

Barbara & John



Parents of Ryan and Jake, who is 18 and has a dual diagnosis of Mitochondrial Disease and Dravet Syndrome.



THE BEGINNING

Don't try to fix it. You don't have to deal with it all in one day.

<https://youtu.be/wocPN7sDuQQ>

Blyth: Yeah so if you're thinking -- there's a parent, -- you know, you're talking to yourself ten years ago or a newly diagnosed family who's got questions, anything you wish you could say to them that you haven't said?

Barbara: I just think I would say to them, "Take it one day at a time."

John: Right.

Barbara: Don't try to --

John: It sounds so cliché, but it's just --

Barbara: But it's so true.

John: It's so true.

Barbara: Don't try to fix it. Ryan I remember said to me one time, "Why are you trying to fix Jake? Why?" And it was said through the eyes of a child, but it kind of was a real wake up call for me that he was seeing me trying to change something that wasn't going to change. I was trying to help Jake, not fix Jake, but Jake is Jake. I think acceptance is huge and it takes a long time. You don't just accept and it's almost like the stages of grief and you fight it and you deny it and you don't want it. But then, if you can just learn to accept it, then you can learn to live with it. And, I think that happens in phases and I was a much different -- we were both a much different person, in a much different place 15 years ago. And if you had told me when Jake was two or three what this picture was going to look like when Jake was 18 and still here, -it never occurred to me that he wouldn't still be here- but if you had predicted what was going to become, I would have been so much more afraid and I think unable to handle it.

Where I feel lucky that, this happened to us in snippets. It happened in phases. We grew into the situation as Jake grew sicker and as he declined. It's been such a gradual progression for us that we were lucky. But I think anybody faced with a situation like this just -- take it a little bit at a time. You know, don't think what if, what if a year from now, what if five years from now, what if -- it's the what-ifs that will really keep you up at night and I think get you just stuck in this bad place. And you know, worry is not going to really help you in the day to day.

John: Well, I think you said it. I mean you really have no choice but to take it one day at a time and to try to look at the big picture as in where you're going is overwhelming. I think that's where -- I think that scared us. And the fact of the matter is, that I guess you do evolve in your own way. Barb evolved her way, I evolved my way. As long as it brings you back together at the end, I think you're okay. And if you can trust that process then maybe, you know, there's some solace in that -- from that. It's -- but to try to look at it as in I don't know where it's going to go and you try to plan for that and we've all tried to plan, it's just -- it's too overwhelming. But the fact of the matter is you do evolve, you adapt, you actually gain strength and you don't have to deal with it all in one day.



A LONG INDEFINITE TIMELINE

He has taken over the entire home

<https://youtu.be/zdRzPXXqE3o>

Barbara: I think a big part of that for us and for him is keeping him home with us. For me as his mother, one of the reasons I have always wanted him home is because he's so safe and secure in the home environment with the people that he loves. And whether that's his family or his caregivers or relatives that come or friends, he feels his safest here. And that's been for me a big driving factor in keeping him home and caring for him at home even though it's hard. He has a lot of needs. He's around the clock, but he is the most comfortable in his environment here.

John: you know that he is aware of his family and the quality of life he has here. He can't express that. But that's why we're making the commitments to keep him at home whether that be emotionally or whether that be financially, whatever we have to do to keep him there and comfortable at the same time is what we want to do. But that's -- that decision in itself is a struggle because there are sacrifices.

Barb: It's not -- it's not your typical home, you know, where you have space and freedom. Everything really that happens in this house happens with Jake in the back of your mind and how it's going to affect him and what his needs are and if it's going to be okay for him, even something as simple as having friends over. You know, if it's a bad day, where can he go that he's comfortable, who is going to be with him, do I need to take care of him while I'm trying to host something? It -- it goes into everything you do. The phone rings and he is asleep, you don't want to talk on the phone. It's just -- it's part of everything which is okay. But it's just -- that's how it is.

there is nothing in here that doesn't have Jake's name on it, whether it's a bag of balls or stuffed animals or cards laying around or if you go to the other room where we've got all this equipment, you know, he has taken over. He has literally taken over my bedroom. He has taken over -- he has taken over the entire home.

You evolve into all these things.

<https://youtu.be/eDGhKcckYks>

Barbara: I think you evolve into it and that's what I was going to say. I remember when we ordered his first "stroller". That was not a regular stroller. And I was so excited to get it because I thought, oh, here is -- you know, this is going to be so helpful to me. And the delivery guy brought it in through the front door and put it in our foyer and it was this gigantic clinical looking thing. And it just -- he was four or five and it just -- he sat in it and it swallowed him up and I thought this is the ugliest biggest thing. I just didn't want it. You know, I was like not -- you know, I didn't fight it, but it startled me to see it.

But that being said, because I'm -- I'm in the trenches every day, because I'm the hands-on mom, I very quickly realized how valuable it was. So I used it and I loved it. And I also think you evolve into all of these things. Like if you had told me 10 years ago, you're going to have a stander, a massage table, a commode, you know, a Rifton school chair, all of these things sitting in your home; I would have not panicked, but it would have depressed me to sort of see that coming in the future. And I think for me it's just been -- whether I even realized it or not, it's evolved into something. And the way that it's been easier for me is not seeing all of it coming, you know. I remember asking somebody when he was a little boy. He was probably five and I said, what am I going to do when he's 10? You know, what am I going to do when he's 15 and he weighs 75 pounds?

Jake: Mom.

Barbara: And he said, don't worry about that now. You know, worry about it later. Yeah, your mom. And -- and I think he was right. I -- I couldn't worry about it that far out. And even now it's just a year at a time and we get new pieces of equipment. We're about to build a handicap bathroom. But it's come in phases. So it's been easier, at least for me, to adjust to having all these things.



END-OF-LIFE: DIFFICULT QUESTIONS AND MAKING ARRANGEMENTS

The unknown is the hardest part, not the day-to-day

https://youtu.be/RD07pT_AGEo

Barbara: It's as frightening to think that he won't die before we are not able to care for him anymore as it is to think that he will die. I'm -- I'm as afraid of both scenarios. And the other thing that I think John and I both are very afraid of is having him suffer. So we want his quality of life to be everything it can be while he is with us. And we want to be here when he dies. And we want to be the ones caring for him when he dies. And the unknown of both of those things is probably the hardest part and the most frightening part, not the day-to-day. The day-to-day is our normal. It's dysfunctional, but it's normal to us. And the shift -- when that change happens and the shift when that happens, our biggest hope is that it's done as best it can be for him and that we come out of it in the best way possible because it is going to be a huge change for us as well. And we're aware of that, but I don't think we can plan as to what's going to happen, you know.

John: Well, we've learned that. You can't plan --

Barbara: We don't know anything.

John: -- for anything every day is -- one at a time. And we each deal with that day as best we possibly can in our own way with -- but that always circles back with Jake's care in mind.

There is no planning. You're just there.

<https://youtu.be/5EiVxX6YM5M>

Barb: He stopped eating about six years ago. He stopped walking independently probably when he was, I don't know, seven or eight. So everything again has come in phases. And he's -- they can't really give us an answer as to what's going to happen. Some periods are worse than others. He'll go through a month or two of being really sick and we have said a dozen times over the years this is it, this is really it, we think this is the problem. We've created a DNR with a set of his doctors which sounds so hard for me. It wasn't very hard for me. I'm -- I'm very action-oriented, so -- unlike John who doesn't really like to talk about the prognosis and his end of life. I want the DNR filled out. I went to the cemetery and picked out a plot. I'm reading -- I'm thinking about his funeral in my mind all the time which sounds so strange. But it's my way of sort of preparing myself for it whereas John doesn't like to do that.

And the prognosis, it's just unclear, which makes it a little bit harder. If they had said, you know, I think statistically kids with mito, 80 percent of them die by the time they're 20 years old. His physician who treats him for that has a handful of teenagers in his practice and when I asked him why, he said, there just aren't any, which startled me. I remember that -- I have moments where I'm startled by that type of thing but he is 18. And you know, he could -- he

could get sick and pass away in a month or he could still be here when he's 25 and we just have no way of knowing, you know.

Barbara: We can't plan anything.

John: I remember saying to physicians years ago as in when he was four or five or -- you know, what is the life expectancy, what -- because I always did that from a -- I wanted clarity with regard to what the plan is. Well, he won't live past this date, then I can say, okay, I can plan around this. There is a beginning and there is an end and I can -- I can work towards those numbers. And I like to put a metric around something and you can't and I think that's frustrating. It frustrates me because I simply -- I can't plan. And all of these things, we've had a -- a conversation about the date. There is no planning. You're just there. You don't really know what tomorrow is going to bring and tomorrow could be many more tomorrows or tomorrow could be tomorrow.

Barb: So we kind of feel like everything is put on hold until his life ends. And you're just -- you don't want to feel like you're waiting for that all the time and you don't want to make it about him. But the ripple effect to us is, you know, we're here as long as he's here and it is just is what it is. And we have -- we have a baby, you know, for as long as we have him, you know.

What was most helpful was the talk around creating the DNR.

<https://youtu.be/dDhhQYe11i0>

Barb: Actually filling out the DNR was not a big deal at all to me. It was just a check mark, type A, paperwork done. It took the burden of a few of the what-ifs off our shoulders. What if we're in this emergency situation? We don't want to make those decisions in a crisis, so let's think about them. That to me is helpful. What was almost more important was the talk around creating the DNR. You know, he would sit and ask, "How do you think Jake's going to die? What do you think that's going to look like? Where would you like him to die?" He started to talk about questions -- to ask questions that really made you stop and think. Not only did he want the answers, but he wanted me to give him an answer, so he knew I had thought it through. "What are you going to do if you're alone? Who are you going to call?" And I'd say, "I'm sure I have somebody I can call. I can think of 50 people." "Who? Who is the person you're going to -- let's think about who it is, because" --



THE MARRIAGE

You decide where you want to be.

<https://youtu.be/g6t8aZX79Jc>

John: I think you're trying to define yourself. You're trying to compare yourself to your friends or peers with regard to the relationship that they have with their significant others or whatever that may be. And in this particular case, it's very different. There is no way of cutting it

because we don't -- we're about the three of us. It's -- it's very rarely if ever -- you know, I don't know if I could pull a percentage out of it, but it's never about the two of us from that standpoint. I think though that, you know, as I said, if you decide to somehow get through those times, good, bad or indifferent; I think you do come to some sort of peace. Now that time could take 11 years, 6 years, 1 year. I'm not -- I think it's all dependent on who you are and when that comes.

I think -- I think my journey was long or has been a long one from that standpoint. There -- I don't think there was a day that went by that I somehow did not resent Jake, but I resented the situation and kind of -- you know, what about me. And at the end of the day you do realize to a certain degree that that's selfish. And I felt selfish and I always felt conflicted with that, which I think exacerbates the situation because now you are being selfish and you shouldn't be selfish, but maybe you should be selfish. But eventually you come at peace with all of these feelings. And I -- I also think there comes a moment of truth whether you decide do you want to remain in that situation, good, bad or indifferent. Do you -- are you at peace with this. If you're not at peace, then like so many of us you split up and you go separate ways or whatnot or you -- you see that -- you -- you come to that moment where you say I want to be here no matter what. And there is a lot of fights and, you know, where we have them. We've had, you know, blowouts from that standpoint where those were struggling times from that standpoint as in -- and it was -- a lot of it was frustration. We would -- we would go out to a restaurant and then suddenly get called out or, you know, away because Jake threw up all over himself and we had to come home immediately. Typically what would happen is there she wanted to be home. My frustration would come through and, you know, you'd have these conflicts if you will.

But I think at the end of the day, there -- there is that moment where, speaking for myself, that, you know, good, bad or indifferent, the length -- amount of time you basically come through it and then decide where do you want to be. And I guess in my case, I want to be here from that standpoint. And other -- and maybe there is others that it's exactly the opposite and maybe they find peace in that as well. But it takes a while. It takes a while from the standpoint of -- and I -- and I can't predict how long that's going to be. You know, I think you hang in no matter what in a -- in a relationship as long as you think you should or can or whatnot until eventually you find peace in some way, shape or form.

It was a big disconnect.

<https://youtu.be/TlItboFbwL8>

Barbara: It's also so individual and that adds to the struggle because in the early days all I wanted to do was talk about it. Do you remember? This was all happening to us and I was reading everything and talking to the doctors and asking people. And John would come home from work and I'd say, "Guess what I found out today." And he'd say, "I don't want to talk about it." And I remember thinking, "How can you not want to talk about it?" You know, when he talks about our blowouts, John was -- early on especially, his response to -- we had a lot of crisis going on with Jake. We were in an ambulance every three weeks. His response was, "I've got to go to work. I have got to go to work. I've got to support this family. I can't lose my

health insurance plus I don't really want to be there because it's -- it's rough." And we had a 3 year old and Jake was a baby.

And I was really in the trenches and my way of dealing was I have to fix this. I have to -- I have to find out what's wrong and fix it. And I couldn't understand why he just kept burying himself somewhere else. And it -- it was a big disconnect, I think, for a while. And John, if I can speak for you, is also the type who doesn't like to share his feelings. And so we would kind of bumble along and then something random would happen. We would be running late and aggravated and we'd be in the car. And he would just turn around and something would come out of mouth so profound really about Jake, but it was always in the heat of the moment where I think he would just sort of snap and it would all come tumbling out.

And as bad as those moments were, I think they were also really therapeutic for us because I would finally get a sense into what he was feeling, whether it -- it would be him saying oh my god, we are so damn trapped or I'm so miserable. And it -- and it would always shock me to hear it, but then it always sort of led to us being able to talk it out. And it was -- it helped. Even then it didn't come out in a very organized traditional way and therapy for us, ironically, has not been that useful. It's not something that John embraces, I guess, you know, when -- to have a strange person come in and say to us, and how are you two doing. He doesn't want to tell her or him or he just doesn't want to share. For me, it's been more helpful, but it's also just more about me and how I'm dealing with it, not as much about how we're dealing with it.

It's the three of us forever.

<https://youtu.be/8qwVEBI5Gyg>

Barb: you know, I -- I talk to a lot of other parents. And one of the biggest issues especially with kids like Jake who -- he has seizures. He has seizures at night. He has seizures in bed at night. He needs to be safe. We tried forever to come up with a good solution where Jake was safe, I wasn't worried, we could sleep. I mean, you know, who cares about sleep after a while. But it's really common and I get more mothers saying to me, oh, my son is -- is four and he seizes at night and he's still in bed with us because I'm not, you know, feeling safe leaving him. And I always have to write them back, my son is 18 and he's still here and it's okay. And when you tell them it's okay, they're so relieved. And it's not normal and it's not normal in general.

And other couples -- if we ever shared all of this with other couples which I guess we are now; but if we ever did, they would look at us like we were just the most messed up couple in a way. But it's our dysfunctional function like I always tell you. We -- our priority is Jake is safe and we get sleep because John has to go to work. I have to function. We have time together and ironically I think we actually go out more than most couples because I have help. We go out every weekend, sometimes both nights. And people say, "You go out? How do you go out?" We go out all the time. And the only time that we can be alone is if we go out and that's even harder. We have to leave our home to be together.

John: Like there is a dark side to that too.

Barbara: You know, we just can't sit home on a Friday night and have some wine and watch a movie without having Jake on top of us and that's okay, but it's not okay. And there is this frustration of we can't even have a normal life at home. We have to leave our house to be together. And John who travels, when he's home on the weekends, the last thing he wants to do is leave the home. So it's the three of us forever.



SELF-CARE

It's hard to do but we do it.

<https://youtu.be/2-luFVAP1pg>

John: I -- as far as self-care is concerned, I don't --

Barbara: You're not very good at it.

John: Yeah, I -- you know, I -- self-care, I probably escape which is probably not necessarily a good thing. You learn over time that that's not a good thing.

Barbara: By escape I think you're talking about traveling.

John: Which I feel guilty about, yeah.

Barbara: He escapes by traveling for work.

John: Right, I travel.

Barbara: You know, that's not --

John: You know, and I escape and that's -- you know, I --

Barbara: You work out.

John: Yeah, but -- I know. But it's -- I mean work out, it's -- that's so simple from that standpoint. I think truthfully I escape. I'm not -- as I said, I'm not saying it's a good or bad thing, but -- and I do. There is times when, you know, we're here and it's frustrating and I look forward to, you know, basically -- there is that sense of when I leave that normality --

Barbara: Getting out of the environment.

John: -- and control of -- and by the way, I feel guilty about that because I have that outlet and Barb never has that outlet. Now I've come to find out she actually looks forward to when I'm leaving because it's one less -- one less person to take care of I found that out later. She's --

Barbara: It's true. The dirty truth.

John: She starts to ask me when I am leaving from that standpoint. But -- so maybe she gets her escape when I leave too.

Barbara: No, that's not true.

John: I don't know, but --

Barbara: It's easier. You know, that's not -- okay, here we go. So it's --

John: Well, maybe you don't think -- you don't have to worry about me from the standpoint of and it takes that pressure off of you.

Barb: I don't think that there is a tremendous amount of room for self-care in this situation. I think you need to be selfless because it is the only way to have a child like this at home and be able to -- to do it. You have to be somewhat selfless. You have to, you know, give up your sleep. You have to give up a lot of leisurely activities. You know, I -- when I see my girlfriends all drive by in the morning on the way to tennis or the way to the gym or the way -- wherever they're going, coffee; I've sacrificed a lot of that. But I do make a point to go with my girlfriends, I would say, a couple of times a year. He thinks more than that, but I do get away. And when I get away, it's great. It just gives me sort of -- I can step away. Even if it's two days, I can step away and come back feeling like I got away. And we get away. The other thing is we've -- we try to get away once a year. It's our forced vacation. We joke about it. He has some work trips that we go on. And left to our own devices, we would probably never go anywhere four, five days or six days. And the times that we've gone, we have complained and worried and been completely stressed up until the time we step foot on that plane because we don't want to go because it's so hard to leave him. But it's always great when we get away and we actually have a taste of normalcy. We're like, gosh, this is what it used to be like. And so it's reassuring when we do that for me to know we still have a connection. We're still okay and we probably will be okay when we don't have Jake. But it goes a long way. It's just forcing yourself to do it that's really hard for us, but we do it.



SIBLINGS

Coming full circle, I think it's been a gift for him

<https://youtu.be/ru9ddjTO1Hc>

Barb: Early on he wasn't as self-conscious about Jake and then when middle school hit, he suddenly -- when girls came into the picture and new friends came into the picture, he became really self-conscious about Jake, to the point where he would say, "Please don't bring him to my games. If I'm having -- I'm not going to have friends to my house because Jake is there."

I remember as a mother it just crushed me and we had a lot of talks about accepting Jake and trying to find the balance between "I get that you're a middle schooler and this is embarrassing.

Jake was kind of embarrassing sometimes." And those were a couple of hard years, I think, when Ryan really struggled with it and I didn't know how to help him. But then, like you said, it evolved into the kids getting to know Jake and the more they got to know him, they embraced him and the more that gave Ryan confidence to say "Hey my little brother's kind of cool." To the point where Jake, even at times, was a chick magnet and I hate to say it like that but, Ryan would be like "Here's my little brother and I'm really good with him" and the girls would say "Oh he's so cute." We have cute babysitters around all the time and the boys would say, "Who's babysitting tonight? We're coming over." So, for Ryan, there was some element of good that came out of it, and not to mention the fact that there are lots of people who have siblings who are different for whatever reason. And I think it's so prevalent today that that also has helped him.

And now coming full circle with it, I think it's been a real gift for him. He is a really sensitive kid. He has a lot of perspective. I think it's not easy but -- and I worry about Ryan moving forward and becoming an adult and a father of his own. And will *his* kids be okay? So, it kind of -- for me it turns a corner into thinking about that way now, about his future. But he's turned out great despite all of this. And I think the big key for us early on was trying to make Ryan's life normal and not always make it about Jake.

I don't want him thinking about Jake's life expectancy.

<https://youtu.be/ynbbpp3sWOM>

Barbara: We try not to talk about Jake's life expectancy with Ryan. I think he knows the big picture, that Jake won't live a long healthy life. I don't like to talk about it with Ryan because I'm not sure he can handle -- I'm not sure he really thinks about it, literally. We were recently in the hospital and he called three times a day. "How's Jake doing? How's Jake doing?" And I said, "He's doing okay."

We're honest with him but I don't promote that piece of it with Ryan because it'll be enough to deal with when it happens and I don't want him thinking about it. He used to think about it a lot more when he was younger. "Is Jake going to die? When's he going to die?" You know, he would ask questions and I would say, "Well at some point. I don't think he'll live as long as the rest of us, but I don't know, actually."

I don't think he thinks about it those terms now. He thinks about it almost more clinically. "What are you doing for Jake? How is he doing with it? Have you thought about a new med?" He's kind of funny. Now he's almost like our peer in managing Jake.

I worry about how Jake's death will affect Ryan in phases.

<https://youtu.be/i3VtrSY4uqM>

And I have always worried and still do worry about the day when we do lose Jake and how is that going to affect Ryan. And I worry about it in phases. You and I've talked about this before, how I used to say, "Please just get him through middle school." You know, "Okay now he's in high school, he's getting his license. He's going to start doing all kinds of crazy things.

Please just get Ryan through high school before his brother dies. Please get Ryan through college." Because I don't want to set Ryan on some sort of trajectory of downhill something because of the drama when it happens. So, I'm -- for me, I'm grateful that the older Ryan is, the more mature he is, the more he might be able to handle it well, because he'll just be that much more grown up and aware is what I'm grateful for, I guess.

John: Well, I think he's there. I mean, he and I talk about it. I think he's -- his expectations are much more in line with ours, from that standpoint. I think he also understands the pros and cons, though Ryan would be very sad when Jake is no longer here. I think he understands though the ramifications around the caring aspect if it were -- perhaps when he was thirteen or twelve or whatever, he didn't really understand, which was thank God that Jake didn't pass away. But I think now, when that day comes Ryan will understand, though it's a sad day, perhaps the blessings -if you would- behind it, from a long term care perspective. We have--

Barbara: He's much more aware.

John: We though, we have always said, and that's a concern is that-- you know, depending on Jake's time here or what not, is we don't want Jake to become a burden for Ryan. That's a pretty big piece here from that standpoint. And Ryan has involved, in some cases very similar to you, from a caretaker perspective. And my fear would be is that Ryan would inherit it, and he would want to inherit it.

Barbara: He would want it.

John: And we don't want him to inherit that.

Barbara: That's another worry.

John: It's a worry, because he'd want to. If something happened to us, he'd probably stop everything and care for Jake, because that's what he knows.

Barbara: Which is rewarding, but not what you want for a 21 year old.



CONTROL

What if something happens to one of us, the healthy ones?

<https://youtu.be/CVUog-chWBs>

One of my stranger fears, if you will, is I've spent years anticipating the end of Jake's life, and what's that going to be like, and how's our family going to handle it. And every now and then, I get this worse fear that what if something happens to one of us, the healthy ones that we're not anticipating that loss. As much as I think I'm preparing for the loss of Jake, I can't think of anything worse than being shocked by the loss of somebody else in the family instead. And I've seen it happen to a couple of families. And it's just -- that's normal life though. That is real life. But it does occur to me -- it's strange to me that -- it doesn't feel right to spend so much time worrying about the loss of one family member. Except that's the reality and I always then think, God forbid, it's not that family member and then, what would that do. I don't know. It's a fear. I don't know if you think about that but I do. You probably do. Do you?

John: No. I don't.

Barbara: Told you. He's the type A.

John: Right.

Barbara: Worrying about what you can't control. It all comes down to control and we have talked a lot about control. I'm a person who likes to control. And it has taken me a long time to accept and get used to the fact that I am in a situation that I just cannot control and I have to give up my element of control. And my answer to that is to control everything I can around it but then, just accept that it is what it is. I think that anticipated grief or death centered around something else that I hadn't even really thought about much less am able to control, it's very unsettling to me.



IMAGINING THE FUTURE

What will the impact of Jake's death be on us?

<https://youtu.be/3HqdRP7bnyU>

Barb: I don't think about the limited life expectancy piece constantly. I think about it often and I think about it more in terms of what is that going to look like, how is that going to happen, how am I going to handle it, how will that affect our family, how will it affect me personally. It's going to drastically change my everyday because I am really Jake's everyday. How will it affect us? You know, we were talking last night about this and it's the day that you dread obviously. You know it's inevitable. It is for everybody. But what will the impact be on us who -- we've lived this type of life for so long and is it going to be the type of thing that just transforms us and, you know, something else -- we just don't know. You know, it's the unknown. But it's always in the back of my head as far as just sort of worrying and waiting, anticipating it going to happen. You know, it's possible that it will happen at home. It's possible

that I'll be home alone. John travels. He's gone a few days a week. And I've thought a lot about it. But I'm not sure that I'm as prepared for it as I think I am or as I would like to be or as I try to be.

John: Well, it's a game changer. It changes everything. It changes -- in your particular case, you are 24/7 engaged with him. Our relationship over the last 18 years has evolved around that, good or bad from that standpoint.

Barbara: It's the three of us.

John: It is --

Barbara: Sadly.

John: It is the three of us. It has always been the three of us.

Barbara: He is the third wheel.

John: We knew each other of course before Jake. But 18 years later where is it, I -- I don't know. And that's a scary part, right?

Barbara: Yeah.

John: We had that conversation last night as in she has to completely redefine herself, what she does even day-to-day. I don't see her picking up a tennis racket or playing golf or this or that or running into that typical life that she would have had maybe if it was not for Jake. And that's not a good or a bad thing. But how does she redefine herself on that. Then how do we redefine ourselves. As I said, I made the joke that Jake has been sleeping in that bedroom or in our bedroom since he was seven months old. It just changes everything from that standpoint.



IDENTITY AS A PARENT

I have learned ...

<https://youtu.be/4u5ie92Yqkw>

John: I think I'm most proud of myself is that I have learned to adapt. I've also learned that I have patience and last but not least, probably discipline. Because as dark as those times were: good, bad, or indifferent, at the end of the day I didn't exit left. Same with Barb, right? Not to pat myself on the back for that, but I think so many people or so many men especially in my position might have, well statistically would have, from that standpoint. It's not that those times aren't difficult but I didn't -- so that discipline and that patience almost -- and I think it's made me more patient as time has come along. And I've had people say that to me recently. Saying, even professionally, "I can't believe how patient you are with --" And I think a lot of that

I got from Jake and the experience because I've learned the value of that patience of just a second.

Barbara: I have learned that -- what have I learned about myself? I guess I've learned that -this sounds so cliché- that I can handle way more than I thought I could ever handle. And I've also learned that I have -- I guess I found out a lot of things about myself and my interests and it's sort of -- I don't know if this is something I've learned, but it's taken me into a lot of new directions that I never, ever, ever would have thought about or considered or that probably would have ever been a part of my life. And as hard as this has all been, and as foreign, as it's all been to us, I've kind of embraced the whole side of medicine and care giving and grief and you and -- I've talked about this many times, but I like it. That sounds so bad, but I do. I enjoy the world that I've gotten to know and to me that's been sort of a refreshingly good outcome of a lot of this. But, I'm not afraid of a lot anymore, because I just feel like 'what do I have to lose?' I have learned a lot of perspective and I think that's all been a positive and a gift. As hard as it's been, there's been a lot of good that has come out of this, for me.

I'm proud of keeping it positive.

<https://youtu.be/kfj3uTecyWU>

Barb: Probably I'm most proud of going through this experience and continuing to go through this experience, and keeping it positive. There's nothing I hate more than seeing parents in the trenches, who are just wallowing, and full of anger and sorrow and negativity and regret and all those things that -- I feel like, if you can't take the situation and live well with it than it just brings everybody down. And who wants to live like that? I guess I'm the most proud of trying to make it as positive a life experience as I can, and also proud of our family for getting through it, for having a solid healthy child who's older, who is okay; he's well adjusted. For us being okay and not -- you know, somehow we've made it through. And for Jake being as okay as he can be. So, that's the takeaway for me and also what I'm most proud of.