



DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION
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Department of Health and Human Services
Centers for Disease Control and Prevention
Epilepsy Foundation

YOU ARE NOT ALONE

A Video for Parents of Teens with Epilepsy

P R O C E E D I N G S

(Music.)

GRAPHICS - It's made me stronger.

FEMALE: We have gone through a lot of ups and downs with epilepsy since Mesha [sp ?] was seven months of age.

(Music.)

GRAPHICS - You have to be positive.

MALE: I am very proud of my son and where he is today and how he got there.

(Music.)

GRAPHICS - We have finally become a team.

FEMALE: I have been wanting to share what we went through in hopes that it might help other people in some way.

(Music.)

GRAPHICS - The key is to reach out.

MALE: You are thrown into situations that you are completely unprepared for.

(Music.)

GRAPHICS - Teach yourself to swallow the fear.

FEMALE: We were very scared the first time she had a seizure.

(Music.)

GRAPHICS - There are no such things as strangers.

FEMALE: For years, I felt like I didn't have anybody. Nobody could understand what I was going through.

(Music.)

GRAPHICS - Only friends we haven't met yet.

(Music.)

GRAPHICS - You are not alone.

(Music.)

GRAPHICS - The Danyliks

FEMALE: Bill is a wonderful, wonderful father and a wonderful son-in-law. And I always say that to Mary, you've got a good husband.

MR. PAT DANYLIK: Me and my dad are close. We cook together and play catch or Frisbee or stuff like that.

MRS. MARY DANYLIK: I have always wanted to be a mom and have children, and I stayed out of work for that reason, to be able to be home when the kids got home and just be there for them.

MR. PAT DANYLIK: I am really close to my mom. We have definitely been through a lot together.

I was seven when I started having seizures and I was diagnosed. I was in kindergarten. And at those times, I was having about like 50 seizures a day, including sleeping. My mom or my dad would have to sit by the bed with a little red button

when I was asleep, and they would just have to push it every time I had a seizure just to document it.

MR. BILL DANYLIK: We would switch nights sleeping with him, so you missed a night of sleep every other night. So, fundamentally, we were exhausted.

MRS. DANYLIK: You hear your kid going "ma," and you're like, he's having one, he's is having one. So you get out of bed and you go to his bed and you rub him, and you just stay with him until it passes.

MS. ALI DANYLIK: When I first saw him have a seizure, it was scary. It was really scary for me. I didn't understand it at all, and the first thing I thought was like, is this like contagious or I am like -- does it run in the family now?

MR. BILL DANYLIK: We know it was tough on Ally, although she was very kind of quiet about it, but she was very young.

MRS. DANYLIK: She had her friends and we tried to do the best we could to give her the attention and let her know that it is going to be okay, that things are going to be okay, but meanwhile she would see her brother having a seizure on the kitchen floor.

MS. DANYLIK: I don't know that I would call it like jealous. I was just kind of I guess wanting more attention.

MRS. DANYLIK: They didn't want to do brain surgery because of the area of the brain that it was in. He would have lost control if they had gone in the area, his right side. It got to the point that when Pat was six years old he just said, you know, I do not want to have another seizure and if it means that I can't use my arm, I would rather take that chance.

MS. DANYLIK: Even at like the worst of times, he was always so brave, even for like the family, when he was supposed to be the one that was scared. We were all more scared than he was.

MR. PAT DANYLIK: I was seizure-free for five years, until last summer, which was when they took me off my medication.

FEMALE: Then all of a sudden he got them bad. And at first he didn't tell his parents. But then he told his mother that he was getting them back. So he had to go back into the hospital.

MR. BILL DANYLIK: It was such a letdown.

MRS. DANYLIK: It was.

MR. BILL DANYLIK: We thought we were done, and it was just a gut kick. You know you just though, oh, here we go again. So, you know, next thing you know I'm on the phone with her and I'm in the car and on the way back home and meeting her at Children's Hospital at midnight.

MRS. DANYLIK: Because they were just continuing and we had no medicine.

MR. BILL DANYLIK: And you just feel like, here we go again.

MS. DANYLIK: When I came home, I thought Pat was going to be really upset, and I looked at him and he was just like, hey. And it was when I started crying that he started crying.

MR. BILL DANYLIK: When he was little, we saw everything that happened. Now that he's a teenager, he is out and on his own. He is in different places. He is in more dangerous places.

FEMALE: Mountain biking. He wants to climb out of airplanes.

MR. BILL DANYLIK: Mountain biking. He is just a normal teenage boy. He wants to do some things that are dangerous even without seizures going on.

MS. DANYLIK: Even more dangerous. He just wants to do them.

MR. BILL DANYLIK: So we have less control over the situations he puts himself in, and we have just got to hope that we have impressed upon him that he has got to be a little cautious, given what he is dealing with.

(Music.)

GRAPHICS - Let them fly when they need to.

FEMALE: Letting go sounds so simple in words, but it is really not. And you can't just all of a sudden go let go, where you've been micromanaging your child's life.

FEMALE: Through the years, by him telling me, you know, let go, I have let go. It has been very hard. He is already 26 years old.

MRS. DANYLIK: Once they are controlled on the meds, the only thing you can do is just that's it.

FEMALE: It can't just magically happen when they're 18 or when they're 21 or 25. It's a process.

MALE: Because you always ask me, are you taking your meds? I'm like, yes, I'm taking my meds. I'm sorry. I'm taking my meds! Did you call?

(Laughter.)

FEMALE: Where are you going?

(Laughter.)

FEMALE: Call me. Call me when you get there. Call me 15 minutes when you're there. Call me in the middle when you're there.

FEMALE: Sometimes I just tell her that she needs to think a little more positively. If not, with some things, she is not ever going to quit worrying.

FEMALE: It has been good for me and for him. I mean, I have a life of my own now because I have let go and he says,

mom, whatever is going to happen is going to happen, whether you are and here or there, and I have to live.

MRS. DANYLIK: If he wants to jump out of an airplane, well, you know, have a parachute on you and go ahead.

FEMALE: Even though you're scared to death -- and she is grinning like a fool here because it is hard, it is very hard to do this, to step back and say, okay, I am not going to micromanage every aspect.

FEMALE: He came home one night and he had been out. And he was gone to somebody's house. And I just kind of looked at Wayne and I said, if he stays out until 2 or 3 o'clock in the morning, he is going to have one. "Kathy, he is 29 years old."

(Laughter.)

FEMALE: "He will be fine."

FEMALE: I tried to give up asking her if she took her meds. I couldn't even make it a day.

(Laughter.)

FEMALE: I couldn't even make it 24 hours.

GRAPHICS - Make them aware of what epilepsy is.

FEMALE: It's peoples' reaction, which is the hardest thing that can make life so difficult for the person with epilepsy.

FEMALE: That's true.

FEMALE: A lot of people have no sense, no idea, of what epilepsy is. They have no idea what a seizure is itself. They just don't know.

MR. PAT DANYLIK: They would just fire off, like rapid fire. And my finger would want to move left, right, up, down, left, right, up, down, left, right, up, down, like constantly. And that would happen to my whole body.

FEMALE: I didn't know how naive I was until I had epilepsy myself.

FEMALE: Try to teach people around you about epilepsy. Make them aware of what epilepsy is.

MALE: One thing that we have to tell people is that epilepsy is not a disease. It is a condition. If I touch you, you are not going to get it.

FEMALE: You have to change it one person at a time, to let them know what is real and what's not.

MR. BILL DANYLIK: It is really smart to put in on the table so to take away a lot of the stigma.

MALE: The hardest thing is educating everybody else around him, including family.

FEMALE: I have never seen Oprah Winfrey or anybody talk about epilepsy. They talk about all kinds of things.

MALE: They don't want to talk about it.

MR. BILL DANYLIK: How come there aren't any commercials about epilepsy? And you know, that's a good point. It is a perfectly fair point.

MRS. DANYLIK: There isn't.

MR. BILL DANYLIK: You know, why aren't people talking about epilepsy?

FEMALE: I have been tempted to write to people or to call some of these people and say, hey, what about making a show on epilepsy?

(Music.)

GRAPHICS - The Arzolas

MS. ARZOLA: I was real young when I became a mom. From there on, I just, I love kids to start off with, so I guess that is why I had more kids.

(Music.)

DAUGHTER: It's fun most of the time because there is just four girls living there and we are either arguing or laughing. So it is one or the other all the time.

(Music.)

FEMALE: It's only quiet when everybody is asleep.

MS. ARZOLA: My mom had to work all the time. As a matter of fact, my mom had two jobs. There was a cycle. I think sometimes that I am going to end up like my mom. She had to work two jobs to pay off the house.

FEMALE: It is real hard for my mom to be a single parent and to do all the bills and to take care of her kids by herself. And without my father, it is like she is my father, too.

FEMALE: She is very independent. She is "the" independent woman.

MS. ARZOLA: Well, I work 40 hours at one job. I come home, rush, drop off the baby, and make sure they have something to eat. If they don't, either I go to the groceries at midnight, after I get off my second job. I will go to the groceries or I get them something to eat or I leave them money. Order the pizza. I will leave or go get them chicken. Come back. My life right now is in a time schedule all the time.

FEMALE: Patricia and my brother, they're divorced, but we never divorced Patricia and the girls. They have always been with us, always, always.

FEMALE: My Aunt Margie, she is very creative. She is nice and she is fun to be with.

FEMALE: I guess since she was little I've always kept an eye on Roxanne. She was in her freshman year in high school, and they would always send her home because she was getting sick, but this was before she was diagnosed.

MS. ARZOLA: Off and on, I had to be missing work or doing this or go pick her up from school. She missed a lot of school.

FEMALE: A couple of doctors said I didn't have epilepsy, which I did. And they were just telling me that I had headaches and I was going to go deaf.

MS. ARZOLA: She would have off and on seizures at night. I would sleep with her some of the times.

FEMALE: It took them a long time to diagnose her, and I knew she was embarrassed.

FEMALE: Yeah, people actually thought I was ignoring them, and I was like, I didn't hear them or anything.

FEMALE: Like we would be eating, and at first we didn't know. She would be like, huh? And we were all like -- I would tell a story to her, I had to repeat everything to her. And after a while, I told my mom, I think she's -- we honestly thought she was going deaf.

FEMALE: In class, one of my science teachers, when I was in eighth grade, I would be listening to him fine and I would look at him, and then all of a sudden I wouldn't hear him. I missed the whole lesson.

FEMALE: I saw her very first seizure. We were at my aunt's house and she -- we were making burgers, we had just come from swimming.

FEMALE: I asked her, Roxanne, are you hungry, and she didn't answer me. And all of a sudden she fell.

FEMALE: I just heard a big thud on the floor, and when I turned around she was on the floor. I got real scared because I didn't know what would happen.

FEMALE: If I hadn't gone through my epilepsy, if I didn't know what epilepsy was, when Roxanne had her first seizure I would have panicked. I wouldn't have known what to do.

MS. ARZOLA: Then Margie called me that she had a seizure, and I said, what are you talking about? At that time I rushed to her apartment. I picked up Roxanne and I rushed her to the hospital.

FEMALE: It scared me for me to see it. I had experienced it, but I had never seen it.

MS. ARZOLA: They took her blood. They didn't see nothing wrong with her or nothing. So I took her to the doctor and they told me she had an ear infection.

FEMALE: I told her, take her to the Epilepsy Foundation, and then she did. And I am glad she did, because they are the ones that diagnosed her.

FEMALE: Even though I have epilepsy, I am still going to do whatever it takes to achieve my goals. My mom inspired me by telling me I could do it.

MS. ARZOLA: I just have to be strong for her and for all of us because we are all girls. I see my daughter and I have to be strong for her.

FEMALE: She is always there for us. She is our everything.

MS. ARZOLA: Roxanne is not the only one. I have my baby, so I have got to think of her, too.

MALE: How do you do it, Superwoman? How do you manage to be strong and at the same time not so strong that you limit your daughter from being Roxanne?

(Music.)

GRAPHICS - We have finally become a team.

MALE: It took a good few years for us to finally see eye to eye, but my mom and I, we have finally become a team. It's a team effort now.

MALE: Take time to know each other. Take time to talk about the issue.

FEMALE: He would say, mom, you are not going to make it if you don't calm down. (Laughs.) He would talk to me, and I would say, okay, I am going to be fine. (Laughs.)

FEMALE: You are the closest person and they trust you. And they know that you love them. And they love you, and that's why they're taking it out on you.

(Laughter.)

FEMALE: But they need you. And everything around them is just collapsing. So just be there.

MALE: You can't run from epilepsy. You can't run from your family, because those are the most important people around you. And every time I open my eyes, who is there? My mom.

FEMALE: Not only did he teach me how to be stronger, he taught me how to be wiser.

MALE: If I could give advice to one teenager and one parent of a teenager, it would be sit down, talk. Understand what's going on with each other. Talk to each other.

(Music.)

GRAPHICS - More Danyliks

MR. BILL DANYLIK: One of the important things is to find time to get away from it. Otherwise, you know, it becomes your entire life.

MRS. DANYLIK: I love to paint, and it was one of the things that I was able to do to relax and to get my mind off of what was going on.

: This is about the time that -- these are water colors, and that's what I was doing at '96, when Pat, I guess, was in his worst stage. And I would do this to relax.

(Music.)

MR. BILL DANYLIK: On a daily basis, it is more guitar. I will go downstairs in the basement, you know, and it's an hour or two worth of escape during the day.

(Music.)

MR. BILL DANYLIK: The real passion, the thing I really love to do, is cook. We would use it when were going through the worst of it as a way to take some of the pressure off, some of the tension off.

MRS. DANYLIK: Food and friends were sort of like the thing while --

MR. BILL DANYLIK: But that we could do here.

MRS. DANYLIK: Yes. And Pat, we'd know where he was.

MR. BILL DANYLIK: Yes.

MRS. DANYLIK: There would be other kids there.

MR. BILL DANYLIK: So we would have people here.

FEMALE: We would just try very hard to be as normal as possible. And Bill would be cooking, Ron would be helping.

MRS. DANYLIK: Ronnie and Bill, they cook. Carol and I, we'd, you know --

MR. BILL DANYLIK: Eat.

MRS. DANYLIK: Eat and eat.

(Laughter.)

MRS. DANYLIK: And she was just there through all the hard times.

FEMALE: Pat came up to the table -- I remember this -- and he was talking, and it was a high table. And then I just remember, he went right down, banged his head, his chin, on the table. And then I remember Mary saying, we can't do this anymore. We can't do this anymore. And I said, yes, we can.

MRS. DANYLIK: Look at this.

MR. PAT DANYLIK: Fine.

MRS. DANYLIK: All right, I'll see you after school then.

When he was little and he was walking to school, I didn't walk with him. I would stand up for a little bit and then you would see him. But gradually, it is sort of like, he is going to fall and he is going to have one, but you want to have him feel as though I can handle. I am going to have to.

MR. BILL DANYLIK: We treat him as normally as we possibly can and give him the support so that he is confident enough to deal with the situations he is going to have to deal with.

MALE: (Glitch in recording) dad. It would be like sometimes you would be at the park tossing around the baseball and then he would start to have one. And then the most that I've done is just pretty much stand around and wait it out while his dad would help and stuff. And recently I've just been like he's

been able like to just lean on me sometimes just so he doesn't fall over.

MRS. DANYLIK AND FEMALE (IN UNISON): Here's to friendship.

(Two glasses are toasted.)

(Laughter.)

FEMALE: Here I am arriving at my daughter's house.

MRS. DANYLIK: I had my mother, so my mother was there to support both of us, in trying to keep our relationship going.

FEMALE: When Mary and Bill wanted to go out on an evening, I would come up, because they only lived down the street. So I would come up and I would take care of the house.

MRS. DANYLIK: We like would go out to dinner and try not to talk about it, because, you know, which is hard to do.

FEMALE: I would do the laundry, take the cleaning machine out if she needed anything done, clean up, and take care of Alexandra.

MR. BILL DANYLIK: Yeah, we stepped up to the plate together, worked really hard together, and found a way through it. And yes, so I think it did pull us together as a family.

MR. PAT DANYLIK: That will be good, yeah.

MS. DANYLIK: When I go to school, I will call him all the time, definitely keep in touch, and always come visit. I'm not going far away.

MR. PAT DANYLIK: Well, it's going to be weird, Ally.

MS. DANYLIK: When I leave?

MR. PAT DANYLIK: Yes, I'll be like an only child.

MS. DANYLIK: No.

MR. PAT DANYLIK: Oh, what am I going to do Sundays?

MS. DANYLIK: You can't take my room, though.

MR. PAT DANYLIK: Oh, I can take your room.

MS. DANYLIK: No.

MR. PAT DANYLIK: I can take it.

MS. DANYLIK: No.

MR. PAT DANYLIK: I'm taking it.

MS. DANYLIK: There's no way.

(Music.)

GRAPHICS - Take care of your needs.

FEMALE: Just try real hard to take care of your needs so that you can take care of their needs.

MRS. DANYLIK: You keep your husband and yourself connected in some way. Try to get out. Just have somebody there for your teen who you trust.

FEMALE: When I had an opportunity, I would sit down and write anything that came to my mind. I would play all kinds of music. I would go from Mexican music to opera, because I was so desperate. I didn't have anybody to talk to.

FEMALE: I read things that were funny. I read books and I laugh a lot. And I watched a lot of movies that were very funny. And I would just be laughing like some crazy person.

(Laughter.)

FEMALE: And that would make me feel better.

FEMALE: I use humor as a defense mechanism, as a lot of people do. But I would joke, I would say, Lauren is such a great kid. She had it right under the kitchen wall phone. I held her with one hand. I dialed 911 with the other hand.

(Laughter.)

FEMALE: I had a very good psychiatrist friend that I used to go with, that I used to see on a regular basis. And she would counsel me. And that was my outlet, where I wouldn't have to burden anyone with my problems but I could just let it out during these sessions. You know, I would go in there and cry and tell her, and then I would feel better and just go on home and deal with things, because that is what you have to do.

FEMALE: I gave a lot of my burden to God. I'm a true believer and I don't think I could have gone through all this if it hadn't been for God.

GRAPHICS - Information is the antidote.

FEMALE: If I can tell anyone out there in the world that are newly diagnosed, information is the best thing that you can have.

FEMALE: Absolutely.

FEMALE: It is the antidote.

MALE: Parents need to be very educated in this whole process, and they need to know what are seizures, what are the treatments, what are the side effects of medications.

FEMALE: I had the dimmest, darkest superstitions about what epilepsy was. I really did not know what it was.

MR. BILL DANYLIK: There are an awful lot of resources out there.

GRAPHICS - EPILEPSY USA

GET THE WORD

MR. BILL DANYLIK: For instance, the Epilepsy Foundation. As soon as you talk to your doctor, there are always leaflets, pamphlets. There are a lot of resources out there. Take advantage of them if you can.

GRAPHICS - ENTITLED

GRAPHICS - OUT!

MALE: Don't be afraid of information. Don't be afraid of technology. Michael has a vagus nerve stimulator, and it has cut his seizures by at least two-thirds. And it works.

FEMALE: Knowledge is power. It helps you deal. It helps you cope. It helps you separate the myth -- and there are huge myths that surround epilepsy. There is all sorts of wrong information out there.

FEMALE: Do research. Don't believe everything you hear.

(Music.)

GRAPHICS - Arzolas (continued)

FEMALE: She is very close to my mom. As a matter of fact, I am always teasing her about it.

FEMALE: My grandma, she spoiled my mom. She is like, every time she sees my mom, oh, miha, what are you doing? And she talks about how we are and how am I doing. Am I doing all right? Am I taking my medicine? Are we doing okay? Do we need anything? We're like, no, we don't need nothing, grandma.

MS. ARZOLA: She has always been a mom to me, all the time. She has helped me a lot with my girls.

FEMALE: I love her a lot, because I thought she was one of my daughters. And she was young when she get married.

FEMALE: It is very important for family members to help out or even just to give advice that is good.

FEMALE: Patricia would call me. She would tell me Roxanne is tired and she has got a real bad headache. And I would tell her, well, massage her hands or, you know, just keep it dark. Try not to get her to move too much. And I helped her out a lot. She would call me all the time for help.

MS. ARZOLA: Roxanne, she is already 16. She will be 17. So she knows what she needs to do. She needs to be

responsible because she is going to be closer to 18. When you turn 18, that is when they are really going out into the world. So I told Roxanne, you've got to be responsible for yourself. Make sure you take your medication. You know you have got to take it regardless of whether you like it or not. You have restrictions on certain things. When you turn 18, the kids usually go wild. She knows she can't drink. She knows she can't be over there doing other things that kids can do.

FEMALE: I want to be a lawyer, so I am studying to be a lawyer. And I want to college, and that is where I am going right after I graduate.

MALE: The resiliency that you see in Roxanne's life is something that almost seems like it is second nature to her, because she has seen so much of it in her mother.

MS. ARZOLA: God gives me strength. I pray to God every day before I go to sleep. And that is it really.

(Music.)

GRAPHICS - You have enough stress without trying to hide it.

FEMALE: I think you need to be open about it. Again, you have enough stress as it is without trying to hide it.

MALE: I picked and chose who I told. And as I got older, I told everybody.

MS. ARZOLA: She was embarrassed at first. She didn't want to wear her ID bracelet. I told her, well, if I buy you charms to make it a charm bracelet, would that help?

MALE: It is a great conversational starter.

(Laughter.)

MALE: I'm serious. You get it out right there.

MALE: I never looked at it that way.

MALE: You get it out. People will look at you and say, what's that? And you go, I have epilepsy. And if they don't like you, they walk away. And you say okay, fine with them. We're going to go somewhere else. But trust me, you need this thing.

FEMALE: I guess it kind of brought out my real friends. And it was just kind of sad, because all of these people that I had hung out with for so, so long weren't really my real friends.

FEMALE: I lost a lot of my friends because of his illness, but they weren't friends because they left. Anybody that abandoned ship wasn't a shipmate. That is how I look at it.

MALE: The worst thing to me was when we tried to hide it, when Michelle tried to hide it and we tried to hide it. And as soon as we came out and we told our friends, we made her understand to tell her friends. And then we found some people among her friends that could handle her when she has a seizure,

so she could go out. She could go to the movies without us, or she could go out somewhere else. But the key is to come out with it.

FEMALE: Once we stopped being ashamed and told people, and said, you know, if Guillermo has a seizure, don't hold him down, do this for him, then we started getting like a little army of people who Guillermo was going to be able to be safe with.

GRAPHICS - Reach Out

FEMALE: It's very important as a parent to reach out for help, because it's scary.

FEMALE: One of the things that has helped me survive is that I am not ashamed of saying I need help.

MALE: We were very isolated. We didn't know about support groups and other things. And it's really great to be able to find other people with problems that we can find out the things that we are experiencing are common.

FEMALE: I know when we went to our first meeting I just go, oh, my God, where were all these people that many years ago? I just felt like crying because you had all these people talking about the same kinds of things that we were going through. And just to be able to bring it out, to talk to someone and not be scared that they were going to look at me strange.

MALE: In the support groups that I facilitate, I always try to create an environment where they know it's not my support group but it is their home.

FEMALE: Don't keep it to yourselves. Get out there. Share your situation with other people. And you will be surprised how many people out there have the same thing going on for them.

FEMALE: They understood normal. They understood what I was going through. And they told us, hey, this is normal.

MALE: No, you're not alone out there. That's what I would say. You see the sparkle at the end of the tunnel when you meet somebody else or another couple or another person with epilepsy.

(Music.)

GRAPHICS -

Many thanks to the families who shared their past and present with us. Without your experience and the wisdom that it brings, this video would not have been possible. We look forward to a future where our children reach their full potential and are met with acceptance.

(Music.)

GRAPHICS -

Special thanks to the Epilepsy Foundation and affiliates in Central & South Texas and Massachusetts and Rhode Island.

(Music.)

GRAPHICS -

For more information on epilepsy and CDC or EF program activities, publications, and other partner organizations, visit www.cdc.gov/epilepsy

You Are Not Alone

2004

(Music.)

GRAPHICS -

Produced by the American Institutes for Research for
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CDC

(Music.)

END