

# Community Stories

## with Sam Sullivan

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### A Conversation About Everything

*We spoke with Sam Sullivan, former mayor, city councillor, and MLA, non-profit creator, spinal cord injury survivor, salon host, proud Vancouverite, and possible advocate, about... everything.*

#### INJURY

I was skiing when I broke my neck. I had just turned 19, living in Vancouver. I went on a run that was steep and ended up going quite fast and then crashing. Somewhere in the whole thing I felt my neck break. I experienced it as feeling my body was expanding, the size of the universe. I experienced it as a sound like multiple sirens going off, very loud noises going very broadly.



Then, I experienced my body going into a fetal position but when I opened my eyes my arms were up here. I said to myself, “You broke your neck – don’t move.” Eventually, people went down and got a piece of plywood to carry me off the mountain. They took me down, sort of bouncing, which is probably where more damage came.

#### REHAB

Initially, I was quite strong in that I was interested in experiences. “Wow, I’ve never broken my neck before. This is interesting. I’m going to live this one and really, really embrace it, and see how it goes.” But then, over time, eventually you get worn down and you say, “Okay, I’ve had this experience, I think I’m ready for the next thing. Why don’t we just get over this one here and move on?” And that’s when it all sinks in. This is not a light thing.

There are some panicky moments where you really need someone to be there, though sometimes you need to be able to reflect as well. I would say visitors should ask the person they’re visiting, “What can I do? What do you need from me? How can I help?” You should be saying to me, “We’re going to get through this one, we’re going to figure out how to get you better.” I think there is no real advantage in saying too early to someone who hasn’t accepted it, “Hey, you know, maybe you should just get used to this and whatever”. There are medical people and other people who should say those messages. That’s one of the takeaways from my experience.

#### METAMORPHOSIS

It was lucky that I was able to stay at [GF Strong](#) [Rehab Centre] for quite a while; I think it was over a year from injury to being discharged. It was only in those last couple of months that I actually learned how to get in and out of bed. It took quite a long time because of my injury. After leaving rehab I was with my parents in my

family home, but realized I was going downward, becoming suicidal. I needed to get out of the house. Eventually, I went into the only place I could: a paraplegic lodge – a type of social housing. I had to keep my blinds closed because I couldn't open them myself, and I couldn't sleep with open blinds with so much light outside. That did not contribute to my emotional well-being to be in the dark room all the time. There I dealt with suicidal thoughts and contemplations.

Eventually I went through a very real scenario where I rehearsed a dry run in my mind.

A gun blast, blood, brains, dripping down the wall, the smell of the gun. That was a very powerful moment. Then eventually, after a while I felt very calm, deep in thought. My thinking process went, "Okay, this is good, I think I can handle that. But it certainly would be great if I could somehow donate my body to someone who probably was in worse shape than me; who would it be?" Some people would be thrilled to get what I had. I dwelled on that for a while, then I thought, "What about me?" What if I was to take this mortal body on and see what I could do with it? Eventually, I thought yeah, that could be interesting.

The key in what happened there – and only in retrospect can I understand it – is I killed the old Sam. And I always refer to him in the third person. At that point, I killed the hopes, dreams, aspirations, and all the baggage of the previous me. Then I was able to say, "Okay, let's start from scratch."

## REBUILDING

After this I was faced with the question, "What do I do with my life?" I ended up purchasing motivational literature, a book called *How to Get Control of Your Time and Your Life* and things like that. I'd go through all the exercises and try to figure things out and that was very helpful.

One day I did all my morning things, got up, and went down to the bank to cash my welfare check. I got there and the bank manager was just closing the door because this was in the days when banks closed at three o'clock in the afternoon. I

realized, "Oh my god", I only got out at the same time everybody else is going home. Now I have to go home and start getting undressed to get ready for bed.

So, I did things like to-do lists and time analysis. The very first thing I did was analyze getting up in the morning – I would lift up my leg, put it on, put my sock on the other leg, put my sock on, put it down, then the other leg again, and then put my shoe on. Well, what if I put my sock and my shoe on at the same time and I didn't have my legs going up and down? Then I would celebrate how much time I'd just saved, you know, 4 minutes times 80 years. Wow, that means I've just now come up with 12 weeks!

*“ The key in what happened there – and only in retrospect can I understand it – I killed the old Sam. ”*

It seems to me that I never had a point in my life where I was not solving a problem or looking at my next to-do list. I have a tendency towards depression but find if I'm constantly solving problems, it prevents the dark part from arising. In fact, I would

use my disappointment at not ticking a box on my to-do list to cultivate anger or frustration or negative emotions and channel them to a desire for forward motion.

This all happened over a period of time I call the Seven Lean Years. And now I had my model: ticking boxes on to-do lists, time analysis, channeling emotions, moving ahead, kill the old Sam. Those are the fundamental pieces that had to be done and informed what happened in my life moving forward.

## NONPROFIT

The key was figuring out what I want to do. "Okay, I really don't know what I want to do with my life, what did I used to do when no one paid me and when no one forced me into doing something?" I was going skiing. I was playing in a band. I wanted to start a little business and these sorts of things. Once you have a good idea of the directions you want to go, then your mind will organize things as they come to you. And you will pick out and grab the right things that will help move you forward.

The most important thing was me discovering this model of setting up nonprofit societies. This

was an accidental discovery; I volunteered and got involved in some fundraiser and I asked, “how do you get one of these funding systems going?” Well, you have to have a nonprofit society, and then you apply. That was quite a revelation. So, the [Tetra Society](#) was probably the most important innovation. The purpose of it was to recruit people like engineers to work with clients and build custom-made assistive devices to help them. I was the executive director, I had a board, it was a lot of administrative work, but I was able to raise money. We called ourselves “Tetra”, we all had “tetraplegia”, and there were actually four of us. Everybody was on welfare. We looked into an engineer’s hourly rate, it was around 400 bucks an hour, and all of us made 396 per month on welfare, I remember that. Whoa, that’s not a very sustainable model if for one hour of an engineer’s time, it cost us an entire month! So, I wrote a letter to an engineer’s magazine – maybe there was a retired person or company that is willing to help? A guy (Paul Cermak) answers that he just took early retirement, and says, “My wife wants me out of the house, can you give me something to do?” The very first thing he did was fix my fridge: My grandmother had given me a fridge, and the freezer was on the top, and I had to pull it down. When I tried to put something in, it would flop back up with the spring. I just couldn’t figure out a way getting my elbow on there to hold it down. So he came over, looked at me struggling with this, got a clothes hanger from the closet, bent it and hooked it around the drawer handle. Then I pulled it down and the hook came around a little tray. And it was open, just like that, within minutes he revolutionized my diet.

I wanted to go skiing again but because I was so uncomfortable when I get cold, I thought what else can I do? I heard a guy talking about ultralight airplane flying and I thought that’d give me the challenge I needed. I found a plane and the [Disabled Ultra Lighters of Vancouver Society](#) was born. We did that for a while and were successful; we got people flying. Then the company went bankrupt. There was a fundamental flaw in the whole program: you have to get people out to these remote places.

***“ What did I used to do when no one paid me and no one forced me into doing something? ”***

So then, we went into sailing through [Rick Hansen](#); he had this sailboat gifted from Margaret Thatcher. We found the old sailboat in a farmer’s field somewhere. And Rick said, if you can use it,



I need somebody to actually do something with it. So, we fixed it up. That became the [Disabled Sailing Association of British Columbia](#).

But we still wanted to do hiking. So we had the [BC Mobility Opportunity Society](#) – BCMOS (I wasn’t very good at naming that one) to be more about getting out there. We originally used a big golf cart. I remember we were not welcomed by environmentalists when we would come crashing through the bush with this big vehicle-tank, so we came up with another solution with a one wheeled vehicle, which I had drawn out on a napkin. I gave the drawing to Paul Cermak (the first Tetra volunteer) and then he designed and put one together using an old lounge chair, a wheelbarrow wheel, you know, just stuff he found. And that enabled me to go out to the forest and people would be able to take me around. So that’s how those things, the societies happened.

You know, I wish everybody could have their own society so they would be able to then have control and agency. Because I was doing all the work, recruiting the engineers, fundraising and all, I had really great access to all this stuff. So even when I was on welfare, I was sailing, going hiking, doing all these things. I do regret that for



most people I was never able to do with TETRA what I wanted to do, which was that everybody gets access, just like I had, right away. We always ended up with a long form filling process.

## NO ADVOCATE?

I've never thought of myself as an advocate. What I wanted to do was fix my own life. I would say, "I want to go sailing, I want to go flying. How do I do that?" I realized I was good at fundraising. I've never thought of myself as such, but people would say, "Well, you sure know how to fundraise!" And so in a way, I guess I was raising money for other people too. I wasn't saying, "Hey, I want to go sailing", and I don't say "Hey, I want to create a program where all sorts of people go sailing." In fact, regarding sailing, the first thing I did is go to the Royal Vancouver Yacht Club, and I said, "You know,



we have people from your club who have injured themselves or their son has injured themselves. We want you guys to be able to continue even if you have a bad accident. Look at it as we're what

you do for any of your members or their family who end up in a situation where they can't go on the regular yachts. Look at it as an insurance payment because you might end up like this and you would like to have access to sailboats". You have to be a bit clever with how you frame it.

So, about advocacy, that's not where I was coming from. I was coming from a personal level. I always wanted to stay in a position where we're doing this for ourselves; we had little boards, and all our boards were disabled people. All of them were on welfare. That was strategic in many ways. When we had able-bodied people with money on the board, they would get freaked out when you're taking a quadriplegic on his own out in the ocean. "What? I've got assets, I have a home! I'm not going to get sued, we can't be doing that, you need to get more processes, etc." They're really getting in the way of our fun or what we are trying to accomplish. And so we realized, okay, if all of our board members were quadriplegics on welfare, who's going to sue us? Go ahead, they're going to take my wheelchair?

Well, maybe I should say that I did advocacy because I was always pushing for wheelchairs in transit. I came in as mayor, as the city councillor, with a stick. I didn't come with my hand out. I said, "I've worked myself into this position where you need my vote, and I am now with agency. I'm not asking for anything from you, I'm telling you that this is the way we need to go. We need 100% transit accessibility and we need more taxis."

## THE MAYOR

I've always had two areas that were really important for me. One is drug addiction and overdose. The other is housing. They are the two areas that I failed the most spectacularly at, as you can tell with where the city is today. In my own defense, I analyzed those to be the two problems that seemed like there was no way out of. I chose them, and I said, "These issues are

the most important, and we need to start moving on them.” So at least I can say I was accurate in analyzing them as impossible to solve.



Regarding housing affordability, my experience of it was that everybody was anti-density. For disabled people, to have compact, vibrant, diverse neighborhoods – it’s much easier to make those accessible. People don’t have to drive everywhere, and transit is much more possible. Everybody who lived in their little single-family home hated density. All the people who were looking out for the future of the city loved density, but there were very few of them. I said, “Wow, this is so important, and it’s the right thing to do.” I’ve always been attracted to the right thing to do that everybody thinks is wrong.

My assumption was that all the bureaucracy comes from the top, risk-averse leadership that didn’t want to lose the election. I said, I’m going to be different, I’m going to say, “Go for it.” I would ask for forgiveness, not permission, in addressing the housing issue. But I found out when I came in and pushed for density, the city council said

“Density is good! We want it”. I was stunned to discover on numerous occasions that the bureaucracy is internally generated. People given the option of getting right into the job or creating bureaucracy around the job will naturally default to bureaucracy. To see all the internal machinery, all the bureaucracy that ended up going around it, that tries to not do density, “Oh my God, this is gonna be a nightmare!” So that was a real shock for me. Because I thought all I had to do was say, “We are the political leader, we got elected.

***“ I came in as mayor, as the city councillor, with a stick. I didn’t come with my hand out. ”***

We want density, call it EcoDensity, eco for ecological and eco-nomic. We want to address house prices and environmental issues.” And yet that didn’t do it. That was a powerful lesson that I wish I knew before then.

Regarding the drug addiction issue, when I first got elected I used to go out with this group, ‘Shame the John’ in East Vancouver. I would go out with them and they’d walk around the street and try to shame the johns, which is shaming prostitutes in a way. I was totally new to this and didn’t really know anything about it. And I said, “Wow, these women are prostituting themselves, what’s going on? Well, they are forced to because they’re drug addicted. Why don’t they just not do drugs anymore?”

Taking a step back, I remember when I was in GF Strong, of this moral issue around disability. I see the history of disability where originally it was seen as a moral issue caused by your sins or the sins of your fathers or bad karma, and it was somehow your fault. Then we moved into the medical model, “you need to be fixed, we need a doctor to look after you. And you need to be on a ward in a hospital.” And then, one day somebody said, “Excuse me, I’m not sick, I’m disabled, it is a totally different thing, you know”. This is not a short-term problem you fix it’s a long-term problem you manage. And that insight moved us along to a community model of disability. Agency, you know, you just need to give people the support they need and get out of the way.

When I heard about the prostitutes, people said, “I guess they just didn’t want it enough [to get out].” Where have I heard this? I remember in GF Strong, somebody said, “Well, the guy in the next bed, he got

better because he really wanted to get better.” And what about Sam? “Well, I guess he just didn’t want to, he didn’t have that same sort of willpower.” Oh, wow. So, this disability is still a moral issue. It’s about willpower and desire?

If we think of drug addiction like the disability problem, then we still have one foot in the moral model and another in the medical model. We need to move past that and see it as people who need the supports. Then they can get on with

their lives. You know, in the 90s, Switzerland solved their overdose problem and their street disorder problem with their [four pillars approach](#). And here, we are still today, stupidly doing stupid things, and not emulating other countries that have solved the problem.

### Proudest Achievement

The most exhilarating thing for me was being able to get out of bed by myself at GF Strong. What a miracle to be able to do that. Those are the moments. I'm supposed to say flying the flag, or the Olympics. But while those are interesting, wonderful things, there wasn't a sense that I did anything useful. I happened to be there when a flag needed to be flown. I tried not to fly the flag, I said, "Give it to Gordon Campbell, give it to the mayor of Whistler. I'm busy, I don't want to go to the Olympics and twirl a flag." It certainly was interesting and fun to do, but I wouldn't call it an achievement.



### Advice for those living with a disability

It's hard to just say, "Set goals." You also have to know why. You have to get to that point to where you find out why you want to do what you want to do. But I know for sure that setting goals was a revolutionary thing for me. Also, just recognizing that life is very precious. Recognize what a miracle it is and how we are the luckiest people ever in history, even myself as a quadriplegic. I would rather be me as a quadriplegic than someone living more than a few 100 years ago. People today don't grasp how difficult life was then in every aspect. To have what we have today is just so miraculous, and so beautiful.

### THE PUBLIC SALON

When I retired from City Hall – or as my mother helpfully reminds me, was thrown out of City Hall – I found myself asking again, "What am I going to do with my life?" I went back to my standard question, "What is it that I do when no one pays me?" And so, I developed this thing called a Private Salon. We would put these little private dinners together, and invite a real scattering of different people that were very different from each other. We'd come together for dinner and just share; it was very interesting for me. I loved to do it and Lynn, my wife, loved doing it. We asked ourselves, "is there a way to turn this into a job somehow as I had done originally with my injury?" So we said, let's have a [Public Salon](#). It was hard when you scale up from a little dinner to a theater, but it was still fun.

We were able to put on the Public Salons for about four or five years, having received a million dollars from a foundation in California. We tried to raise additional money to bolster that, but eventually we ran out. We had to try to make it profitable on its own, but it wasn't designed for fundraising, it was designed for giving me pleasure. Fundraising would be a real challenge. So, we had to totally revolutionize it a couple years ago. What I do now is bring in an international speaker, that's the star, and then have local responders who give them questions, comments, critiques, etc. So that's the new model and it seems to be working. I brought in a former chief planner of the World Bank, Alain Bertaud,



and a recent Think-Tank Salon included experts on addiction and mental health. In a way, I'm still on those two issues of prices and addiction, now attacking them from outside, not from the inside as mayor.

## MAKING A DIFFERENCE

I can't say it comes from any enlightenment really, that I decided I'm going to help the world and I want to solve everybody's problems. But when it turned out that way, I certainly wasn't disappointed about it. I was happy that I could make a difference for some people. I wouldn't

recommend to people that they should decide to save the world or whatever. I think you should put your own mask on first before you put it on others. Remember, all of that was me being self-absorbed. I wanted to go sailing. I would have rather just been given a whole bunch of money, and then I could buy a sailboat.

But, we had to do it the hard way because I was on welfare, and the genius of our civic society is you can't do it unless you do it for others too, so

I needed lots of involvement. Then I realized this is fantastic. At one point in the beginning, I was going sailing, buying sailboats, going in regattas, etc. And then at a later point, I was the only one not going sailing, I was filling out forms and fighting bureaucratic battles. I then recognized that it was so important. When people asked me, "Why are you doing this, all this bureaucratic work and lobbying? The only answer I can give is "I'm doing it for Sam. The 19 year old kid, suicidal and sitting in a dark room where the blinds don't open." I wanted to reach people who were like me.



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