

Frank and Jeanette

Parents of Alex (13) and Frankie Jr (21).

Frankie has multiple progressive conditions including the DNMT1 mutation.

1	<p>Title: Frankie: Losing his voice but still communicating</p> <p><a href="https://youtu.be/deG8pECf8Sw">https://youtu.be/deG8pECf8Sw</a></p> <p>Parents at the bedside of their 21-year old medically-complex son talk about how they have developed their own styles of communicating with him. As his degenerative condition progressed over time, they adapted how their communication style.</p> <p><b>Janette:</b> So each one of us has a very different way of communicating because Frankie doesn't really communicate. We use these -- these are Wi-fi connected to the TV, so we put things that he likes so that he can hear through his tympanic, because if we cover the ears, he leaks, so it's no good. Sometimes we have -- if its someone new that he doesn't know, we use an amplifier so that he can sort of hear people that are new, but I think through time, we've all adopted our own way of doing it. So he knows if it's me if it's the way I touch him. So if I'm playing with his hair as you saw me doing or if I grab his hand in a specific way like this, he now knows that it's me and he'll actually tighten up. So I think every person is completely different. His brother actually grabs his cheeks and squeezes them up. So he knows and you could see instantly that he recognizes that it's Alex. Then Frank actually --</p> <p><b>Frank:</b> It's my voice. When he was young, he would just want me to tell him a story with my voice. He would say tell me a story with your voice. So now I just try to give updates on the sports. The Bruins, the Celtics, the Red Sox, what's going on in the World WWE Wrestling. Sometimes, like an idiot I'll scream and I have to scream. I shouldn't have to do that, but I'm just trying to get -- Frankie, Frankie, and I'll get excited to try to let him know that I'm there. He'll look at me. I almost feel like he wants to say just shut up dad.</p> <p><b>Janette:</b> Yeah. It's so funny because you could see his expressions sort of change. There is slight changes, so that's how we feel like he knows. It's funny because Frank also uses a lot of his sayings. Frank has a memory bank of all of his sayings.</p> <p><b>Frank:</b> Good point. I actually when he was in the hospital for that one month in 2020, I had a lot of time. I still have a lot of time. I write down all his expressions. I have it written down. I know it by heart. What's up Frankie. He would say nothing much. Frankie, are you done eating? When I say. Okay Frankie. These are sort of expressions. I have so many.</p>
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	<p><b>Janette:</b> Frank is really good about responding to himself with Frankie.</p> <p><b>Frank:</b> That's right. That's funny. He'll ask a question and I'll answer it the way I think he would answer it. So that's what I've been doing especially since he became non-verbal. He was saying mom and dad at least a year ago, and now that's gone, but we just cope.</p> <p><b>Janette:</b> We use the routine of how we normally interacted with him as a way of being like-- it is sort of our own personality completely attached to his.</p> <p><b>Frank:</b> He loved his music. Like I said, he is a very unique young boy as he grew even. Adapted to the sports, music, loved Michael Jackson. So he would come in here like any teenager bare that music on loud and she'd be like -- Frankie, come downstairs its dinner. Beep, Frankie is not home, leave a message. She'd be like come again. Frankie is not home, leave a message. She'd be like get your butt down here now. Okay, okay with that deep voice.</p> <p><b>Janette:</b> Yeah, it was so funny. I knew what he was watching on TV simply because of what he would do. He would keep getting up, closing the door. If he closed the door, I knew for a fact that he was watching the divas, WWE wrestling girls.</p>
2	<p>Title: Frankie: He was the life of the party; loved costumes and school.</p> <p><a href="https://youtu.be/kBAjCdx6Mc8">https://youtu.be/kBAjCdx6Mc8</a></p> <p>Parents at the bedside of their 21-year old medically-complex son share stories from his years of loving dressing up in costumes and getting up early for school.</p> <p><b>Janette:</b> He has always been the life of the party. Frankie has always been extremely outgoing. Costumes, I have put them in the attic. I have 150 costumes. It's odd that I never brought that up for Alex to wear, but I feel like there is sort of his and that is always what he wanted. So he had to always been in costume and the school was actually really good at playing it up like the principal that retired the same year as Frankie. Wednesdays are your costume days. That's the day he could wear a costume and be in character. He loved the movies.</p> <p>There was a store in Florida, cowboy store. He wanted an authentic cowboy costume. I'll buy you one at party center. No, we're going to this store. The lights were on but the doors were closed. I was like Frankie, they're closed. He is like the lights are on. He is banging away, banging away. The lady opens and goes we're closed. He goes no, you have the</p>

	<p>lights on. She was like -- you know what, you're right. Why don't you just come in, we'll get you an outfit. Thank God, I had my mother with me because he had to get the hat, the belt, the shirt, the shoes, the boots [00:12:00:14]. She was like -- I'm so glad I opened, it is the best sell I've had all week. I'm like I'm sure it is. In school, he would get up at the crack of dawn, like what is it 4:30-5'o clock in the morning, ready to go. Dad, I'm ready for school.</p> <p><b>Frank:</b> Dress himself. Come down in our room. Dad, dad. What? I'm ready. Frankie, its 5 in the morning, 4 in the morning. Please, we can't go now.</p> <p><b>Janette:</b> Yeah, he loved school.</p> <p><b>Frank:</b> He loved school.</p>
3	<p>Title: <i>Mom: I know that he has completed everything in life. I look at the glass as half full.</i></p> <p><a href="https://youtu.be/nl8ZPy0iP18">https://youtu.be/nl8ZPy0iP18</a></p> <p>Parents at the bedside of their 21-year old medically-complex son talk about all of the things their son has been able to experience – including his meeting WWE Jon Cena – and how they take such comfort in that.</p> <p><b>Jeanette:</b> He has been also been very lucky and fortunate with the people around him that have sort of helped us check off those boxes.</p> <p><b>Frank:</b> That's her. I give mom credit there. We did a lot, seen a lot with him. Make a wish was pretty huge for us. Dr. Casey, the angel saint that she is. I mean obviously as a parent you are in the woods sometimes. You don't always see the trees when your child gets a diagnosis. I know she had to move him up. At least when he went four years ago, January. We went to meet John Cena.</p> <p><b>Janette:</b> He was about to age out.</p> <p><b>Frank:</b> What a trip? Alex came with us.</p> <p><b>Janette:</b> He was in a wheelchair at the time.</p> <p><b>Frank:</b> He knew he was meeting John Cena. His mom set it up where he had a stack of jerseys, hats. He was getting married and we even bought a gift to John Cena. John Cena, loved him.</p>

	<p><b>Janette:</b> He was like I know buddy, I'm your number one fan, you're my number one fan. He is like -- I go what. I've been signing for about 30 minutes here and it's all for him by the way. You're selling it. No, it's all for him. That's what he wants, so he will be wearing your stuff every day.</p> <p><b>Frank:</b> He did. He would wear it to school, with the autograph being all proud of it. We met him and then we went to the WWE big event at the Barclay Center. We were shocked. He requested to meet Frankie down in the locker room again. We got a picture. That was a great picture with John Cena.</p> <p><b>Janette:</b> Yeah, we have those.</p> <p><b>Frank:</b> He was like unbelievable. He was over the moon, his brother too was over the moon.</p> <p><b>Janette:</b> In the grand scheme of things, it is sort of sad that Frankie had everything. He was pretty typical, you wouldn't know. Now this is what he is today, but in the grand scheme, you sort of balance the inequalities and you come up with the fact that we've had a lot of people, angels, doctors being very supportive and helped us tick the boxes. So Frankie I feel had lead a pretty complete life despite his disabilities. So he has been blessed in that. We're not here forever, so at some point, I can go surely saying that he is not going to miss -- I think my husband said to me, why do you do all these things. Why are we doing? We are preparing to go to a senior trip. Pandemic is horrible that it happened, but it is also positive that it happened because with pandemic he has been home, so he has been safer. Because of pandemic, the class trip is not Disney, the class trip is Cape Cod, so Frankie can go. So we're planning on going and ticking that box. He's like he is not going to remember. I don't care, I'll remember. So I know that safely he has completed everything in life. The only two things he hasn't done. Well, he hasn't gotten married and hasn't had a child. The way I see it which if you believe in God which I do, then that becomes an angel because he is still pure in these things. So you always have to look at, with every negative, there is always a bright side. So you can opt to look at it as glass half full or half empty. I like to look at it as half full.</p>
4	<p>Title: <i>Being my son's advocate: I can spend all my time researching; the medical world leans on the word 'reasonable.'</i></p> <p><a href="https://youtu.be/fszK65Phep8">https://youtu.be/fszK65Phep8</a></p> <p>A feisty mom describes how she goes deep on researching her son's symptoms and considering the pros and cons of tests and potential treatments, whether they apply to her son, and whether insurance would consider the procedure/treatment Reasonable. She tells the</p>

story of how she had to pressure a doctor to run a swallow study test because of her conviction that her son was aspirating. "what you're looking to do is it reasonable to conduct a test, would insurance pay for it, can we rule it out so that we can then go hunting for something else. So if you have those three things in a row, a doctor more than likely will actually help you if they're a good partner."

**Janette:** Doctors are amazing but they've hundreds or maybe thousands of patients. I have one patient here. That's it, so I can spend all my time researching about him. So I always think that in life everything happens for a reason. Initially I wanted to go to medical school and my life detoured and instead I went to law school. One thing I learnt in law school is anything medical requires one specific word, reasonableness. So if I use that word. I don't want to do but I think from a legal context, they get trained to listen to that word specifically.

You're a mom, you're in the hospital with no other time but a laptop to do research. So they did. When they did the FES, the procedure came out that he had bronchiectasis. I said this comes completely out of left field. I don't even know that this is. So I start researching and it comes out that if you have a lot of infections, overtime it takes its toll and it affects your lungs. So I started looking and I said could it be all these infections, but we were so on top of it. He does all these things. I don't know. So I looked at it and said to go ahead and do a Barium swallow study. So I said to the nurses -- can you get a doctor, I need him to do a Barium Swallow study. They brought a doctor in. The doctor looks at Frankie. She makes him cough, she makes him swallow. She goes he doesn't need a Barium swallow study. He doesn't aspirate. I remember I looked at her and I'm like how do you know. She says because I've been a doctor for a long time and I've done this test. I looked at him again and I looked at her. I had had it. I had requested something. I said to her -- so you have x-ray vision. She goes --no, I do not but he doesn't need it. I said fine, this is how this is going to go. She looked at me and I was like you're going to walk out that door, I'm going to call my pediatrician and I'm going to request him to call in here and do a second opinion on you. something happens to my son between now and then, I said there is going to be hell to pay. She looked at me, fine you could have it tomorrow. In we went and sure enough my son is aspirating. We could see the skeleton moving and it is going like a river. So the doctor had been in the room. That's the day I realized that you have to push through. It's a job. I am a mom, but sometimes its just a job and I have to arm myself with the tools because when I showed up into the room, she was like we did these tests too. I'm here to prove you wrong. I looked at her and I was like I cannot believe that she is embarrassing me in a room full of people. There were 10-12 in there. I said to her I hope to God that I am wrong because I already have a

baker's dozen of diagnosis. This one is a pretty shitty one to have. She goes fine, so they pop him in. He goes ahead. They give him barium; they give him crackers. You see it all going to the wrong spot. I go -- look here. He aspirates. I think that the key what I've learnt since then is to use the word reasonableness.

**Frank:** The doctor's stuff, she handles it all. She is the pit bull. She is the driving force and I prefer that, but I think one common denominator. I think you must both see with Courageous Parents is you need a strong woman man. We can be anything together. We made that decision a long time ago, but you need someone strong. Both of them. We both are strong but I say this a lot. I don't want to use the word battle but if I have a problem, a situation, I'd take her on my team seven days a week. But she will research. I am going to say I am the negative. How can I not? Sometimes I feel the world is coming down on me. I'm trying to run a business and keep this situation, what happened with Frankie, it's like she has been certainly a rock I have to say.

I've had other parents ask me what do you do, what makes you strong. I can literally write a three-page manual or it might be a one-page manual of what I do. The first thing I write is I look at -- whenever something happens, I know people tell don't look at Google. I don't care. I look at Google. I narrow down what I want to find out. Then I make myself, I start researching and I go to like really good sources like the Mayo where I normally I go to and learn a little bit about it, so I can speak intelligently to whatever it is I'm researching. Then I find out what things affected. Then once I have all my ducks in a row and kind of figure out does it apply to Frankie. Yes, this is a pro and a con. Why yes, why no? I don't just verse myself on the pros why I want a test done, I also go look at the con because every parent wants a test, but there is reasons as to why not wanting a test as well, what's not good, what is best not to have. So I will immerse myself in both.

Then when I go in I tell the doctor which I did for the neurological which they sent all the way to Mayo clinic to actually see if a physician is there. Does it apply to Frankie? Does he fit comfortably in all this? This is if a doctor tells me -- yeah, this is what he does. Because there is also the insurance piece. The insurance when you ask for approval to do a test or whatever, what they think that it's reasonable to do those tests and it always comes back to that word reasonable and they're like it would be get approved for us to do the tests. I said fine. Then can we go ahead and do the test because I want to rule it out. So questions like parents always want a diagnosis whereas I feel doctors don't want to give a diagnosis because if they feel that you're shooting from the hip that you might not know. Well, what you're looking to do is it reasonable to conduct a test, would insurance pay for it, can we rule it out so that we can then go

	<p>hunting for something else. So if you have those three things in a row, a doctor more than likely will actually help you if they're a good partner because what you're looking for is a partnership. You're not looking to be better than the doctor. You're looking to partner with the doctor. I think that it's the outlook that you're looking to give off. That's what is important. That's what makes you an advocate and that's what I have learnt along the way.</p>
<p>5</p>	<p>Title: <i>"CPN has been like a therapist for my husband. He goes in there and learns about all sorts of things."</i></p> <p><a href="https://youtu.be/9dwlrIclY1Y">https://youtu.be/9dwlrIclY1Y</a></p> <p>Jeanette, the mother of a 21-year old son with progressive medical complexity, shares how hearing the experiences of other parents (via Courageous Parents Network) has helped her husband Frank see that he is not alone. Frank describes the benefits he has found from watching, reading. "CPN normalizes what we're going through. It fits you in to where you belong." Jeanette shares that CPN content helps her think through decisions and anticipate end-of-life.</p> <p><b>Janette:</b> So your website has been amazing to kind of dive into and just learn a lot about things and what not. But the thing that I appreciate the most was what Dr. Casey told us about it. She told Frank about it. It has been therapy for Frank. Frank went from completely not understanding and sort of -- I'm going to say it, being in denial about everything to sort of becoming more accepting and realizing that he is not drowning in a cup of water. So I feel like its been like a partner for him. Kind of resisted. I know I have resisted, let's go talk to a therapist. Well, I don't feel like I need that. I felt that at one point he needed it. He is like if you don't go, then I'm not going. We're not similarly situated but I feel like your website has given him a boost up to put him similarly situated to where I am, and I really appreciate that. He has been the therapist for my husband. He loves it. He loves going in there and learning about all sorts of things.</p> <p><b>Frank:</b> Well, you know its true. Dr. Casey referred us, me to the Courageous Parent Network and when I started getting the emails. Sometimes I could be at work or whatever, but I would never ever delete them. I would go back and I would read them. I would search for similarities that I was experiencing with Frankie. I was just so relieved to see other families and look at their videos about the parents talking about the child in terminal illnesses and how it educated me to realize I'm not alone. It's a sad thing. That can never change, but I should cope with it and you'll get through it. Whenever I get them, I immediately forward them to her. If I don't have a chance to read it, I'll read it when I am at home just going through the phone and say I want to I'll read that Courageous Parents Network. Something that might pull my attention. So</p>

it's very important to me that I really do enjoy it. It has helped me a lot and be a part of it and now hopefully the rest of my life.

**Janette:** I feel like it kind of moves you from. Everyone life is different, it's a t sort of normalizes what you're going through, I don't know if the -- we belong in this category. Whereas this other people are over here. We are over here. We belong to this group. Somewhere where you belong. It was also very instrumental -- I know that when Frankie was in the hospital for those four weeks and the hospital was saying I think this is the end of the road for Frankie and it didn't feel like that feeling. I actually used your website because you had in there parents that had been in both sides and had to have made the decision either to stop things and not go forward or just go into a sperate time of journey. At the time, what helped me come with the plan for Frankie that made sense that I was comfortable with. I called it the whip. It was like wait and see. We would intubate but we would not trach. So I got to see a lot of videos you had of parenting talking about what it felt to go through a traching. I learnt that is not necessarily something that I wanted to explore for Frankie because the condition that he has is progressive and it is not going to get better. So it felt like it helped me make my decision that what I do and the decisions that I make are not for me. They are actually choices for Frankie, but to see other parents have to go through that, it actually helped. It was highly emotional. It helped to desensitize the situation and normalize it. It is just a choice that you're making and you're making it for somebody else. I did see that, the dads and their role and how they play when they have a child that is terminal and having an illness and how they cope with it. I did see that, yes. Again, all positive readings, I enjoy it. I think it has helped me. I think we realize we're on this road, it's a difficult one, but we're going to be okay.

**Janette:** It really actually changed Frank. I'm going to tell, its true. Its really changed him and that has made it so much easier for me, because he said when we were talking little bit earlier about is she the one that goes to the doctor and stuff. I would say in the very beginning yes, but I would say that in the last three-four years no, because I now feel like I have a team that is supporting me in making the decisions for Frankie. He was always a valuable player and everything obviously but it made him someone that I can actually depend on. Before I used to call my mother first, what do you think about this because they're in the medical field. But now who I call first is him because I know that he is right there with me right at the trenches. So one thing that has happened.

**Frank:** One thing I want to say is this has occurred and what Frankie's complexity with his health is a situation like no other. I can't say. It is a situation like no other. It's incredible to see what has happened and what has transpired. Each day goes by and you just look up. The week goes by

	<p>and the year. You're just like where did the time go to see how much he has declined, but you're not alone.</p>
<p>6</p>	<p>Title: <i>"I can't save my son but I can make his life better."</i></p> <p><a href="https://youtu.be/UKMYhCA-Pqw">https://youtu.be/UKMYhCA-Pqw</a></p> <p>the mom of a 21-year old with a rare genetic condition (DMT1) describes how she thinks about parenting with such a unique condition. "I thought to myself you know what, I can't control what I cannot control. This is where I became a little crazy according to my husband because what I then decided what I can control is the experiences that my son is going to have from here to them. So I turned my life into a bucket list checklist based on my knowledge of Frankie."</p> <p><b>Jeanette:</b> As to how long he has, absolutely no idea. I said -- well, kids it's all about five ten years max. He goes -- yeah, but he also has something really important that nobody else has. I'm like what. Well, who put him on a wheelchair? I'm like I did. Why did you do that? Because he has this thing called Cataplexy and he walks around and falls. You didn't want him to crack his head. He goes he should have already been gone. He goes but you are two steps ahead anticipating what he needs. So however long he lasts you is however long you are anticipating his needs. He goes it is going to be kind of cruel because you're a really good advocate so you get to see him wasting away and shutting down. The DNMT1 is essentially shutting down his whole systems and is concentrating towards the center in his core. So that's why he is still around. It is sort of like it is what it is and he is losing all these things right in front of us.</p> <p><b>Interviewer:</b> So Janette, that doctor said something really powerful which is that because you are so good at anticipating Frankie's needs, he will live longer, which gives you time to see more losses.</p> <p><b>Janette:</b> Yes.</p> <p><b>Interviewer:</b> Talk about that. The better you are.</p> <p><b>Janette:</b> It kind of feels like a weight on your shoulders because it felt at the time because I even said to him. Is there now somebody else I can talk to? He goes unfortunately not. Your son is an NI rare unique. What does that mean? He goes he is patient one in a really unique and rare disease. He is the write-up. He is the research. I kept thinking that can't be right. So there is like sites like yourself. I went on Facebook. I put myself in the rare gene, rare illness sites looking for someone and discovered I am unique in it. It felt like it was stressful but then I thought to myself you</p>

	<p>know what, I can't control what I cannot control. This is where I became a little crazy according to my husband because what I then decided what I can control is the experiences that my son is going to have from here to them. So I turned my life into a bucket list checking based on my knowledge of Frankie.</p> <p>Well, we're not finding a cure because there is no cure. So we're putting comfort in quality of life is the new road that you're on. I feel like they moved us into a pact. They started putting things together for the home. There were a lot of things that we didn't know about that I stumbled upon because he was on wheelchair. Someone tells me that when your son is incapacitated, what's the first step. The first step is go find yourself a DPH, social worker. No one tells you about that. There is a licensing agency. Once I had that social worker, she told me everything that I needed. So it became a way of getting a team behind us to support us on our journey. So we maybe rate and unique and on our own path, but there is a lot of people that sort of support us and are there to sort of act like a sounding board or give us information and help us.</p> <p>Yeah, I can't save my son but I can make his life better and improve it as I'm going. He had asked me one time, why do you do this. I get emotional about it. I said -- he doesn't know what we're doing. He might not know but if he goes. I said that I know that he had a full life and he really has had a better life than I would say a lot more people. Dr. Casey had put him in Make a Wish. So he got his wish granted. Most kids don't get to meet one celebrity that they want. He got to meet the celebrity he wants and a whole entire team [01:13:00:12] because it was the whole entire WWE. They were at the 25<sup>th</sup> anniversary. So he got to do that. He got to travel whenever we could. Dr. Casey would approve it. We connected with someone to take us with oxygen. We travel with a ton of equipment. I learned really well to call ahead of time the airlines, the TSA what to do to get us into -- we were going to go to Aruba. I find out that when you travel places, you can call places and they'll outfit your room exactly like I have it here like I'm in the ICU. So we learnt a lot of things along the way that people help us to get through that. Then we check off the things that he has done.</p>
7	<p>Title: <i>Parents on the burden of chronic caregiving (with inadequate nursing). "I am so used to my circumstances that I don't realize the stress."</i></p> <p><a href="https://youtu.be/kqnGM1HLVik">https://youtu.be/kqnGM1HLVik</a></p> <p>Parents of a 21-year old son with progressive medical complexity describe how accustomed they have become to the chronic stress, which isn't good. Mom notes that stress reduction for a parent is a very individual thing. For her, "All I want to do is sleep for a week." They</p>

describe details of what they have to arrange to go on a date, or on vacation, the extra hurdles.

TC: 1:23:30

**Janette:** You don't realize that you're in stress. Recently -- you asked me a month ago, do you have any stress. I'm like no, absolutely no. Why would I have any stress? Because I am so used to my circumstances that I don't realize it. I actually broke my crown because I don't realize that I cringe at night. For the last month before that, I woke up, my tongue hurts. It was like swollen. I'm literally biting my tongue and I don't realize it because I am clenching and I have stress. What I want the most if someone were to ask me I want to be able to send me somewhere. I don't care where it is as long as it is a clean room. I don't want to pick up anything, All white is what I prefer and I want to sleep for a whole entire week. Have someone take care of me, give me my food so that I don't have to think about what to do. Yoga sounds like work to me. I don't mean to be whatever. Like yoga to me is exhausting. I have to sweat and then have to take a shower. Then I am going to be hungry right after that. I just want to be. As for meditation, I actually know how to meditate. I learnt that as a child by a product of something. I don't know that that would work either because being quiet, all I'm thinking is all the things. I want to sleep because I'm unawares. Also, when I am awake, I want to be busy. They probably think I am nuts in my younger son's school because he is in middle school. On special occasions like Valentines, I am always bringing them little some things. I do that because being busy trying to put a little goodie together but I want to -- everybody is really expensive. So I can't do everybody, but I want it to be meaningful and creative, so taking that time to not think about my son is being busy, doing busy things. So I don't know how someone would equate it, but definitely you need to go ask the person what they want. It is a very individual thing. For me, its sleep at the time that I want it. I like to sleep in which I can't because machines are blurring all the time in our house. If its not the machine, he wears a BIPAP, so you hear it coming off and you hear that machine beeping. There is noise being away from the house, but how can you be away from the house without being --like feeling that you need to be in the house. We don't travel until someone specifically is here that can act as a backup to the back-up. That means that my son is going on a baseball tournament in June. My parents are flying up. I trust my mother because she has been with this team and knows how to take care of him. If she doesn't know how to take care of him, I've trained her to be a mini me, so he has to be aware. I took my other cellphone. I promised him, good grades. He was learning about Vikings. So for February school vacation, I took him to Iceland but I only went Monday to Friday. That's when we have a nurse. Otherwise, he is by himself and my mother couldn't fly up

to go. When many years ago, seven years ago, we went to Italy for my 40<sup>th</sup> and kind of anniversary. We hadn't been together on a vacation.

**Frank:** Frankie wasn't that bad then.

**Janette:** He wasn't that bad then. So my parents flew up. I meant printing a booklet up, this is how it is. But I needed to feel comfortable and letting people know we are going off and this is what you do. This is also the stress. If something happens to you, is your child going to be taken care of. There is so many stresses that go under that people don't think about. Extra hurdles that I have to jump through to think about. One of things was our nursing wasn't the greatest. We weren't sure. We had a nurse that was always late, right. So if we went out to eat for lunch. Okay, we have a nurse. Let's go out to eat. I walk in, I tell the hostess I need to be on the go. My meal can't demure. You can't take your time because I might need to be a nursing shift age or I might need to leave at a moment's notice. Sometimes that happens too. Like someone calls he is having a seizure, whatever. Okay, can you pack up the food. Here you go, take my card and I'm out. You got to preempt what you're doing. There is a lot of it that goes into it that people don't realize.

8

Title: *"You have to adapt. You have to learn to live without."*

<https://youtu.be/FNrEQOeC5Kc>

Parents of a 21-year old son with progressive, complex chronic conditions share how they are constantly adjusting their thinking and feeling to cope with their situation. "We are preparing to detach." Once a month she lets herself cry in the shower; he talks to the dog. They lean on their blessings.

**Frank:** You have to adapt. We were a family of four. We still are a family of four. But Janette, I and Alex are forced to a let's go to a movie, let's go to Dinesh Kavitha. A sporting event, a school event or for dinner. The stress and the sadness is always there. You take it with you, but you have to adapt. You have to learn to adapt. So maybe that is God's small gift to us based on what has occurred here. This is not God's doing but for me I don't believe that for one minute. We're giving a lot of time to prepare ourselves, to adjust. You have to.

**Janette:** And to learn how to live without and that is sort of what we've done. For Mother's Day, he asked me I am going to take you out. No, for Mother's Day, I want to be here. That is what I did, I stayed here. But when my birthday was kind of sad, I am not going to lie. To make it better, we printed different nights out to dinner so that it didn't seem like we went off for my special birthday. We went out to eat. It sort of seemed routine. It is sort of sad to say --okay, Frankie, we'll see you later. We're

	<p>learning how to do that. It's a preparation. I kind of feel bad because I have a friend that lost a son when he was 23. I can't put myself in her shoes because it was an accident and sudden. Even though this is still going to be sad, we're learning how to prepare to detach. Sometimes we equate everything with things. You know what, at some point our kids do detach from us in a different manner. Of course, this is more permanent but it is learning and then you say to yourself. Frank used to say when Frankie first went to Cotting. He went in there. He was talking, walking, doing everything.</p> <p><b>Frank:</b> Walked into the school.</p> <p><b>Janette:</b> We used to say he is the best of the worst and now he is the worst of the best. It kind of pancaked. I really think it's an outlook and always constantly trying to tell yourself, well, silver linings, look for them because they are there. What can you learn? What can you find to make you sort of happy? That's kind of how I go through it.</p> <p><b>Interviewer:</b> Do you ever let yourself feel sorry for yourself?</p> <p><b>Janette:</b> Once a month in that shower.</p> <p><b>Interviewer:</b> What about you?</p> <p><b>Frank:</b> I guess it would be hard not too, right, but we got a dog. We got a dog. Alex wanted a dog. It's been good for me because I like to go for walks anyway but now I take the dog for walks multiple times a day. I talk to the dog. He doesn't talk back to me. He is my best friend. He literally is. They sent me a best friend. I go walking by a church. Not that I go by a church to pray to God and have any type of thoughts. I just say thank you for blessing me for my health to do this, a good wife that is supportive of me, two great boys. I wish I could change this with Frankie, but I got Alex too.</p>
10	<p>Title: A parenting journey like this "tests a marriage in every way." A bond cemented in poop.</p> <p><a href="https://youtu.be/fXPQq1wOuXQ">https://youtu.be/fXPQq1wOuXQ</a></p> <p>Parents of a 21-year old son with complex chronic conditions talk about how their marriage has been forged in the face of the challenge. "He is my best friend. He is the one I trust on everything. It's a lot and it's a lot of stress. Marriage with a child that is complex, special needs and now terminal is a whole bag of crazy. I think we learned to be friends and respect each other and recognize that we're in it together."</p>

**Frank:** Another thing that people tell me a lot and I appreciate it, I do. I don't want to misunderstand. I don't know how you do it, Frank. I don't know how you and Janette do it. I mean friends, family, aunts, uncles, strangers. I would look at them and say you would do it too. I don't know, I don't think I could. You'd do it. I'm not saying we're anything extraordinary.

**Janette:** I take that as a half. I think most people would do it but some don't. I know plenty of parents that have sort of broken up from having a child like this.

**Frank:** I know. It tests you in every way, trust me. We knew a long time ago. We don't want to get overly detailed. But when Frankie would have -- like I said, he wouldn't go to the bathroom sometimes for a week, and would have to go in the shower. He would have to go -- literally in the bathtub sitting in one time. We were like ---

**Janette:** So there is one night that Frankie, this is when he could do things for himself. I was studying, I was in law school. I hear the water go on and I hear him wrenching. I don't do puke very well. He is the pro at it. I went in there and the water was up to Frankie's shoulders and it was dark in color and he is wrenchin. So I quickly ran and grabbed Frank. Wake up, wake up Frank, he is sick. The poor kid just puked up all his hotdogs that he had for dinner. They are floating everywhere. He goes what are you thinking. We didn't have hotdogs for dinner. Even if we had, hot dogs don't get swallowed whole to be floating everywhere. I am like you are right, it is coming from the other end. I said you have to definitely wake up and do it. Now few weeks before, I had purchased a ton of Clorox, like tons of jugs of Clorox, because my mom was into this prepa thing. I said to myself as long as I have salt, pepper and Clorox, I can eat anywhere and anything. So I had a ton of Clorox. Once we realized he was belching from both sides. Frank took care of him. Took him into our shower, showered him down, sent him to bed [01:52:01:12]. Then it was the process of cleaning that bathroom., there was atleast an inch worth of everywhere. We looked at each other and he goes we have to be together forever. I don't think anybody in the whole entire world that we would meet if we separated would put up with this nonsense. We lost it and we were laughing at 3 o' clock in the morning which are now tears streaming cracked up. So that was a turning, I think that night we looked at each other and said -- I would say our relationship changed to one that no matter what, I could not stand him for nothing. We are going to be friends and we are approaching our relationship as friends that are best friends that support each other. He is my best friend. He is the one I trust on everything. I think that's why through this, it's a lot and it's a lot of stress. My mom always says relationships have to be like roses because marriage is difficult. marriage with a child that is complex, special needs and now

	<p>terminal is a whole bag of crazy. We are still together I think we learned to be friends and respect each other and recognize that this what we're doing together.</p>
<p>11</p>	<p>Title: <i>Getting Guardianship with DNR Rights: A mother's tips</i></p> <p><a href="https://youtu.be/5Ab64rRdlf4">https://youtu.be/5Ab64rRdlf4</a></p> <p>The mother of a 21-year old son with complex chronic conditions offers some tips for getting guardianship with DNR rights. She talks about the MOLST too. "It's good to have all your ducks in a row."</p> <p><b>Jeanette:</b> As to getting the guardianship. I have a friend that got told that it was going to cost a ton of money. I did it myself. Now disclaimer, I am a lawyer, but it is not what I was doing, but it's a very simple process depending where your child is at, you can go to the courts, the clerks help you. you fill out the form, you pay the fee. You need the -- for us, it's the care report, that's three clinicians. You pop it together, you pay the fee, you serve it, get assigned and start the process you go into court. That's it. It was very simple. I was in court all of five minutes. I had to get two different guardianships. The first time that I got the first guardianship, Frankie was still talking and I wanted to leave him with rights, so I did. I left him the ability to decide if he wanted to watch WWE female diva wrestling, he could. So he could decide who his friends were, who he was calling, what he was doing. That was left. He could decide where he wanted to -- if he wanted to be part of his care. I left him with rights, but now that he is completely bedridden, non-communicative, completely declined, I had to go in and get an additional guardianship. He is also on anti-psychotics, so that requires a Roger's. I also just recently got it upgraded to the most max which has the Roger's for anti-psychotics. That gets checked once a year and then I have DNI and DNR rights for him. I also have home care, hospice comes in the house. It has to be one of those people or a doctor to fill a MOLST. It was harrowing for me. I am a control freak, so I don't want anybody because I wanted to lead by my gut with what I feel is in the best interest of Frankie at the moment. If at the moment, it is not right to let him go, then I don't want to let him go, but I feel that if there is a MOLST in place, people will follow the MOLST and not listen to me. So the MOLST that I have is hidden in a spot. If I feel like bringing it out, because nursing is always required to provide breaths of life until ambulance or whatever come in. If I feel that -- I always say Frankie has pulmonary issues, he is already broken. If you're going to do compressions and break him, then don't break him. That's when I'll put out my MOLST but everything is set up in place ready to go. I did that on purpose because I wanted to -- I did that with the help of PACT in the hospital [02:03:00:20] and hospice that comes in. I put that in place just in case I lose it in the moment. I'm not that kind of person. I lose it after the</p>

	<p>fact. It's good to know what you can do and have all your ducks in a row ready to go.</p>
<p>12</p>	<p>Title: "I would like clinicians to know that I am specialized too – in my son. I am his shadow."</p> <p><a href="https://youtu.be/b-UB4cVo81Q">https://youtu.be/b-UB4cVo81Q</a></p> <p>The mother of a 21-year old son with complex chronic conditions says, "What I would like clinicians taking care of someone like Frankie to know is that I want them to listen and to recognize that I am a team member. They are clinicians but I am one too. At this point in time, I am just as equally immersed as they are in that diagnosis of anything. I am specialized in two ways: I am specialized in what my son has because I have spent a ton of time researching it; and I am specialized because I am only taking care of him."</p> <p><b>Jeanette:</b> What I would like clinicians taking care of someone like Frankie to know is that I want them to listen and to recognize that I am a team member. They are clinicians but I am one too. I get to see him everybody and at this point in time, I am just as equally immersed as they are in that diagnosis of anything. I am a specialized. I am specialized in two ways. I am specialized in what my son has because I have spent a ton of time researching it and I am specialized because I am only taking care of him. So I am his shadow, I am him, I can talk for him. We had an instance with the DNMT1 when it first came up that they didn't want to tell us much. They said its very complicated, its new. I looked at the doctor, the immunologist. I said its new for you too. She is like yeah, so why can't it not be new for me and we just walked the same thing. At that moment, when they took us in the room. When the published about Frankie, they sent me the article to peer review it and give the okay for it because I am in the same doc step. I think having a clinician listen to you and consider you part of the team member and know that it's a relationship, it makes it easier for them and it makes it easier for us to advance the best interests of that child.</p>
<p>13</p>	<p>Title: <i>What are you most proud of about your two sons?</i></p> <p><a href="https://youtu.be/RYYK6nxUb7M">https://youtu.be/RYYK6nxUb7M</a></p> <p>The mother and father of a 21-year old medically complex son and his 13-year old brother talk about what they admire most about their two boys. For Alex, the brother - it's his empathy. For Frankie, it's what a fighter he is.</p> <p><b>Jeanette:</b> I think empathy. It's amazing what a little person can like empathize with somebody else that they're going through. It's amazing to me how Alex navigates it. He is in middle school now, so he is a little bit</p>

nervous. He doesn't want -- he didn't care before about people to know. Now we're at the stage where we are really open about Frankie, but he doesn't want to do that. We actually are onboard with him doing that. Most parents are like why, its his brother. Yeah, but he needs to learn to get his own legs in the experience. Maybe we spoil him too much because we try to keep his life typical but we want him not to feel like he resents his brother. We had an opportunity to go to school. The archbishop was coming to do a special blessing and that's huge. We wanted to bring Frankie, but in the end, he was like I don't know how I would feel about that. I could have taken it like that's your brother. I said okay, but I do want to know why you feel that way so that I know to better you. It wasn't like I'm going to punish you for thinking like that. He surprised me because the reason for it, I completely could get onboard. He goes if someone saw my brother and they weren't thoughtful like I am and later on they used him to hurt me, I would go nuts on them. So for me, I saw it as a safety that he recognized that others are not empathic as he is and not as understanding. So I said valid point. He goes -- mum, are you mad at me because I don't want him. Absolutely not. I said it is your life experience and you need to charter your own life. We are onboard for the package but it doesn't mean that you have to go rammed down your throat. So I think allowing each child to be their own individual despite the fact that they are in a circumstance, I think its important.

**Frank:** Yeah. For me, it's with Frankie, Janette and I have must have taught him, he never gave up. He gave a fight. He is just amazing when it comes to that, he is very persistent. While inside of it, he was like don't touch me. That was part of his condition related. I am very proud of Frankie's persistence and fight in him, amazing. I really say to myself wow, he did because he had lot of good impressions on a lot of people with that type of attitude. He never would want to give up. With Alex, I just see we're shaping and forming a really fine young man where he has just got a good heart. Needs maturity, he is 13, but he has got a good heart, I see it. He is loving, he is caring. Long way to go, this will shape him in that respect, but we're proud of him because like Janette said he knows his situation we live in. We has never thrown it on our face. Anything, take care of Frankie. That makes you feel bad, which we now do a lot more with him.

**Jeanette:** We do a lot more. Frankie got more than Alex did. Alex really has taken a lot of back seats to a lot of things.

**Frank:** We have to divide ourselves for vacations. He doesn't get to -- that is true. A lot of the stuff that we can't go away together right now.

**Jeanette:** Frankie visited many places. Instead when we do a vacation when we can with Frankie, it is always going to be Florida to visit family

to make sure that we get as much time with family. So he doesn't really get a lot of choices in what he does and having it together as a family, but he has not once complained about that.

**Frank:** Yeah, he is going to be a special guy, Alex. He has got a good heart. He is going to go places. So far, he is in the drama. He wanted to do the play. I couldn't believe he went out of his normal circle in doing that. Frankie, I want him to have Frankie's passion and heart. I am so proud of Frankie that he is a fighter and never gives up and he'll tell you that too.

**Janette:** Still here today, is he not? Wasn't supposed to still be here today.

**Frank:** I am going to say it. Its been a privilege. It's a privilege to be his father.

**Jeanette:** I agree with that for both of them.

**Frank:** Of course, both, yeah. Being aware that we have two children and that they have their own relationships. It is kind of like hodgepodes. Like I told you, we went to the hospital. Frankie didn't wake up for any of us and he woke up for his brother. They have their own unique relationship. We don't sometimes see it but we don't force them upon each other but they're both really special in their own very unique way.