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Two summers ago, Andrew Papenfus was enjoying an afternoon coaching a kids' summer basketball camp at Santa Clara University when he suddenly crashed to the floor as he shot a ball and went for the rebound.

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At 22, Papenfus was the picture of youthful strength and vitality: He played varsity basketball for Santa Clara and was in his junior year, studying marketing and entrepreneurship. But on that summer day, the lanky 6-foot 6-inch forward was flat on the hardwood having a major seizure.

Testing at a local hospital revealed he had a tumor in his brain. He was referred to <u>Dr. Mitchel Berger</u>, chair of neurological surgery at UCSF, who successfully removed the tumor in October 2014.

Today, Papenfus is a newly minted college graduate, happy, healthy and grateful to be looking forward to a bright future.

What was that first seizure like?

I remember feeling a tiny bit funny just before, like I was struggling to keep up with the drill we were doing. And then I went for a three-pointer but missed. When I went to get a rebound, I had this sudden feeling that my hamstring had torn because I was on the ground and felt almost paralyzed.

I felt my body tense up and convulsions taking over. It then hit me that I was having a major seizure. Things started to go black and I actually remember wondering if I was dying or even dead.

Everything was confusing, but I could sort of hear one of my coaches urging me to relax and breathe. I also remember hearing a snippet of the song "Riptide" by Vance Joy running through my head. After about two to three minutes, I came to, although I was still pretty out of it for a while.

How did the doctors make your diagnosis?

I was immediately taken to a nearby hospital and they did a CT scan. It was taking a long time for them to come back to me with results, and while I knew that this often happens in ERs, I still had a feeling something was up. Then they sent me for an MRI of my brain. I vividly recall lying in that MRI machine having the strongest feeling that they were going to find something bad. Sure enough, after the MRI, they called and said that they had something of concern to talk to me about.

While my parents weren't there yet, I feel grateful that I had many of the coaches who act like a second family to me gathered with me when I received the news. The neurosurgeon on call told me that I would need to have surgery to do a biopsy right away – the very next day, in fact. This would be able to tell us if it was cancerous or not.

What did you feel when they suggested you have a brain biopsy right away?

It turned out that one of the nurses at that hospital was someone with whom my dad – who is an ER doctor in Colorado – had worked years ago. So even though they weren't with me, they were able to talk to the team beforehand and felt comfortable going ahead.

As for the actual surgery, well, they are drilling into your skull! But the recovery was not that bad. They only take a small tissue sample. I was in the hospital for a day or two, mostly just nervously waiting for the results. When the results came in, they told me I had a grade 2 astrocytoma, which is in a bit of gray area in terms of whether it's cancerous or not. It definitely needed to come out, but thankfully it was a slow-growing tumor, so I had a bit of time. It was then that I was given the referral to see Dr. Berger.

What happened after the biopsy surgery?

I felt remarkably fine – despite the fact that I now knew there was a tumor in my brain and I was on an antiseizure medication. Two weeks later, I was cleared to play basketball again. They said I might have another seizure, but no one could say when or how severe. In fact, I did have another a few weeks later (again, while on the court), and I realized that I had to slow down a bit.

What happened at your first meeting with Dr. Berger and with the team at UCSF?

I just remember that I was immediately impressed by his confidence and caring. He really understood my perspective in terms of wanting to remain active and how important basketball was to me. I never felt like just another patient with him, and in fact everyone at UCSF was so positive and reassuring. Dr. Berger was also refreshingly straightforward with everything as he walked me through my options. Of course, I knew that the tumor definitely needed to come out, but the question was when. And that was largely left up to me.

Meet the care team



Mitchel Berger Neurosurgeon

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What made you decide to go ahead with the surgery when you did?

I had been a walk-on player at Santa Clara, and to go from that to becoming team captain and having just come off a great season, I didn't want to throw it all away. So the timeline was key. Dr. Berger explained that I could, if I wanted, wait until after the season – until the following spring – to have the surgery. And at first this was my plan. I love basketball so much and I had worked so hard. If everything went smoothly, I figured I could maybe still play half the season.

In the end, I sat with the decision for nearly three weeks. And I changed my mind – I wanted to do it as soon as possible. It just became clear to me that I didn't want to risk my long-term future and my long-term health. I want to be a dad someday.

And of course, there were the continuing seizures to consider. For one thing, if you haven't been seizure-free for 90 days you can't drive, so I wasn't able to even do that. So I was really just taking it day by day, not worrying about things that may or may not happen. There's that saying: "Worry is interest on a debt you may never pay." Still, there were definitely days where I would cry and think the worst.

What were the days/moments before surgery at UCSF like?

My surgery was initially scheduled for Sept. 23, but because I ended up getting a little sick and had a fever right before surgery, it was delayed until Oct. 6. But by the time that date rolled around, I sort of had already gotten a lot of my nerves out. So I just said goodbye, told them I loved them and was put under anesthesia.

Your surgery was unique in that you were awake during it, right? What was that like?

You start out totally under, but once they get into your brain and are about to start removing the tumor, they wake you up. That is so they can ask you to talk and move while they remove the tumor bit by bit, to ensure they aren't harming functional tissue. Because of where my tumor was, there was a chance that they'd have to cut into a part of my brain that controls my right leg.

I actually had a seizure during the surgery – which Dr. Berger had told me might happen – and to control it they poured a cold solution on my brain. What's crazy is that to me I felt like they were splashing cold water on my legs. All the systems get crossed up there! After four or five hours of surgery they finally finished up and sent me to recovery.

What was recovery and getting back to normal life like?

Dr. Berger said that he was able to get 100 percent of the tumor, which was great, but to do so, he did have to push into functional tissue a tiny bit. So right away I couldn't really control my right foot. This was definitely scary because of my athletics, but again, this was something I'd talked through honestly with Dr. Berger. Beside the fact that it wouldn't likely be permanent, this is something that had to be done to safeguard my long-term health.

Still, that first week or two was tough. I started physical therapy to strengthen my right foot right away. It took three agonizing days to get movement back in my foot, and I had to use a brace to hold it up because it was floppy. I immediately started rehab on my foot to regain strength. My mom came for a whole month to help me, and my college put her up in housing, so I stayed there with her.

How did you manage to stay emotionally strong through all of this?

I relied on my strong religious faith a lot during this journey – as well as my supportive family, friends and especially my girlfriend, Dani. She's really been my rock. Overall, this whole experience definitely has put some things in perspective, and given me an intense appreciation of how great it was to be able to come back and play with my teammates when I did. And I've been happy that I'm able to be an inspiration to others with a variety of health struggles – so that I can demonstrate that with a positive outlook you can really get through anything.

What is your prognosis and do you have any limitations now?

I feel great. There's no way to guarantee that something won't grow back. It's unlikely, but not impossible. And, despite the fact that I am tumor-free, seizures remain possible. I have had a few – which Dr. Berger explained to me is not uncommon and may be due to scar tissue near the affected area of my brain. But these seizures are nothing like that first one, which lasted several minutes. Some of these are 20 seconds and are mild. The most recent one was about 20 seconds of feeling like my right leg wasn't under my control. Otherwise, I'm totally healthy and can do anything I want.

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