

One downhill bike ride and Dr. Robert Kyler knew he would never walk again

When Jim Vance ran to help his friend in the ditch, Kyler was already trying to diagnose himself.

By Monique Calello, Staunton News Leader

STAUNTON – It was over in a second before Jim Vance could process it. They were riding downhill fast on their bikes. It was their typical "go-to quick two-hour ride," said Vance.

On a paved road in sparsely populated farmland on an early July morning, his friend Rob Kyler was out front descending on a long, steep hill. Next door neighbors during the summer in upstate New York, the two rode bikes together all over the world.

Kyler liked to go down hills quickly, and when Vance looked up he saw his friend's bike veer to the right into the gravel on the side of the road and flip over into a ditch.

Vance came to a sudden stop and ran to the ditch to find Kyler lying on his back on top of his bike. Conscious and moaning, he asked Vance to move his leg for him. Vance straightened Kyler's arm out, took his helmet off and gave him water, but wouldn't move his leg. He was worried he might cause further damage.

"He was already trying to diagnose himself."

Dr. Kyler led a healthy lifestyle

Radiation oncology medical director in private practice at Augusta Health's Cancer Center, at 58 years old Dr. Robert Kyler led a healthy lifestyle.

Physically active his entire life, he was in good shape and enjoyed exercising, being outside and working up a sweat. Athletic, his vacations were tailor-made for cyclists. And he reaped the benefits in total health. His face had a rosy glow, he was muscular and full of energy.

He was the physician; not the patient.

The dichotomy of shifting from one identity to another didn't surface until later. At the moment, lying by the side of the road in excruciating pain, he knew when he couldn't feel his legs that he'd suffered a spinal cord injury.

"I never bike by myself because it's just not safe," said Kyler as he looked back on that July morning from his living room at home. There is subtle irony in his voice as he talks about how he followed safety rules for cyclists — the guy who always had the high-intensity LED blinking lights.

Sitting in his wheelchair, his primary chair, he calls out to Fritz, his dog. His rosy glow gone, he is pale and slightly dehydrated. Wearing a bright green t-shirt from rehab and sweatpants, his muscles below the waist have atrophied.

He is still building strength in his upper body while working through constant neuropathic pain and pain from the damage developing in his shoulders.

With a body type that is tall, long and lean, it is essential he build muscle in his chest and shoulders. He keeps an electrical stimulation (e-stim) bike in another room to keep the muscles in his legs from further atrophy, which helps to reduce swelling.

Now his life isn't about working up a sweat and using up all that good energy from exercise. Now his life revolves around utilizing the best methods to conserve energy.

Making sense of the accident

Trying to make sense of the accident is impossible. The irony spills out everywhere. While he may have been a risk taker on the bike from time to time, he wasn't doing anything risky on what was supposed to be an uneventful ride; a ritual before he and Vance headed to a late morning workshop they liked to attend during summer.

Vance said Kyler was riding maybe 35 mph, tops. That's fast, but not crazy fast according to other cyclists. In bike speak, they were cruising.

It was an accident for no reason, plain and simple. He grapples with this brutal truth as he attempts to accept he will never find the reason why it happened.

"As I was going down the hill, I just lost control of the bike and don't know how because I've been down that hill multiple times."

Kyler said he hit something on the road and was thrown from his bike. He landed in the ditch, his feet pointing uphill.

"As soon as I landed, I realized that I had done something pretty bad. I couldn't feel my legs, couldn't feel my waist. Really from the mid-chest down."

Vance called 911 and sat there with him until the ambulance arrived, which took him to a landing zone a few miles down the road. A helicopter was waiting to airlift Kyler to a hospital with a trauma center in Erie, Pennsylvania.



Learning new normal: Paralyzed, rehab and painkillers

Even before he saw the scans from the ER doctor, Kyler knew he was paralyzed.

"It's weird. There's this dichotomy. As a physician, you're taught to be very objective and look at the facts and analyze things. That's what I was doing initially because that becomes second nature to you. There was that intellectual part of me that said, you've severed your cord, you are never going to walk again."

After seven hours of surgery to stabilize his spine, followed by surgery on his neck, he remained in ICU for a week before he went to the Shepherd Center in Atlanta, a facility specializing in spinal cord injuries. Kyler spent seven weeks there as an inpatient, followed by six weeks of outpatient rehab.

Much of that time was spent in a drug-induced haze from painkillers, which also helped to shield him from the full emotional impact of what had happened.

It was at the Shepherd Center he realized his life would never be the same.

"You can't even roll around in bed. When you don't have any trunk strength, the lower two-thirds of your body is dead weight. It doesn't help you."

His center of gravity off, Kyler had to learn a new way of moving. He realized that being paralyzed was much more than not being able to move his legs. He had to learn how to do everything again.

And he was so tired. Given the limitations imposed by his health insurance provider, the Shepherd Center had to do as much as they could within the coverage time period.

He was in exhausting therapy every day, all day.

Come evening when he was lying in bed, he'd binge on "Game of Thrones."

"I used that as a way to distract myself from facing or thinking too much about what I was going through."

Teacher becomes the student: 'Pain is inevitable, suffering is optional'

For years, people suffering from chronic pain that medicine alone could not alleviate had come to Kyler for advice.

Now the teacher of the meditation- and yoga-based program would have to become the student.

He had a list of principles, mantras and sayings that he'd mentioned hundreds of times.

"Pain is inevitable; suffering is optional. Pain times resistance equals suffering. You're not ever going to get through life without some pain or unpleasant circumstances, but it's the degree to which you resist and push it away, that causes the suffering."

It would be different being the one who needed to listen and apply them.

"I still suffered. I didn't want to be there. I didn't want to be going through any of this," he said. "But I realized, I can't go back in time and change this. The more I resist, the more I try and wish it away and complain and feel sorry for myself, the worse it's going to be."

"The transfers are a huge part of what you learn," he said. "It was so hard at first because you're weak and your balance is off, and again, you have all this dead weight that isn't helping. You learn how to use it."

Having to learn how to do simple things he used to do with little effort were now tremendous challenges—and when he accomplished them, significant milestones. Learning how to sit himself up in bed. How to get himself to the edge of the bed. And the "transfers"—transferring himself into a wheelchair, out of a wheelchair, into a car.

"Stuff you take for granted. When you think about spinal cord injuries, most people think, oh, you can't walk anymore. If it were just that it wouldn't be so bad. But what people don't see is that there's no bowel or bladder control, and it's a whole new way of learning how to regulate that," he said as he rolls himself out of his bathroom after explaining the devices and items he needs to urinate, empty his bowels and bathe.

"And get dressed. How long does it take you to get dressed?"

It used to take him five minutes in the morning.

At the start of his rehabilitation, it took him over an hour to put on underwear, pull on pants and socks, get his shirt on. Now he can do it in 15 minutes.

"It was so frustrating to all of a sudden be at the very beginning."

Building up his endurance and strength were concrete tasks that he could do that weren't challenging psychologically.

Kyler learned the basics to function at home almost independently, though he still needs some help. Wilson Workforce and Rehabilitation Center provided a home assessment to fine-tune everyday living to help cultivate this independence.

When he goes to WWRC for physical and occupational therapies, he calls it finishing school. His occupational therapist is helping him with the way he's transferring from his primary chair to his car. She will observe him and offer more efficient methods to get himself, and his wheelchair, in and out in a way that won't wear him out.

His therapists are helping him prepare for a trip. Experiences that usually meant packing a suitcase and grabbing his bike gear now require careful examination and a vastly different itinerary.

From buying the right mobile toilet seat to getting back into a pool ahead of time, he needs to deconstruct the trip in advance and conduct a trial run. Since the trip involves going into the water, he wants to go into the water first with a therapist's help. He must regulate his bowels and said he is like a baby who poops in the pool. Feeling infantilized, he cracks jokes about bodily functions to ease the discomfort that might be felt by others.

It's this discomfort that creates a disconnect between the person sitting in the wheelchair and the chair.

Kyler is matter of fact with an incredible sense of humor and wit given his circumstance. He just bought a Tesla, and he wants to make it work even though it isn't wheelchair friendly. But will it ultimately be the right car for him? It is up to him to determine where he wants to expend his energy, even if now that energy is essential. It is a balancing act between fighting the disability and living with the disability and deciding what quality of life is best for him. And that's his decision to figure out.

He's going to work with a company that makes equipment to lift his chair into the trunk so he doesn't have to take it apart and bring it into the passenger seat, then put it back together in order to transfer in and out of his car. It's expensive, but he can afford it financially.

Whether or not he can afford it physically and then mentally remains to be seen. He isn't hiding from the pros and cons and his occupational therapist gives him options. They work out the transfer in the Tesla, and then they try out a wheelchair accessible van. It's up to him. And it should be. He isn't helpless in this respect.



Physical therapists help him manage pain. Now that he is in a wheelchair, strength and flexibility in his shoulders are critical, and injuries sustained from the wear and tear of adapting to the wheelchair will require shoulder surgery. Any smart drive device for his wheelchair won't be approved by insurance for a one-year time period following the date of his accident, and until he can provide evidence of shoulder damage.

He cracks an offhand remark that insurance companies are waiting to see who lives a year after their accidents.

"Attrition rate," he jests.

It helps to ease the tension most of us feel regarding insurance coverage rules. This particular rule surrounds a device that will reduce shoulder damage, alleviate pain and improve quality of life. Waiting for the damage to happen requires an offhand remark, and Kyler has the wit to deal it.

According to his physical therapist at WWRC, almost all "outside the home" devices, including any to make his vehicle handicap-accessible, are not covered by health care insurance providers.

Kyler paid out of pocket for a \$15,000 stair lift at home, something he came to discover he can't use safely or independently to get to the second floor of his house

He wanted it to work so that he didn't have to depend on his wife so much. But it didn't work, and as a result, he moved his bedroom and bathroom to the ground floor into what used to be his home office.

It has a makeshift feel. It wasn't meant to be a bedroom and there's a "I'm still figuring this out" feel about it.

"Nancy has had her life changed as dramatically as mine. She has been on this journey with me every step of the way. My hope and goal throughout the rehab process was that I would be able to become as independent as possible so that she could go back to becoming my spouse rather than my caregiver, but the fact remains that I still need her for so many things and would not be where I am now without her."

Reactions from others spur blog to write about his experiences

After Kyler's accident, his daughter started a blog on Post Hope, a support website normally used by patients to journal their experiences, as a means to update people on her father's progress. While at Shepherd, when Kyler was finished with therapy and alone at night, he began to post. He remembers thinking it could be more than a "how's Rob doing."

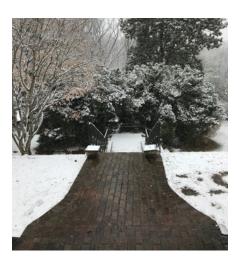
"I realized this is more than going to the hospital, having an operation, going home and recovering. This is about learning a whole new way of living, and I never knew anyone who had ever been through this. Statistics would say that most people haven't."

Most people don't want to ask a person what happened when they see a person in a wheelchair. All you see is the wheelchair, Kyler says.

"I never did," he said.

There is an overwhelming sense of helplessness, and in this feeling it is easier to stare at the chair than the human being sitting in it because we cannot imagine what this must feel like. It is frightening, and in this fear we become silent. A chasm forms that dehumanizes the individual with the disability.

"I think for many people it makes them uncomfortable, and they are scared to ask what happened. What is it like? What are your issues?"



His home in Staunton is a house of steps. Multiple sets of steep brick steps leading up to his front door and a staircase as soon as you enter. Although changes have been made to his home so it is wheelchair accessible, the steps are a reminder of what he can't do. He will never walk up those steps again. Extraordinarily beautiful landscaping of a house on a hill that now feels extraordinarily brutal.

One of those scary questions might be: Does it bother you?

This gut reaction is one of those thoughts you keep to yourself. A question that lingers. Our minds begin to fill in the blanks quietly while he sits in the room alone.

Thoughts flood in... questions we are afraid to ask ourselves.

It must be so hard.

How do you stay positive? How do you stay strong? Are you depressed?

I don't think I could do it.

What is the hardest thing for you? Do you feel alone? Do people treat you differently?

As human beings, another person's experience is a mirror. The questions feel too personal. We haven't figured out how we feel yet about what we are seeing, but we yearn to know so we can understand.

Kyler saw the blog as an opportunity for those who may be interested in learning the process of recovering from a spinal cord injury. What's life going to be like? How has it changed? To give people a chance to ask him questions and express their feelings.

Perhaps this shared understanding will help more people see the human being instead of the wheelchair.

It is also giving him a chance to say what he is feeling at every step of his rehab.

For Kyler, the blog became a form of therapy. He had to solidify thoughts surrounding his experience and write them down, which helped him come to terms with what happened and the journey ahead.

"What was I thinking at this point? How was it? What were the difficult things for me? That's what it became," he said.

Physician-patient bond

Less than four months after the accident, Kyler returned to work.

First a couple half days a week; gradually more. In retrospect, he thinks he may have started back earlier than he should have, but he had to do something outside of just being at home. He wanted to feel useful again.

It wasn't long before he was back at work full-time.

Kyler's life was about taking care of himself while helping others. Although the accident happened at 58 and the average person who suffers from a spinal cord injury is about 20 years younger, he believes because he was in good shape and took care of himself, it helped his recovery.

He says work is going great. If anything, he finds it more gratifying than ever. After the accident, he wasn't sure he would ever be able to go back to work. He also had time to reflect on his career and realized how much he loved and missed his work.

And he's learning to adapt. He has a power assist chair that helps him get around the clinic and alleviate stress on his shoulders.

"It's not all happiness. I have chronic pain. I've got chronic neuropathic pain that's there all the time."



The pain gradually gets worse as the day goes by, and he has to deal with ongoing pain that never goes away. It waxes and wanes. It's been bearable, he says, but it's a constant presence in his life.

"Again, it's ironic because the class that I taught was for people with chronic pain that had reached the limits of what medicine can provide. And that's kind of where I am now. All these medications don't help with this kind of pain. So I'm just learning. I've had to really put into practice what I taught people, which is acknowledge the pain, be present with it, don't push it away, notice it, and watch it come and go and accept that it's there."

Acceptance is different from resignation, he says.

Sometimes Kyler is in resignation rather than acceptance, he admits. It has taught him a deeper empathy and genuine connection with his patients. Almost every one of his patients has an issue he connects with now. He knows chronic pain. He knows what it's like to take a handful of meds. He knows what it's like to deal with constipation, incontinence, depression and having to go back to work with all of this happening.

Of all the doctors Virginia Lloyd-Davies has seen, Kyler is the most compassionate, she said. When she heard about his accident, she burst into tears. Diagnosed with anal cancer, she said she is part of the NED club now—no evidence of disease.

"Having been through absolutely agonizing cancer treatment two years ago, I'm extremely grateful to be in good health. Rob Kyler is a large part of the cause of how I'm doing now."

Never in her wildest dreams did she think Kyler would be able to return to work.

"He had been through the fires of hell, just as I have, just as so many of his cancer patients go through this incredibly difficult situation. He is the same person—deeper, richer, if possible, more compassionate because of his own vulnerability. The pain he had been through and continues to go through makes him understand pain and trial in other people."

Lloyd-Davies mentions that even under dire circumstances, he managed to keep his sense of humor. She begins to laugh and says he cracks her up. He wrote in a blog post that he always felt doctors should go through some kind of health issue to improve their compassion, but what he had in the mind was a bad case of hemorrhoids.

He is not only their physician now, but a patient right alongside them. They are going through it together. And for Lloyd-Davies, she too has learned to put mindfulness into practice. Her experience was so painful and terrifying, all she could do is say, "I'm alright at this particular moment."

Kyler hopes to teach meditation again someday, but said he needs to strengthen his own practice first.

He thinks his patients sense he understands them. For him, this understanding is therapeutic. A shared experience he didn't expect. A bond he hopes will make him a better doctor.

"When all of sudden you've been told you have cancer, it's probably not all that different from what it's like realizing you're never going to walk again," Kyler said. "Your life changes dramatically, and it's never going to go back to the way it was. And yet somehow, you keep moving forward, and you keep living your life."