

Ryan Didn't Let Chiari Get In The Way

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Returning to sports after Chiari surgery is a very controversial subject. That's one reason we thought we'd share it through an interview. As a teenager, Ryan was focused on getting back the life he loved, but now as an adult he is focused on giving back to the Chiari community. That's why Ryan's is a Good News Story.

*****NOTE:** Before engaging in strenuous sports, Chiari patients should discuss the matter thoroughly with their doctors. ***

When did you first start having symptoms and what were they?

The first noticeable symptom was severe headaches; they started occurring during the summer of 1994 when I was 16 years old and about to begin my junior year in high school. From the onset of the first headache they rapidly increased in frequency, severity and duration. I kept what I was going through to myself and hid it from practically everyone in my life. First it was easy to hide them, both my parents worked, so I could go a little late to school, take extra time at lunch by going back home or leaving a little early at the end of the day to go home and sit in the dark with no sound. By the end of October they became too debilitating and I knew it was time to face them.

Now that it is 13 years later and I understand what other types of symptoms can occur, I know there actually were others. A year earlier I remember these odd dizzy spells that happened occasionally. Also, I would randomly go through very short periods of time when my coordination would seem to completely disappear or my balance would be totally off. Those symptoms never increased in severity or frequency and I ignored them.

The last symptom occurred a day before I had the surgery when I seemed to lose the feeling and use of my right hand. By the time I woke up from the surgery my hand was fine.

As a teenager, were you very active at the time?

From the time I was little I played 3 sports, did karate and played the saxophone. I grew up in a neighborhood where nobody's parents let them in the house before dinner or it was dark, whichever came first. When I was 12 it just became Football, Basketball and Baseball all year long. Actually that is not true, my father was a teacher, so grades were priority number one, no questions asked.

I can honestly say the eight or nine days I spent in the hospital after the Chiari surgery was the first time I spent more than a week being inactive. You'd have to check with my parents, I think I was 5 or 6 the last time that happened.

Once you started having symptoms, did the diagnosis come quickly?

I was very fortunate in that regard. My mother is a nurse so I went straight to a neurologist. He (Dr. Thomas Conley) immediately ordered an X-Ray and MRI. It was a few days before the film was ready, but he immediately diagnosed the Chiari malformation from the MRI. I am pretty sure that was on November 6th, 1994. He told me I needed to go see some specialists as soon as possible. I saw several surgeons, but met with Dr. R. Michael Scott on Friday December 2, 1994, he decided not to wait and I had surgery on Monday December 5, 1994.

I imagine no one had ever heard of Chiari before, what was your impression of what it was and what you were facing?

Absolutely no one knew what it was, including many people in the medical community. As for what I was facing, my family and I only knew one thing for certain, that nothing was for certain. After I met with the first two surgeons for a consultation, I will definitely say I understood there was a very high likelihood that I was going to have major brain surgery, but what would or could happen in the meantime was a guess at best. Forget about the outcome, after a few more consultations with different surgeons I really was afraid. I definitely feared what the future held in store, but this particular fear outweighed that by leaps and bounds. I was 17, so grasping the seriousness of the situation didn't take much. What terrified me the most was having a clear understanding that several experts couldn't agree. These were the people who I was turning to, who would most likely operate on my brain and spine and I had no confidence in them, let alone that I would wake up. That fear lasted right up until I met Dr. Scott.

Were you afraid you wouldn't be able to finish high school or play sports?

I feared both situations and much more. The question of finishing high school eventually became not a question of "if" but "when." Depending on how much school I missed would determine if I had to repeat my junior year.

Competitive sports was a resounding "No" every time I asked, followed by another "No" when I asked about most recreational sports activities. My family and I laugh about this now, I even had one surgeon laugh at me and say "I'd pick up squash if I were you" when I asked him about sports. It was quite an interesting appointment from that point on.

The answer to the question of returning to competitive sports would end up playing the most important role in my recovery.

What was your surgery like and did you recover quickly?

The surgery, what I experienced at Boston Children's hospital and two specific images made me the person I am today and permanently set in stone my perspective on life. There is nothing figurative about that statement. The lessons I learned and what I saw firsthand in that hospital has driven my life from the moment I left a week later to this day.

I only remember the phrases "this hurts," "I'm in pain" and "why me?" repeating in my head over and over during the heavily sedated 2 days following the surgery. What I woke up to stopped me from ever feeling sorry for myself again over the past 13 years.

The little 12 year old boy I shared the room with was named Walter. He was mentally handicapped, had severely deformed hands and feet; as if that wasn't enough he was obviously at the hospital to have neurosurgery too. Walter's mother had Multiple Sclerosis and even though the room couldn't fit a cot in it, she slept for the entire week in a regular chair just so she was there to hold his hand when he woke up crying in pain during the night. That scene played out every night I was in the hospital.

Yet somehow every morning when I woke up, Walter was already up trying to play a video game. He could hardly press the buttons because of his hands were deformed, but every morning he tried. Walter also made an attempt every morning to say "Good Morning" or "Hello" the minute he knew I was awake. Sadly I also learned Walter likely wouldn't live very much past the age of 16. His mother never left his side even though she was in pain and defines white real sacrifice is. Walter made it perfectly clear that there were no limits in life and I would only have myself to blame if I found one.

The first time I was able to walk far enough to pass another room door I happened to look in and the image I saw is burned permanently into my brain. There was a mother and father holding each other with their heads leaning against one another crying while they looked at their infant lying attached to monitors and tubes in a hospital crib.

I tried to get discharged the next morning, that scene really bothered me, not because how sad and unfair it was to that infant and the parents. I was bothered by the fact that I was taking up a bed someone else needed much more than I did. There was I couch I could recover on just fine back home.

Unfortunately Dr. Scott was out of town that day and wouldn't discharge me until he returned a few days later.

The physical pain Chiari surgery caused was worse than I had imagined it would be. Psychologically the pain became even tougher to take than the physical pain. Walter, his mother, the baby and the parents permanently stopped the "why me?" Now I kept repeatedly asking myself "why them?" It didn't seem fair that the patient in that wing that had all the physical attributes to deal with pain was suffering the least.

After surgery, did you know right away you wanted to return to sports?

Yes, but that was all because of Walter, the little boy I shared a room with.

How did you get back into it?

I took myself out of the lineup with two Football games left in the season, and told my family, friends and coaches about the headaches. Basketball preseason and tryouts started a week later. The previous season as a Sophomore I was shooting guard on the Varsity team. They just hired a new Coach because ours was overseas for a year. Nothing physically had changed yet other than the headaches and everything was still up in the air. I was meeting with Dr. Scott that Friday, I didn't know that I would be getting operated on the following Monday.

Tryouts ended on Thursday night and I made the team. The new coach had no clue that I might be having brain surgery eventually. I had to meet Dr. Scott the following morning so I explained to him that I probably was going to have my left shoulder scoped but the doctor said I would be back full speed by mid season at the latest. That was pre-op, I knew I was lying to him and if I had brain surgery I was never going to be able play sports again. I felt bad about it, and I didn't know that my whole life view was about to change.

As far as I knew I was never even playing ping pong again. I really thought I was never going to play a sport for the rest of my life.

When did you get back into it?

That is the funny thing; I stopped by practice the first week in January. I was 4 weeks post-op and I was driving up to Boston for my first follow up appointment with Dr. Scott a week later. I told my friends and the coach I would was going to be cleared to play the following week.

No one was laughing, but no one believed me either, they were my friends so I am sure they thought I was just trying to be optimistic about life.

This time I wasn't lying, I was dead serious and it ended up that I never really lied to the coach to begin with. On January 31st, 1995, a little over 6 weeks post-op I checked in to my first game and a minute or two later I hit a jump shot. That turned out to be the only shot I took that season even though I continued to play.

Did you run into any resistance from family, doctors, or coaches? Did anyone tell you you were crazy?

Absolutely! I am sure even my parents would have felt better if Dr. Scott never cleared me, and they were in the room before the surgery when he said, "There is no book that says what a patient can and can't do after this surgery, so we will see how you're doing after the surgery."

I heard over and over people say, "It's just sports, be thankful you have your health." Football, Basketball and Baseball, at 17 years old that was my passion in life. If you are passionate about something, then it means your heart is running the show.

Eventually what I made people understand was that it had nothing to do with what the actual activity was. It was about taking back what I loved in life. It was about what Walter would never have the opportunity to do. What "might" happen wasn't a reason I could accept as a valid reason why I shouldn't take back my life. To me that would have been the same thing as if I just spit on him.

My family, friends, teachers and coaches quickly realized that this was how I was going to approach the rest of my life. It wasn't just some

macho attempt to see if I was tough enough to handle pain.

Besides, having the full confidence and endorsement of the Head Pediatric Neurosurgeon at one of the best hospitals in the country was good enough for me.

It sounds like you had a lot of support from your family, friends, and school. Do you think that helps with having a positive outcome?

Not only do I think it helps, I would say it might be the most critical part in having a positive outcome. I know how fortunate my outcome was. Some of my family and friends seem to think I tend to downplay how hard it really was on me. I can tell you one thing I am absolutely positive of, it was everyone's love and support that helped me keep it together psychologically prior to the surgery. Especially during the period of uncertainty right after the initial diagnosis when no one seemed to have any answers.

What are you doing now and do you have any symptoms or limitations?

Ironically I herniated a cervical disc as well as some other damage. I had two cervical vertebrae fused together with a titanium plate and crews a little over 3 months ago, back in October. Most likely I will be having at least one, possible two more fusions and plates put in later this year.

Until 2 weeks ago I was pretty sure I did it playing in a pickup Basketball game but I ran into a friend I hadn't seen in a long time and he reminded me I actually came to the game that night and had mentioned pulling a neck muscle changing a bulb in my kitchen ceiling. The sad thing is, I realized he was right.

The moral of the story is that you don't need to worry about Chiari Malformation. It is really those 60 watt light bulbs that are the real danger.

There were definitely some rough times with the headaches following the surgery, but after a few years I started feeling like I did before the symptoms started.

The plate and the others that will go above and below it make it hard to look left and up, so no more swinging a bat or golf club righty. That's why they make left handed clubs and I just picked up a used set last week. Now I will lose 20 golf balls per round.

The only limitation I really felt I never was able to overcome, is that athletically I was just never the same, especially when it came to quick reflex actions. To me, that is a small price to pay in life to get through Chiari malformation.

You've expressed an interest in getting involved as a Chiari advocate, what brought that about?

That actually is so weird that it is borderline scary. I had never actually looked Chiari Malformation up on the internet in my life. I was even more oblivious to the fact that foundations existed, let alone other patients. My surgery was in 1994, I didn't have an email address for another 2 years when I was a freshman in college. I was up in the middle of the last month a few hours short of exactly 13 years to the day since I had the surgery. I had just joined Facebook because recovering from this fusion surgery has been the most boring event of my life. For some unknown reason I decided to search the "Cause" application for Chiari, and I almost fell over when it actually came up.

I proceeded to make a donation, but as I read the posts I became upset and angry to see people looking for answers to the same questions I had over a decade ago. Not to mention the misdiagnoses.

Right up until I stumbled across the young college student's website I was planning on taking two years off from the business world so I could return to school full time for my Master's Degree in Finance.

Because I started working on raising awareness by returning to my old high school and getting the Basketball booster's programs help, I realized I want to make a difference in young people's lives. So now I have applied to Master's programs in Mathematical Education so I can become a teacher and also return to Coaching Football.

What do you have planned on the Chiari front in the coming year?

While I have been recovering from the neck fusion, I have been working on several plans to raise awareness, as well as money for the foundation. Hopefully over the next year I will be in a position to make it all happen.

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