

John and Denise Fried

J: My name is John Fried. I'm here with my wife Denise. I was diagnosed in August of 2014.

D: This is August of 2020, six years. Quite a bit of a change. Quite a bit of a journey.

J: We never expected to have it this long and we're so grateful that we have had this time together.

D: We are. So, in August of 2014 we were slammed. It was incredible. Everybody who has received that diagnosis and everybody who loves someone who's received that diagnosis knows exactly what I'm talking about when I say we were slammed. It was not just a matter of John being sick, it was about, we needed to change our whole life. We needed to do things to react to this diagnosis that would take into account that he wasn't going to be able to walk. We've got a two-story house with a basement. We had a big decision to make. We had big changes to make. Luckily, we were in a position, we were close to an ALS Clinic, we were close to the ALS Association. We were able to make good contacts right away and get a good start on putting the things into place that we needed to have happen.

J: I was still working at a successful job and I had to stop that. I was engaging in leisure activities like racing cars, I had a race car and several other vehicles. I had to turn over those things and my financial arrangements completely to Denise. I had to give up driving. All of those things created a lot of stress, for both of us. We had to modify the house, so construction added to it. Somehow, we didn't kill each other!

D: Not yet! There were a lot of changes for John, personally of course. For both of us it was the decision on where to live, which was a crazy decision to have to make. We literally got a piece of paper and drew a line down the middle and said reasons to stay in our house and reasons to try to find someplace else to move. It came down to staying in our house. We contacted the ALS Association and found out who did that kind of work. Who had the experience to do that kind of work to make our house a livable place for both of us? For a guy in a wheelchair and for me. So, it was right away, literally within a couple of months of the diagnosis that we had a plan in place, and they started work on changing our house, doing that kind of work that needed to be done so that we would be able to stay in it and we've been able to stay for 6 years. That was huge and we've always been glad, we've always been very glad that we made that decision. If we had decided to change, I'm assuming that we would have been glad about that too. We're

surrounded by good friends, we've got a lot of resources close to us and we feel very, very lucky. We know that not everybody that has this diagnosis, or a similar life changing illness has those kinds of options and we know we're luck when it comes to that. One of the first things that we did after the diagnosis was, umm, we're not from Wisconsin. We went on a tour to family around the country. I don't know if that is something other people have to do. You have to somehow let people know so we started catching airplanes and hitting the road to tell the people that we love the situation. So, that was hard, that was difficult, but it was also good. You know there's that opportunity for everybody to say how much they love each other. We had that sort of a thing happen without it being...people said what they felt right away. It wasn't a, you get down to the last minute and oh, yes, by the way I love you. It was right away, and we get lots of support from that family even though they're far away. Luckily, we have developed quite a circle of friends who are very supportive here and we have some children who are still in the neighborhood so that's good too. One of the big things that we had to do, John already alluded to, was assess to our financial situation. There is no doubt about it that any time a serious illness is diagnosed people have to do that, any serious illness, I'm sure they have to do that. In our situation it wasn't so much we had to do that because we had to cover the cost of drugs and doctors or things like that because insurance covers a lot of that but remodeling a house insurance doesn't cover. That's a big one, assessing that and just diving into whatever resources we had. We look back and we are just amazed that at some point in our 30's we bought, maybe even in our late 20's, we bought a disability policy. We bought it ourselves. We had a friend who sold insurance and he needed to sell things to make a living, so we bought a disability policy and that thing kicked in, it's just amazing.

J: Yes, 30 years without a need and I almost cancelled it. Then I received the diagnosis and I thought, man, we dodged a bullet.

D: A huge bullet! We also received really excellent support and I know people aren't going to believe this, but from the Social Security Administration. They worked to help us figure out the disability options and were really, really helpful. I know it's sort of normal to dis the government, but this is one that really, really worked out for us. Then all along we had the ALS Clinic close by, but we've got to give a shout out to the ALS Association. Just knowing that they were there was somebody we could call that could say have you tried this? Have you thought about this? We've got these resources available to you. We've been extremely grateful for that. We try to support that with the fund raisers and the activities the Association puts together. We enjoy the fundraisers. The annual Walk, we are very sorry it's not in the format that it's usually in,

but we know that the format, for this year, will have to work in a pandemic. In the past, when it was a big Walk, and we could call friends together, we would have friends from out of town come, family from all over the place come.

J: Church.

D: Church friends, just have a wonderful time getting together with those folks and if we raised a little money that was good too. We went to the big Gala Dinner, that was fun, it was a lot of fun. To get dressed up and go downtown, have a good time. We inspired, one of our daughter's friends was inspired to put together her own little fundraiser. At a local bar in the area that has volleyball courts. She put together a volleyball event, it was so much fun.

J: Pierre Delamar did a fundraiser by walking the Pacific Coast Trail. He hiked 1,000 miles.

D: He did, yep, so that's meant a lot to us. To be able to both call the ALS Association and to support the ALS Association, it's an important thing to us.

J: I think one thing we did that defined all of our actions up to this time, is we committed to try to squeeze the most value of our life out while we were experiencing this horror. We, I think have committed our time and energy and resources and called upon others in the selfish attempt to make our life livable and normal as it can be.

D: Normal, the new normal. There's no doubt about it that over 6 years of living with something, we've been lucky that John's progression has been slow. That has given us an opportunity to anticipate some things. Other things just kind of dawn on us, oh my gosh, we should be doing something about this. There are lessons we've learned, and I have got a list of them. One of them is to try to be ready before it's necessary. We started really working on getting this motorized chair well before the insurance was going to approve it. We started hounding to get that done before it was there, so that it was with us when it became absolutely necessary for John to be in a motorized chair.

J: We have to thank the Closet for bringing one sooner than the approval of the insurance. I needed it way before we got it.

D: Yes, that's true. There's lots of other ways we tried to live by that, being ready, having things available before we needed them. The other one is, it's kind of along the line of equipment, is to know that you're going to make mistakes. You're going to get something that you go, oh this isn't right. You might spend a lot of money on it, but forgive yourself, let it go. We've had four shower chairs, only one of those was really a mistake, the other three we have used because there's been a progression of need as

John needed more support for that rolling in and out of the shower. We needed a different sort of a chair, one of them was really, actually, of course, the most expensive one was a dud, but we had to move on.

J: Fortunately, we gave it to the Closet.

D: We did give it to the Closet.

J: So, it's their problem.

D: Yep, one of the things that also goes along with that is sometimes the simple things can be the best. We had been trying to find some sort of tray for John's motorized chair, something that would attach to it and be fancy and spiffy and all that. We finally just gave up and got a lid off an old crate and said, you know what? That reaches across your lap and it's flat and we can put your mouse on that and it's just fine and we already own it. So trying things that are already available helps you learn a little bit more about, either it works out just fine or you learn a little more about what you're actually looking for, what you really need, by trying things you already have. I think John already said that we should accept help, that's a big one.

J: Yes, it's tough.

D: It's tough to take when your grownups, you think, I can take care of myself. There're times when you really, really need to accept help. Especially right after the diagnosis because it was like, I don't think I can cook, and somebody would bring supper over without us even saying anything. Supper would just show up. It's...so accept those things and be grateful for them. The other thing is that for a long-time people would ask me if we had any help and I would say, no we're fine, we're taking care of stuff. Then I'd realize, we did hire people to help us. Having somebody come by to clean the house was an enormous help. If you can at all afford those things, that don't seem to be specifically related to the condition, you may not realize how much that's really, really helping you because it frees you up to address the things that are related to taking care of John, taking care of your loved one personally, that was a big one. The other one, another lesson that we learned is to go outside. It's just kind of, go outside. For a while we made sure we went outside every day. This was even in the middle of winter in Wisconsin. We would go outside every day. That's kept us in touch with neighbors, it's helped us to meet new people, new friends. It's just been important for our mental health, I would say, don't you think?

J: I think it keeps me in touch with the rhythms of the year.

D: Yes, but when you're with those people, talking with neighbors, be honest with them. We've had really well-meaning people invite us to do things and we finally learned that we should just say, we should just explain, we really can't do that. We really can't go out to eat anymore, it's too difficult. We would love to see you in your backyard and, we'll say, for a glass of soda. Just be honest with people and let them know, you don't have to burden them, just give them the picture of what's really going on with you so they can react, so they can respond to you in their best way, because they'll do it, they will do it. We sometimes talk about what it was like for people who...Lou Gehrig, you know, who had ALS at a time when there was no internet, really no telephone system that was all that wonderful. The fact that we've got computers and big, fancy TV's and telephones and text messages and Zoom get together, it's just amazing in keeping us connected with the world and up to date on what our friends and family have going on, what's going on with ALS, what's going on, just in the world. So, we're grateful for that and that's a lesson that we've learned, that we should be grateful for and take advantage of as much as possible. Sort of an aside, we have learned that, it's kind of back to the equipment thing, we've learned that acquiring equipment, we probably already alluded to this some, is not as easy as running to the store and buying a new bicycle. Getting a motorized wheelchair, getting some of the other equipment that we've needed, especially if insurance is involved is really complicated. It can take a long time and it can be frustrating so I guess the lesson here is to try to develop a relationship with those people who are providing you equipment so that you are getting...so you feel like you're at least getting a good response, so you get some sort of good reaction.

J: The most surprising thing to me is that the doctor, in France, who developed the neuroscience under 60 years ago discovered ALS, and we don't have anything of value to combat this awful condition. What the hell?

D: There you go.