

disappeared, or started avoiding me in the hallways and not returning phone calls. So, I pretty quickly realized who my true friends were, and people who were just there for their own selfish reasons. It was a great learning experience for me, as it kind of gave me a

good crash course on true friendship, and the friends that stuck with me are still around me today."

One of those friends who stuck with Nick was Suzzi. And over time that friendship bloomed into romance and then marriage.

"My wife and I were friends in high school and ended up going to the same community college, and during that time, our friendship turned into a relationship," says Nick. "We dated for six years, all through college, and then we were married the summer after I graduated."

Suzzi says she's a very strong woman and her marriage has only enhanced that strength. "I believe that our relationship has only made me a stronger person both individually and together. I know that friends and family had questions at first about our commitment, but once they got to know Nick, they understood why we worked so well."

As with any successful relationship, Nick says a big part of theirs is communication. "We can't avoid the fact that I'm in a wheelchair, I have a spinal cord injury, and there is stuff that comes along with that," he says. "Early on, we really had to talk about how that had an effect on the relationship and how it could slow things down, or kind of hinder activities. But, we did a really good job of communicating, we're very open with each other, very open about how I felt, and it's worked, it's worked out really well."



STEPHANIE D. LOLLINO,

executive editor of FacingDisability.com, is a Chicago-based television producer and writer who has been working with the

website since its inception. She says her extensive background in research, media and creative communication turns the task of im-proving the lives of others into a dream job. "Making people aware of SCI, and everything that goes along with it, is something I'm really proud to be a part of." Stephanie enjoys outdoor sports and fitness—especially with her two daughters and husband.



facing disability.com

for families facing spinal cord injuries

Hill Foundation 737 N. Michigan Ave., Suite 1560 Chicago, IL 60611

> Phone: 312-284-2525 Fax: 312-284-2530 info@facingdisability.com



Reprinted with permission from the April 2016 issue of:

New Mobility Magazine The monthly magazine of United Spinal Association



KEEPING & STRENGTHENING FRIENDSHIPS POST-INJURY

BY STEPHANIE D. LOLLINO



It's no surprise that a spinal cord injury can change friendships — in some cases making them stronger, and in other cases, causing them to end abruptly. Sometimes that's for the best, since fair weather friends may not be friends at all. But here are some tips from Facingdisability.com vloggers for how to navigate those other times, when friendships can be saved, nurtured and even blossom into more.

Same Friends, Different Reality

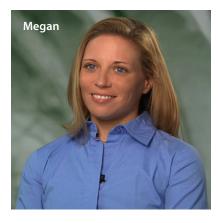
Almost inevitably, there are social fears after the trauma of a spinal cord injury.

Megan, injured at age 18 in 1995, says that beyond the physical changes she faced after her T5-L1 injury, she felt certain she was going to lose all her friends — and that was terrifying. "My greatest fear was that all of my friends would abandon me and that I would never have a family or a husband or children or anything like that," she says. "That I would have to give up any thought of ever having a normal life."

NEW MOBILITY

APRIL 2016 **37**

Luckily, none of that came to pass. "I had enormous support from friends, a very close circle of friends, that were always there and said, 'no matter what, we'll be there for you,' which was very helpful because I went back to school three months after my accident."



Today when Megan addresses her friends on the subject of her life with a disability, she always tells them, "It's not easy to live with any kind of disability, it's a hard life, but at the same time you can be happy and fulfilled."

For Vicki, a C5-6 quad, today the biggest problem with her friendships is reminding them of the more concrete realities of using a wheelchair. "With my friends, it's really funny, because they forget I use a wheelchair," she says. "They make plans to go somewhere, and I say, 'what's the parking like?' Or, 'am I going to be able to go to the bathroom at this place?' and they suddenly gasp, 'Oh! I forgot! We'll have to reconsider.' It happens."

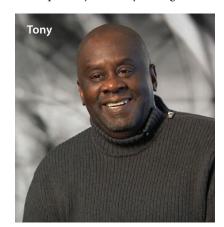
After Vicki's diving accident, the then-22-year-old quickly realized that in addition to handling all the physical changes of her injury, she also had to take the lead on helping her friends deal with her injury. This is a strategy she employs today as well.

"When I meet someone new, it is my job to make them feel comfortable with my wheelchair," Vicki says. "It's still true nearly 30 years later. I meet people who are uncomfortable with my injury and the way my body looks, and I have to help them understand that I'm OK."

This is especially important during those times when she's really not all that OK. "Sometimes I'll have a change in my health status. Things like a bout with autonomic dysreflexia or a broken bone from a fall," she says. "When I can see the worry on my friends' faces — that's when I know I have to get back to reassuring them it's all part of living with paralysis."

After all, nondisabled friends have no idea what it's like to live with an SCI unless they're told — as uncomfortable as telling them might be. Chase has lived with T11-12 paraplegia since age 17, and says that although it took a while for his friends to become comfortable with him again after his 2007 injury, they got through it. "I'm closer with my friends now, definitely very close with all my friends. I'd say I'm with them probably every day," he says. His secret? Being open and honest about all that his injury entails, and showing he's OK with it. "I came out and just said, you know, 'Hey guys, I wear diapers sometimes, I pee my pants sometimes, and I'm going to need help doing this — help doing that,' and they just kind of accepted it. And, it's normal now."

The key is to remember things are different for everyone post-injury, including our friends, says Tony, a C5-7 quad injured 25 years ago when



he was 27 — but that most situations improve with time. "Just understand that this is a learning experience," he says. "Everything is going to change because the person in the wheelchair is going to get better at some things. And the person in the wheelchair is probably not going to need some of the things that they used to need [right after their injury], they're going to end up needing new things. Everything is going to evolve and change — but for the better."

It may sound hard to believe that life can get better after a spinal cord injury, but Michelle, a C6-7 quad injured at the age of 21 in 2002, says it's true for her as well. "I am very happy," she says. "I always say it's kind of strange, it took this tragedy to happen to me to put my life in perspective. Like, before I was injured, I didn't go to concerts, I didn't go to plays, I really didn't go out of my comfort zone, but now it's like I push myself to do things like that."

Perhaps having wonderful, supportive friends has helped her recovery? "My friends have been great," she says. They were very supportive while she was in rehab and that continued when she was released. "Before we got the lift in the house, if I needed someone to help me with stairs, they would."

And she is supportive to them in turn. "You know how there's that one friend in every bunch who everybody needs to get advice from? Well, that's me! So now everybody's always at my house — 'Oh Michelle, I need to talk," she says. "So they're great, I love them! And if I ever need a ride, I always have one."

The Pain of Friendship Lost

Giving yourself some time to adjust, and your friends' as well, is often all that's needed for most relationships to get back on track and feel comfortable again. But for some friends, nothing seems to work.

At age 62, in 2008, Nova had a fall that resulted in T6 paraplegia. She says her greatest fear was losing her deeply loved, longtime friends. Not only did that partially come true, but she was shocked by how easy it was for some of them to detach.

"I have written emails to people who didn't know what happened to me, or heard back from people who did know what happened to me, and tried to touch bases, and no response," Nova recalls. "And I remember writing to this one woman whom I've known for 25 years, saying: 'I don't want to pressure you, and I don't want to impose upon you, but I'm hurt, and we have such history with each other. I love you, what's wrong?' One friend didn't reply at all. Another wrote back: 'I feel like an awful person, I just don't know how



to handle it.' And I responded, 'I'm totally willing to help you handle it because I don't want you out of my life. I'm not embarrassed to answer anything, feel free to ask."

The friend who wrote she felt like an awful person is much younger than Nova and they had become friends while working together on setting up commercials and personal appearances for professional athletes. Nova was an important mentor and as the friendship grew, Nova recalls, "She even began to call me her mother. Her own mother had been dead for a long while." Nova's husband Don called this friend the day after her surgery to inform her about the fall and her diagnosis. "Don said she could hardly speak because she was crying so hard. He tried to console her and called her a few times after that to give her updates on my progress," she says. "She sent a huge box of presents to the hospital that I received a week after she heard the news."

"Almost six weeks after my surgery — when I was not drugged so deeply that I could not talk — I did the best I could to write her a thank you note, and to call her. For weeks, I only got her voice mail and left countless messages. She never called back."

"It's been almost eight years now since Don reached out to her to give her the news about what had happened to me. My heart is broken, and I have tried every way to give her reassurances about how much progress I have been making. I also want to let her know I will still answer any questions she has and try anything to help her feel more comfortable with me."

Nova says that though she was not able to recover that particular painful loss, she has learned to focus on those who journey with her. "I am totally blessed with relationships that actually grew and intensified in the love expressed in friendships both new and old," she says. "So, I have chosen to focus on those relationships and put all of my energy into honoring them with reciprocal love and friendship."

Breaking Free of the Friend Zone Nick was 17 and still in high school when he was injured at the C5-6 level in 1995. He says it was hard finding genuine friends at first.

"Some friends were great, they were there taking all the blows with me, and really supportive of everything going on and wanted to help with whatever they could," Nick remembers. "Other friends just kind of

The Psychology of Friendship

"In my mind there are two types of people who leave a friendship, and they are very distinct," says Dr. Lester Butt, rehabilitation psychologist at Craig Hospital, in Denver, Colorado. "It's important for people with a spinal cord injury to appreciate the difference."

"The first set of people who leave are those with whom your relationship was predicated upon fragile kinds of parameters, things like, 'all we did is party,' 'all we did was go out and hunt.' These are activity-based relationships," he explains, and "if the person with a disability can no longer engage in those activities, the friendship might not have as much power for the non-disabled person, and they can leave."

The second subgroup of friends who can detach, withdraw or potentially leave is very different from the first network. "These are people who care so deeply, care so much, or feel that they have such little skills in terms of understanding that they pull away," he says. "The person with the injury has to appreciate or discriminate between those two, to be able to reach out to the latter group. It is vital not to leave friends behind who are really caring."

Johnathan, who became paraplegic at age 19, tells how he was able to preserve friendships that fell in the second subgroup. In the beginning, his friends came to the hospital every day. "But once I was home, my friends would visit and say, 'We're just stopping by, and we're going to get something to eat.' And I would think after they left, 'Why won't you just come and get me, and take me to get something to eat with you, instead of only just stopping by?""

So he let them know how he felt.

"And once my friends understood that I wanted to hang out, and come out, and do different things, we started to actually go do those different things."

Butt says Johnathan's experience is typical of the way strong friendships can begin to grow after a spinal cord injury — and of how the person with the disability usually must take the lead.

"It is very important to be able to educate friends that even though how someone with a spinal cord injury gets from A to B might be transformed, and how they access social or work activities may change, their heart and their brain remains the same," says Butt. "And usually, so do their values, dreams, goals and humanity."