



Navigating Glioblastoma: A caregiver's perspective

An interview with author Sally Connolly

Sally: I think that for so long people didn't want to talk about cancer, but I really think that going public with the journey, with the treatments, with how you react, with your emotions during that time is so helpful for the people who come behind you because they're at the beginning and for so many kinds of cancer, there's no roadmap that tells you, well, first you're going to do this and then this, and then if it comes back, you're going to do that. And all that uncertainty is just terrifying.

Diane: Peter Connolly was diagnosed with glioblastoma, an aggressive type of brain cancer, at the age of 61. Over the next three years, he endured three brain surgeries, radiation therapy and chemotherapy treatments with debilitating side effects. His tumor would disappear only to return with a vengeance. Each time he was put on a new drug and eventually needed more surgery. In March 2016 he participated in a clinical trial, but the cancer continued to grow. And on May 21st, 2016, Peter Connolly died. Throughout it all Peter's wife, Sally was at his side. It wasn't easy being her husband's primary caregiver, but she persevered with love and determination. His memory had become unreliable, so she attended every doctor's appointment and took notes. Eventually those notes, along with homework assignments from a writing class she took called *Write Your Life*, evolved into a book: *Navigating Glioblastoma: A Caregiver's Perspective*, which was just released in September 2020.

I'm Diane Atwood and you are listening to the *Catching Health* podcast. In early March of 2020 I visited Sally at her home in Maine. As we sat at her dining room table, sipping tea. She told me her perspective of Peter's grueling Odyssey, and she shared some of the struggles she faced and the lessons she learned along the way.

Sally: He was diagnosed 2013 July, but first before the diagnosis, he had a craniotomy and pretty significant, and it was a very large tumor on the left side, front to back and when they do pathology on the tumor, that's where they decide what stage, what grade the tumor is. And so, this was the worst of glioblastoma.

Diane: Meaning what exactly? What made it the worst?

Sally: So, the surgeon was very blunt, which I actually appreciated because I don't think my husband would have taken it seriously enough if the surgeon hadn't been so blunt. He started right off before he had even done any surgery, and he said you have cancer of the brain. And so, everyone else had called it a mass or a lesion. So, when you're a rookie in the cancer world, what does that even mean? And, the surgeon was the one who said, you have brain cancer, you will absolutely die of it. You need to update your will, your health proxy, your estate, you know, everything and I'm thinking to myself, but he has the surgery tomorrow. I'm supposed to do this between now and then? But, you know, it really took us aback. So, he had the craniotomy and he didn't feel too awful.

Diane: Did they actually remove part of his brain or did they just do the biopsy?

Sally: Great question. So of course, MRIs are pretty wonderful. Because it was so enormous, they absolutely wanted to remove it because Peter was having more and more pronounced symptoms. He had been hiding a lot from me about his balance, about his cognition, about headaches, about exhaustion. And, therefore I was pretty gob smacked hearing this because how could he have such a big tumor? And he shared with the surgeon what his symptoms were, and I was sitting there as the spouse who had just been on vacation with him for a week and I was astonished.

Diane: Wow. Can you walk me back a little bit now that you do know what he had for symptoms? What were the first signs for him that you learned about?

Sally: The headaches and the exhaustion for sure, and I had thought that he was just getting older, you know. He would come home, he worked for IDEXX, he had a very responsible job with IDEXX, and he would come home exhausted and he would say I'm going to lie down before supper. So I would call upstairs for supper and he would come down and he would eat, and if I was going to watch something on TV, he would lie down on the couch to watch TV, too, but when I looked over he'd be sound asleep. What I didn't know is that he was popping ibuprofen just constantly.

Diane: Was his headache in one particular spot?

Sally: Good question. And I don't know. We had gone out to Oregon. He had a convention out there and so I was exploring Seattle and, that's where the convention was, and then we went and stayed with friends in Oregon and he just seemed to be lying down a lot, coming back after a session at the convention and lying down in the hotel room. And, when we went to see our friends in Oregon, we used to live there, and we wanted to go hiking in Columbia Gorge, because that's what we had always done together, and six miles, three miles in and three miles out at Eagle Creek and I had no idea and I can't even imagine if he had had a stroke. When we were three miles in in Columbia Gorge, how we would ever have gotten him out of there, because there were places that were not even a foot wide that you had to put one foot in front of the other big drop-off and all of that.

Diane: And he did it.

Sally: And he did it and he seemed tired, but I was tired too. So, it was just amazing to me. But then when we got home very shortly after that, we were just taking a walk and I said to him, you're making a lot of noise back there. He was behind me and I could just hear leaves constantly, and he said, I know I can't seem to lift my right foot. So, I stopped and turned around and said what? And he goes, yeah, I just can't seem to lift up my right foot. So, he thought he had Lyme disease.

Diane: Even with the headaches and the tiredness, he hadn't gone to a doctor because ...

Sally: Right, and he had been having trouble with his right side, but I didn't know. Weakness you mean? It felt funny and he couldn't make his hand and his leg do what he was telling it to do.

Diane: How long do you think that was going on?

Sally: I have no idea. That's a great question. And I'll never know the answer because he was so good at hiding. He was so good at hiding. How old was he? He was 61 at diagnosis and really too young to be that tired from work, but I was just...

Diane: You don't expect something like that. No. Who would expect something like that and you, and those things that you described, like if you're coming down with a cold, you're suddenly more tired than you would have been when you were even 50.

Sally: Right, so. Okay. So, he, he did test a negative for Lyme and the doctor, his PCP listened to the symptoms and was very concerned right out of the gate, and so he sent Peter in for a NMRI. NMRI? It was a brain scan basically, and it showed this enormous mass.

Diane: Oh, and you said it was on his left side.

Sally: On the left side. It was shaped like an hourglass from front to back. The MRI or whatever the scan was, was astonishing to look at because it was where a skinny little ventricle should be, was this huge white hourglass and, frontal cortex all the way to the back, and it was the 4th of July weekend. I can't remember the day of the week, but let's say he had the scan on a Friday and the PCP called him and said, you have a large mass. So, Peter came home from work that day with this news and I was just thunderstruck. And then nobody called the next day and nobody called the next day. Because it was the weekend. So, I was like, I guess this can't be too bad or we would be getting a call. And then the following day, the surgeon called. He said, Peter needs to be in the ER right now, almost sounding like how did all this time elapse with him not going to the ER? So, Peter was out front digging a big hole to plant a tree. So, I had to go out and say, actually we're supposed to be at the ER right now. And he, he kind of argued, I think he wanted, he felt like, well, I've got to plant the tree before I do anything else, and I said from the way this surgeon sounded, maybe the tree should wait. So it was a, it was a hot summer day and he was all dirty and sweaty, so he took a quick shower and we went to the ER and I had this vision of sitting there in the waiting room for a long time, but we walked in the door and they admitted him immediately. So, all he could think about this work, and let's just say he was very grumpy.

Diane: Do you think he was in denial? Was he in shock?

Sally: He was, he was in shock. He was extremely annoyed that this thing could ever happen to him. And I burst into tears right away, but he, he didn't seem distressed. He seemed irked more than anything, and I'm sure he was thinking to himself what a pain in the neck. I have so many projects that I'm working on and, you know, I want to get a tree planted and all of these things, and I just don't think that maybe he was thinking about the repercussions and what his life might look like after.

Diane: And yet to even think about that it's sort of overwhelming probably too. So. Sure. So, do they do surgery that day?

Sally: Well, it was the 4th of July. No, it was the 5th of July. It was our 38th wedding anniversary. Oh, my goodness. The surgeon came in, had a long, long talk with us, as I say, made it very clear how serious all of this was and that he would have the surgery first thing the next morning. and he had talked about that there was an excellent chance that he would stroke out during the surgery. Cause he, he and the PCP could not believe he had not had a stroke because the tumor was so enormous. And so, he, he said, and if that happens is a chance that he could die because this thing is so huge and was allowed to develop for such a long time. So anyway, I started thinking about money.

He had always done all the money and I didn't even know the passwords to get into where our money was and I, I didn't know, passwords for our bank. I couldn't even have told you how much we had in checking and saving. I mean, I really was a fool, but that's how it was.

Diane: That's not an uncommon story.

Sally: I would like to have thought that I was a more enlightened woman, but I would say to him, you're awfully busy, wouldn't you like me to do the money? And he would say, no, no, I'm fine. I like doing it. So anyway, we're sitting there the night before the surgery and I brought that notebook that I had no idea what was going to fill up. but on the back pages, I said, Peter, if it ever happened that you died or the other risk of course was severe cognitive and physical, impact. So, I said, I don't know anything about our money. And his first response was, I'll be fine, don't worry about it. And so my response is, but what if, you know, I feel like if it's Murphy's law, if I don't know anything about the money, then the worst is going to happen to you, but if I get all the information, then maybe you really will be okay. So anyway, I sat there in a chair and he gave me all the passwords to everything. How he, I mean, they were all up here, so it's a good thing I had asked because he had never written down passwords anywhere.

Diane: It's amazing that he still had that cognitive ability.

Sally: It absolutely is. So, he came out of the surgery beautifully, did not have a stroke. Very crabby afterwards, and all he could think about was work, calling work, talking to work. I'm saying to him, you know, you're on an awful lot of drugs, are you sure you want to be corresponding with people at work when you're on like five different kinds of things, because they give you anti-seizure drugs, a couple of kinds of antibiotics, they put you on dexamethadone to reduce swelling.

Diane: it shocks me that he came out of, I mean, they're removing pieces of your brain.

Sally: Well, I think for this first craniotomy, because there was another one, years later, they, so they drill from here. Above your eyebrow. Up here and then around behind the ear. And then they pull the skin back, they take out the bone, and then they were able to just reach in and pull the tumor out because it was very rubbery and it very clearly defined edges.

Diane: So, they're not cutting into any pieces of his actual brain tissue?

Sally: Not this time and I think because of that is why he was as able afterwards as he was. He was able to talk to me with no slurring. He was able to move his right hand, his right leg. So, everybody was very encouraged. He was there for maybe four whole days. When they said they were sending him

home, I was kind of like, wait a minute. Am I, am I ready for this? What do I need to know?

Diane: What did you need to know in retrospect?

Sally: Well, he didn't want me to know anything. He was gonna take care of all the medications. He was going to take care of communicating with our insurance company and finding out from IDEXX, what they're, because there hadn't been any time to sit down with IDEXX and say like, what kind of leave do I get for something like this? And so, it, all of those things happened after the fact, and I thought that I should know everything, but he didn't think that I should know everything. So, I knew a minimum, like what drugs he was going to be on, and I'm scribbling in that book as fast as I could, in terms of what the, only the neurologist at this point. And the other people we saw were the social worker navigators who, are at the hospital and also at, well, it was Maine Center for Oncology Medicine at the time that we were there, now it's New England. So, it was nice. That's a fabulous thing to see someone. Two social workers would come in and chat with us, give me heaps of pamphlets and things. And then we would see a friendly face when we went up to see the oncologist. But at this point, you know, we don't have an oncologist. There hasn't been any pathology yet. He's just home on drugs to recover from the surgery.

Diane: Did they suspect at the time that it was a glioblastoma?

Sally: Nobody's said that word to us at the time.

Diane: Until the pathology came back?

Sally: Yeah. If the surgeon had his suspicions, he didn't tell us that. Yeah. But he confirmed that it was cancer because only cancer would grow to such a great size. So, he stayed home, and he recovered and talked to work three or four times a day. He was, you know, just like a concussion, you're not supposed to be on screens, you're not supposed to watch TV, you're not supposed to read, all of the things that he wanted to do, and so he's on his cell phone all the time, his Blackberry.

Diane: What did he do at IDEXX?

Sally: He was the director of research and development for quote Companion Animals Division. eventually he found out that IDEXX was the best-case scenario for being out on leave. They paid a hundred percent of his salary for short term leave, which I believe was 90 days, and you could re up for that. And then they had 60% for long-term leave. And, your job was guaranteed whenever you could come back. He began to do some work from home, and so he finally said to me one day, I need to get into work. I need notebooks, I need this, I need that. And so, I said, okay, but you can't drive because, oh,

he was also on Lorazepam because he was having a lot of trouble sleeping. So, I drove him in, and I said, do you want me to come in with you? And he goes, well, yeah, I guess so. So, he walked in, he had a closed office, but in front of his office were all these cubicles and word got out that Peter is here, and all these heads popped up. Peter's here and he's waving to everybody, and he's saying, I'm recovering, I'm recovering. And it's like, he has the chicken pox. We had not started yet at the oncologist's office. I don't think at this point, we even knew who the oncologist was yet because he was still in recovery mode, but he went into his office to get the things he needed, and his hands were just trembling. And thank God, his administrative assistant saw that too. She said, you sit down, I've got a box, tell me what you want, and so he sat there and told her what he wanted and I'm like over there going thank you, thank you. And so, we walked out of the office and people wanted to chat and Peter said something to me like, well, I think we should be going. I said okay. He couldn't wait to get in there and now he couldn't wait to leave. We got in the car and he said, Sally, thank God you came in with me. He said, I couldn't remember anybody's name. Oh dear. And he said it was a mistake to go in so soon. And he said, I couldn't have been there another second. Wow. What a profound moment. It was a profound moment and it was a profound moment for me too, because he seemed so fine at home. And except for being grumpy with me that I thought, well, I don't know, he's acting like this is going to be a breeze. I don't know, maybe it's going to be a breeze. I began to believe the myth, but now I saw brain surgery is a very serious thing. that surgeon had said to us, brains are not supposed to be exposed to the open air. So even minor brain surgery is going to have an impact on the brain. So, after that, we went to the cancer center, he got the best oncologist. I felt so blessed with this man. He was wonderful from the very first second, Devon Evans. Fantastic, fantastic guy. And his two nurse practitioners phenomenal. He's just the best because this is just my opinion, he remembers there's a caregiver. And that's such an important thing, for the oncologist to remember to say hi, Sally. How are you doing? I got more and more honest with him as the three years went by to say not good, not good. The steroids are making me out of my mind crazy cause he's so grouchy with me.

Diane: So, the surgery wasn't the end of the treatment, it was the beginning? He had six weeks of radiation, five days a week. that's just exhausting.

Sally: He was losing a lot of his hair anyway, but he lost all of it on the left side of his head and had like a sunburn where the radiation was, and most of the exhaustion kicked in after he was finished, which they had warned us about. And he had a little break and then he started on Temodar, which is a pill and one of the side effects was nausea, so he took Zofran, which is like a mega mega anti-histamine drug, it sort of dries up your stomach, and then he

would take the Temodar. And how long would he be on that? Well, they had said a year, the standard of care, which was a phrase I had never heard before, but the standard of care was a year. And then we found out after six months, that the data only goes up to six months, but the standard of care is to stay on it for a year or until you can't handle the side effects anymore. So somewhere before the year was up, he was very ill. I mean, really exhausted.

Diane: So, you're saying he was very ill as side effects from the treatments that he was getting, as opposed to very ill from the cancer.

Sally: Exactly.

Diane: And the cancer came back?

Sally: Well, not while he was on Temodar. He had just had it with Temodar, he just felt so sick because it interfered with work. Oh. He was tired. He didn't feel good. It was just hard for him to be at work.

Diane: So, he did go back to work.

Sally: Oh, he went back full time. He was driving himself back and forth. Yes. Whatever. So, his first MRI, after going off, it was clear. And the second MRI, after going off, it was clear. So, he believed that the reason he had been feeling so sick was only because of the Temodar and that now he was going to be a hundred percent and he kept saying to the oncologist, when am I going to get my memory back? When am I going to be back to my old self? And the oncologist was so truthful with him and would say, Peter, you are at the height of your cognitive abilities right now. This is the best it is ever going to be. And even though I would write that down, it was almost as if it bounced off his brain like Teflon, because he never seemed to internalize that and believe that was the best he was going to be. So, by the Christmas of 2014, the tumor was back, and it was about the size of a walnut. So again, because I had nothing to read or look at it, I had no idea what was the next, what do you do next? Is this the end. So, it was not the end. So, the next standard of care drug was the generic version called bevacizumab. It was an anti-mono-clonal antibody. And the name of it became with an a. The brand name. Avastin. That's what you started with and that was an infusion. So, it worked, the tumor went away. That's pretty miraculous. And I forgot to say when he was doing the Avastin, he was also doing a clinical trial for something called TR105 and I need to go back to side effects for the Avastin and the TR105. He's covered in a rash from head to toe and his nose was bleeding, bleeding, bleeding at unexpected times. He went off the TR, the TRC 105. I don't think it was as long as a year and the tumor was back and again, it was about the size of a walnut at the time. He was astonished when Dr. Evans said, okay, so the tumor is back, once a tumor has escaped Avastin, we don't really have a whole lot, um, for you. He was astonished. We were told over and over again

that there was no cure that anything that you're doing, Peter, will only extend your life, but there is no cure. And as I say, that was like boing for him, but for me, the time has come for somebody to kind of take charge here, and he was very resistant to this, but eventually when he paid the mortgage twice in one month that was the domino that made me say, okay, I need to be doing the money., and he agreed, which astonished me. He said, yeah, sometimes my brain hiccups, I'm thinking maybe you do the money and I'll watch you. Cause I have been watching him. Right. So, after one month of that, he said you can do it all. Thank goodness. Is must have been hard for him to give things up. It was very hard, very, very hard.

Diane: So, at this point you're writing all this stuff down for your own purposes.

Sally: But not saying a word, I didn't ask any questions. When the choice came, so what shall we do next, I did not participate in that choice, and I had several friends who had had spouses with cancer, who could not believe, but I felt that Peter was in charge of his own health decisions. I was taking over a lot of things, but I thought that should be him. So, this last, when the Avastin wasn't working Dr. Evans said, well, there's do nothing, which I was beginning finally, to understand why he said do nothing because it seems such an odd thing at the beginning, the standard of care or a clinical trial. So, Peter said, well talk to me, you know, the TR105 may have worked because all the time he was on that, the cancer didn't come back. But at a price. Yeah. But he paid a huge price. I would try to say to him, let, can we talk about quality of life and he said, we'll talk about that later, I'm too tired now. So, he chose clinical trial, which is very common that when the person's at the end of their rope in their health, that's when they decide to do a clinical trial, when they're so unhealthy, it would be a miracle for it to work. So that started, almost five months of going back and forth to Dana Farber. And I was so nervous about driving in Boston and where was I going to park and all that that I said to Peter, we're going to take the train. And we'll catch a cab from North station to Dana Farber, and it was an ingenious idea because he loved the train and you know, you have more room and if it's pouring rain or if there's a traffic jam, you're like nothing I can do about it. I'm not driving. So, it was really, really, you're good. We went down there. We had a long, long day talking to, Dr. Riordan? Yeah. Who was extremely well known in brain cancer. He's one of the, the top people. What you don't know at the beginning of being diagnosed is that if you go on certain drugs, like Avastin, you're not eligible for most of the clinical trials. My goodness. If I had known better where to look, maybe I would've found that out, but I felt as if I wanted to know about caregiving. But the gist of the clinical trial was that because Peter kept forgetting to go off meds, he kept not being able to start the clinical trial for this thing called Ponatinib and I had no idea what the odds were for this

because there were only four people on it, plus Peter, if he could ever get on it and the, there was something else and there were only five people on that. They were always so tiny that I didn't really trust that it was enough people to be very definitive. And I wondered if they were all as sick as Peter when they started. What I have learned since then is that it's so much better for people to start clinical trials at the beginning. Now he's falling because his right leg isn't cooperating. Because the tumor is continuing to grow? To grow all this time. So, he has quit the Avastin. There's nothing working on the tumor. The gist of it is that the tumor got so huge that, do you need to go out? Sorry. C'mon, all right, fine be like that? Let me go close the door. the tumor was so huge that nothing was going to work on it, and they said you need to have another craniotomy, and I'm just sitting there saying, wait a minute, what? We're like this big for the tumor. It's like a peach? Same place. not quite the same shape, but this, in that ventricle. and I just gasped when I saw how big it was, how could it have grown from a walnut to this big in like two months? I mean, it was, it is a brutal, aggressive cancer. And I can see why it's a hundred percent terminal. So, I did talk to Peter about that. I said, do you want to go through that again, the headaches, the recovery from brain surgery? And I said, you know, back then you were really healthy. Now you've been through an awful lot, and he said, no, no, but they, they, the doctor said that I needed to have surgery. And he did. I mean, in Peter's defense, they didn't even say, well, if you want, it was like ...

Diane: To have the surgery, even though they know what the outcome is going to be?

Sally: Absolutely. So, he had it. So, he did. They removed it, it was even bigger because there was a gap between the MRI and the surgery. So, it all went well. but then he started to slur, and he couldn't walk anymore, so they decided that there was fluid building up on the brain and now we needed yet another brain surgery. So, they inserted a shunt. OH, my God, that's so much. And it prolonged how long he was in the hospital and ... So, then they wanted to send him to Spalding Rehab, which is in Charlestown, and I said, that was when I finally opened my mouth. And I said, absolutely not. I said, we have rehabs in Portland. They sent him to, what's on Brighton Avenue? New England Rehab? Yes. Thank you. And, he was there for a week and hated every second of that, but I said to him, you know, if you just do what the PT, ST, OT tell you to do, the better you are, the sooner you can come home. And the idea was that we would go back, and he would start the pinata nib. And so, they called him at some point when I wasn't home, told him to go off a drug, he didn't go off it, so everything gets delayed to go on the drug. We go in, his cancer has grown back. How long is this? This must be weeks. Not as many as five weeks. The cancer was back, and it was a significantly sized

tumor. So, let's start the ponatinib and he was on it for one month and then they did another MRI and the cancer was bigger than it had ever been before.

Diane: You mean, bigger than the hourglass? Oh much.

Sally: It was almost filling the left side of his head. What a bastard of a cancer. Unbelievable. So, they had, Oh, you could do this. You know? Well, the standard care, this is what they're telling him in Boston. Peter said, I want to talk to Dr. Evans. I'm going to do what he recommends. So, we went in and, Oh, thank you god. I'm sitting behind Peter, and Peter says, so what should we do now? And so, I'm just looking and going like, look at him. So, Dr. Evans said, well, really hospice. And I was so grateful to that man for being the one to say it, because I had been thinking hospice for a really long time. I needed their help. he accepted it because it came from the doctor. So, he was probably under hospice care for, I'm going to say maybe a month, a month and a half at the very, very most and most of that was at home. And, they were helpful for me. He wanted to go to Ireland and I just panicked thinking what that last trip home from Boston had been like. How was I ever going to get him to Ireland? And the social worker, God bless that woman, took me out into the driveway and said, you know you're not taking him to Ireland, right. And then she said, it's so common for people at the end of life to make these kinds of decisions. And it's too late. So, she said, get an Ireland video, get Ireland CDs, play Irish music. But, you know, you're not, and this has helped me so much in facilitating caregiver support groups. I can say, you know, it's very common for people at the end of their life to have some big dream like this, but it doesn't mean you have to make it happen for the person. I don't say to them don't do it, it's a terrible idea. I just say you don't have to do this. So, you currently facilitate a caregiver's group there? Yes. it's a stage four cancer. The patients go in with Patty and have a support group for them. And then my group is the people who are taking care of them. So, I have a lot of empathy for people who are at that stage.

So, Peter died in hospice. I got, so I just couldn't manage him anymore. He was so heavy. He went to Gosnell. It was very hard for me to give up the reins, even though I, I was the one who called them and said, I can't do this. It's just yummy. So heavy, you know? Cause he'd be up all night. He had that sundown syndrome and I would have to keep an eye on him.

Diane: And so, you weren't getting any sleep, so you were deprived. So that's an interesting place to be in to be able to admit that you can't do this anymore.

Sally: Yes. and the most, what Gosnell told me is that the most common scenario is that everybody waits too long to get them into Gosnell. And I can see why you think, oh, this is my purpose in life, you know, to take care of this

man, wouldn't it be lovely if he could die in his own bed. But then, when you look at what the, the nuts and bolts of making that happen are with someone who has, I was told he had agitation, later I read that it's called combative dementia. So, if I had ever seen the word combative, I probably would have had him at Gosnell sooner, but I mean, he certainly was agitated, there's no question about that. And, he was only there for three days. He died in the middle of the night when I had finally had, I just came home. I was so tired. And, they called you and said that he had died. They did. And I said, you know what? It's okay. He didn't want me to be there when he died.

Diane: I find that totally interesting too, because I know that for a fact that there are people they'll wait until you leave the room and then they'll die.

Sally: And then he took a long time to die, and one of the nurses said to me, was he a stubborn man? I said he was the king of stubborn men. She goes, yeah, they take longer to die. But their hospice is just a wonderful organization, and the people who work there are so much better than the average person at acknowledging that everybody dies and there's good deaths and not so good deaths and let's see what we can do to make this be a good death.

Diane: And, good for one person is not good for somebody else.

Sally: Right Absolutely. I think that. the most important part of talking about someone who's had any kind of disease where someone has had to be a pretty serious caregiver is to look for the resources in the community. And I must say that the New England Center for Cancer Medicine and Maine Medical Center, they made sure that I had every brochure from every support group, therapist for Peter, you know, all the different therapists that could help him walk and talk and you know, all of these things and, and, to live close, like we do to a good hospital and, and to have the Dempsey Center so close, it was, it was a godsend to me. That caregiver support group, the facilitators were phenomenal, and they were pretty much the same ones for the whole journey. And I was, tutoring high school students in Portland who was first language, wasn't English and Tuesday, it was Tuesday afternoons. And that's when the caregiver group met and I would be in that car exhausted from working with all these students, writing research papers and so forth, and it would be snowing or pouring, and I would just get there, get there, get there. And I said, I have to schedule everything around the support group because I live for it. It's keeping me from losing my mind. And there was another woman there whose husband was a pill to her. So, the two of us commiserated that, why are some men so angry? They're nice to everybody, but they can't be nice a hundred percent of the time and the person that the congeniality falls away from is the spouse every single time.

Diane: Cause you're safe?

Sally: Because you're the safe person. Right. it's very distressing to be spoken to in monosyllables or snapped at when I ask a simple question and be told leave me alone, will you just leave me the hell alone? You know, and you're so trying to be compassionate and, and it's like, the person doesn't want that. It's hard and you end up walking on eggshells the whole time because you're so afraid you're going to put a foot wrong. Even though really it isn't about you, but on the other hand, you're the one that's taking the abuse. So, I just went silent a lot of the time and was really careful to not say how are you feeling today too many times, and to just pat him on the shoulder or give him a hug and hope for the best. I don't think I was very good at how to deal with it. I think I needed to just say to myself, don't take it personally.

Diane: So how did you take care of yourself?

Sally: I went for lots of walks. I have, still, phenomenal friends. I've been so good all my life about having great friends wherever we have lived, and friendships are so valuable. And then my sister is my best friend. She was calling me frequently and emailing me frequently. And, so that was wonderful because I could be my real self with her. And then I have two brothers and, one of them would come out and cook and then go out in the yard and he would edge every garden and plant things and put mulch down. And this would make Peter so happy because he liked his yard to look nice.

Diane: Family's important, and you know, lots of times when people say, well, I don't know what to do, well, you're just naming some practical things.

Sally: Yeah. Yeah. And I have recommended to people that you have a list written down someplace because people say to you, is there anything I can do? And they'll say, just call me and you never do. I mean, I would never call somebody and say, can you cook tonight? Or, you know, can you drive him for once to chemo instead of me every time. But they called me, you want to go for a walk? You want to go to the beach? And I would think not really, but I'm going to do it anyway, and then I'd be so glad I did.

Diane: All that you're telling me is why it is so critical for caregivers to figure out a way to take care of themselves, no matter what the reasons are or what's going on.

Sally: For me, the most therapeutic thing was going back to teaching ESOL, the English speakers of other languages. I needed a purpose. once he died. So that's what you do. I had tried to do it during the three years that he was diagnosed, and I was in and out and in and out. Now I had time and my friends were saying, it's too soon, Sally. You know, I think you should just go for walks and go to the beach and read books and you know, so forth. And I

had started writing my book, but I needed something else. And so, I just called my supervisor at LearningWorks and I said, do you need a teacher? He said you don't want to come back and be an assistant. I said, no, I want to teach. He said, do you want to teach on Mondays, Tuesdays or Wednesdays? I said, I'll teach all of them. I needed to go have something else that, that reminds me there's a world out there.

Diane: Four years have passed since her husband's death, and Sally Conley continues to explore what the world has to offer. Only because of COVID-19, like many people, she now lives mostly in a virtual world. Masks help her keep in touch with best friends. And she's still teaching online using zoom and WhatsApp. The caregiver support group she used to attend was at the Dempsey center in South Portland Maine. She also facilitated a drop-in cancer group there. She's now helping again, virtually with the Center's *Write Your Life* group, the group that inspired her to write her book, *Navigating Glioblastoma: A Caregiver's Perspective*, which you can find on Amazon.

I asked her if she and her husband were ever able to resolve some of their issues. She just said that's an important part of her book and she didn't want to give it away. So, I guess we'll just have to read it to find out. You have been listening to the *Catching Health* podcast. I'm Diane Atwood, and I've been talking with Sally Connolly whose husband Peter died of brain cancer in 2016. *Catching Health* is sponsored by Avita of Stroudwater, a memory care facility, and Stroudwater Lodge, an assisted living community, both in Westbrook, Maine. Find out more about them at northbridgecos.com and you'll find more *Catching Health* podcast episodes and information about health and aging at catchinghealth.com. I hope you have a great day.