

S1Ep4 The Momma & The Papa Transcript

Shelly (00:24)

Hello and welcome to the Uncomfortably Speaking podcast. I'm your host, Shelly Rohe. I'm a disabled white woman in my mid-50s. I have long strawberry blonde hair and blue eyes. I'm wearing an orange and white shirt with diamond patterns so small that the shirt looks pink, and I have glasses on. Today I'm very excited to talk with my parents, Mary and Chuck. And I think I will just turn it right over to you to introduce yourselves.

Mary & Chuck (00:56)

Hi, I'm Mary Rohe. I'm Shelly's mom. I'm a white female in my very early eighties. I have short graying hair and I am wearing a very bright yellow top this morning.

Hi, I'm Chuck Rohe. I'm Shelly's dad. I'm a white male in my early eighties also, just a little bit earlier than Mary. But I'm yeah, a white male. I have a tan shirt on, and I wear glasses and hearing aids, so I sometimes don't hear everything the way I should but make the best of it.

Shelly (01:40)

Well, I wanna thank you both for being here. It means a lot to me to have you on this podcast and talk about an uncomfortable topic. So, I think we'll start out just as we did with my big sis Raquel, with some impressions of me as a baby.

Mary & Chuck (02:01)

Well, I remember you could never sit still. You were moving all the time. And I think back to when you were born, you were a face presentation baby. Now normally peop, babies come out with the back of their head. You came out face first. It was like I'm hitting this world running. And I don't think you ever slowed down. You were one that wanted to move, you wanted to do tap dancing, you wanted to do ballet, gymnastics, you wanted to go to YMCA camp, you wanted to go to Concordia Language Camp, you were doing mountain bike racing, and you cartwheeled everywhere. So that's what I remember.

Shelly (02:44)

Yep. I remember I was always wanting to see what was around the corner and what was next. And I wanted to be a part of everything and see everything that was going on. I tried a lot and then would move on to the next thing pretty quick. Do you kind of remember that?

Mary & Chuck (03:06)

Well, it seemed like at one point in time you felt that you were probably two years older than your sister. You were always trying everything, wanted to go here, there, and yeah,

like mom said you were could never seem to sit still. I remember the summer when you didn't hardly walk, you would just cartwheeled everywhere and climbed up the tree and sat up there and read your book. Yeah, you used to climb the trees as high as you could possibly go. Way up into the little branches. Yep. And then

Shelly (03:38)

Did you, did you remember that I tied a time capsule to one of those top branches, and I was really thinking it would stay there until I was old and gray, but it blew down the in the very next storm.

Mary & Chuck (04:00)

I don't remember that, but it doesn't surprise me.

Shelly (04:04)

Dad, do you remember going out to split wood and you wanted to have the rig pulled through the gate for the cows so that they didn't get out. You wanted to lock the gate behind and so we had me and the, the jeep and I almost ran over a cow because I did

Mary & Chuck (04:26)

Yeah.

Shelly (04:28)

I couldn't reach the brake real well and so its eyes got real big.

Mary & Chuck (04:32)

So, you were supposed to kinda coast it through the gate? okay.

Shelly (04:35)

Yes. That was all I was tasked to do.

Mary & Chuck (04:39)

Well, I remember you were always a daddy girl. So you like to be with whatever he was doing and where he was. And so I guess that doesn't surprise me. As far as driving,

Shelly (04:49)

Yeah.

Mary & Chuck (04:49)

I don't really remember being with you when you were learning to drive. But I know dad wanted you all to learn stick shift. So he probably did a little more of that. But I think too in those years when you and your older sister were doing it. You know, you did most of your training with the instructor from school. Yeah.

Shelly (05:09)

instructor. And I was wondering if maybe I wanted to learn and do a good job before I had my parents with me. I don't know if that was

Mary & Chuck (05:22)

That could be. That wouldn't surprise me. Yeah.

Shelly (05:27)

Dad, do you recall when you were the snowmobile instructor? I was taking the on the snow class. I don't know what it was called. Yeah. But

Mary & Chuck (05:37)

On the snow test? Yeah. Yeah.

Shelly (05:40)

I just recall being so scared to take my turn. Everybody was watching and my dad was the instructor. To me, it was just a sign. That was something that I wanted to do so well, and I knew I was letting my nerves get the best of me. So, all that put together the cow in the pasture and the snowmobile, I think I was pretty certain I wasn't going to get my license when I did. So, do you remember how I was when I did get my license?

Mary & Chuck (06:27)

I guess I don't really remember that. I think the typical teenager I passed, but yeah. Pretty happy, pretty excited. And I don't think

Shelly (06:35)

Thanks.

Mary & Chuck (06:36)

we sensed that you were feeling like you were a failure because I think, you know, kind of a nervous, scared feeling is kind of typical for kids. And I always thought you were a very confident person. Yes, I think so.

Shelly (06:50)

Well thanks. I think I covered it well. And that's kind of what I yeah, that's kind of what I want to get at with this is, I guess I want to hear from you like your impressions and mom, I love that you said you thought I was a confident driver because that would be my next question. What were your impressions of me? What was it like when I first took off without you in the car? Do you have

Mary & Chuck (07:23)

Well, it seems like it didn't take very long for you or your sister. Once you got your license, you were gone. You were off on your own and doing your thing. So I don't think I ever felt like you weren't confident driving. We probably didn't realize either how far away you went and where you all went.

Shelly (07:44)

Right. Yeah, that was that was something

Mary & Chuck (07:48)

Those were the days.

Shelly (07:49)

else, right? Yes. When I moved out to California and started touring and driving big rigs and getting commercial endorsements on my license. Were you aware of all that I was doing?

Mary & Chuck (08:04)

Well, you told us how you were doing some of those things, yeah. You drove the Hummer to Zumbrota and down to City Hall. I got to see you driving that with the big trailer behind it when you

Shelly (08:17)

Yeah.

Mary & Chuck (08:17)

were doing promotions. So yeah, we were aware of it, probably not moment to moment or whatever, but and impressed. I can't even back up a vehicle on a load of trailer, so

Shelly (08:29)

Well Thank you.

Mary & Chuck (08:33)

I just remember the 9/11 when you called to say you were letting us know you were all right, and we thought, "Well, what in the world you mean you're all right?" Here you were in Washington DC, a few blocks from the Pentagon when it got hit. So most of the time we didn't really know where you were.

Shelly (08:53)

Right. I'll never

Mary & Chuck (08:55)

Mm-hmm.

Shelly (08:56)

forget that because it was important to get through to you to let you know that I was okay. And cell service was interrupted, so it was hours before I could get a call out. I remember saying to you, "I just wanted to let you know that I'm okay." And the response was, "Where are you?"

Mary & Chuck (09:18)

Yeah,

Shelly (09:21)

And

Mary & Chuck (09:21)

I remember that too, 'cause we really didn't know you were right there.

Shelly (09:25)

Back to the subject at hand. So, I was going on these big marketing tours, driving trucks and all kinds of big rigs and had commercial endorsements on my license. And I say this because I had to have a certain sense of competency to do that and I had to fill out truck driver logs I had inspections. I had to go to way stations a lot fast forwarding to twenty well, 2006 I guess was when I had the seizure. What, what were your impressions?

Mary & Chuck (10:10)

I guess probably, you know, I- I don't know that it hit us at that it was as serious as it was. You know, it was kind of you're far away. You're hoping everything is going well. And

Shelly (10:24)

Right.

Mary & Chuck (10:25)

to get a call from a stranger to say you're in the hospital and it's kinda like, well, until I can talk to her and I know for sure what's going on, you know, it's like, does she know what she's talking about? Or doesn't she and how bad is it? I don't know. What did you think? Well, yeah, kinda about the same thing. We're just, just kind of kind of in limbo and kind of trying to figure out just really what's going on and Yeah. So

Shelly (10:55)

I remember

Mary & Chuck (10:55)

No, it's

Shelly (10:56)

What happened was I had a seizure in my casting office and had gone by ambulance to the ER and then had to wait and in LA, emergency rooms are packed. So it was hours it was, that was early afternoon or late morning and then I didn't get seen until after dark sometime. I think it was around 10 PM and I remember somebody saying to me, "We thought you were just here for verification for a fender bender or something. You were up on your heels clicking around talking a mile a minute on your cell phone."

Mary & Chuck (11:42)

Okay.

Shelly (11:42)

I remember Dory had been there in the waiting room with me. And she was the one that kept her cool and said,

"Hand me your phone, who should I call?"

Mary & Chuck (11:54)

And I think that's one of the scary things for parents is when you're that far away and you don't really know what's going on and you're depending on somebody to tell you and you're waiting hours for what's going on, you know, is it really a major thing? Is it just a blip in the road that's gonna be over and

Shelly (12:15)

Right.

Mary & Chuck (12:15)

done with? Or what's what's happening? It gets kind of blurred on what happened when.

Shelly (12:18)

It's all, yeah, exactly. It's all the blur right? I lost my driver's license at that time because I had a seizure and the protocol was to revoke licenses. I ended up having brain surgery doing the few months I needed to, to be on seizure medication and get past the brain surgery, but then because the threat was gone, I was able to take the road test again and get my license back.

I had moved home in 2011 and then in 2013 had the brainstem brain tumor rupture and that's when, I didn't lose my license, but I knew it was in jeopardy. And so, I wanted to try and train myself to drive. After surgery, my eyesight was affected and I had tremors in my right side and my right side had been paralyzed, but as I got some feeling back, I

thought I, I can do this. So you have been there every step of the way since then. Can you talk a little about what it's been like through trying to learn to drive again.

Mary & Chuck (13:54)

Yeah, I guess that was, I don't know, it w- it was tough to I guess, understand w whether you really were going to be able to drive again and I know you really wanted to but. I don't think I ever thought you couldn't again until that day that when you were given the van and you were going to drive it and we were on the streets of Rochester and you

Shelly (14:21)

Yes.

Mary & Chuck (14:21)

ended up going, "I can't do this!", and Dad took over and I think that was one of the scariest times for me when I realized, you know, this is not something she's probably going to do the rest of her life. You know, you sometimes you just hit that point where you say, "You tried darn hard and it's just not going to be."

Shelly (14:44)

I applied to receive a van that a group home provider was surplusng out of their fleet and ended up being awarded a van that was wheelchair accessible and I was very excited. But when I got behind the wheel, my heart started pounding. I couldn't turn real well to look behind me. I couldn't see because my eyesight was so bad I couldn't look out of the corner of my eye like I had. And I think what I realized through a lot of this recovery process has been that I'm apt to say I can do things before I try them. And some of the things I'm trying, I just, no matter how much I want to and how much I try, I'm not able to. And it gets very frustrating and I want to cover it up. I don't want people to know. So

Mary & Chuck (15:58)

I think that's a big part of your life is that you look at it as a failure and I don't think that's right at all. It's a change in life circumstances and you have to just kind of accept what can I do, what can I not do, and you know, what can I change? You're still the same person, but you just are not able to do some of the same things.

Shelly (16:22)

I sent you some thoughts before this and I equated being able to drive with becoming an adult. It was like a progression. This is the steps. You need to do this. You go to high school and then you graduate and then you go to college and so it was just a process in that. So it was one step closer to becoming an adult. So when, when a person becomes disabled and wants to adapt their vehicle, they have to go through the I don't know what every state is, but for Minnesota it's MnDOT And a doctor assesses what your abilities are and then can write prescriptions for what kind of adaptations to make for a vehicle.

My re- reflex test was fine. I passed everything. But It was the road test that was so frustrating to me because most people would have at least a three-week training. And because there's only one place in Minnesota that does this, to get that three week training, I would have to go every day an hour plus away. And my medical rides would not cover that. So the two of you took me up. Two days in a row to see if I could just test out. What was that like for you?

Mary & Chuck (18:08)

Well, it was it yeah took time away from you know the our, our lives but yeah we were willing to do that. It was, I don't know, we, we kinda questioned somewhat whether you would ever really be able to, to drive again. It's you know, the whole driving situation, the traffic and the speeds and everything has changed so much now. And you know, for you with your compromised eyesight and, and movement ability, you've only really got your left hand to- to control things with and you had to learn to eat all over and on everything such a change for you, you know, being limited to just one hand and, and basically your left foot.

It's I think that's one thing though too, like you said, you kind of equated driving with adulthood. And you already passed that when you were eight- sixteen. You got your license at sixteen, right? You had already passed that at sixteen. So there was nothing really to prove, you know? You were fully adult long time ago. And

Shelly (19:29)

Right.

Mary & Chuck (19:30)

as far as driving again, like Dad said, things had changed so much too in the years you weren't driving. There's so much more traffic. I mean just going between here and Rochester on 52 is a whole lot

Shelly (19:42)

Yes.

Mary & Chuck (19:42)

different than it was, you know, like in 2006. So

Shelly (19:46)

Right.

Mary & Chuck (19:48)

I don't think we were surprised when they when

Shelly (19:52)

Were you, were you kind of relieved to know that

Mary & Chuck (19:57)

Probably in a way, yes. Like I said, when you tried driving that van, that that scared me and I thought I- I, I think thinking of you out there, by yourself driving was a very scary thing for me.

Shelly (20:10)

I know that

Mary & Chuck (20:11)

Yeah.

Shelly (20:12)

when I took the on the road test with that instructor, it was a two-part test. So, I could do the in town under 30. And when she wanted to get on the highway, I couldn't do it. I collapsed. I started crying. I- I don't think I've ever experienced a panic attack, but that sure was close!

Mary & Chuck (20:40)

Mm. Yeah. I think that's understandable.

Shelly (20:41)

I- I just was Yeah. And then she said, "Well, I'm gonna have to revoke your license." And I remember just being devastated. I don't know, I didn't know what that would mean really. I used to own a house that was way about ten miles out of town, and it was past the geographical area of the buses. So, the only transportation I could get were the paratransit vans that required a forty-eight hour advanced notice, nothing I did was spontaneous. It was all planned. What are your impressions of transportation?

Mary & Chuck (21:34)

We have we've gone through quite a bit of that, Shell. Yeah. And that is not a good system, you know. It should be easier to be able to get a ride and to be able to get around, especially in a med city where they're famous for helping people with disabilities, with medical problems and issues. And it should be much simpler. And you have had a battle. Getting rides, getting to go where you want to go, without having to sit in the rain or the snow or whatever, waiting for rides that don't show up on time. And it's

Shelly (22:09)

Yep.

Mary & Chuck (22:09)
not a good system.

Shelly (22:11)
Yeah. I've often said I would pay for a ride the same day. There aren't even ride companies that operate like an Uber or a Lyft or taxis that would have a same day rides for people who use wheelchairs. It's been hard to like, compromise on living my life, I guess. I don't know how else to put that. I have to plan everything. It doesn't get easier to, to know that I have to plan and I can't depend

Mary & Chuck (22:53)
And you can't depend on it, yeah.

Shelly (22:56)
Well, I can't do two things in a day. I've called the two of you to help me with the rides. Especially

Mary & Chuck (23:04)
And that's all right. That is okay. Don't ever feel like that's a bad thing. As long as we're capable, Shell, we're here.

Shelly (23:10)
Well I n

but the two of you have just said you're over eighty and

Mary & Chuck (23:17)
Yeah.

Shelly (23:18)
you have to lift my chair into the vehicle. And I, I thankfully, have a portable chair, but it weighs 70 pounds. And so it's still something that I feel uncomfortable asking for help. I don't have a lot of people I know that don't work. And so the two of you end up being my first call. And

Mary & Chuck (23:46)
And that's all right, honey. That is totally all right.

Shelly (23:50)
Well, do you ever feel like the lines have been crossed between caregiver and parents?

Mary & Chuck (24:00)
It's always daughter first. It's always if we can help out one

Shelly (24:01)

I, thank you.

Mary & Chuck (24:05)

of our kids, we will do it. And that's where it comes in first. You are our daughter.

Shelly (24:12)

Thank you.

Mary & Chuck (24:12)

And we

love you.

Shelly (24:15)

I love you, too!

I always thought.

Mary & Chuck (24:17)

Well it's There's breathe, Shell, breathe, breathe.

Shelly (24:19)

You made me cry.

Mary & Chuck (24:23)

There's so many people, Shell, that just pull back into a shell when something like this happens. And you know, like my cousin, he had a terrible accident and you know, ended up with Amputation. amputation with a lot of disabilities similar to you, not, not necessarily brain, but you know, he tried getting out and and stuff a little bit and and had a little accident with his wheelchair and after that it just seemed like he kinda pulled back in and he pretty much just stayed in bed and you have been a charge ahead, full speed ahead all your life and you still are you're amazing, you know?

We're very impressed

Shelly (25:10)

Thank you.

Mary & Chuck (25:11)

with all you do. So

Shelly (25:13)
Thanks!

What I was trying to get out and couldn't because I was overcome was that at this point in my life I was hoping to be there for you. And I feel like

Mary & Chuck (25:26)
Yeah.

Shelly (25:29)
there is a bit of that, I wouldn't say failure, but I'm disappointed in myself because I can't do more. And

Mary & Chuck (25:40)
And that I hope you will just learn to let that let that that go. You know? Focus

Shelly (25:45)
Well that's

Mary & Chuck (25:47)
on what can I do and how has my life changed. It's not gonna be the same and never will be as it had been many years ago, but you've accomplished so many things even after becoming disabled. So just keep

Shelly (26:02)
Thank you.

Mary & Chuck (26:03)
going forward with what you can do.

Shelly (26:06)
I appreciate that so much that I know that there have been times when I didn't want to show how scared or sad I was. And I know that the time when I was in so much pain. I didn't want to burden anyone. But I also didn't want to get in my wheelchair or the smaller portable chair. So, it- it reduced places I could go and I couldn't see people as often, and I just stopped reaching out and sort of became

Mary & Chuck (26:49)
A little bit of a reclusive. That was a hard time. That was a very hard time. Yes. Hard for you, but it was also hard for

Shelly (26:50)
I write Yes. And I don't wanna do that again.

Mary & Chuck (26:57)

us when we couldn't do anything about it, you know.

Shelly (27:01)

It was after knee surgery and then after the bad drug reaction. And I finally got home and I finally started to heal, and I was finally able to start recovering. That I think was the beginning of all of this. Trying to kind of systematically assess where I am. So, what would you like for me to get out of this podcast?

Mary & Chuck (27:31)

I think just confidence in how much you've accomplished and how far you've come and get rid of this idea of failure for good. Yeah, but like when we've been out with you and you attended some of those luncheons and whatever, it's- it's just amazing that so many people know you. And admire you. Yeah.

Shelly (27:55)

Thanks.

I feel so blessed that I've had so many opportunities and it's almost, I- I call it like my Forest Gump life that somehow, I seem to be in situations; I don't know that I create them but I certainly want to be someone who says yes to life.

Mary & Chuck (28:23)

And you're such an advocate for people with disabilities. So just keep it up. All right.

Shelly (28:28)

All right, I will.

Well, thank you for coming today and being on my podcast. I am

Mary & Chuck (28:37)

Our pleasure.

Shelly (28:38)

so thankful.

Stay tuned for a couple of thoughts about today's episode, some key takeaways and maybe some questions I still have.

Here's what I've learned so far:

My abilities changed. My circumstances changed. My worthiness didn't.

Driving represented more to me than transportation.

Trying harder doesn't guarantee the outcome I want.

Independence and autonomy aren't the same thing.
Receiving help doesn't change my place in my family.
I don't need to prove that I'm still the person I was.

Future Questions:

How much of what I have been calling “failure” is actually internalized ableism?
In what other ways has my fear of failure, and need to hide or mask it,
manifested as internalized ableism?

Can I acknowledge something I can no longer do without turning that into a
judgment about myself?

What would independence mean if I defined it for the person I am **today**, rather
than the person I used to be?

Mindful shift:

From:

If I can't do what I used to do, I've failed.

Toward:

My abilities have changed, but my worthiness hasn't. Independence isn't doing
everything by myself; it's having agency over my own life—even when other
people are part of how I live it. That's interdependence!

Thanks for joining us today. This is Uncomfortably Speaking, and I'll see you in the next
episode.

Mary & Chuck (30:36)

Bye-bye.