Mm-hmm.

MK: I'm sure no one would ever tell them that they'd never be able to look at themselves in the mirror again.

ABK: Right.

MK: And that's who I am. I'm not a set of boobs. I've always felt that way about myself though. I worried more about what I could learn, not really about how I looked.

ABK: Yeah! And like when you're like... I was dealing with the biggest part of my cancer and my main thing was like 'what's going to have me *be alive* for a long time?' You know what I mean? This is the primary concern that gets lost in the process. I mean undergoing additional surgeries and stuff, that all takes additional risk. I need to get on with my life. I'm a parent, I have a life. I mean I can't be consumed with this whole thing that they're asking me to go through.

MK: And I would have to have gotten expanders put in and get the expanders filled and so on until they looked right. And then have the expanders removed, so they'd be cutting into me *again*. Sticking breast implants in and then do radiation. There's no way! I just couldn't do it.

ABK: And that's the other thing. The thing that was really upsetting to me, cause I would have had a very similar procedure [to that] and they wanted to take a muscle out of my back and put it on my front. I can't even deal with that. And I would have had to postpone my radiation. I had radiation because I had lumpectomies and I'm thinking I'm not going to postpone my radiation for this! I gotta get my radiation done. I have to cure my cancer.

MK: Right.

ABK: It's totally- it's very odd. And I'm wondering about putting it into an autistic context too and our relationships with our bodies in terms of anti-sexuality or self-acceptance being really a part of our sexuality. If we could find a way to take that body acceptance that comes out of the communities that we've been talking about and bring it into the broader community, so that more women are given choices and that there's just more of a demand for this kind of thing...the movement Flat and Fabulous is getting some traction.

I'm wondering what we need to change like from surgeons to popular culture to help women and non-binary people feel empowered when they're put into the positions like we were put into...and also *have* the power to get what they need, because it's often denied, right?

MK: Yeah, we're doing it right now, yeah? Right now! This conversation – I'm going to start it as soon as you're done getting this together. I'm going to share it on my blog, and then we're going to start a conversation there. And we'll just keep moving the information around. People have to know this before they go in, because they're side-swiped.

ABK: Yes.

MK: Nobody warns you about this. No one warned me that after I had my lymph nodes removed that I would have constant pain under my arms. No one told me about lymphoedema and how dangerous that could be. I had cancer in one of my lymph nodes.

ABK: Yeah.

MK: A few of them I think.

ABK: Yeah.

MK: Outside of my breast, so. Yeah.

ABK: Well the idea is that, I mean it gets put on women and non-binary people all the time that we're supposed to just endure it and be thankful, you know. If you try to even ask questions about it or anything it's like a form of ingratitude to them, you know? And so there's this really uneven dynamic that makes it very alienating to try to seek care. I mean every time I go in to seek care there's a sort of feeling that I have that it's not going to be easy. I'm not going to be able to be authentic. I have to have a *plan* to communicate within that culture, because it is a very strange culture.

And what's weird is you see all the pink and the power and the marches and everything like that – but that movement as far as I can see, is not the same as like the Flat movement or the other movements...

MK: No, no...

ABK: ...for real empowerment of women, right?

MK: The 'Save the Ta-ta' movement.

ABK: Mm-hmm.

MK: Save my ta-tas? My ta-tas are full of cancer, I want them gone! And I... yeah, just letting people know that it's okay to just be your original self, and not be pushed by vanity or not be pushed by society as to what a woman's supposed to look like. I think autistic people are already maybe at an advantage for that.

ABK: Yeah.

MK: Because we don't easily get pushed around. I stood my ground. I was not going into surgery until this man agreed to take both my breasts off.

ABK: Mm-hmm.

MK: And he kept sending me home and then bringing me back, sending me home, bringing me back. And I'm like, this is it. This is my decision.

ABK: The reconstruction they were saying for me would have been three extra surgeries, plus going in for these appointments and things like that, right? And you would think it would be like a *no-brainer* that somebody might not want to do that but I had to say no again, and again, and again to that.

MK: It's almost like they think you're not mentally able enough to make the decision.

ABK: 'Hysterical'. Like it's hysterical or something to not want to do this thing.

MK: Right. I was 'hysterical' for, you know, wanting my ovaries removed. It was causing my cancer, you know (mine was hormone driven) and we were trying to shut my ovaries off but they just wouldn't. I kept ovulating.

ABK: Right.

MK: And so a natural idea is just be to have them removed. Well, I had to wait 90 more days – until I had a 'cooling off period', because I'm 'silly', I'm a woman.

ABK: Right.

MK: [sound cuts out] ...choose to have my ovaries removed? (laughing)

ABK: That's the idea. If anyone thinks that it's essential to someone going into breast cancer care understands women's equality, I would say that is not true. I would say that actually there's really a lot of gendered problems within that system and to be prepared for that.

MK: Yeah... yeah. And be prepared to argue and you have to stay strong.

ABK: Mm-hmm.

MK: And do your research. Look around. Listen to other women, what they've been through, like I said. I went straight to Flat and Fabulous. And I just started listening to what these women were saying and it's like yes – that rang true to me. Now for someone else, maybe it wouldn't.

ABK: Mm-hmm.

MK: And I'm not going to put anyone down for wanting to do the reconstruction. I understand. I used to be young. I would definitely say if I was in my 20s, I might have went for that.

ABK: Right.

MK: But being an older woman, I mean, they're milk-bags, ok. I nursed babies with those.

ABK: That's the thing, it's the *choice* that matters. The problem is that we saw with the research mentioned earlier that not every woman is being given an equal choice. It's great that they've developed things that can do this for people but it also should be more than a footnote if somebody wants to *not* do that.

MK: That wasn't an option put on the table for me. I had to find that for myself. I mean, it's the flavour of ice-cream they sell. You know if you go to the radiologist they do radiation – of course they want you to do radiation. If you go to the surgeon, and his techniques are his thing and he loves the way he does things, that's what he's selling. It's a product.

ABK: Right. A product.

MK: You can't really blame them, it's their product.

ABK: It's the way they do it, and I mean, there's demand for it. Now, I think there was more demand for it 10 or 15 years ago and they maybe haven't caught up with where people are at in terms of the demand, so they might not even understand *how to do it another way*, I mean. I think it's great that our national health care here in Canada covers it because any woman who wants to have it, it's great. But I think what's happened is that having it as the default, they haven't really caught up with where people are really at in terms of that, right?

MK: Well, yes because after my surgery, guess what I found when I looked in the mirror?

ABK: Hmm...

MK: I found extra skin. I am not perfectly flat. And that's exactly what I asked for. I showed the surgeon, look at the Flat and Fabulous, that's what I want, and I still have loose skin like in the [study] you talked about...

ABK: Yeah, leaving it there almost as though you're going to have buyer's remorse, or maybe they don't know how to do it? I mean, that's another thing that can happen.

MK: I think it's [the idea of] buyer's remorse. I think that they just don't think women have it together enough to make that decision. It's just so insulting.

ABK: It is... it is. So it's been a while since your initial cancer diagnosis and you're now managing and living with cancer. I'm the same way. I don't get a cancer-free moment. It is what it is, right? I'm wondering: how do you find support going forward, as you're navigating the health system? What's your plan going forward for that?

MK: I got a really great oncologist. This little tiny woman, and she was very supportive of the surgery I chose. And so I meet with her once every six months, she refills my prescriptions. I stay in touch with my family doctor, if anything crops up. Like, I had a lipoma come up on my scar. Scared the be-Jesus out of me. It was just a lipoma. So I watch myself extra-closely. I try not to think about it constantly. And that is a hard one. I'm at the three-year mark and it is getting easier. I take my pills. I'm on exemestane. There are side effects I've learned to deal with. I have fragile bones now. The medication is eating away at my bones. I'm weaker. I'm slower. But, that's okay; now I have more time to sit around and crochet.

ABK: (laughing)

MK: I have an excuse for not moving the couch and sweeping under it now. And it's just a new me, and I think that's...I hope you're to that point where it's okay, where it's not on your mind all the time. Being autistic I am, I have OCD and I take Celexa to help me not perseverate over it and worry constantly. And that has helped me. Just one step at a time, one day at a time.

ABK: Mm-hmm. Well, I think we've started a great conversation about it because, you know, this is just the beginning with these new movements going public about the issue. And it is a tough issue to talk about. And I really want to thank you for talking about it in such an honest way.

MK: I want to thank you for having me here. I remember when you were going through your stuff, I tried to reach out, but I knew--I knew what you were going through. And it's just so heavy, just having... I reached out but then I pulled back because I could just imagine. I could feel you from across the interweb.

ABK: I remember chatting with you about it. It was you and a couple of other people, autistic women, that I talked to about it that was really, really helpful for me to kind of understand it from a systematic perspective, and deal with it. That was really, really important.

MK: I'm glad. Yeah.

ABK: Well, Melanie, thank you very much for being on the podcast, and I'll put a link to your social media and blog on our podcast blog so that people can go and find the Autistic Grandma blog and social media. You've given us all a lot to think about today and thank you very much for your being on the show.

MK: Thank you so much for having me.

ABK: We were speaking with Melanie Keiling. She spoke to us from Indiana.

(Theme song – soft piano music)

ABK: You've been listening to Noncompliant: The Podcast. I'm your host Anne Borden King. Noncompliant is recorded at MCS Recording Studios, engineered by TJ Liebgott and Nathan Greavette.

Links

[Autistic Grandma page on Facebook](#)

['Going Flat' After Mastectomy: Patient-Reported Outcomes by Online Survey](#). Dr. Jennifer Baker, et al. *Annals of Surgical Oncology* (2021)

[Women Who 'Go Flat' After Mastectomy Report Being Generally OK With It](#). Kate Kneisel. Medpage Today. February 5, 2021. Study Authors: Jennifer L. Baker, Don S. Dizon, et al.

[Flat closure after mastectomy: Are your patients satisfied with the results?](#) Kimberly B Bowles.
San Antonio Breast Cancer Symposium, Published February 2020.