Brenda Murray

Brenda is the mother of Sam, Simon (13) and Solomon (4). Sam suffered a stroke in-utero and was medically complex from birth. He died in October 2018 at age 15.

1	TITLE: *Shifting my expectations for Sam's life* https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-shifting-my-expectations-for-his-life/ Description: In this clip from Courageous Parents Network's virtual interview with Brenda Murray, Brenda talks about going from trying to do EVERYTHING to help Sam develop his potential -- the exhausting pressure that parents feel -- to recognizing that all that effort wasn't working. There was a shift from cure to comfort. Transcript: **Brenda:** Any parent that has, you know, a new born baby you have huge expectations. And although we knew he was severely brain damaged we still tried everything, very intensive therapy, you know, in home, out of home, in-patient, out-patient. So, we traveled across the country to find answers in ways that we could help him. Because I guess, at a young age we just didn't know to what degree this would really present itself. Maybe he could learn to walk, maybe he could, you know, maybe he wouldn't have a full vocabulary but maybe he would have some speech. They just couldn't tell us. So, of course we tried hard and we tried fast and we tried everything we could to try to get that potential to the highest we could for him. And those were exhausting years, to say the least. And we did for a very long time. And, you know, I think your expectations then change as time goes on. I don't remember how old Sam was when I started to feel like, this isn't really working. All the therapy and intensiveness that we were putting into this, nothing had changed for him. And I can remember sort of thinking, but nobody is saying it's okay to stop either. And I remember feeling that way, like I don't know if any of this is going to ever work. And feeling like, I guess I needed to say it, so I sort of started to say that to the therapist, to the medical world of, you know, they've started to take my lead, I guess, where I said, this just isn't -- all this effort isn't getting us anywhere. Is it okay to just make him comfortable? And so, those expectations started to change over the years from, I guess, from cure because in the beginning we really were trying to see could we try to reverse some of this brain damage? Could we have other parts of his brain take over for that? And so, it became apparent it just wasn't going to happen. And, you know, there was a shift. There definitely was a shift from cure to comfort. And probably about in the middle part of his life I would say that started to happen, so.

	Interviewer: Brenda, do you remember, I mean, it may be very hard to remember because now this would be a while ago, do you remember feeling pressure as his mother to make it be otherwise? Like if I only try harder, drive further, make more phone calls, like my effort is the difference between where he is now and where he could be? **Brenda:** Yes, of course. Yes, and I'm not sure if I placed that on myself or if I felt pressure from the medical world, like you know, more can be done, we should be doing more, we need to try harder, more time put in. And quite honestly I had no more time. I had no more energy. I didn't have any more to give. I tried to just live in the moment because thinking about the future was a little overwhelming and terrifying. And quite honestly thinking about Josh and I aging and becoming older, and who would take care of Sam? I mean his needs were so chronic and so specific that -- and I've referred to this more recently like, I was Sam's person, like I knew him inside, outside, everything he did and I couldn't imagine somebody trying to care for him that way. And that to us was terrifying to think that, I mean, nobody wants to lose their child but the thought of him outliving us was actually more terrifying. I couldn't imagine somebody giving him the level of care that I felt he deserved, the same that we did. So, I guess I tried not to get too far ahead of myself with wondering how long he would live, what event would take his life. I had several scenarios sort of in my head that, you know, had presented themselves that I thought, okay, next time this happens that could be it, you know, a seizure or an apnea episode. Whatever it was, it just -- I didn't know but I knew -- I could feel things sort of speeding up in the last two years, and I really felt like something was changing. Things were becoming different and a shift even more so in the focus of comfort for him became crucial. Everything else fell to the wayside. Nothing else mattered. I just wanted him to be comfortable.
2	TITLE: *Considering Medical Interventions: Tubes and Surgeries* https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-decision-making-re-tubes-and-surgeries/ Description: In this clip from Courageous Parents Network's virtual video interview with Brenda Murray, Brenda thoughtfully shares the spectrum of interventions they considered and the decisions they ultimately made for Sam as they balanced the risks vs benefits: Yes to Feeding Tube, No to Hip Surgery, No to Spinal Fusion, No to Trach. These are all big decisions. "There is a lot of guilt. What if you don't do it?" The doctor looked at me and said, "You're not a bad mother if you decide not to do this." She talks about who her sounding boards were -- family, social worker, pediatricians.

Transcript:
Brenda: When he was about three years old, I had been able to feed him orally up until that point and I was very prideful about that. But, you know, it became apparent that you probably no longer feed a three-year-old with a bottle. It just was like how long can I do this? He couldn't drink from a cup. He couldn't sit up. He had no head control. Those are all things you need to eat. And so, aspiration was becoming an issue, swallowing was becoming an issue. And then we were presented with the feeding tube, and then I really fought that one very hard which I think a lot of -- I don't know if it's more of a motherly thing. I mean that's your primal instinct to feed your child. And I thought, no way you're not going to do that, that's not how this is going to work. But it became apparent that we had to do this, and he needed more and more medications. And even just for the ease of delivering those medications, I agreed to it. And yes, in hindsight that was the best thing I ever did. But I was very prideful about -- I did not, I did not want that for him. I could feed him. He was going to gain weight but I was losing that battle. So, that was the first kind of intervention.

And then it was years later where as he grew his hips were becoming an issue with dislocating. He never walked. He never weighed, you know could bear any weight on his legs. So, those are all things that you need to keep your hips in their sockets and they were not staying. And his muscle tone played a big part in that. So, that was a very agonizing decision that was lots of sleepless nights and, you know, consultations with orthopedic surgery. And, you know, Josh and I talking about it. I think there's a lot of guilt with what if you don't do it? What if you just wait and see if this is going to get worse? And I can remember being in an orthopedic surgery appointment, and I had done these several times and we had looked at the X-rays several times, and it was sort of coming to the point where I needed to decide what to do. And within a few months we would have to decide this. And I think the doctor looked at me and he realized I was agonizing over this. And he just said, you're not a bad mother if you decide not to do this. And I didn't know that that's what I needed to hear, but that's exactly what I needed to hear, because I really was worried about what people would think if we chose not to intervene. Your child has pain, of course you're going to intervene and fix that and help him.

But in Sam's case he would never walk so it wasn't like doing the surgery would give us that hope of him walking or weight-bearing. It was never going to happen, it would be strictly from a pain standpoint to relieve that for him. And so, we did decide to sort of wait and see if the hips dislocated. And the pain went away, and it never was an issue anymore after that. And they told us that could happen as well. So, we were fortunate where that decision just sort of was made for us where the pain didn't get worse.

Now, when you say you want him comfortable, maybe that would have meant we did have to do the surgery to make him comfortable and to put him through the risk of the surgery. But we were fortunate on that one where we didn't have to do that.

So, a spinal fusion was another difficult decision. They're all agonizing. Those are huge surgeries. Those are not, you know, one-hour surgeries. And I didn't know if Sam would survive the surgery and then the aftercare. To be honest, I don't know if I'm going to survive it. Sam was an irritable kid to begin with, just you know, and it was like, oh, my gosh! I can't -- I don't know how this is going to work. So, we did not do spinal fusion. In the last several years, sort of an issue that I would say blindsided me, I didn't anticipate this being something that would really be so prevalent in Sam's life, was his breathing issues. And that really took me off-guard. His anatomy started to change in such a way that his palate was becoming narrower, his airway was narrowing. So, anytime there was any little bit of swelling from a simple cold or respiratory illness his apnea became very severe. It was incredibly challenging, it is very hard to watch.

So, we consulted and talked about a trach, and what that would mean, and what all of that would mean for us in our home, and more machines and more learning curves and all of that. And that may have been the most agonizing decision of all. And we decided not to, and it was a ton of thought, and a ton of appointments, and lots of professionals giving us their opinions. It was like we tried to make the best educated decision we could about that. And that's just what we chose. That's that was our decision to not do that. It's not for everybody, but that's what we chose.

We were very fortunate to have a wonderful social worker. I bounced everything off of her. Every little thing that would change, I bounced it off of her, usually first. And then she would say, okay, I think you need to call this person or that person. And then, so, you know, having all the specialists and you have to go to the right one to ask the right questions, and so we did that. We have our support system, we have a wonderful family. I talk to my mom a lot, my sister, you know, just people that I felt comfortable sharing this really kind of private information with and making these really hard decisions. So, we tried to use everybody in our circle to make the best educated decisions we could. And I feel like that was the thoughtful thing to do. And it sort of settled us saying, okay, we touched all the bases. We talked to everybody and this is the consensus, so.

Interviewer: What role did Sam's primary care -- who about his pediatrician?

	Brenda: So, we had several over the course of his life. Do you want me to start from the beginning with that pediatrician or the one that we ended up with in the end? **Interviewer:** Why did you have so many pediatricians? **Brenda:** Well, they would leave. They moved on to other hospitals or clinics. A few times, I had one in particular, really did not share our vision for Sam. And he made that very apparent, and it was a little hurtful. But I also in hindsight thought I just think he doesn't understand the bigger picture. I will say that we did have pediatricians throughout most of his life, in the last few years, we switched to a primary care provider which was a family doctor instead. And I didn't really do that on purpose. It just -- we ended up liking this other clinic better and we switched. But I can see now how important it was to maybe have a family doctor because pediatricians deal with, you know, colds and flus and things like that in kids, and not always chronically ill children. So, it was hard for them to see outside of that box sometimes. And so, having a family doctor who deals with elderly and children and all age groups they knew what an end-of-life situation would look like or could look like. They could advise us a little differently and support us in a different way. So, I'm really glad we made that decision. But I did work tirelessly over the years to find the right ones who supported us.
3	TITLE: *Becoming Sam's Advocate* https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-becoming-my-sons-advocate/ Description: In this clip from Courageous Parents Network's virtual video interview with Brenda Murray, Brenda shares how she has been changed as Sam's mother – "I found myself in some very low places because I was frustrated and exhausted, and through that I found my voice." **Interviewer:** It sounds like that you were obviously a very strong advocate for Sam. Did it just come naturally to you or did you have to like give yourself pep talks when advocating for him in the face of providers who are like the experts, but suddenly they're -- like how did you find your voice as his mother in, not like this but like -- holding -- **Brenda:** Yeah, so that did not come naturally to me. It did not. I was quiet and shy and really didn't even speak up for myself in situations. But here I was with this boy who couldn't say a word, and could not advocate for himself, could not say what he wanted. And I found myself in some very low places, some of the lowest I've ever been personally because I was frustrated. I was tired. I'm exhausted from, you know, the level of care this was taking.

	And through that I found my voice. And I realized that it took a boy who couldn't speak to give me my voice. And I never would have found it without Sam. So, I do owe that to him. I do. I wouldn't be the same person if I wouldn't have gone through the good and the bad and all of it. So, yeah.
4	TITLE: *There were moments when I thought I can't do this. Learning self-care.* https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-i-cant-do-this-learning-self-care/ Description: In this clip from Courageous Parents Network's virtual video interview with Brenda Murray, Brenda speaks honestly about some of her lower moments — "It cracked me." — and how she brought herself back up and learned how to take care of herself so as to be able to keep going. Transcript: **Interviewer**: Were there moments where you felt, oh my god I can't do this, and if there were what got you through that moment. **Brenda:** I definitely thought I can't do this. I do remember a specific time where Sam -- we never figured out what happened but he was crying, like literally non-stop and I want to say it was eight weeks, which is a long time to do that. I couldn't figure out what was wrong with him. And crying, I think is a primal thing built into us, that it's supposed to grind at your nerves. It's supposed to, you know, your baby is crying, you go take care of them. This was different. This was like, I don't know if it was neurological. I'm not sure what it was but my nerves were shot. I was tired, my nerves were shot. I can remember -- and this is sort of bearing my soul. I remember in the middle of the night I went out into the driveway and I just collapsed. And I said, Josh, that's it. You have to take me in. I'm losing my mind. Like I can't do this anymore. But I also didn't know who could take care of him if I didn't. So, there was that. So, you feel stuck. I really felt stuck, like I can't do this but I also have to do this. And I did go stay with my parents that night. I just had to not hear the crying for like a day. And Josh took over and he took care of him and we were all fine. But I just -- I needed to clear my head. It cracked me, like it really, really cracked me. And I was very honest about that experience with his social worker. I think I called her the next day. And I scared her terribly because she thought, who am I going to find to take care of Sam? And I said, no, no. I'll be fine. I got to have a break though. I just have to have a break. This cracked me. And I did. I got better. But I think it's your choice to get better too. I didn't want to stay in that place, that scary place in my head. I couldn't stay there but I needed to find ways of self-care in little ways because I had to survive this. So, it was like I could have years ahead of me and I did. I had

	years ahead of me, yet I am doing this. And so, I found things to do for myself, very small, you know, very small things but they made a big difference. And so, yeah, it cracked me for sure, for sure. **Interviewer:** So honest of you, but I suspect most -- it would be the rare parent who couldn't relate to that, even as yours sounded particularly extreme. What are the little tips for self -- what little self-care things did you do that you can share with us? **Brenda:** So, they sound silly but little things like, I'm going to paint my nails today, you know, because it makes me feel better. I have to go run an errand. I'm getting myself a latte today. Or like, here's a funny one and my husband always laughed at me, every time I had to take Sam for a clinic visit. I'd stopped in the cafeteria and get a piece of cheesecake because gosh, darn it, that was really hard and awful and that sucked. And so like I just -- I kind of -- I call it like I had the "I deserve it" you know, like I deserve this. This is hard, this is messy, this is scary, this is awful. I got to find some little things in my life that bring me joy, and so yeah. **Interviewer:** I love that. Cheesecake! **Brenda:** Yeah, right. **Interviewer:** Fingernails, pretty nails and cheesecake, and a latte. **Brenda:** That means different things, but it was like I just had to find small things because I couldn't do big things. Like it wasn't an option. I couldn't go take a vacation and get a break. That was not an option. So, little things.
5	TITLE: *Finding Palliative Care … and how it helped* https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-finding-palliative-care-and-how-it-helped/ Description: In this clip from Courageous Parents Network's virtual video interview with Brenda Murray, Brenda discusses how she found palliative care — "When we started to shift our focus of cure to comfort with Sam, I started to express that at every appointment and to whoever I came in contact with" — and the referral from a nurse that ultimately made all the difference in their ability to care for Sam. She describes the various ways that palliative care supported them — in appointments, care planning, end-of-life. Transcript: **Brenda**: I knew about it but I think I misunderstood it. As most people, I'm finding do. When we started to shift our focus of cure to comfort with Sam, I started to express that at every appointment and to whoever I came in

	contact with. And I think I was at like a routine neurology appointment for Sam, and I was expressing these things to him, and he had kind of a dumbfounded look on his face. He didn't know what to do with that information. And also in the room at the time was a neurosurgery nurse practitioner who was refilling Sam's baclofen pump, and we just kind of doubled up on the appointment, and she happened to be in the room. And the neurologists left the room. He was done and she stayed in there and she said, I heard what you said. And she said, I think you need to see palliative care. And I said okay, I don't really know what that means, and she said, I don't think you know how to ask for it but that's what you're asking for. And she said, I'd be happy to make a referral for you. And I said, well, isn't that like hospice? And I said, Sam is not actively dying. What are they going to possibly do for us? And she said, no, no, that's not what it means. I think you just need to go see them and hear what they have to say and they can listen to you. And so that was the first time somebody suggested palliative care to us. And then I did have the appointment with a lovely palliative care doctor and I remember walking in and she said, you know, Sam was with me and she said, okay, she said, I read the whole file. That was shocking. First of all, she read, I mean the file was, you know, and I thought, wow, okay, this is going to be good. And she said, I want you to tell me the story from the beginning. And I was like, how long do you have? And honestly I think I was in there for two hours which is unheard of for a clinic appointment. And she heard it all. She heard it all from the beginning and up to where we were at at that point. And she said, okay, what can we do for him today? You know what can we do to make him more comfortable today? Whether that's tweaking medications or whatever that was going to look like, we weren't sure yet. And so it came into our lives at a very crucial time. I was looking for that but I didn't know what it was called, I didn't know how to get there. I think I actually said to the doctor in that appointment. I said, are you sure Sam's really a candidate for this? I mean he doesn't have cancer. I mean that is the stigma that it has and she said, no, he's absolutely the perfect candidate for this. She said, Brenda, he has had life-limiting things happen to him. And so she said, yes, he is definitely a candidate for us to help you. And from that point on, they really were by our side with tough decisions that came down the road. They said, we will be -- we can be in every appointment with specialists if you want us there. And so I didn't utilize that right away, but in the last few years, I have them at every single appointment listening to everything everybody was saying. And they were like an advocate in the room for me when I didn't know what to say. And they would say, you know, they would look at me and they would say, is this what you want because this is what -- if you decide to do this, this is what it will mean. And it was like, okay, it was just that person to kind of further explain the scenarios I

	guess, and having that support was so crucial. And I emailed them. We just -- I don't think I could have provided Sam with the end of his life that I did without their help. It wouldn't have happened that way. There's no way.
6	TITLE: *Palliative Care helped us plan his end-of-life at home* https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-palliative-care-helped-us-plan-his-end-of-life-at-home/ Description: In this clip from Courageous Parents Network's virtual video interview with Brenda Murray, Brenda shares how palliative care helped her develop a plan to care for Sam entirely at home, including through his end-of-life. "I turned to them and I said, What can you do to help me so I don't have to rush him off to the ER and he's not going to be hooked up to machines? Which is just not what we wanted for him." They helped us get all the documentation and planning reviewed and agreed upon by his pediatrician, his nurses, everyone. Transcript: **Brenda:** They helped us come up with a plan to have at home, that was our wish to have Sam at home. And it was not a possibility to have hospice. We did look into it. It was a conflict between them being here and keeping our in-home nurses. We couldn't do both, and so we could not have hospice. So, when that happened, it was their suggestion, I think you need to call hospice, and this was about a year ago. And we did, and we met with them and even just having that whole meeting with our whole, you know, our nurses and our social worker with the hospice person, that actually needed to happen. Even though we didn't pursue that and we couldn't, it was vital. It needed to have everybody in the room to hear everything. And so when we kind of hit that brick wall and couldn't have hospice at home for him, we -- I turned to them and I said, listen I think we're -- we are hospice. What can you do to help me so I don't have to rush him off to the ER and he's not going to be hooked up to machines which is just not what we wanted for him. And so they helped us devise, I think they called it like an escalation plan. It was sort of this set of scenarios that I gave them. I said, okay these are things that have happened that could potentially happen again that are life-threatening, and I would need to know in these scenarios what you would advise me to do. And so it was about a two or three page document. We worked very closely and I tweaked it, they tweaked it, up until a few months before he passed away, it was tweaked again. Because he changed, you know. Things changed with him and I said, you know, I don't think I would do this if he presented this way. What would you suggest I do? So it was always a work-in-progress, but we had this plan and it was well thought out and it was signed by them. It was signed by his primary care provider. We were all on the same page. His in-home nurses were on the

	same page, like that was so important to make sure that everybody involved was always in the loop. That was really important for me to make sure that anything that changes with Sam, they were the first to know. And I wanted that documented too. I wanted all of that so that it just was locked down. I don't know how else to say it, like I didn't want there to be any holes in the plan. And in the end I didn't even look at the plan but it sort of like, you made the plan and then you don't need it, and that's exactly how it went but I could have very well needed it, and there was a well thought out chain of events, I didn't want to have to think in the heat of the moment. He is very uncomfortable, I don't know what to do. How much could I give him of this, or what should I do. And it was all there for me. Just like hospice would have this plan on what to do for a person if they were not comfortable. And so they -- that was crucial for them to provide me with that document, and yeah, we worked on that very hard together. **Interviewer:** Wow. So you were in charge of all the medications and everything? **Brenda:** Yes. That's a pretty big burden. And I don't take that lightly. I think I somehow wondered and I just proved myself to them that I could maybe handle this or that -- and I -- you know I told them I'm not afraid. I am not afraid to do this. I owe it to Sam to give him a peaceful end to his life, if that's in the cards. Sometimes we don't have a choice. But I watched this boy suffer a majority of his life, and I thought if I have a choice I would like him here with us, and if I have another choice, I don't want him to suffer. Show me what that looks like, help me. What can I do? I'm not afraid.
7	TITLE: *Sam's End-of-Life* https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-my-sons-peaceful-end-of-life/ Description: In this clip from Courageous Parents Network's virtual video interview with Brenda Murray, Brenda gently and comfortably describes Sam's dying process: how she was coached to support him at home, how it happened, what it looked like, and how peaceful it was. Transcript: **Brenda:** I always wanted to know what that looked like, and even in the last few days of his life I asked -- I was on the phone with palliative care and with his primary care doctor giving them the play by play on what I was seeing, and I said, what is this going to look like? I want to know the truth. I mean, is he just going to start breathing? Is he going to have a seizure? Like what -- what's going to happen? And the palliative care doctor told me and she said, I

can't tell you that, but she said, I can tell you that what we would tell you is to just treat the symptoms. If he has a fever, treat the fever. If he is having apnea, you know give him something for that. You know, it was like just treat the symptoms, take one thing as they come, don't get overwhelmed by the entire picture.

And so to back it up a little bit, we had all sort of contracted this really awful respiratory virus, one by one we just -- we were going down like flies, all of us in our house. And we took a short family trip in the motor home just the week before he passed away, and we all started to get sicker while we were on this trip, and we were in a close environment. And I really, really always try to keep Sam as isolated as I could, but it was inevitable. And we came home on a Sunday night, Monday morning he had a fever. And I thought, here we go. Here we go, he's going to go down too. And a few years ago he had had a really bad respiratory illness, and it weakened him. And it was -- I think you had mentioned this before when we talked, it was sort of like a dry run for us. It was very scary. Nearly life threatening. But he made it, and I knew the next time he presented with something like this, the chances were very slim that he would survive it. And that really rammed up my efforts even more to make sure I had the tools on hand to make sure this kid was going to be comfortable and not in distress.

And so he had the fever, then the coughing started and it went so fast. I kicked it in the high gear. I kicked it in the nurse mode, you know, and I used all of my tools I had here to try to help him, and I went as fast and as hard as I could. And I want to clarify, I wasn't trying to save him. I was trying to make him comfortable. That was always the goal. I just wanted him to be comfortable. And as fast and as hard as I went to try to do that for him, my efforts were just futile. The illness really got bad quickly, and about the second day in, he started sleeping.

And I in hindsight can look back and see the signs of the dying process started on that second day already. And so he started to sleep more. There were a few apnea episodes. But we got him through those. You know, the coughing was nasty. I won't go into detail, it was nasty. But -- and then I had a conversation, I think it was -- so this was like a Monday. It started on Thursday. I had a conversation with his primary care doctor. And I said, listen, I don't know what's happening here. I'm really not sure but his oxygen levels are scary, like scary low. And he said, and I asked him too, I said, what is going to happen here? And he just said, Brenda, he just won't wake up again. And I hung up the phone and I realized he had been sleeping for two days. He had not woken up and I switched in that moment from being his nurse to being his mother. And I went into his room and I crawled into his bed and I told him all of the things I needed to tell him because I knew this might be it. And I had no idea that I would only have hours left. I had no idea.

	But I knew it was important to tell a person that they can go, to tell them that they don't need to stay there for you, that you are all going to be okay when they're gone. So I told him all of those things that you're supposed to do. And like I said I wasn't sure if this would be it or not, but it was necessary for me to release him, to release his soul to just say, you don't have to try so hard anymore, Sam. You're tough. You're almost too tough, you just don't have to do this. And somehow through the course of that evening we all ended up in his room which we don't really do, but we ended up in there and it was beautiful. You know my youngest was up on the bed with him, and he -- we were all laughing and talking, and then it was just getting late and I said, all right, we have to go to bed, you know. And Sam was resting peacefully, probably the most peaceful I have ever seen him rest and breathe rhythmically in at least several years. And so that gave me peace seeing him. There was no struggle. I just -- he was so peaceful and I got my youngest to bed and I -- his room was right across the hallway, and I just thought, okay, I'm just going to lay here for a few more minutes with him and then I will -- I was going to sleep in the chair in Sam's room that night. I just thought I probably shouldn't -- I should not be far away. And as I was laying there literally minutes after my youngest went to sleep I heard something change with his breathing. And I came in and I looked at the pulse oximeter on his finger and there was no reading. And I actually thought there was something wrong with it. I clipped it off and I clipped it back on again and I went, he's still no reading. And then I looked at his face and his body let out one more breath. And I looked at the clock and I looked at the time and then I yelled for Josh. And he came in. He looked at me and he said, that's it. That's it. He's gone. And it was the most beautiful experience besides the day he was born. I wanted to be there. I told him that if I had that wish that I could be there, that would be an honor to me. I was not going to be afraid. I owed him that. I felt like I owed him that after a lifetime of medical interventions and tubes and needles and machines, and I didn't want him hooked up to anything if I had the choice. And in the end, I couldn't have asked for a more beautiful peaceful ending to that boy's life that he deserved. He really deserved that. And there was no struggle. There was no gasping. There was -- it just -- there was one more breath and it was beautiful. It really was beautiful.
8	TITLE: *Grieving Before and After: The exhale is a slow process* https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-grieving-before-after-bereavement/

Description: In this clip from Courageous Parents Network’s virtual video interview with Brenda Murray, Brenda discusses her grief journey — from anticipatory grief when he was little to bereavement now that he has died. “I realized I was holding my breath that whole time. Because that’s what you do. You live in this anxious state all the time because you just don’t know what’s going to happen next. And I literally thought I would just exhale and let it all out. And that’s not what happened. I am learning that I think the exhale is a slow process. It isn’t happening overnight, but it’s happening. The things we couldn’t do before that now we can do, and just taking those steps and being hopeful for the future.”

Transcript:
Brenda: I think I have the gift of time to sort of envision it, think it out. Not everybody has that gift of time and I learned after finding you guys with Courageous Parents Network, what I have been all these years was really anticipatory grief. I had been grieving the anticipation of his loss for 15 years really because he wasn’t even supposed to survive. And so, all those years I carried with me this thing, in the pit of my stomach everywhere I went, everything I did, every moment of everyday I wondered, is today the day? What will happen? How is it going to go? How will he die? I don’t know. I know he will, but I don’t know how.

And that was so helpful putting that term with the feeling I had all those years and I really thought that the moment he took his last breath I would stop holding my breath, because I realized I was holding my breath that whole time. Because that’s what you do. You live in this anxious state all the time because you just don’t know what's going to happen next. And I literally thought I would just exhale and let it all out. And that’s not what happened. I am learning that I think the exhale is a slow process. It isn't happening overnight, but it's happening. The things we couldn’t do before that now we can do, and just taking those steps and being hopeful for the future, and like I said, during those small things that families take for granted that we couldn’t do. We could not come and go as we please. We couldn’t take a vacation. All those things change for us in that moment, and it was like just taking those steps and doing those things is part of the, I guess, the exhale for me, like, okay, we can breathe again, every move we make doesn’t have to be so difficult anymore. And that is not how I thought it would go. I really thought I would just let it all out, but it’s in the doing really, that’s what I'm finding out.

Interviewer: You're living into this new part of your life --

Brenda: Yes.

Interviewer: -- which you have never had --

	Brenda: Right. **Interviewer:** --ever, ever. You'd be, Sam made you a mom and that's all you ever knew. **Brenda:** Yeah, right. And you know we're finding out too. And I'm, I mean it's only been a couple months since he's been gone and I used to sort of be jealous of families that could come and go and do what they want and not have to think about, oh, you have to get a nurse if you want to leave. Or whatever you needed to happen, the major coordination that always had to happen. And we're now living in that, and I am coming and going as I please, and I'm -- I said to Josh the other day, I go -- why am I still busy? I go, I'm exhausted. I'm like, what? I was way busier before. I had to take care of Sam too. But I was home more because I had to be home with him. And now I'm like, maybe the coming and going isn't what I always thought it was. Maybe he really thought us that this being here, is the best place to be. And so, I'm finding my way in that too, like it's just new found freedom, but maybe that's not really what I want after all. You know, you have to find the balance in it, but it's fresh, it's new. I am just trying to have grace for myself on that one. So, we'll navigate it and figure it out. I had hoped that everything we went through in Sam's life could be turned into something positive and useful and good, and I do think that's a choice that you make to do that. And so I hope I can do that, just surviving it. I hope that's an inspiration to people just to go, okay, she's not flat on the ground, she survived it. And like I said, ask me in a year how I feel because this is so new for us that I don't think I'm in denial. I said to Josh, I'd go, I know that's like the first phase. Am I in denial? And he goes, I don't think so. And I honestly think that that anticipatory grief, I thought it was a curse. But I really now think it was a gift. I worked through the big parts of grief before he was even gone. And I don't want to feel like that anymore. I don't want to feel stuck, I don't want to feel sad anymore. I was sad for a very long time and I'm going to be 40 next year and I think I can easily have half of my life left. I really, if I have control over that I don't want to be in that place anymore. I want to move on and feel freedom and happiness and hope for the future. So -- but I think it's a choice and sometimes grief is funny, it does hit you out of nowhere. And you are sad. But overall I want to have it be positive, I guess.
9	TITLE: *Finding support in the Before from bereaved parents* https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-finding-support-from-bereaved-parents/ Description: In this clip from Courageous Parents Network's virtual video interview with Brenda Murray, Brenda shares where she has found her

	strength and support. "I was fortunate enough to have a few really, really good friends, just like two in my life that had walked this path and survived it. And that was the key for me, they survived it. Because I knew I needed to survive it too." Transcript: **Brenda:** I will tell you that over the course of Sam's life, I did try things. I tried support groups that weren't for me. I always say my motto is try anything once, and I tried that once. And it wasn't for me. It just didn't fit. I was fortunate enough to have a few really, really good friends, just like two in my life that had walked this path and survived it. And that was the key for me, they survived it. Because I knew I needed to survive it too. And I looked at them like, all right, they're not dead. I'm not going to die from this either. It changed them forever. But they are still functional human beings out in society, contributing and they were the inspiration to me, and I confided in them several times with things that I knew you couldn't tell just other casual friends, these details. You could not do that. But they had lived through losing a child, a medically complex child, and that was crucial to me in keeping my sanity sometimes. And now, we're all on the other side of this and I joined them. We're all bereaved parents now and it's just like I couldn't have done that without them. Josh and I, he joked and he said, when she asks you that, tell her it was because of coffee every morning. We just had this really honest heart-to-heart talk almost every morning about the brutal honesty and how hard this was.
10	TITLE: *Words for Bereaved parents* https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-and-bereavement-a-mothers-wisdom/ Description: In this clip from Courageous Parents Network's virtual video interview with Brenda Murray, Brenda shares some of what she is learning in her early days after Sam has died – "I would say, try not to judge your feelings too much. Just let them present themselves as they come." "I am trying to have grace for myself." Transcript: **Brenda:** I think I would say, try not to judge your feelings too much. Just let them present themselves as they come. Kind of like just what we're talking about. Funny things make you, you know things creep up on you. Like you see a commercial and it triggers something in you and you're bawling all of a sudden. So what, bawl, you know, cry. It's like that's how you feel. It triggered something deep in you. And then there's times where I laugh, it's just, it's like and you know like I said to Josh this morning, I said, I say that,

don’t analyse your feelings, but I'm analysing my feelings. Because it’s like, should I feel this good? Is that okay? Should I feel more sad? So I'm just trying to sort of be, I don't know, have grace for myself and allow the feelings to come as they do and if in time they change or they don’t, so what? It is what it is.

And I was saying this to my Mom the other day and she said, Brenda, I don’t -- I think you are feeling appropriate. I think you are. She said, Sam -- she said, I think you're not really missing him because he's just you. He just became you. And I had a friend the other day tell me that too, the one who lost her child as well. And I said, I don’t have a feeling yet for when I looked at Sam's picture, like the word ‘love’ doesn't even do it justice. That is not deep enough for the way I feel about him. And she said, I totally get that. She said, I didn’t either. I still don’t have a word for it. But she said, I can tell you over the course of time that I felt like he became me. Our fibres just meshed. He changed my life and he became me, and I don’t miss him anymore because we just become one. And you know, my mom had to point that out to me, she goes, that’s why you don’t miss him.

Interviewer: Because he's here with you.

Brenda: Yeah and that, because you absorbed him, like you were him. And he is you and I was like, yeah. I like that, that’s good. That’s good.

Interviewer: That’s very beautiful.

Brenda: Yeah.