



Patient Power

Advice From Cancer Survivor Sajjad Iqbal on Becoming an Empowered Patient

Sajjad Iqbal, MD
Patient Advocate

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Andrew Schorr:

Welcome to Patient Power. I'm Andrew Schorr in Carlsbad, California. We're going to skip over to Ridgewood, New Jersey. I want to introduce you to Sajjad Iqbal was a pediatrician in New Jersey for over 35 years and then diagnosed with head and neck cancer, has had quite a journey. Sajjad, thank you for being with us on Patient Power.

Sajjad Iqbal:

Thank you very much Andrew. Thank you everyone. It's a pleasure to be here and thank you for giving me the opportunity.

Andrew Schorr:

So our goal is to detail a little bit of Sajjad's story. Quite a journey with very rare cancer, which he'll explain, and really the story of being a powerful patient, particularly with a rare head and neck cancer, to get really successive treatments that he needs, often never done before, so that here, even after being diagnosed in 2002, we're doing this in 2018.

He's here when the even two-year survival was bleak when he was diagnosed, and also being optimistic. Sajjad, I mean the headline, as we get into it is you learned, not only diagnosing it yourself as a physician, but not an oncologist, but you had to really push to get what you needed and then also to stay positive along the way. Am I correct?

Sajjad Iqbal:

Indeed. Indeed.

Andrew Schorr:

All right. So in 2002 when this started, what were your symptoms and what were doctors saying it was?

Sajjad Iqbal:

Well it started one early morning that I had woken up with a pain on the left side of my face, this whole area. The kind of pain that I had never experienced and so it lasted for several hours. Finally it went away but remained a mystery what the pain was. I knew it wasn't the ear pain.

So over the next two or three days, I found that actually I had developed paralysis of the upper half of my face, here, this area, but not the rest of the face and the paralysis was rather mild. So I went to the doctor and my neurologist and they immediately labeled it Bell's palsy, which is, as you know, a mild self-limiting illness.

Andrew Schorr:

Right and I just want to skip ahead. You went from doctor to doctor. They were all saying Bell's palsy, Bell's palsy. But you diagnosed it as something else. What became the diagnosis?

Sajjad Iqbal:

There's a little bit of an interesting story behind that that I was frustrated for several months and I happened to run into an old classmate of mine from medical school, and he pushed me to diagnose it myself and not look to the others. So on his urging, I thought about that and turned out it parotid cancer in my left parotid.

Andrew Schorr:

Very rare. Very, very rare.

Sajjad Iqbal:

The parotid cancer themselves are rather uncommon, but the kind it turns out in my case is one in two million.

Andrew Schorr:

Wow. All right. So this, you were on a quite a journey and you ended up having, let me see if I have it right. You had surgery and cosmetic surgery to kind of rebuild your face at that time, back in 2002 and you went for a while, but then it came back and eventually it came back also in your lungs and even much later in your back.

Sajjad Iqbal:

Yes. In my bones.

Andrew Schorr:

In your bones, and so this led to unique combinations of radiation and then chemotherapy that often had not been done for anybody before, right?

Sajjad Iqbal:

True.

Andrew Schorr:

What was the role you played as a powerful patient so that you got even highly experimental treatment that now we can see on the back end, worked?

Sajjad Iqbal:

Yes. There are three phases of that. After my initial surgery and all that, the routine at that time was just give radiation afterwards. I wished for radiation as well as chemo. Nobody had done that before and that is becoming the standard, what I did and pushed for in 2002. Also in 2007, I was the one who pushed for getting trastuzumab (Herceptin) treatment for my cancer, and that is now becoming a lot more, not routine, but a lot more in treatment for my kind of cancer.

Andrew Schorr:

Right. Now let's stop for a second. When you talk about Herceptin, or I know and then you even had some prostate cancer drugs that came in play, it related to the biology of your cancer type and that's where cancer care has gone is, not just where is it, but also what is the biology of it and it may be that there are drugs like Herceptin for breast cancer or pertuzumab (Perjeta) for breast cancer for her two new positive tumors applied to your very rare parotid cancer that had spread.

Sajjad Iqbal:

Yes, and see that's the, that's one of the things, we as patients need to push for is the arcane thinking by the FDA, as well as insurance companies, who will continue to deny such care to the parotid plan patients for example, that just because they don't have breast cancer, they shouldn't get Herceptin.

Andrew Schorr:

Right. It's about the biology. So here you are with a type of head and neck cancer and they're a variety that some can be quite rare. You as a patient have to keep pushing and get smart minds to, you had to convince them basically and then you're talking about whether insurance would cover it. So you had battles with insurance, you had battles with doctors even though you're a physician. There are hundreds of thousands of physicians; you had to really become the master of your own fate, if you will.

Sajjad Iqbal:

That is very true.

Andrew Schorr:

Now we should mention for our audience that Sajjad's been through a lot, right? I mean including the removal of 20 percent of his lungs through video-assisted thoracic surgery that he had to push for and find the right person to do it. But he had strong lungs, his body has survived these surgeries, etcetera. And so what would you say to the head and neck community, people worldwide where otherwise it can be debilitating, disfiguring or even hopeless when they say I'm sorry, the statistics are this and there's nothing we can do? What's sort of the operating system you would say Sajjad to the audience who's watching today?

Sajjad Iqbal:

I have coined a multi-faceted message. One is never give up hope and I had a problem with quoting statistics, five-year survival is this much or two-year survival is this much, and that's, the reason is because how do we read the survivor statistics is based on the work that was done ten years ago. You wouldn't know five-year or 10-year survivor until five or 10 years have passed. So this work is based on an old data. Medicine had advanced so much. There are newer treatments so the patient, look at me. I was not supposed to survive two years.

Now I have survived 16. Similar patients in my situation are now surviving four, five, six years. I know about somebody who has survived six years. Nobody has survived, you know, this much, so we should not get hung up on the prognosis figures because they are outdated. Second that we should always feel optimistic.

When we give up, emotionally give up, our body starts fighting, so in order for our body to fight the cancer, we must be optimistic and never give up hope and the third thing is be your own advocate. I have total faith in my doctors, yet I will always take charge of my condition. If any doctor is not, is too busy to give me enough time and answer my questions and satisfy me, then he's not the right one for me.

I don't care how many diplomas are on the wall. If a doctor is not giving me enough attention, that's not any, if I ask a question and they give me an answer which does not make sense to me, I won't accept it.

Andrew Schorr:

Well, you are in a unique position in that for 35 years you had patients coming to you, right, and often we patients, certainly we're terrified with our cancer. We don't want to upset the doctor. We want the doctor on our side even though something might make sense or isn't a complete answer or could there be other options, maybe there are limits to their knowledge, but so you as a physician, counsel us a little bit on still having respect for ourselves and not being afraid of, if you will, disrespecting the doctor when we don't feel the information is complete.

Sajjad Iqbal:

And it's not disrespecting the doctor. A good doctor never feels disrespected, because you ask questions or you challenge what they are recommending, because a good doctor is secure in his or her professional knowledge. So he is going to welcome you to get a second opinion, whereas somebody who is not that secure is going to feel disrespected, and you don't need that doctor. This going to the doctor for your cancer treatment is not like going to your doctor to have your throat infection treatment or diabetes or hypertension. This is your life. Your life depends on these few months that are coming. You don't do the right thing and you're going to die and you do the right thing and you have a fighting chance. So we cannot put a blind trust in the doctors, any doctor, but that doesn't mean that we are disrespecting them.

We need to ask questions. We, first of all, we need to make sure that we are comfortable with the doctor. If a doctor comes across as hurried or arrogant, break the chain now. So this is a unique opportunity early on when the cancer is diagnosed for you to get a second or third opinion if necessary and find out which doctor clicks with you, which doctor makes the most sense to you. Once you find doctor, stick with him or her.

Andrew Schorr:

Wow. So you know, your message is so strong and I think also having medical training yourself and years of experience and giving us that perspective as well is invaluable. You know, you're a gentleman who's dealt with head and neck cancer and where its spread around your body and you've had multiple treatments, and the prognosis early on was terrible, and here you are living many years.

I hope that people with all cancers, patients and family members will hear you loud and clear and I couldn't agree with you more and it's inspiring Sajjad to hear your story and your passion. So what's your outlook for the future? You know, you had these recurrences. You had a variety of surgeries and chemo and this and that. How do you view your immediate future? What's your hope going forward?

Sajjad Iqbal:

You know, I, as I said earlier, I consider myself an incurable optimist. I never give up hope. When they told me that I had a 30 percent chance of surviving two years, I said well, I'm a baseball fan. A .300 hitter is an incredible hitter. You can't get him out, so I said I'll be a .300 hitter and when they said nobody has survived for five years, I said well somebody has to so I'll be that one and when somebody questioned that logic, I said hey, listen.

Nobody climbed Mount Everest until Sir Edmund Hilary did and now a lot of people do. So I will be Edmund Hilary. So I think that it's very important. Now I am optimistic about my future. I don't know when the cancer will break through the current regimen. I know it will eventually, but I keep a very close watch on what's going on in the field of cancer treatment, and you don't have to be a doctor to do that. It's all over the Internet and news and hopefully it won't happen too soon.

I'm waiting, when it does happen, I'm going to go for the immune therapies. These off generation immunotherapy, the so-called checkpoint blockade, they probably are not going to be given to me because of the test that I had done. The PT1 blockage is not that active in my case. However, the CAR T-cell therapies are past maturing, and someday I may need that. So I am very upbeat about my future.

Andrew Schorr:

Wow. Well, I love this guy, folks. I just love him. I will say I think, you know, you're right and I think one way we can look at it is, if you have recurrences is, can the best available therapy be a bridge to what's next with medical science moving forward and that's why it's so important for our audience, patients and family members to say informed.

We're committed to that and now my new best friend, Dr. Iqbal, is here with us to inform you and I hope we can do another interview with you Sajjad sometime and hear that you're doing well and maybe comment on where things are headed, for all cancers really, but certainly your more rare cancers and the head and neck cancers, that supply so much. Thank you for being with us today. You're so inspiring.

Sajjad Iqbal:

You're most welcome.

Andrew Schorr:

Dr. Sajjad Iqbal, *Swimming Upstream*. Look for that book, and we'll see you again and check back with you. Thank you so much for being with us.

Sajjad Iqbal:

Thank you very much.

Andrew Schorr:

So I'm Andrew Schorr signing off, reminding you that knowledge—and strong advocacy like Dr. Iqbal's—can be the best medicine of all. Thanks for being with us.

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