

Episode 44 Hidden Childless Stories 4.37 pm

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SPEAKERS

Berenice Howard-Smith, Steph Penny, Sarah Lawrence, Palo Baker, Michael Hughes, Charlie Bishop, Berenice Smith

S Steph Penny 00:00

It was a bit of a journey of, kind of after I got married, I then got diagnosed with this raging autoimmune disease, which my husband and I then worked out. Oh, it's got this shockingly terrifying rate of miscarriage and stillbirth and major deformities in the baby and significant risks to me as the pregnant person and we started to go this is really terrifying, stuff like they were significantly adverse medical outcomes. And so we've kind of felt, even though we wanted kids of our own, we kind of felt a bit backed into a corner by this whole new disease, kind of news. And we felt like the risk was just too terrifying for us to even embark on that journey. We made the really difficult decision to remain childless. But we felt like it wasn't really a choice. At that point, we felt like we really had been cornered by all the medical information I was receiving. So it kind of felt like forced choice. So I coined this term childless by forced choice, because sometimes even though it technically is a decision, we effectively feel like the decision has been taken out of our hands.

M Michael Hughes 01:21

Welcome to the Full Stop podcast, with Sarah Lawrence, Berenice Smith and me Michael Hughes. If this is your first time here, our podcast delves into the many facets of what it means to be childless, as well as what is going on in the wider, childless community. Our hope is that with all our special guests, we can help you craft your own narrative, and what it means to be part of the childless community. We also aim to educate those who are not in our community, so they can begin to understand support those in their lives, who may be facing a life without children. Now, there are many ways that people arrive within the child's community. And we are extremely privileged to have these three courageous and beautiful souls with us today. So over to you, Sarah.

S Sarah Lawrence 02:11

Welcome to this episode, everybody. We are here to talk about some of the lesser known

reasons why people might be part of our community. So we all know the big ones, you know, the ones that we often talk about. But today we've invited Steph, Paolo and Charlie on to talk about they're very different stories. And but how they came to be in this community. I think it's Jody that talks about the the many doors to which we all come into this community. And I think this episode is really going to illustrate that it was obviously there'll be some shared experiences. But they'll also be some very different stories. So it may sound slightly different and separate. So because we're going to have to be very organised, which is most unlike us. So we hope you don't mind that I say no, I don't see that sort of militant or anything, but we want to get three voices across because we think that all of their stories are so interesting, and so varied that they're going to appeal to lots of different people that are out there listening, dear listener. So with that said, I am going to shut up and I'm going to invite each of you if that's okay to sort of share your story about how you came to be a member of our community. Who who would like to go first? Is there anybody that would like to step up? Steph, how about we come to you,

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Steph Penny 03:25

okay. I was waiting for someone else to stick their hand up. First of all, thank you so much for having me guys on your podcast. It's a It's such a privilege to be part of this community and to be able to share, like this, and I feel privileged to be able to share it with with Paulo and Charlie today. So, so thank you so much. Um, look, I came across this community by speaking to other childless people, and kind of hearing their stories and they began to share resources with me that I had no idea existed. I was just existing in a silo, you know, as we often do in our journeys. And then people started talking about all this this amazing book, or, or have you seen this person's website? I have you. And then so I started researching and went, Oh my gosh, there's this whole global community. This is incredible. So it was such a, it was such an education. For me. It was such an eye opener to realise that not only was I not the only one, even though I felt like I might have been, but that there was a an incredible sense of solidarity, amongst other childless people, right? Like it was so exciting. It's like, oh, it's like, it's a whole thing. There's this thing out there in the world about being childless. And I was so relieved because yeah, my story of childlessness is a bit different to even the even within the minority of the childless community you might say like a sub minority. Because I never tried to conceive I didn't ever explored my fertility. I don't know if I'm infertile or not, never had a miscarriage or tried IVF. So I heard lots of those stories and kind of went off, do I even kind of fit in this group after all, because I'm childless because of chronic illness or medical condition. So it was kind of, it was a bit of a journey of, kind of after I got married, I then got diagnosed with this raging autoimmune disease, which my husband and I then worked out. Oh, it's got this shockingly terrifying rate of miscarriage and stillbirth and major deformities in the baby and significant risks to me as the pregnant person, then we started to go this is really terrifying, stuff like they were significantly adverse medical outcomes. And so we've kind of felt, even though we wanted kids of our own, we kind of felt a bit backed into a corner by this whole new disease, kind of news. And we felt like the risk was just too terrifying for us to even embark on that journey, we made a really difficult decision to remain childless. But we felt like it wasn't really a choice. At that point, we felt like we really had been cornered by all the medical information I was receiving. So it kind of felt like forced choice. So I coined this term childless by forced choice. Because sometimes, even though it technically is a decision, we effectively feel like the decision has been taken out of our hands, by by circumstances, perhaps by medical conditions or by other things. So it was a bit of a complicated journey. It took us a while to get there. And even when we made the choice, we kind of revisited it a couple of times and went Ah, are we really? Are we sure? Do we want to and then we go through the data again, and the the worst case scenarios and go no,

it's still pretty terrifying. Let's, I'd rather not. Let's not do that. So I'm still in this childless community, even though my reason for being childless is a little bit more hidden. You can't see my medical condition. You can't see the risks that it carries. But just as real as the invisible grief of childlessness. Wow,

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Sarah Lawrence 07:28

thank you, Steph. I think so many people are going to resonate with your story about I've had to make a forced choice. So not not a choice, in essence, really, is it? So it's kind of backed into a corner. That's a real, real image that thank you for sharing.

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Palo Baker 07:46

Thank you.

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Sarah Lawrence 07:49

Okay, I'm gonna come back to that because I've got a thought so my brain is fizzing. Having heard your story. I liked Thank you, Steph, who would like to go next? We'd like to share this story. Next. Palo, thank you.

P

Palo Baker 08:09

I joined the community because I've been involved in support groups, since the year 2000, when I helped set up the myasthenia gravis Croyden branch, and that was a few months after I was diagnosed with it, it's a rare autoimmune condition, which causes paralysis of all of the voluntary muscles. So, hands, the laces, eyes, breathing, seating, tucking all those sorts of things that are affected, that was diagnosed within a year of our decision to start to have children. And there were conversations with the doctors about safe treatments and unsafe treatments. So at that point, we were adamant that we were going to continue down the road trying to have children. So I had to refuse the best course of treatment. So there was some, you know, aggravation between me and the doctors about what to do and it was agreed that we will try if need be a maximum of two IVF treatments. And if that fails, we would call it a day and I will start the treatment that they wanted me to know myasthenia gravis is a life threatening condition because it affects the breathing muscles. So the first five years I had sub optimal breathing the first month I was diagnosed in hospital with the crisis manually died because my breathing got so poor, and they had a cot outside my bed ready to rush me to ICU and put me in an induced coma. If my briefings were any lower, so it was a really hard time. So we I was trying to get pregnant I was dealing with work, I was off work for six months, when I was initially diagnosed. I went through the crisis, I had a Timex Summit, which is open up surgery, when they removed the glands from behind the heart, which is meant to help us I'm very high dose steroids on steroids for 19 years. Eventually. Anyway, so I was off work for six months went back to work, terrible situation. But anyway, you dealt with the FSG. I had 13 emergency hospital admissions in the first two years. And at that point, I decided I wasn't going to count anymore admission, I was sent home in a taxi twice because I collapsed at work, I'm really good at falling. That's a really useful skill, how to fall and not hurt yourself. Anyway, so all this

is going on, I'm trying to get pregnant, I'm trying to get the disease under control. And I'm trying to cope with work. And, of course, it's all too much. And the body can't possibly deal with all of that. So we got to the stage where we went through IVF. And it failed. And the doctor called me in and said, This is never going to work for you, your eggs, too poor. You know, basically, that was it. I did try and get IVs through the NHS, but because I was 37 I was declined. And at that point, I'm very ill, that doctor told me this is not an option anymore. So I was pretty much destroyed for about six months. And two weeks after the conversation with a guy named Dr. I rang my Nero and said, Right, okay, I will start the isotype print, I will take the treatment that you want me to. And we started that and I put sort of having children to the back of my mind then because I had no choice about anyway, they weren't able to get my condition under control. I just wasn't able to manage everything, and neither were they. So we decided to sell up leave London and moved to Birmingham. And I, I've always had gotten problems. I've also had really bad periods very painful. I went on the pill in my early 20s. Because of that anyway, so upshot was at one point I was in hospital, my blood, my red blood count was nine and I was receiving I was going to leave my senior and they were like, well, we can't give you white blood cells and red blood cells. Because it's, we can't. And so it's kind of unhealthy. So we stopped, you know, said right, okay, we've got to deal with this and the guy ended up instead, right? Okay, have a look, you've got really bad fibroids in almost. So I've been reading really heavily. And I had an emergency strikes me at that point in that and then I'm

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Palo Baker 12:51

at 41, I'd love to travel. So anyway, so that's sort of my situation. And after that, I went onto methotrexate. And of course you can't, you know, I've had the hysterectomy, I'm not gonna get pregnant, I'm on another drug. I can't, it's just all over. So at that point, I knew that dreams gone. So I've been involved. Like I said in me, my senior Gravis Association, and I was the forum administrator for some time. And I've been involved in support groups since. And that's one of the things that's been a key driver. For me. That was why I joined the community. And last year, I realised there wasn't a support group for with childless women with chronic conditions. So I set up a support group. And we're just over 90 members now after about 10 months. So that that's a bit my history is much truncated. Now, obviously, you can imagine with loads not behind it, but that's me. Panic, wow.

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Sarah Lawrence 13:52

Well, what I've been through so much, that's amazing. And then to bring something positive out of all of that, we're coming back to this.

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Palo Baker 14:01

Yeah. I just, I couldn't I mean, I've been through IVF. And to add on everything else, honestly, that I mentioned, trying to catch up somewhere along the line with how you feel as well and other feelings. It's it sounds like a real roller coaster. And then try to sort of pause and catch up with life, but your situation must be just incredibly difficult to do. Thank you.

S

Sarah Lawrence 14:29

Thank you for sharing and then bringing about something positive life support. Incredible helps us Wowzers. Okay, thank you for sharing. As I say we're going to come back. Charlie, can I come to you lastly, to introduce yourself?

C

Charlie Bishop 14:43

Yes, of course. And, you know, thank you so much. I echo Steph's comments from the start of the podcast. Thank you so much for for inviting me to join, to join this podcast and to have the privilege to listen to the other experiences is being shared as well. And they really are quite different having had the chance to listen to Stephen and Parlo before before me, mine is a different story again. So, though I found out I was infertile at 17. And I was born with a condition called Mayer-Rokitansky-Kuster-Hausler syndrome, where I'm born without a womb or with an underdeveloped womb and a shortened vagina. It can also affect other parts of the body. But in my case, it's that element only. And there are other effects to kidneys, and bones and hearing that can happen with in some cases as well. So I mean, I remember being being diagnosed at that age. And, and of course, that's, that's often the first thing that many of us think about, you know, you're taught, you're told at 17, that you don't have a uterus. And the first thing is, oh, my gosh, I can't get pregnant, and what does this mean for the future, and suddenly, those very adult topics of, of Children and Family, become to come to the forefront of your mind. And that makes it very, very hard to kind of process and really grieve through that trauma when when you're so young, yourself and so unprepared for, for understanding what that means. And, and I think it took a year, several years to really kind of start to process that to think about what other options were available. And I echo the points raised, they don't really feel like options. I think Steph said the same, it's here there are there are different routes to or paths to parenthood, if that's a path you want to take, but but at the time that they were the only options and I was very keen to to have children and that they didn't really feel like much of a choice. Like there, there wasn't, they weren't really things that I thought I really want to pursue those with any kind of great, great vigour. And I think also, coming to terms with my own infertility was something that really hit me later in life in my 30s, early 30s, where it suddenly became more like prominent to me where I'm getting that little bit older, if I was going to explore some of these options, then. But I also wasn't at the right place in my life to do that in the way that I'd wanted to. And also, not being able to carry my own child kind of brings about some other complications, limited access to NHS funding to support some of these these processes, for example. And then you're on top of all these things, then trying to navigate just life in general. And it came a little bit too much. And, and I started advocating for Mr. Koh, about about eight or nine years ago, and got involved with the charity Myth Connect, which was founded in 2014. And that's the aim is to connect those with Mr. Koh together, and it was viewed through that community. And through the types of resources that we were compiling, that I found the childless community, because it became very apparent, by the time I got to my my mid 30s, that this was very likely, you know, the path to parenthood just just was unlikely to happen to me. And so I was trying to kind of find my place and in, in the in the world and in the community and within the societal expectations, as it were. And I was finding that there were others in the community that had those same feelings and those same thought processes, and that so much of the content in in our community in the myth community is very child focused, because that is often the thought that first comes to mind when you're thinking about your uterus and or lack of, in general infertility conditions. And I think it was, it was a real realisation for me that actually we needed to do more, to be more inclusive to those in the community, including myself, which is, you know, it's just one of

those things that just kind of glazed over a little bit that that actually we needed to have more resources that spoke to those who, who either chose not to, with Mr. cage or who had tried and, you know, endlessly and not being not being successful. And, and so that's where I came across the childless community and probably been involved in various different things for the last few years and and hopefully being able to share and signpost, others to those resources as well.

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Sarah Lawrence 19:50

Thank you for sharing Charlo I'm really struck by how all three of you are sort of, I guess had to go through your own journeys, albeit they They probably on the surface sound very different. But I imagine it took a lot of internal strength to be able to cope with what you've been through. And then that that phrase that you said Steph, childless by forced choice is almost like a little sub heading isn't it that could cover so many situations within our community that many of us probably aren't even aware of. So and then so too old for all of you to give back, it must feel like it's part of your healing as well.

S

Sarah Lawrence 20:31

Yes, for sure. What was the turning point you thinking? Because obviously, going from having to heal yourself to then healing and helping others? Do any of you recognise that point at which it became a, a sort of a tipping point, you're right, I've got to go and help other people.

P

Palo Baker 20:47

I don't think it's so much a tipping point. One thing was when I was diagnosed, I thought, crikey, it's a rare condition. There are about 15,000 people in the UK have it. So it's poorly diagnosed, the average diagnosis time is two years. And with any autoimmune condition, the drugs, they give you a pretty horrendous, it's a sledgehammer to crack a nap. And they destroy your bodies, and nobody knows what's going to work and you try one dragon, then the next dragon and the next until you fight, you know, you're working through the lowest level of toxicity first, to the most awful drugs, and you take what you have to. So as soon as you're doing that I was diagnosed with that I wanted to help people, I wanted to reach out to other people. And I wanted to talk to people who are in the same boat as me. And so that is that you're looking for that connection, that feeling. It's not just me, it's like, wow, this is really rare. This is so unusual, you know, having an affair does happen. So you reach out immediately sort of people. And so my first thought was what can I do to help other people who are going through this. And that was why I immediately I joined the association. And there wasn't a branch in my local area. And they asked me to set that up. But I was the founding chair for that. And we set that up. And we had about 12 members almost immediately. And that was in London. So obviously, there's a lot more people there. So it was a very gradual learning, but actually helping others is healing me. That took time. I didn't recognise that straightaway, I did it because I wanted to help. And I wanted to support other people who were experiencing what I was experiencing, which frankly, was extremely challenging on every single level. And so, you know, and over the years, I've realised they healed me far more than I heal them. And what they gave back to me with a validation and a feeling that I have a purpose, I spent most of my time at home over the last 20 years because I can't engage much my physical abilities much limited. The treatments that I've had have had terrible effects on my body, I've had numerous

surgeries that I have severe generalised arthritis, this is my second arthritis surgery, they will no doubt be many more. So, you know, it's this is how I can actually feel engaged with society and with people and still feel that my life has value. And there is a contribution I can make. I'm not used to, you know, from being a very active, I was a finance manager manager for Barclays Bank post fly around Europe and advising companies and auditing them and things like that. So for me to go from that position where I was, I was being fed pureed food, I couldn't move my arms, I couldn't even press the buzzer on the nurses, you know, thing that they give you a press release of help. And I remember looking at the doctor, and she looked at me and she knew I didn't even have the strength to do that. So it's kind of when you go from being very active to No, then it's you need a sense of purpose and a reason to get up in the morning and to continue to face each day. And to find joy in each day as well as part of that.

C

Charlie Bishop 24:11

Such a good point, Paulo and I mean, I've found I mean, I don't have any any physical characteristics but what I was unprepared for was the psychological impact of dealing with everything that comes with the with that that's such a young age as well. And that that I think was the hardest thing for me in terms of what comes next and how to find support. And obviously, I suspect we're all in the same boat when when we were maybe diagnosed or in those those earlier days. resources weren't the same as they are now and I mean, I was I was diagnosed over 22 years ago now so it's you know, it's a completely different world now than it was then and and I found And it took a couple of years really for me to find any, any kind of specialist support but the myth that there was a hospital in London which had her diagnose me and they ran support groups. But I think I probably went to the first one about two years after I was diagnosed and, and it was then that I realised that there were so many people who've been through far worse diagnosis like journeys, and I had I'd actually had a very smooth period of diagnosis from, from going, going to the doctors to say I didn't have a period to being referred to a gynaecologist. It was probably six or seven months, I guess, with with all the testing, it was actually quite, quite quick. And I but I was from the southeast of England, close to London, there was probably that the location probably had a lot of advantage to that when there was some people with these horror stories of years of diagnosis which considering the you know, there are not that many reasons why someone wouldn't start their periods and the types of tests that that you could do even back then would have been able to identify this quite easily. It's much, much more common than then your condition as well. One in 5000, female births, you have miscarriage, but still, and I think that's what really drove home for me or why I wanted to end to give back to the community and do something and exactly what that was, I think, was something that took a bit more time to answer your question, Sarah, but like being involved in that community, and really trying, what could we do to improve the awareness of the general public of the medical community of the those with MRKH and their family so that they can understand more about what this means and and now now to be be able to be involved in in research projects, where, where universities and other groups are actually looking into the psychological adjustment of these conditions, which is, I guess, really the it's, it's that unseen part of any of these conditions when it comes to infertility actually trying to manage those feelings around grief and trauma, and grief and trauma for something you never had. But but there is a loss there. And it's really difficult to explain that to people. And so having that common support network with people who understand that's, that's been invaluable to my journey as well. I completely agree with you.



S

Steph Penny 21:38

Yeah, I agree. I agree with so much of what you've been said, Charlie, and Paolo, the the horrors of diagnosis, and how long it takes and the tests they put you through to, you know, to determine or to eliminate this and that mine took eight years to get diagnosed my autoimmune disease, and it's another rare one, like yours, both of yours, which is called lupus. And a lot of people have heard of lupus, but I really don't know anyone who has it. So there's actually not a lot of support in Australia. There's a bit in the UK, the UK does lupus a lot better than Australia does, at the moment, but I resonate with what you guys are saying about that journey to diagnosis. They basically had to rule out every other disease on my plate. And I spent time in hospital and they took all this blood out of me. I didn't even know I had that much blood. But apparently, apparently I do. So I don't think I know anyone. I just listen to your stories and reflecting on who I connected with around childlessness. I don't think I know anyone who's both childless. And living with lupus, I have to say like, I'm struggling to think of anyone who was in the same kind of sub minority as me, but what I think there was a tipping point for me though, and sharing my story. It was that people were asking me to, to write a book. I'd written a book a few years ago, and and people were like, Oh, that's great. And I'm a bit of a creative so I express myself through words and through music. Don't ask me to draw my drawings. Terrible, but I, I like other forms of artistic expression. So I'd written this book, and people were coming up to me going, Oh, what's your next book gonna be on stuff? And I'm like, Well, I don't know. I just I wrote a book about surviving singledom. You know, and particularly in the church when everyone else seems to be married. So I was like, I'm kind of happy if that's a standalone book. And people were like, oh, you should write a book about marriage. And I was like, Oh, hell no, like, seriously, I need to add another book, to the plethora of marriage books about surviving marriage or like, Nah, I think you've come to the wrong girl for Uh, for that anyway, a couple of people made the same suggestion. And I was like, not not not not going to do it. And then a friend of mine at church who was also married without children, at that point, said to me, you know, why don't you write a book about marriage? And I was like, I don't really think I need to add to the the wealth of marriage books that's already out there. And she said, No, no, no, Steph, I don't mean write about what it's like to be married. Can you write a book about what it's like to be married in the church and not have children? And I went, yeah, yes, I could definitely write a book about that. So that was, I guess, a tipping point for me in terms of writing words that would hopefully reach out to others. And even that, that simple, but powerful message of how you're not the only one. It's not just you, you're not alone. So I, I realised my story was niche. So I actually took it upon myself to interview a bunch of other childless people for that book. So I'm going and my story may not resonate with many people. Let's include some other stories about infertility and IVF and interviewed 14 Wonderful people about their childlessness stories, but I think that's what when you guys talk about what gives your life meaning. I think for me, that's being able to write and publish a book and you know, or produce music and put songs out there. For me, that's those words last forever, that music lasts forever. And to know that that stuff is going to outlive me, those words are going to be around long after I'm gone. Like that's a kind of legacy. And that's really meaningful to me that my words might continue to reach out and, and encourage and inspire other childless people long after I've shuffled off this mortal coil. So yeah, I think that's given me a lot of purpose left by the void of childlessness.

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Sarah Lawrence 32:04

So it almost feels like you've almost all found this purpose around giving back legacy, connecting others bringing it together, recognising that actually, maybe it's a small group, but it's a much needed voice that you need to sort of gather everybody in so that you're all

together. I was wondering if I could go back to something you said, Steph, earlier. You mentioned talking about if something was the effect, you're sort of saying, you know, about the childlessness around, I kind of came away with it sort of like, am I part of this community, the childless not by choice community because it's childless by forced choice. Now I, obviously with the counselling, I worked with a lot of people that are kind of one foot in one foot out. I was wondering, could we explore that a little bit? Because I think there's quite a lot. There's quite a number of people that think, am I part of this community and my, should I be part of it? Am I I don't want to use the word worthy. But you know what? I mean, do I qualify? explore that? Would that be okay?

S

Steph Penny 33:09

Of course, I definitely resonate with that. I definitely had that experience of wrestling with the dilemma of well, I'm childless, and I don't want to be childless. So it's childless, not child free. But there's all these other people here who've been trying to conceive for a really long time, and I didn't, that wasn't my story. So is my story. Not not as valid. I was gonna say, is it valid, but I know that it's valid. But it was more a question of belonging, I guess. Like, is this the place? where I belong? And if not, well, where the heck do I do I look for another tribe, you know, another community where I can belong. So yeah, I I guess I wrestled with the words and the language. A bit words are really interesting to me. I'm really interested in language, and nuance. And that's where I came up with the forced choice because I thought I asked some people in the childless community do you think I'm like childless, not by choice? Or do you think I'm childless by circumstance and, and someone messaged me at one point and said, Oh, you're childless by circumstance, because your medical condition is a circumstance. And I was like, you know, that's true. Like, I went away and thought about it. I mulled it over and I went there. Absolutely. Right. Like it is a circumstance. At the same time, it lacks some of the, the meaning for me, like a lot of people when they say childless by circumstance, they're talking about not being in a relationship, you know, they haven't found the right partner. They're childless by singledom which is its own cohort, you know, and with its own challenges, and I thought, well, I don't really identify with that group either. So what about people like me who feel like, you know, they're facing just a really difficult decision, a really risky version of of of childlessness, where it might be actually too dangerous to even start trying, you know, along with my lupus, so I resonate with what others have shared about having other feminine issues. You know, I had endometriosis for a very long time, very painful. So there was that. And there were other factors kind of piled on top of that, where I was kind of going. It's not really, yeah, the choice is taken out of my hands. But I technically do have a decision I tuned in fraud on it is what I'm trying to say I tuned in fraud for a long time. And that's when I went, let's come up with something completely new then. Because I'm not finding anything that's really satisfying. So hence, the fourth choice. And I put it in my book. And what I was saying about it was that this might resonate with others who also feel like they're in a difficult life situation, where, yes, they have a choice. But it's such a dangerous choice that it's there pretty much not willing to look at it. And I can think of people I know with significant mental distress, or past trauma, or perhaps disability, or the limited in terms of their mobility or their functionality, who might also feel like, well, yes, I could be a parent. But the efforts and the psyching up it would take to get there. And could I kind of follow through with it once it started. And all those questions, I thought perhaps forced choice might be a better fit for people in those sorts of circumstances as well, I guess is kind of also a benefit to people from the outside looking in, even within our community to thinking about what you said about language and how that matters. And, and I wonder sometimes whether perhaps we talk too much about the reasons, the obvious reasons, albeit painful ones, like failed adoption. IVF not working, because actually, they're kind of ones

that maybe unite us a little more largely within the community that we're in. And by not having a phrase for all of the other reasons why we're here. We don't know the words. So actually, what you're probably also doing step is empowering within the community by giving people phrases they can use that they feel are appropriate, as well. It's the first time I've heard something, certainly in all of the time of World childless week and of doing the podcast and that, but I've heard a term that I think sums up so eloquently, what other people are going through that they could choose to use it if they wanted to. I think that's incredibly empowering.

B

Berenice Smith 37:43

Language does matter. You're right. And it matters both inside and outside. As you're saying it gives people who maybe haven't faced childlessness, or they're not in that circumstance, a bit of a, like a code, a bit of an understanding or a description of what it's like for us to be inside that circumstance. So absolutely, language, language matters, for sure.

B

Berenice Howard-Smith 38:05

And it protects your privacy a bit too, because I'm conscious that the three of you are sharing very private personal stories, and very privileged and honoured to be listening to those as I'm sure our listeners are as well. But also, sometimes you may not want to say that, but actually you're implying something. And the more that phrase grows, and I think the more that we can do to to advocate for that phrase to say that that actually, this is a thing too. So you've got to just have a sense of there. This wasn't something I chose. It wasn't a situation I wanted to be in. So thank you. It's an incredibly brilliant phrase and very empowering show for everyone within our community too.

S

Steph Penny 38:42

thank you. I'm glad I hope it does help people.

M

Michael Hughes 38:46

Well, I just want to say that I, I'm gobsmacked again, because I have been feeling the emotion while I'm listening to your stories. And I just feel so privileged because I do recognise that I am one man in a group of five women. And I would not get the opportunity to have such a interesting and personal chat with with people like this. So I really want to thank you for this. All three of you. You are certainly beautiful people in my book. I think about Charlie the I was counting when it was but it was a might have been last year. A good friend of mine reached out to me. And she had a friend of hers. So we're all about the same age, who has a daughter with Mr. Koh and her mother had absolutely no idea what to do. So my friend reached out to me says Can you help? Yeah, okay, was it. So I actually had to research what it was. And then I was able to put them in touch with an Australian organisation. So that was, that was really, really great. But I will certainly be forwarding this, this episode on to a friend of my friend. Because because she's. So I guess this could start a conversation around how she was dealing with it.

And this, this doll was extremely angry. Very, very angry to the point that her mother couldn't even bring the topic up. So she was looking for support to somehow, you know, get behind that with her daughter and help her out.

C

Charlie Bishop 40:53

I'm actually not I wasn't too angry myself. But it's, it's certainly something we see quite a lot in, in the community and through the through the charity, but I would, I would say for, like, my personal experience was, I mean, I tried to block it out, if I'm completely honest. So those first couple of years after diagnosis, and I think, to be completely honest, back back then with it not being so with other information resources not being so accessible, it was easier to hide away from some of the these things if you didn't want to know, I couldn't just go in Google it, or I guess we could Google but there wasn't much information that was online at those times. And certainly social media didn't didn't exist. 2020 plus years ago, when when when I was diagnosed, so it was it was easier to kind of go into into myself a bit more. So I would say it was less anger and more, bottling up those feelings. And it just became a topic we just didn't talk about at home. And it's been really interesting for me, because my, my mum joined the board of a charity. So I run and kids connect. And she, I asked her if she would be interested. And because she'd seen I've been kind of advocating publicly for a few years. And, and suddenly she has this connection with the community that she's never been involved in, but that she has, I feel like she's really found her, her place in it as well. So I'm really proud of her for what, what she's, she's always been quite negative about how she reacted in those early years that she feels that she let me down. And you know, a lot of mothers take on so much pressure after a diagnosis that, that it's somehow their fault, something that they did in pregnancy that's led to this. And, and it's not I mean, the research has shown that that's, that's not the case, it's just one of those developmental processes, it's quite complex, and they're still trying to find out all of the causes. But certainly, there's nothing specific in a pregnancy that a person could do to cause it. And so I think there was a lot of a lot of guilt there. From from my mom's side, and, and, and then that that became, I think, quite difficult for her to, to handle. But then as I say, we didn't really talk about it until, you know, probably early 30s, early mid 30s, we never had a conversation about about it was just kind of ludicrous. Really I was going to all the support groups by myself, they were they knew I was going I made by my own kind of friends at the at these groups and, and then just you know, took took the initiative because that's what I wanted to do. And it was never a disrespect to my parents. It just it just became something we just didn't talk about. But I speak to plenty of mums. Now and dads sometimes but particularly mums, who contact us and yeah, seem similar to your friend, and just don't know what to do. They don't know how to what can they say what can they do? How do they make it better? And unfortunately, there's no there's no easy answer as I'm sure you imagine microwave sir. It's so it's it's so different for every person, every person deals with grief differently. And also, I mean, some people can be really quite young when they are diagnosed if they have some of the other associated conditions, for example, with kidneys or maybe scoliosis or something like that, that is diagnosed much younger. The parent may know before the child does depending on the age and what I mean most the majority would be diagnosed probably from 15 16 17 kind of age range but but even still trying to navigate those kind of informative years with adult challenges almost becomes very, very tricky. And I mean we have built some resources on our on our page on our website to try and support parents by sharing parents experiences to help others are going through that. And it's an area that we can continuously reviewing as to how we You can, how we can build more resources to help. And it's it's a case unfortunately have a lot of a lot of patience, a lot of listening a lot of, you know, I'm here for you without perhaps being too hot or seemingly too smothering to the, to the person that's going through that because I think,

particularly those, those first few months, first year, two years can be really delicate and really hard for that person themselves to navigate their diagnosis, let alone articulate what that means to their family, even if maybe they're talking to their friends, but I think sometimes sharing something so personal, and how it's making you feel with your parents feels it was also quite, quite awkward. And but it's Yeah, I mean, if it helps to redirect her in our direction, we're happy to have a chat with her as well, Michael, but yeah, hopefully we can build some more resources to help those in a similar similar situation.

M

Michael Hughes 46:04

I'm when I was thinking of listening to your story. I was listening to you know, Steph was talking about how she was siloed. We all understand that siloed and then you have these, these an autoimmune disease that again, would compound that soil that that that loneliness, I guess that that the fact that now you're restricted, probably just your home and and that must I'm sitting here, gobsmacked, I can't get the words out to just think about what what that must be like. So for, for you to just turn that around and go? Well, I want to give back I just, I'm going to shut up in a minute. Because I can feel the emotion welling up.

P

Palo Baker 46:50

I think in some ways, when you are stripped of everything that you know, about yourself, your body, what's going to happen in the future, what's happened in the past, you reach a point of being so low, and I can't, I can't explain how low I have been in the past. I cannot tell you the debt I have experienced I really can't. And that crawling out of that is hard. And learning to think this is my life now. And but what do I do with that? You know, I'm, I was mid 30s. I couldn't, I couldn't just ignore it. I couldn't pretend it would go away. I was in hospital at the time. I couldn't talk i i had to spend a lot of time with myself. And I had to really get to a point where I could accept my external reality. And think right, okay, so if this is what it is, this is what it is. I've always been extremely mentally strong. I've had enormous challenges in my life. I was born blind in one eye, I'm Asian, I'm female. I was brought up in a sexist hierarchical society. I'm a minority, as minority, the minority of a minority of Americans, I have been that the whole of my life. So I'm used to fighting for myself, I stood up to my parents, all my peers. The girls, my age went into arranged marriages when they were 17 to 21. I fought against that I went to university I had I got a degree, I had a career. So I used to fighting. I'm used to being on my own, saying, This is what I want. And I'm not going to accept what you're giving me. So for me, when I was told I had my senior grabby, I was like, Oh, I can deal with this. I've dealt with this. And I've dealt with that. And I've dealt with the other. What can they do to me is a hell of a lot more than I could ever have imagined. And so I went through all the physical degradation but unable to look after myself having other people do things for myself that I never thought I would have to except, except maybe when I was in my 90s. And, you know, so I have to accept that when you are faced with an impossible situation. You have to deal with it. You don't have a choice. You know, it's like you're strong because that's all you are. There is no other option. You don't crawl into a corner and die. That's the only other option. So you find it you deal with it and you you you live through it. And and the emotional stress that every single Rena the heartache that cause every single time, my body was overpowered. That, um, the mental challenges I, I just cannot express that through you. But you get through them, you survived them. And you, you look back and you think, but I got through that I got through today, and you wake up the next morning and you don't know what the challenge is going to be

you don't know if you're going to be in a hospital bed, or you're going to sleep on your own. And you think my challenge to die is tonight, I'm going to sleep in my own day, I'm not going to be in hospital, I'm going to get through the site. And of course, many times I failed. But you accept failure, failure is part of life failure doesn't matter. In fact, nothing that actually happens, matters in any way. It doesn't matter how bad life get doesn't matter how good lawyers get. It is what it is. And it's your life. You know, you deal with it. So it's really not a case of it's hard for other people to understand and accept it. Because they can't imagine living through that. They don't have to. So why should you I don't expect other people to understand me. I don't expect other people to care or guide us. It just says people know what they know what I know. Yeah, I wish I didn't know. I'd love that level of really Oh, honestly. But I can't, I can't hide from that. But what I can do is make that experience meaningful. And what I can do is I can talk to someone else who's given this diagnosis and say, Oh, my God, what am I going to do? Am I going to die? Am I and some of us do die, you know, before treatment, there was a 20 25% chance 25% chance of death with treatment. So since the 1970s, the chance of death is only three to 5%. That's higher than dying from counted. So when everybody was sitting in their dorm, because of COVID outside, welcome to my world. This is where it's like, I always have to be careful, I can't get a cold, that can be enough. So, you know, for me, I guess I've reached a level where nothing really massive. And so many things I don't care about because they're so unimportant. And I feel that the only answer to any questions that worth is worth but it's worth asking is love, love others care for others. And that's kind of what I believe. And that's what I think the support is about is being able to share that and you can still be happy, you can still enjoy the rights that you may not be able to go out with you may or may not be able to drink booze and come up, you know. So you know, people look the worst thing, the thing you should get used to her. And you You know, I've learned I've taught myself loads of things both for years mixing, crocheting, painting, drawing, I'm currently learning to play the piano, and I'm learning him the Spanish language. So there is so much you can still experience and you can still enjoy. You know, I don't believe in labels, I don't believe in tags, but I you know, I am what I am, we're all human beings, the rest of it really doesn't matter.

S

Sarah Lawrence 53:33

I've got one tag, inspirational.

B

Berenice Howard-Smith 53:46

I really, really hope that the eighth or the aim of what we're doing today is to raise awareness of all the other reasons why we are here. It was something we talked about, between the three of us over the course of a couple of months as to who do we get on who would talk so that we can just explain. It's as Jodie says, it's not just the door didn't couldn't, there are so many other doors to this as well. I think that is the most important thing that we can do. There's a friend of mine who is very dear to me who is childless because of depression that can actually would end his life. And he couldn't bring himself to have be a parent because the risk of that being hereditary. And one of the things he did recently was a little kind of thing about being a pocket Buddha pocket. And he had a beautiful thing that he said would just be kind, be kind, be kind. And the way he said it. I'm trying to emulate it. I can't he's just too good a speaker, but it is just that isn't it. It's just to kind of actually to listen, I think as well is so important. We learn it on the podcast but to listen to what people are saying as well is it's an incredibly valuable and important thing and well learning Spanish Spanish is hard.

P

Palo Baker 55:24

All the Romance languages have so much in common. It's just different ending or beginning sort of thing. So if you know one, you know a lot.

B

Berenice Smith 56:16

What plans have you got for moving forward? What, Where? Where are you going individually? You know, what, what plans have you got for your support? Where do you see it all go in? Would that be okay to talk about that as well? Who should we go to? We've not heard from you, Steph. It was difficult to come to you with that one first.

S

Steph Penny 56:39

Yeah, sure. I have recently found a good support group online for autoimmune things. And I found that a lot of people in that particular community actually have lupus, which is amazing. I'm like, Oh, my gosh, you get it to you, you have the thing. You know what that's like. So there's, there's people on there with other autoimmune diseases, of course, we find that a lot of autoimmune stuff overlaps. There's a lot of similarities. So it's a good place to just kind of discuss all things autoimmune. And we certainly were there for each other. And it's a very raw candid space where we can talk about, you know, can't see any light at the end of the tunnel today. I've lost everything. I'm facing the horrors of this. I can't move, I'm bed bound, or I'm housebound, whatever it might be. And I think that's, for me going forward, it's so important to have that kind of support, where you can be absolutely candid, and not feel like you have to filter what you say. And you don't have to protect the other person or coach them in how they have to respond or tell them how to support it, where there's just this kind of implicit understanding, you can be free to be yourself, and you don't have to spend any energy coaching them, you can just sit in silence, or they might respond with something else, or they might help distract you, or send you cat photos or whatever it might be. That's really helpful. So that's really important for me, I'm going to continue writing. So my next book is actually called Surviving chronic illness, that's going to be a really, that's probably the most vulnerable book I've written yet. That's going to be glaringly honest about what it's like to be, as you said, polio stripped of everything. That phrase stood out to me. I was like, Yeah, I really relate to that. And I'm going to keep writing music and putting songs out there. And music again, is it's a really non judgmental space. With music you can there's even times like I love words, obviously. But there's times when I just sit and play because sometimes with grief, both for childlessness and for for illness, sometimes you reach a place where you just run out of words, like there aren't any more words. There's no other way to explain this. I've unpacked it to death. I've reached saturation point, there's no prayers left. There's no There's no words. There's no questions. It's just the and So music is a safe place to just express yourself and have an outlet without having to find language for it. So I think that's going to be helpful for me going forward as well.

M

Michael Hughes 59:33

Before we jump on to the others, Steph, I listened to your song. Angel at my keyboard the other day. Oh, yes. And I need to tell you this, that it resonated with me so much because of the the

day. Oh, yes. And I need to tell you this, that it resonated with me so much because of the the image that I've always sort of carried in my head is my is my boy coming to see me foots asleep my counsel? Yeah, I need to talk to you that And so that's why that song resonated with me. And it actually, so for me, it's that, that that that image is quite melancholic for me in some ways, but your songs not. And so it actually really, it gave me a massive paradigm shifts, when I was listening to it and still reflect over it, you can see that you can probably hear the emotion in me right now. But I wanted to tell you that wow, not quite sure how, where it's going, but I will let you know.

S

Steph Penny 1:00:38

Thank you, thank you so much, Michael low. Again, you put this stuff out there, and you hope it resonates with people, but you never really know if anyone's going to listen to it or like it or whatever. But thank you for saying so because the song. For me, it was an image that came to my mind one day very starkly, and out of the blue. And I felt physically in pain when the image hit me of this little girl at my keyboard. And I was teaching her to play, you know. So that was one of my hopes for legacy in having a daughter. And the song is kind of bittersweet in a way. Like, it's got the it's got the sadness, and the sorrow in there. But I also wanted to convey the beauty of that image, as well. And how it's, it transported me to a completely different place. And that's what grief can do, of course, but yeah, there's this idea that grief is always sad. And sometimes grief is kinda, there's a, there's a sweetness, and there's a stillness, and a grace in that, as well. Michael, I really appreciate your feedback. Thank you so much for telling me that that's what came across to you. I'm so thrilled.

M

Michael Hughes 1:01:51

Thank you for composing.

S

Sarah Lawrence 1:01:54

Thanks for sharing that stuff. Sounds like looking forward to the new book then sounds like it's gonna be really interesting, and a really good support for people that have gone through chronic illness as well. So something else that people can sort of reach out for, perhaps when they're not ready to talk to people, but they want to hear a voice.

S

Steph Penny 1:02:17

And hopefully, a good encouragement for Christians as well. There's often these, you know, there's mist in society about well, if you just try hard enough, you can overcome anything. And sometimes you just really can't. Sometimes your body goes, Yeah, we're not doing that. No, no, I don't care what plans you had. No, that's not going to happen. And I think in the so the Christian circles I travel in a lot of Christians sometimes need to hear that as well. Just that reality check of, you know, as as wonderful as God is, sometimes he doesn't intervene, sometimes he doesn't heal your illness or he doesn't give you children. And sometimes it doesn't tell you why either. He doesn't give you answers. So I'm really hoping these books can just reassure a lot of people who've been down that path of mystery of not knowing where on earth this is going. But still hanging on still surviving somehow.



1:03:09

I think a lot of people in the Christian faith might resonate with that message as well. around that, you know, where they fit within their community, their faith community.



Charlie Bishop 1:03:41

I'm happy to go Yeah, I think I think I was I was reflecting a bit on this roster. While Steph was talking and just just thinking in my in my early 30s, where when I kind of started into advocacy, I think I spent such a long time thinking about a future that I thought I or that I did want but that was seemingly unreachable, unreachable for many reasons. And I think I spent such a lot of time expelling energy on that, that I really, I really came to not live in the present as much as I as I wanted to. So I think that's really something I've learned over the last few years and something I want to continue is actually focusing on on happiness in general enjoy. Speaking to Palo's point about just really enjoying life for what it is and through the good and the bad I think is something that's that definitely kind of resonates with with me and where I see my my journey going. I'm actually getting married next year. So that's very exciting for me. And, and also travel. I think the there the the advantage that my life Yonsei and I have we live in Norway, we're both Brits living in Norway. And it feels like we're now in a in a new a new chapter of our lives to explore. And I think that's something that I'm really excited about what that brings for us in in the future. But whilst also from the kind of advocacy and Mr. cageside, just just bringing different perspectives to to the group, and continuing to engage with people at all ages and stages of their of their journey, we just launched a youth programme for the younger MRKH teachers just a few weeks ago, and then building other resources and support materials and just seeing how that evolves. I mean, I'm not sure I necessarily have a, you know, a five year plan for that as such, but I think it's going to be really interesting to see how, how that evolves as as time goes on. And, you know, being community run means of course, we're listening to what the community needs as well. So I think we've travelled writing, I used to write a lot. And that's kind of how I got into advocacy was started writing a blog for my own catharsis, and, and I admit, that's kind of slipped a little bit over the last few years of life and busyness has kind of got in the way but I'd love to get back to doing that it was a really pleasurable part of my my spare time was was was writing so I'd love to get back into doing more of those can't promise to write a book, although I have always wished to do one so I might be messaging you, Steph for some tips and tricks on that. But yeah, I think there's lots of Yeah, lots of interesting and fun things I think that I see for myself and in the future and definitely with a focus on things that bring happiness and joy it's there's too much time we waste on things that stress and upset us and I completely agree with Palo's point on that we have to enjoy as much as we can.



Berenice Smith 1:06:56

Where can people find the support group? If they're looking for you? We will share it but where abouts could they find it? So



1:07:01

It's MRKHconnect.org. We're also on all the social medias as at MRKHconnect. Within our

website, we also have forums, we have lots of other resources as well. And then across social media sharing various different things from people's experiences to the podcast when it comes out. We'll of course be sharing and various other kinds of resources that will be of interest to the community.

S

Sarah Lawrence 1:07:38

Fabulous, so something for everyone then pretty much we hope so. Yes. Fantastic. Thanks, Charlie. And Steph obviously will share your details as well. But would you like to share where they can find you if they're looking for your books and what have you?

S

Steph Penny 1:07:52

Yeah, absolutely. All my books and blogs and music are in one place on my website so that Steph penny.com.au They are also available at Quran, which is an Australia based Christian bookstore, so you can order through them. And of course, the advantage of ordering through them is you can buy a whole bunch of other pretty things as well, while you're at it.

B

Berenice Smith 1:09:06

Thank you, Steph. And finally, Paulo if we could come to you.

P

Palo Baker 1:09:10

All right. So when people talk to me about plans, I don't make plans. I spent years that I've not been able to move forward with a single day. So no, I don't make plans. My only plan is to get through for that. There are things I obviously wish for I build a lot of slack into my schedule, because my condition is one by definition fluctuates, which means some days I don't function very much at all. And other days, I function perfectly fine. I have probably about 40% of the energy that a normal person has on my best day. So that's kind of sets the baseline in terms of my expectations, because obviously I have to revise those down significantly. And I've had numerous other medical issues over the last 20 odd years. My I think the latest one is severe arthritis. And I'm probably going to be having foot surgery in the next six months and my knees are shot that will. So anyway, so there's lots of other things that I have to take balance. But on the being engaged with other people, France, which is what I like to do, is they alone launched that to chronic survivors, childless warriors, or is that the wrong way around? Yeah, chronic files, childhood stories last year, last November. So I obviously like to engage that and my hopes for that is to give people a safe environment in which they can talk about the challenges they've had. And they can share them in a community of women who have experienced similar challenges. And not feel that they have to explain what they've experienced and all the rest of it. So that to grow that community, and really to build that in terms of the connection. So going forward, we're never going to be able to leave this community, we're always going to be stuck with our medical conditions. And chronic conditions love company, if you have one, you inevitably acquired others over the years, we all know. So, if I can do that, and I can give these women that, that hug that comfort, that friendship, then that I hope will sustain them. And me, throughout declining years, we I mean, no one is promised tomorrow. So I don't think about

what's going to happen tomorrow, tomorrow can take care of itself. Today, the younger someone to be, it's the best thing kind of. So let's not worry about tomorrow, let's just focus on making other people happy, making myself happy and trying to make my life as easy as possible. In terms of minimal strife and minimal aggravation. I have very strong boundaries, I don't engage wherever I feel it's not right for me, I've dipped in and out of many groups over the years. So as long as I feel I'm needed, I will contribute and be involved. As soon as I feel there are enough people here and as it can carry the mantle on and will develop it forward, I'll move on to the next thing and help them for many years I was involved in in my senior groups, and I support that a lot. And I've seen how that's grown. And, you know, there's loads of people there now who do that. So I've been perfectly happy to step back from that the last few years. And of course, I have to balance it with my relapses and things like that. So it's, I don't have plans I want to get through today. Tomorrow. You can't have plans when your life is unpredictable. So you have to embrace it, you can't fight it. So living in the present is really important.

M

Michael Hughes 1:13:03

Where do people find your childless warrior group?

P

Palo Baker 1:13:06

Okay, so that's a Facebook group, and chronic survivors, childless warriors. And I can send you the link afterwards. I've been meaning to try and publicise it more. But as always, I'm constantly balancing my energy with sort of what needs to be done. And my first priority, obviously, is to manage my house, and then everything else has to come further down the list. And it's a case of at the moment, because in my hand, I'm right handed, it's been a quite a challenge. So I've asked a few ladies and they expect forward and you know, they'll they'll sort of monitor things that monitor and manage things, I am involved in other groups as well, like the nonreligious told us not by choice, and child's not my choice of two or three other groups and that I run it in my senior group die and my senior. So you know, there are there are various things that I get involved with, but it's not only on a case by case basis, when I have time and energy, to be perfectly honest.

S

Sarah Lawrence 1:14:06

Wow, you use your 40% Very well, then you're 40% of energy. You're working miracles with that. 40%. Oh, well, thank you. We will share the group if you want us to if you'd rather, if it's too much boundaries, just let us know. ,

P

Palo Baker 1:14:23

That's fine. I would like to do that. I thought this would be a good chance for the people to hear out but and hopefully, you know, for more women to feel that there's a place that they can come to where they will be safe.

S Sarah Lawrence 1:14:33

I love that I think lots of our listeners who are affected by these issues are going to be drawn to all three of you. I think you've got such unique inspiring stories that actually people are going to be drawn to you and want to be involved with your organization's and your books, because you've got three very strong individual voices. And they're going to resonate it if they share that those stories with you. So thank you so much for allowing just to share that with you, it's been amazing.

B Berenice Smith 1:15:03

Thank you very much spent an hour learning. So very much. I feel educated, more educated than I was an hour ago. Thank you for the privilege and honour of listening to your stories and for sharing them with us. Thank you.

M Michael Hughes 1:15:18

I'm still going to max out what everything that Berenice said. Double that because I mean, all three of you. Thank you.

C Charlie Bishop 1:15:32

Thank you so much for having us.

 1:15:33

Thank you, guys.


P Palo Baker 1:15:36

Thank you for the opportunity to say

M Michael Hughes 1:15:40

thank you for listening. We hope you found Charlie Powell on staff as inspiring as we did. And if you want to find out more about our podcast, or you have a burning topic, we have not covered, please reach out to us as we'd like to be as inclusive and diverse as possible. And you can find us on Facebook, Instagram, Twitter, LinkedIn. And we also have a YouTube channel. And of course, at our website, WWE dot for stock pod.com. And here, you can sign up to our listeners list, where you can keep up to date with what's going on in our world. And if you want to donate to our work, you can do that there too. We'd also appreciate it if you could rate the podcast on the app you're listening to us on. Apparently the algorithm loves this, and then

makes us more visible on searches, and the more of our community, we will reach. And personally we love getting your feedback. So please reach out to us if you feel the need to. And as always, it's important for us to let you know you're not alone.

 Palo Baker 1:16:45

I've been trying to speak to all of you for such a long time as well. You're searching on Twitter. We're just kind of a sweet golf intro and little kind of worlds of chat. Sometimes. It's really nice to meet you as a real person here. And one day maybe in real life. I hope that one day I'll get to Australia in which case you are definitely someone well apparently

 1:17:08