



2022

## Living with brain cancer: From researcher to patient

Stephen P. Chelko

*Florida State University College of Medicine*

Daniel L. Fay Ph.D.

*Florida State University*

Follow this and additional works at: <https://pxjournal.org/journal>



Part of the [Neoplasms Commons](#), [Nervous System Diseases Commons](#), [Neurology Commons](#), [Neurosciences Commons](#), and the [Psychiatric and Mental Health Commons](#)

### Recommended Citation

Chelko SP, Fay DL. Living with brain cancer: From researcher to patient. *Patient Experience Journal*. 2022; 9(3):8-11. doi: 10.35680/2372-0247.1743.

This Personal Narrative is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

---

## Living with brain cancer: From researcher to patient

### Cover Page Footnote

This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: [http://bit.ly/PX\\_PtFamComm](http://bit.ly/PX_PtFamComm)

## Living with brain cancer: From researcher to patient

Stephen P. Chelko Ph.D., FHRS, [stephen.chelko@med.fsu.edu](mailto:stephen.chelko@med.fsu.edu), Florida State University College of Medicine | [schelko1@jhmi.edu](mailto:schelko1@jhmi.edu), Johns Hopkins University School of Medicine

Daniel L. Fay Ph.D., [dfay@fsu.edu](mailto:dfay@fsu.edu), Florida State University Reubin O'D. Askew School of Public Administration and Policy

### Abstract

As an academic researcher, my work-life revolves around testing the efficaciousness of pharmaceutical drugs on the prevention of cardiac dysfunction, arrhythmias, and sudden cardiac death in animal models of heart disease. I never thought I would go from someone *studying* a life-threatening disease to a patient *living* with one in twenty-four hours. Yet, that transformation occurred October 8, 2019. I was just appointed to Assistant Professor at Johns Hopkins University School of Medicine (JHUSOM), yet after sitting for my professional headshot I had a grand mal seizure. I cannot recall this event, but I bit the tip of my tongue off, dislocated my right shoulder, and underwent violent contractions. I was rushed to the Emergency Department, thankfully within the same building (JHUSOM). A few scans later, I was told I had 'a mass' in my brain that needed to be removed immediately. Fearing the worst, I followed the advice of my newly appointed neurosurgeon and scheduled surgery for October 19, 2019. I had no time to process *what had* and *what was* about to happen. What followed was two years of post-surgical recovery during a global pandemic, my own personal awe in the power of medicine, resurgence of my seizures and tumors, and now – my road to recovery through chemotherapy and radiation. These two years have taught me so much about the day-to-day difficulties patients with chronic diseases live with, strategies I use to cope with my new normal, and most importantly, *the necessity of caregivers*.

### Keywords

Patient, IDH1 glioma, recovery, treatment

### Part I:

#### The Preamble: Seizures and Brain Surgery

In their 2016 essay, Garau, R. highlighted the prevalence of rare diseases, frequency of misdiagnosed patients with rare diseases, and how symptoms are frequently disregarded or overlooked by providers.<sup>1</sup> In *The Beacon*, Reid J. made a wonderful point regarding the importance of conducting research on Orphanet diseases, "*While a rare disease is rare, ... the prevalence of a disease is of no consolation to those afflicted [by it]*".<sup>2</sup> I often use this quote to inform my own work, as I research Arrhythmogenic Cardiomyopathy (ACM) – a rare disease frequently called Sudden Cardiac Death in Young Athletes.<sup>3</sup>

I regularly hear patients with ACM describe their numerous exams: blood work, echo- and electrocardiograms (ECGs), magnetic resonance imaging (MRIs), implantable cardiac defibrillator interrogations, quality of life (QOL) questionnaires, and even conversations regarding genetic testing for embryonic uterine implantation.<sup>4</sup> I have always sympathized with patients with ACM; however, this has turned into empathy since my own diagnosis.

The past 18 months I have had a plethora of blood work done, a few ECGs, QOL conversations, and  $\geq 15$  MRIs since my grand mal seizure, which occurred right after what should have been a joyous moment: transitioning from fellow to Assistant Professor at one of the most prestigious universities in the Nation. I had never had a predisposition to flashing camera lights, but I am grateful my seizure occurred at JHUSOM where I received immediate care. When I awoke in the ER, I had already bitten the tip of my tongue off, dislocated my right shoulder, and had a CT and MRI scan. None of which I remember.

Then I listened to the most terrifying words I had ever heard, "Dr. Chelko, we found a mass (7.3x4cm) in your right temporal lobe, and we need to act aggressively." A few more MRIs later, I underwent brain surgery October 19<sup>th</sup>, 2019, to remove an isocitrate dehydrogenase-1 (IDH1) mutant glioma. The diffuse astrocytoma surrounding my IDH1 glioma was inoperable due to how expansive it covered my right hemisphere. Let's compare apples-to-apples: a golf ball is 4x4cm; thus, my tumors nearly spanned the size of two golf balls. After successfully removing ~75% of my IDH1 glioma, I left the hospital less than a week later.

My intention writing this is to share some medically important topics and recommendations for others going through a similar journey. These recommendations are meant for all patients, not just those with brain cancer:

### **1. Self-Advocacy**

Patients often know when something is not “right.” I am a research doctor (PhD) that studies the cause(s) of arrhythmias. Therefore, I am not a medical doctor (MD) that can diagnosis, prescribe medicine, and/or treat patients. However, six months leading up to my grand mal seizure, I visited my primary care physician. I told my doctor, “I’m on the verge of passing out sometimes, there is seriously something wrong with me.”

One month prior to my seizure, I passed out at work (JHUSOM), yet was discharged with “vasovagal syncope,” despite symptoms I described to emergency room physicians that were clearly seizure phenotypes. My symptoms always presented in the same order: (a) strong copper taste in my mouth, (b) lightheadedness, where I needed to sit down and put my back against a wall, (c) and uncontrollable sweat, yet shivering cold. All these symptoms subsided within ~30mins. I deemed these instances, “my spells,” that occurred 2-3x/week, sometimes waking me in the middle of the night. My psychiatrist wanted to put me on Prozac assuming I had an anxiety disorder. I resisted.

To be fair, as a researcher and not a medical doctor, I truly had no clue of what was wrong with me. Six months after these spells started, I had my first grand mal seizure. When you know something is wrong, ask for additional exams, blood work, scans, or even referrals. I wish I had been stronger in advocating for myself, by pushing my doctors to investigate my “spells” further.

### **2. People First**

I discovered my disease was sometimes the only thing people could see about me. People living with disabilities are just that, *people*. Since my surgery, I became the faculty co-advisor for FSU COM’s Disability Advocacy Series. We explain to medical and physician assistant students the concept of “Patient First” care. It is quite simple, for example, “I am Stephen Chelko living with epilepsy and brain cancer.” I am not, “the epileptic and cancer patient.” People living with chronic (or acute) illnesses are normal people. A diagnosis should not strip anyone of their humanity and individuality.

### **3. Quality of life (QOL)**

Quality of life is an essential component of patient recovery. I often say to my spouse, “Let me try first.” One can make a frail person feel helpless by coddling that person. I want to resume normalcy. I recovered from my brain surgery, but I’m still accepting my *new* normal. Here are a few aspects of my new normal that I’ve had to come

to terms with:

- a. Accepting reality: I could not accept my diagnosis was real, even after my surgery. Oftentimes, I still don’t accept it.
- b. Resentment and anger: not at anyone or anything, but I find myself extremely angry and resentful. Of course, I’m not perfect and sometimes this anger creeps into the relationships I rely upon the most.
- c. A “No Locked Doors” Policy: this applies at work and even at home (sadly, even the bathroom) in case I have a seizure. In short, I’ve lost a sense of privacy and autonomy. When people offer to help me accomplish simple tasks, that I am perfectly capable of doing myself, it genuinely underscores my loss of normalcy and thus breeds resentment.
- d. Driving: I guess this could be added to the “loss of privacy” QOL aspect, but I feel it deserves its *own* category. I can’t drive in my home state unless I’m one year seizure-free. This has spilled over into numerous aspects of my life, such as grabbing a birthday card for a niece, picking up food at the market to cook for my spouse, and my everyday work commute. Unless these things are in walking or biking distance, I must rely on someone else to drive me.
- e. Medications: I’m on Keppra (1,500mg, 2x/day) and Vimpat (100mg, 2x/day) for the rest of my life. I have a lot of fear about missing a dose, so I either have to plan ahead and bring my medication or miss out on things I would have normally taken for granted pre-diagnosis.
- f. Tests (So. Many. Tests.): I have an MRI every 3 months to check on the progression of my brain cancer. I have a wonderful Neuro Team at Johns Hopkins Hospital, consisting of my neurologist, neurosurgeon, a plethora of amazing nurses, and most recently – my neuro-radiation oncologist. I love my team. *I need my team*. But to be honest, they serve as a constant reminder – that this isn’t going away. I feel like my life has been uprooted, especially considering my QOL just had some annoyingly difficult aspects added to it. When life gives you lemons, you must squeeze them real hard, while grinding your teeth, and say, “Not today, Lemonade!”

### **4. Caregivers**

Caregivers are ESSENTIAL, POWERFUL, and your STRONGEST advocate. Caregiving is not an easy task, so give them time to decompress and try to understand if they make a few mistakes. They are holding the world on their shoulders for you, and they may do things that frustrate you in the moment, like offering unnecessary and unwanted help. I find myself randomly reaching for my

spouse's hand every few hours just to say, "I love you," "thank you," "what can I do for you...?" etc. Surround yourself with empathetic and motivational caregivers but realize that no caregiver is perfect.

## Part II: The Treatment: Chemotherapy and Targeted Radiation

I beat this! Successful removal of ~75% of my glioma, all quarterly MRIs came back as "unremarkable" (which I later learned is a *phenomenal* word to hear), and I had been seizure-free for over a year (02/2020 – 05/2021). I had done it; I had beaten the unbeatable!

I was now adamant about regaining control of my life. The first aspect of this QOL change – getting my driver's license re-instated. This was a little more difficult than expected, but I finally obtained my driver's license on my third attempt (12/2021). Sadly, I used my license for about two months. I had a seizure at work in front of my employees, students, and colleagues on February 9, 2022, thereby forfeiting my driver's license and my independence. Oddly, my MRI scan came back as *unremarkable* in January 2022, so this seizure surely had to be a fluke. Or so I thought. Then I had another, and another, and another. I was averaging about two seizures/week. My Neuro Team reiterated to me that the frequency of seizures did not equal tumor regrowth. Yet, they wanted to move my upcoming MRI (May 2022) to as soon as possible (April 14, 2022).

My neurologist called to tell me the results of my MRI just two days later, I left work hysterical. Lots of crying, incoherent mumbling followed by inappropriate shouting, and throwing whatever objects I could grab nearby. Remember, I run a research laboratory, so some things I threw were quite expensive. The results of my scan:

"There is a new 0.8cm peripherally enhancing nodule in the right subinsular lesion...suggestive of infiltrative astrocytoma. Findings are concerning for neoplastic progression." In essence, my tumors were laying down the proverbial railroad tracks for an impending expansion of my IDH1 glioma and astrocytoma.

I couldn't listen. I told my neurologist, "I can't talk about this right now. I need my husband to additionally listen, I'm too emotional to comprehend any of this." I could not see through the tears pouring out of my eyes to even take notes of what my neurologist was saying. I did not understand what he meant by chemotherapy and especially Proton Therapy. Or even what a "T2 flair indicative of regrowth/invasion" meant. To be honest, I just wanted my spouse as a second ear, but mainly because I *needed* him. I truly needed him to tell me "Everything will be alright." Even if he didn't know or was flat out lying to

me. That evening, my spouse and I called my neurologist back, although the news was still heartbreaking. With my husband by my side, we were able to process the news and we came up with a plan.

Well, to say the next ensuing months were awful, would be an understatement. We flew up to Baltimore to get another MRI, an MR Spectrometer, a CT scan, and to get fitted for my radiation mask. I had to wear this claustrophobic mask for the next 6 weeks during my treatment, every Monday-Friday. My treatment:

1. Chemotherapy: Temozolomide (140 mg/day for 6 weeks), an antineoplastic chemotherapy that specifically targets brain cancers. There are lots of side-effects to chemotherapy, but I was told this would be a very mild form of chemotherapy. Regardless, my neurooncologist wanted me to keep a record of any nausea/vomiting and lack of eating. Sadly, I still have four more rounds of chemotherapy ahead of me (Temozolomide; 300 mg/day). Thankfully, these rounds are only 5 days long and are separated by 28 days between each round.
2. Targeted Radiation: I wonder if anyone has heard the word "radiation" and not been royally freaked. What is Targeted Radiation? *The Gantry* at Sibley Memorial Hospital in Washington, D.C. is a sophisticated proton therapy machine that delivers targeted beams of protons to the precise location where the tumor or cancer resides at, without effecting surrounding healthy tissue. The machine is huge, much bigger than an MRI. Thus, one could speculate these would be easy treatments considering the numerosity of MRIs I've undergone in the past two years. Well, it wasn't. That first day going into *The Gantry*, especially when they locked my radiation cap over my head – I cried hysterically, which is quite difficult given the cap is skin-tight.

I don't know why I cried: maybe because of the unknown, some ridiculous fear of spontaneously combusting, the proton beam would pass through my right hemisphere and kill healthy brain tissue in my left hemisphere, not remembering my name (or worse, my husbands'), the list goes on and on. With tears streaming down my face, a nurse stepped behind me, rubbed my shoulders and said, "Everyone is nervous their first day, but you'll see – it'll be done before you know it." And it was. It was done in roughly ~20 mins.

Radiation treatment is every Monday-Friday at 7:15 am. So far, I've felt extreme fatigue following treatments, I was nauseous once, some throbbing behind my right eye (where my tumors are located), some dull, but long-lasting headaches, and hair loss at the site of radiation treatment.

But I'm trying to figure out if I can utilize this for an upcoming Halloween costume. Consensus is still out.

### Part III: Final Remarks

As I approach my last week of treatment (July 11-15), I would like to end on some "does and don'ts" and self-reflections.

(a) First things first, people never know what to say, *but they have good intentions*. Don't let it get in the way of your recovery. I've heard people say things like, "I had a friend with cancer, sadly they didn't make it, but..." Please, please don't tell this to someone going through cancer. We just want you to say things like, "geez, this really sucks. I'm here for you."

(b) You have caregivers and loved ones who are sitting beside you. In addition to my spouse, I'm staying with my close friends in Washington, DC, which is convenient for treatment. But on top of this, my friends bought thirty pinwheels and have placed one out each morning I go to treatment. Their yard is filled with pinwheels, providing a constant reminder they are here to support me.

This last point deserves its own separate paragraph:

(c) Everything seems so trivial now. Grades and deadlines, they are indeed important, but don't sweat the small stuff. Especially if you're an overachiever like me, where an "A-" is like a death nail compared to an "A." That argument I had with my sibling seems so un-important now. Holding onto grudges, to make some worthless point or trying so hard to not lose an argument, seems so ridiculous now. Mend fences, even if it's the first, second or n<sup>th</sup> attempt. Anyone you love, tell them that. Often. It is worth it. Trust me.

As I approach the end of treatment, I hope my experiences and suggestions are helpful to those beginning treatment. Each step in this process has seemed insurmountable, but with the support of some outstanding healthcare providers and caregivers, I can finally see the light at the end of a long tunnel. One of my nurses gave me some great advice from Mother Teresa, "I know God will not give me anything I can't handle. I just wish he didn't trust me so much." There were times I didn't think I would make it through treatment, but I am stronger than I thought. I'm sure you too are stronger than you think.

### Acknowledgments

I'd first like to thank my spouse, my cheerleader, and the most amazing caretaker, Dr. Daniel Fay. For which I would not have the strength to get through these difficult times. I would be remiss to not thank the myriad of nurses and technicians at the Johns Hopkins Hospital and Sibley Memorial Hospital who have been instrumental in my day-to-day care. Lastly, I'd like to personally thank Drs. Kleinberg (Radiation Oncologist), Weingart (Neurosurgeon) and Lattera (Neurologist/Neuro-Oncologist) - my "Neuro Team." These gentlemen are outstanding physicians, experts of their craft, and have the best bedside manners I've ever experienced as a patient. They are truly, *gentle-men*. Physicians should emulate these doctors."

### References

1. Garau, R. The medical experience of a patient with a rare disease and her family. *Orphanet J Rare Dis* **11**, 19 (2016). <https://doi.org/10.1186/s13023-016-0401-7>.
2. Reid J. Rare disease research helps us understand medicine for all diseases. 2016. *The Beacon*. <https://blogs.biomedcentral.com/on-biology/2016/02/26/rare-disease-research-helps-understand-medicine-diseases/>. Accessed July 15, 2022.
3. Miles C, et al. Sudden Death and Left Ventricular Involvement in Arrhythmogenic Cardiomyopathy. *Circulation*. 2019 Apr 9;139(15):1786-1797. doi: 10.1161/CIRCULATIONAHA.118.037230. PMID: 30700137; PMCID: PMC6467560.
4. Chelko SP, James C, Tichnell C, Murray B. The Johns Hopkins ARVC International Symposium. *Eur Heart J*. 2019 Aug 1;40(29):2387-2389. doi: 10.1093/eurheartj/ehz511. PMID: 31539910.