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Acceptance and Change –
New Ways to Deal with Difficult Thoughts and Feelings

By: Claudia Drossel, Ph.D., Ph.D.

The changes one is faced with after SCI can often seem insurmountable. Emotions ebb and flow as you progress through the early stages of rehabilitation. And while this newsletter focuses primarily on interpersonal relationships, we can’t neglect one of the most important relationships of all – the one you have with yourself. Dr. Claudia Drossel is completing her postdoctoral fellowship for her second Ph.D. at the University of Michigan. In this article she shares valuable tools and tips for anyone dealing with challenging thoughts and feelings, regardless of SCI.

Despite scientific advances in the fields of rehabilitation, biotechnology, and neuroscience, spinal cord injury continues to be a traumatic life event that can lead to severe physical impairments. Recovery from injury is a long process that aims at improving or maintaining health and wellness, living a self-directed life, and achieving one’s full potential. This process poses formidable challenges. Recovery from spinal cord injury demands not only that a person learns new adaptive skills to do everyday tasks, previously taken for granted, but also that the person acquires brand-new skills, which target the prevention or management of secondary medical problems that can arise. Recovery is thus a sweeping behavior change process, with change permeating many aspects of the person’s life.

Like all life events that abruptly disrupt our life and challenge us to change, spinal cord injury and recovery tend to be accompanied by a range of emotional and cognitive responses, such as frustration, anger, helplessness, fear, sadness, rage, apprehension, irritation, sorrow, resentment, distress, regret, gloom, dread, and many others ranging from joy to despair. There is no “right” way to react: Feelings and thoughts vary by individual, and they are fully understandable in the context of the person’s history and circumstances – including the spinal cord injury and its physical, practical, and psychosocial consequences. Unfortunately, knowing that difficult thoughts and feelings are reasonable and understandable given a person’s context does not prevent them from becoming barriers to recovery. For example, as pain continues to be present, it is not uncommon for a person to want to postpone engagement in everyday activities until he or she feels truly like participating, or until he or she has obtained a more positive and motivated attitude. Accordingly, many self-help and therapeutic approaches traditionally have targeted a person’s troublesome feelings, thoughts, the lack of motivation, or negative attitudes. To aid their recovery, individuals with spinal cord injury are encouraged to exert control over their thoughts, feelings, and attitudes, to gain a positive perspective. “Change from the inside” is a consistent message. The assumption is that one has to change things on the inside first – namely one’s thoughts and feelings – before one can do anything else. For many people, this approach does work. But what do you do when it does not work?

Over the last two decades, scientists and practitioners have collected increasing evidence that concentrated efforts to change one’s thoughts and feelings sometimes produces opposite, paradoxical results. Rather than achieving the desired result, attempts to change from
EDITOR’S CORNER

The truth about relationships: “This is easy!”...Said no one ever

By: Maggie Travin, MA, LLPC, Editor

As a clinical mental health counselor I’ve spent a fair amount of
time listening to people talk about relationships: When will I get mar-
ried? I can’t seem to find a girlfriend. How will
I know when it’s “right”? Sex is hard, shouldn’t
it be easy? What am I doing wrong? Why am
I even doing this? I quickly realized while
working with people who have disabilities and
those who don’t: no matter what, relationships
are hard! Whether you are dating, married, in
a serious long-term relationship, able-bodied or
disabled, relationships take a lot of work. Be-
cause of this fact, and at the request of many of
our UM SCIMS participants, SCI Access will broach the infinite topic
of relationships and some of the nuances that make them beautiful,
frustrating, enjoyable, thrilling, and often, utterly challenging.

In this issue we are providing you with a variety of information on
‘all things relationships’ because relationships and relational issues
come in many shades of gray; each with its own unique set of chal-
lenges. Dating, marriage, online dating, sex, fertility, communication,
friendship – I am getting dizzy as I write this! We’ve compiled stories
and information from many different areas including: people with SCI
who have dated able-bodied individuals, a leading specialist in SCI
sexuality, a dating profile guru to touch on the triumphs and perils of
online dating, and much more.

We’d love to hear your thoughts about these articles and suggestions
for future newsletters! Please send a message to SCI-model-system@
umich.edu or call us at 734-763-0971.

Acceptance and Change

Continued from page 1

the inside can make bothersome thoughts and feelings more frequent, and thus even
more troubling. In other words: Sometimes, the more time and effort we spend
on changing or reducing certain thoughts, feelings, or memories, the more they show
up. They appear to be similar to plastic toys in a tub filled with water: The more
effort we spend to push them below the
surface, the more forcefully they pop up.

This is not to say that techniques that
encourage a more balanced or positive outlook cannot be useful: Often, sadness,
despondency, doubt, and worry dissipate quickly. They can give way to optimism
and a fighting spirit that views injury-re-
lated barriers as challenges to be over-
come. However, when negative thoughts and feelings persist despite change efforts,
a different approach may be called for.
Survey research has shown that persons
with spinal cord injury and their family
members tend to be bothered by difficult
thoughts and feelings, suggesting an ongo-
ing struggle to rid oneself of negativity.
Yet, feelings or thoughts of frustration,
anger, helplessness, fear, sadness, rage, ap-
prehension, irritation, sorrow, resentment,
distress, regret, gloom, and dread often
continue, and may even increase while the
person with spinal cord injury is trying his
or her best to feel or think differently. A
vicious cycle may have been put in mo-
tion: The person starts feeling bad about
not being able to feel or think differently,
tries harder to change from the inside, and
experiences even more upsetting thoughts
and feelings. Moreover, additional frus-
tration and helplessness may be related to
failed change efforts ("what’s wrong
with me?") and a growing sense of feel-
ing lonely and being stuck. What is the
alternative, when targeting thoughts and
feelings from the inside has become futile
at best and counterproductive at worst?

Acceptance-based therapies consider
feelings and thoughts something that can-
not be changed from the inside. Change
occurs through participation in meaning-
ful activities. As already said above, a
person’s feelings and thoughts are under-
standable in the context of that person’s
history in general, and in the context of the
spinal cord injury with associated health-
related problems in particular. Studies
suggest that, for individuals with spinal
cord injury, difficult thoughts and feel-
ings tend to wax and wane with second-
ary health-related problems: Managing
health-related problems leads to fewer
difficult and less bothersome thoughts and
feelings. This means that – rather than
working on feelings and thoughts first and
then engaging in health management – it is
useful to prioritize active and meaningful
engagement toward long-term health and
wellness. Meaningful activities come first,
and then thoughts and feelings may fall
into place later.

The question remains as to how to best
motivate participation in activities. To
facilitate engagement, acceptance-based
therapies guide individuals to identify
what matters to them, in the past and in the
long run. This exploration of pre-injury
patterns and long-term preferences gener-
ates a constellation of personal values.
These values point to a general life direc-
tion that guides the selection of activities. The person then tries out the selected ac-
tivities that link up with those values (e.g.,
attending an event with a spouse, in the
service of contributing to the relationship),
taking bothersome thoughts and feelings

Maggie Travin MA, LLPC
right along and paying attention to the experience as well as its long-term impact. This three-pronged approach of

1. building a larger perspective through overarching values
2. selecting concrete and doable activities, and
3. attending to what happens and how it works in the long run

is designed to build resilience. Individuals can focus on activities that are part of their self-directed and valued life orientation without any added pressure to “feel good.”

Often, professional providers, friends, and family members – facing their own troublesome thoughts and feelings related to the extent in which they can be helpful – inadvertently put pressure on a person to “feel good” or “feel better soon.” Even when such requests are not explicit, there is a strong body of research demonstrating that persistent bothersome thoughts and feelings evoke negative reactions from others. These negative reactions may communicate an implicit demand for improvement of mood and attitude, making it more likely that the person with spinal cord injury blames him or herself when difficult thoughts and feelings emerge or continue.

From an acceptance-based perspective, the person with spinal cord injury, and his or her family members and friends, as well as providers undergo a parallel process: We all can benefit from learning how to identify and accept difficult thoughts and feelings and, at the same time, do what matters to us and will work in the long run. A person with spinal cord injury might have the feeling that he or she is too depressed to attend physical therapy; the thought that “one shouldn’t have to catheterize every four hours;” and the feeling that he or she has become unlovable (with the associated thought, “Why would anybody date me?”). A spouse may have the feeling that she should not enjoy walking; or he might have the thought that his spouse with the spinal cord injury should be grateful to have survived.

Acceptance-based therapies teach the skill of noticing and acknowledging these thoughts and feelings for what they are – thoughts and feelings, no more and no less – without acting upon them. In the above examples, what would be the long-term impact of attending physical therapy, adhering to the prescribed catheterization interval, going on a date, walking for exercise, or empathizing with a person’s discontentment? Before taking action, a person learns to ask, “If I did this, would a pattern involving this particular action support my preferred life direction and what matters to me in the long run? Can I tolerate psychological discomfort in the service of that outcome?”

On typical days, before the spinal cord injury occurred, individuals and their families had myriads of thoughts and feelings upon which they did not act. For example, in traffic they might have responded calmly, even though they were cut off, felt angered, or had thoughts of lashing out. They might have gone to work, despite feelings of lethargy and thoughts of not wanting to go. Everyday experience tends to be a bit like Teflon: Many thoughts and feelings are fleeting and simply slip off. They do not stick, and we do not do anything about them. However, after the potential threat to life and the often very serious consequences of a spinal cord injury, including a loss or restriction of activities, thoughts and feelings appear to acquire a different, sticky and pressing quality.

Acceptance-based therapies acknowledge the propensity to get stuck. They focus individuals on getting unstuck, by emphasizing effective action and changing the person’s relationship to his or her thoughts, memories, or feelings. Thus, when concerted attempts to change one’s thoughts and feelings do not work, there are alternatives. Acceptance-based therapies offer a space for troubling thoughts and feelings, while at the same time promoting the flexible and effective action needed to tackle complex challenges and move toward one’s preferred life direction.

**Resources for individuals:**


**Resources for couples:**

**Resources for professionals:**


*Claudia Drossell, Ph.D. is a Psychology Fellow in the Physical Medicine & Rehabilitation Division of Rehabilitation Psychology and Neuropsychology*
Following Greg’s tragic auto accident in February 2003, paralyzed as a C-6, ASIA B tetraplegic, at night he would stare at the ceiling for 3 months in Rehab on 6A. He spoke of dark days and near utter despair. Without the support of his family and friends, his road would have been unbearable. He discovered the path before him could only be managed by continuing to move forward and work toward independence.

As the months wore on, the most important goal he was determined to reach was accomplished, January 5, 2005 – finding the great love of his life. That was the day we met.

Divorced for 5 years in 2004, with a busy and thriving nursing career of my own, I made the decision to begin the task of finding a ‘male’ friend for a potential relationship. My two children were out on their own with thriving and successful careers, so my friends and colleagues encouraged me to “get online and find someone to date, everyone’s doing it.” Okay, fine.

I searched through hundreds of men’s profiles and found not even one interesting profile that moved me for one year. Finally, I was courageous enough to pursue two of them. Sunday lunch for an hour downtown as my first venture out in 5 years couldn’t be that bad! Actually, I couldn’t wait to get back in the car for the short drive home. My cats had to be more interesting to talk with than he was. And that hug he insisted on giving me? It must have lasted 35-40 seconds. The longest 35-40 seconds of my middle-aged life. I hate this!

One week later my life took a turn I was not prepared for. While browsing those darn ‘profiles’ again one Sunday afternoon with my daughter-in-law, we came upon an interesting one. One that I could not get out of my mind, so beautifully written and accompanied by two photos of a stunningly handsome man. I sent him a brief hello that day and knew this man would be in my life in some capacity, for ever. Of course I was not sure at what level, but I knew in my heart that he would remain there for a lifetime.

After reading his response the following day, that life for him was based from a wheelchair, I was rather shocked! Dating a man in a wheelchair? I’m not at all sure that’s for me. “What difference does it make if he sits or stands, Connie”, was my cousin’s reaction. And 48 hours later…I never looked back. This is my personal story. I share it as an able-bodied person meeting someone with SCI for the first time.

Perspective of Dating with a Spinal Cord Injury

By: Connie Pines RN, CCM

Romantic love depends upon intangible qualities. Loyalty, kindness, humor, forgiveness — none of these suffer because of bodily limitations. Looking at the big picture of love/romance, internal qualities far outweigh external ones in importance.

Be realistic about the realities and limitations that dating someone with a disability imposes. Discuss the realities of the individual’s disability when planning time together. These may include intimacy, the necessity of caregivers, a unique living space, specialized vehicle, etc. Don’t be fearful of stepping outside your comfort zone. By all means, talk! When openly discussing the challenges you both face, you’ll be on your way to overcoming a more common problem which is: lack of communication. It may be a bit awkward at first but will pay dividends in the end! Do not be afraid to ask questions! Don’t try to be the hero/heroine. After a devastating accident, it can be tempting for someone who is disabled to seek out an ‘angel’ who will care for and assist him or her. Taking on this role is tiring and can muddy the waters when attempting to separate the caregiving tasks then ‘turn on the romance’ 45 minutes later. Be aware of the implications of blurring the lines or completely taking over the caregiving role. Prepare to make adjustments. There are real challenges to maintaining a relationship when one partner faces significant limitations in terms of where they can go in public especially when first dating. For example, Greg’s existing tickets for a college football game would not be ADA seating, disdainful looks in the grocery line do exist, or navigating the subway/train that is not wheelchair friendly. Every relationship requires negotiations and adjustments.

Always have an open heart in order to be successful at dating. Certainly I wasn’t looking for a man with a spinal cord injury, who...
lived in a wheelchair and was recently separated. However, I was able to look past all those issues and the ‘hardware’ that surrounded him and reach into his soul. In there, I saw nothing but strength, kindness and a vulnerability that was simply irresistible.

Sadly, looming throughout our relationship was Greg’s diagnosis of breast cancer, detected 3 months after we met and fell in love. Sedona, AZ was the site of our beautiful wedding in 2006. The following 3 years brought numerous debilitating surgeries, chemotherapy/radiation and significant pain. Greg had minimal response to therapy. He was not blessed with the gift of a long life.

Greg lost his long and courageous battle with cancer at home with family and friends by his side at age 51 in the summer of 2009.

His adornment and adoration of me were unquestioned and something I had never felt before in my life. Yes, we were vulnerable but ready to face a harsh world and the significant challenges that lay ahead. We seized the moment and were unafraid to move forward together.

Be unafraid to move forward in this experience. Embrace it. After all, lightning could strike!
It’s Okay to be Single
By: Tom Hoatlin and Maggie Travin

A couple holding hands while walking on the beach, an elderly couple sharing a meal, two parents and their children; everywhere you look there are subliminal messages from our culture suggesting that you’re not whole unless you’re part of a couple. However, the “couple majority” might be changing. Research suggests that 46% of single American adults are sure they want to get married; another 25% are certain they don’t and 29% are unsure. Unfortunately, these numbers leave us wondering how many more people would choose to be single if they didn’t feel that it was looked down upon. There is a common cultural misconception that one cannot be happy if they are single and that one should never choose to be single. Interestingly enough, these numbers do suggest that more and more men and women, both able-bodied and those who aren’t, are making the choice to be single.

The choice to be single or “on your own” is a very personal decision. It is not one for everyone but for some, it might help lead to inner satisfaction, growth, and happiness. The story of Tom Hoatlin’s journey to “single” happiness is one that most of us, in some capacity, can relate to, regardless of ability:

“I was married for nearly 25 years and I can say that the happiest part of the marriage was the birth of our beautiful daughter. Unfortunately, six months after her birth a random robbery and shooting would leave me with a spinal cord injury. Much later our marriage broke down due to another interruption. This time it was substance abuse. While I tried many times to get the help we needed, it finally became apparent that I had to end our dysfunctional relationship. What this meant was that at 45-years-old I would be starting over. I would be a single home owner, I would have a single income, I would be a single father of an 18-year-old, and, oh yes, I would be SINGLE!

Being single in my mid-forties was the last thing that I had thought about throughout my married life and dating with a SCI terrified me. Eventually, fear started to give way to optimism; and as I met new people, optimism gave way to excitement. The prospect that casual flirting could actually turn into a possible date and maybe down the road, a relationship, was exciting. After ending a two-year, long distance relationship and my daughter leaving for China for three months, I realized that I needed to embrace the time alone and all the benefits that it could bring. I used to be uncomfortable with quiet but now I love it. I like it when I suddenly realize that I have nothing to do on a certain evening or weekend.

Initially, I bought into the pressure to feel like something was wrong with me if I wasn’t in a relationship. I was all too aware of the societal pressure to be attached. With time, I have found that I really like being single and unattached. It has given me time to get to know myself, time to work on being me; feeling complete all on my own. Admittedly, it’s a process and it’s not for everyone. I don’t know how long I will feel this way. I don’t know what the future holds for me. But for now, for me, it’s okay to be single.”

The cultural definitions of acceptable relationship statuses are ever-changing; and as a result notable magazines such as Psychology Today and Forbes have accumulated lists about why it’s okay to be one of one.

- Staying fit – single men and women tend to work out more and stay more physically active than their attached counterparts.
- More money in your pocket – being in a relationship can be expensive. Dinners, vacations for two, it all adds up!
- Social media – spend less time feeling guilty about what you post or worrying about what your significant other posts.
- Acquiring friends – singles need not rely on one person for companionship and tend to have more friends than their married counterparts. Get to know the friends you have and get to know new ones.

- Freedom – have more time to “do you”, have girls/guys night guilt-free, start a new hobby, date around – the sky is the limit!
- Spontaneity – travel, dine, workout, sleep, the list goes on. Do what you want.
- Career – if your work is important to you, this could be an opportunity to develop your career. You can make choices that would be tough with a family or a significant other to consider, such as moving across the country or changing careers.
- Better sense of self – you have the time to learn how to be self-sufficient, independent, or even just develop a general sense of who you are.
- What you want – if being single isn’t something you want forever (and who can blame you) being temporarily single can be an opportunity to figure out what you truly want in a life partner. Avoid making checklists but think about personality traits or ways of living that are non-negotiable for you. This can help you avoid “doomed” relationships if/when you decide to have one.

The 2010 U.S. Census found that nearly half of all American adults—100 million—are now single, the highest rate in recent history, and 61 percent of them have never married. The census also found that for the first time since it started counting; married couples now make up less than half of American households. In all, 31 million Americans live alone. There is much to be learned from this data but the general take-home message is clear: the tides are changing. Being single is no longer a minority status. As a result notable magazines such as Psychology Today and Forbes have accumulated lists about why it’s okay to be one of one.

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Online Dating

By: Lisa Hoehn

Setting up an online dating profile is daunting for even the most confident—after all, you’re opening yourself up, to some extent, to be judged. For those with a physical disability, who may already be self-conscious about being in the spotlight, that fear can be a halting force. Don’t let it be!

While I don’t have experience dating with a disability, what I do have is experience helping every kind of person make great matches online. Here’s my advice for taking online dating head on:

It’s normal to be nervous, but screw it: Remember, for what it’s worth, online dating isn’t personal. If someone isn’t into you, remember, you’re here to find a great match—not be popular! At the end of the day, you can’t control how people feel about you, but you can be true to who you are.

Do not wait until you meet to disclose: I repeat: do not wait! When you’ve gone back and forth with a potential match enough to set up a face-to-face meeting without mentioning a physical disability, there’s precisely zero chance that he or she has considered it as a possibility. And while a disability is not a dealbreaker for most people out there, deception is! Not only do you risk your match—not be popular! At the end of the day, you can’t control how people feel about you, but you can be true to who you are.

Try disclosing through photos: Photos are the perfect avenue for disclosure for two reasons: 1) they show a match exactly what you look like, so when it comes time to meet there are no surprises, and 2) they serve as a concrete reminder to a potential match that your disability doesn’t define you. (I recommend using a headshot for your main image, then sprinkling photos where your disability is visible throughout your remaining three to five images.)

This is the route that, after that first dateless year, Luticha decided to take. “I decided, ‘screw it,’ and I put photos of me doing cool things in my wheelchair—skiing, climbing a volcano, on the golf course, that sort of thing.” The result: “It got me a lot more traffic and a lot more messages from cool men who I was actually interested in. I didn’t feel embarrassed— I felt empowered.”

If you disclose in the text, be confident and unapologetic: Explaining the origin or extent of your disability is tricky — too little information can leave a potential match with more questions than answers, but too much can make you seem preoccupied or as though you’re looking for a caregiver. My advice is to keep it short and sweet: One mention of your disability, then let the rest of your profile show what makes you you! Steer clear of using “but” in your explanation (i.e., “I’m on crutches, but I still like to do X, Y, and Z”) because it puts more emphasis on the disability than the activities. Instead, let your sentences stand alone (i.e., “I’m on crutches. I love staying active, especially doing X, Y, and Z”), putting emphasis on what you do and what you’ve achieved.

Consider disability specific dating sites: Especially if you’re looking for a disabled partner, niche dating sites can provide a larger pool of matches. eDateAbility.com, Dating4Disabled.com, and DateAble, Inc. all cater to those with physical disabilities—and some even boast forums and blogs that can be used both as support and as a way to get to know other members. These sites and others like them pride themselves on being supportive and having supportive members, which can be comforting when you’re just jumping into the online dating world.

Stay positive and optimistic: It’s time to get real: You’re going to encounter some jerks out there. Big ones. Ladies, you might receive gross, overtly sexual messages (some pertaining specifically to your disability, if you disclose it). Guys, you might experience some radio silence or even cattiness. But do not let this type of behavior get you down! Positivity — both in your profile and in your outlook—is attractive and will ultimately bring you more matches. Just ask Luticha: after revealing her disability on her profile, she received a message from a great guy. One five-hour first date and eight months later, they’re happy together.

Lisa Hoehn is the founder of Profile Polish—an online dating profile makeover service that’s helped people around the world create meaningful connections. www.ProfilePolish.com.
Disability and sexuality is a concept people have a hard time acknowledging. The fact is that regardless of being disabled, it is a very real thing for all human beings. I’ve encountered different misconceptions since acquiring my disability. Most people assume people with disabilities don’t think about sex and sexuality, that it isn’t relevant to them. It’s just the opposite. Aside from being the second question asked after a spinal cord injury, it is also the most neglected piece of information provided and explored. A common theme across all humanity is the desire to be loved and accepted. Being a woman with a disability in an able-bodied world can be intimidating when there has been no transition into a complete change in your life. As a sexuality and disability educator, I was introduced to a video called “SexAbled” that highlights what sexuality means for people with disabilities. It is a great example of the reality of sex and disability, and how influential it really is in everyone’s life, despite individual circumstances. My journey began January 17, 2009. That particular day was busy for me and my two young sons; we had two birthday parties to attend, had to get home to wrap gifts, get changed, and catch up on household chores. On our way home, I was driving over a bridge very near our house. Being in a hurry, I was distracted and lost control of my car. We ended up rolling four times off the freeway into a small embankment, landing upside down. I broke my neck and severed my spinal cord, paralyzing me instantly from the neck down. Luckily, my boys were not severely injured. At that moment, life as we knew it changed.

I was not in a relationship at that time. My ex-husband and I went our separate ways almost 2 years before, and I had just ended a new relationship right before my injury. What I knew about relationships, myself, and sexuality completely changed. I was afraid, confused, mourning the loss of what I thought life was and had been for me. Who was going to love me and accept me now? How am I going to be desired, admired, pursued as I was before in this body that no longer worked as it used to? So many questions ran through my head. I went searching for answers about everything including sexuality. Unfortunately, it was hard to find information on sexuality for women who have quadriplegia due to a spinal cord injury. The little information I found on females with spinal cord injury was geared towards women with paraplegia not quadriplegia. This was unacceptable; I was determined to seek out more information, and create access to information relating to sexuality and women with high level spinal cord injuries.

In learning about my disability and my new life, I also started a personal journey to understand my own sexuality. After acquiring a disability many things change. Acceptance comes over time and is different for each and every person. Being mindful of how specific parts of ourselves change during this transition is key to embracing acceptance. Self-image (how we view ourselves), who we think we are, and our role in society completely changes. Self-esteem (the judgment we have about ourselves) has to be strong and positive to get through the changes in our self-image and how we identify. My role in society was as a great contributor, not only in the work I did, but in what I had accomplished, where I was going, the influence I gave, and the children I was raising to also contribute positively to society. All of this influenced my perception of where I was in my own sexuality. I associated all of these qualities with sex appeal. How was I going to continue this image when my physical body and my entire sexual identity had changed? Mainstream culture forces us to identify sexuality only in the physical, it’s not mindful, nor pays attention to how it influences our sexual identity.

“Let someone love you, just the way you are-as flawed as you might be, as unattractive as you sometimes feel, and as unaccomplished as you think you are. To believe that you must hide all the parts of you that are broken, out of fear that someone else is incapable of loving what is less than perfect, is to believe that sunlight is incapable of entering a broken window and illuminating a dark room.”

-Marc Hack

Love came again. A year after my injury I entered a relationship with someone who was also a quadriplegic. We became
engaged two years later. Six months after our engagement, my fiancé passed away, leaving me with doubts and uncertainty once again. The image and identity I created changed again, but this time my self-esteem had grown. Because my reality was different, this relationship was completely different, based on qualities that went beyond the physical. This relationship, allowed me to grow and learn. It helped me to find my place in my sexuality as a woman living with a disability, a partner, a mother, strong and beautiful. This time, I embraced who I was, and who I had become. I was sexy again, I was desired again, but this time I felt more powerful.

I still wanted to continue my work in providing access for other women with quadriplegia in exploring their sexuality. As I was doing a little bit of research, I stumbled upon the name of a gentleman who was a sexuality and disability educator. His name was Rafe Eric Biggs, and he had founded an organization called Sexability. I contacted him in hopes of being able to collaborate. He was a male quadriplegic from a spinal cord injury, and was looking for a female perspective for the organization. It was the perfect match! Sexability is an organization that is “transforming sexuality and disability.” Among the host of different services we offer, we developed a webinar series on “Transforming Sexuality After Spinal Cord Injury,” in which service providers from all over the nation participate. We covered topics like: transformation of self-esteem, self-image, identity, identifying what works, sexual surrogacy and sexological bodywork, adaptive aids, orgasm, communication, dating, creating boundaries, fertility and conception, all while keeping in mind culture, age, gender, lifestyles and other influences. We provide one-on-one and couples coaching to discuss topics people are not comfortable addressing. We also work with youth with disabilities, their parents, and service providers. This year we launched a calendar highlighting individuals with disabilities as they are in their intimacy, changing the way the mainstream media views beauty. We try to create access to people who would not have access to information and resources regarding their sexuality. Our expertise is spinal cord injury, although we do serve people with other disabilities also (for more information, visit www.Sexability.org). Recovery and transformation never stop. I continue to work on the development of my intimate relationships. My boys are 17 and 12 now; being a mother didn’t stop. That remains a constant and requires work every day, disability or not. I live with my boyfriend, who is also a quadriplegic from a spinal cord injury. Along with the day-to-day stressors we still have a relationship to maintain, disability or not. We are human beings with some of the same patterns and behaviors we’d had even before our injuries, bringing them into one relationship. Loving, accepting, and exploring my own sexuality, allows me the ability to love and accept someone else.

“You yourself, as much as anybody else in the entire universe, deserve your love and affection.”

-Dalai Lama
UM SCI Model System Alumni News

Name: Eric Zeck  
Age: 33  
Date of Injury: 3/15/2012  
Level of Injury: T11-12, complete

SCI Access: Tell us about yourself! Have any significant events taken place since your injury? What have you accomplished? What do you do for work?

Eric: I am 33 years old and I have a younger sister, who is married with a 4-year-old son, Reed. I also have the world’s greatest parents. Last, but certainly not least is Angela, my girlfriend of just over a year. I haven’t had too many significant events take place post-injury other than starting to date Angela, about 14 months after my accident. Many small things now seem significant, since I almost died the night of my accident. I am grateful to be alive to experience the small things.

I have accomplished getting my life organized around my injury. I owned a small business across the street from Oakland County airport doing composite repair and paint refinishing on airplanes. I was back in my shop, working two months to the day after my motorcycle accident. I did my best to work from my wheelchair. But after two years, I slowly realized that I had to adjust my life to fit my disability.

Now I tutor kids and teenagers, usually at a local Starbucks where I can be close to where I can satisfy my coffee habit! I have it set up where I’m never in my chair for more than four hours at a time, which allows me to stretch out my muscles and meditate to help with my constant pain. I was hesitant to let go of certain things from my “old” life – my life before my crash. Today, my life is very different from a few years ago; I’m heading in a completely different direction. Not better or worse… just different, and that’s ok.

SCI Access: Tell us about your injury experience. What were some challenges, positive/negative experiences, etc.?

Eric: I crashed my Ducati motorcycle near my home around midnight on 3/15/12. I called 911. And that was the difference between living and dying, since there was a four-minute difference between my call and the call made by a person who stopped to help. It was immediately apparent to me that I was paralyzed. I looked down the stretcher and it felt like my legs were bent, with my knees in the air and my feet on the stretcher, but then I saw my legs were actually lying flat. I knew my life had just drastically changed. The news from the doctor a day later, confirmed my worst fear – I was completely paralyzed from the waist down with a 0% chance of ever walking again.

The worst experience was when the doctors broke the news to my family (I already knew) and seeing them break down, crying and hurting. It took me until I got home and moved in with my parents for the sense that I had lost everything I had built, as well as my sense of independence and my future, to set in. I’ve never cried like that before; I felt like my soul was being crushed into a million pieces. The part when they told me I’d never feel sex again was pretty bad too.

I’ve found that your outlook – how you perceive your situation - is the biggest determining factor (at least the factors that are within your control) for your happiness, or lack thereof. I found myself focusing on what I had lost, spiraling downward towards a deep, dark depression. The more I was depressed, the more I thought about what I couldn’t do, what I had lost, and the cycle continued until I found it hard to get out of bed. I didn’t feel like working. It took time to start focusing on the positive. I used work as a motivation, thinking “I’ll save up for stem cell therapy or for a cool wheelchair that stands me up, or something else that might help me recover some feeling or abilities.” As soon as I made the conscious decision to focus on what I had, what was good in my life, and how awesome my future could still be, regardless of if I was sitting or standing, awesome things started happening in my life. I met Angela, fell in love with her and now we live together in East Lansing!

One of the things that helped me was when someone told me that he was jealous of what I had. He had a higher level injury and had no use of his abs or lower back muscles. So I started becoming aware of how lucky I was, not only to still be alive but also because of the abilities I still have. There was also a young man, about 18 or 19, with me on 6A at U of M, who was in a car crash, had to have a respirator, and only could use his mouth. I could have lost a lot more that night, I always remember that.

SCI Access: Our newsletter topic is “relationships.” Can you tell us about your experience(s) dating after SCI?

Eric: My views on what I was looking for in someone I wanted to date or be in a relationship with drastically changed after my injury, and it was definitely for the better. I used to date the prettiest women I could, and just kind of hope that they were good people. Now I found that the most attractive quality for me is how good of a person they are, how beautiful they are on the inside, as well as the outside. I know it sounds cliché and it was probably something I should have been looking for from the beginning, but it opened my eyes to how much depth there can be in a relationship and what is truly important. You get what you put out there; positivity attracts positivity. After I got out of the hospital, I thought no one would want to be with me now that I was in a wheelchair. I thought I was going to be alone; I began
Anyone who has a SCI has lost something; some more than others. But we have all lost something. It is HARD to get past the grief, and the loss, bitterness and depression. But in the end, I’m glad I did because I found the love of my life, and I have a brighter future than I ever had before.

SCI Access: Share your advice! Any helpful tips or thoughts about dating, relationships, love, etc.?

Eric: In general, I guess the best rule of thumb is: All relationships are crazy; it’s about finding the one that you can put up with for the rest of your life. That and ‘happy wife, happy life.’

I have also found that being able to get a handle on your emotions in situations where things get heated is always a good idea; it’s something that can take a lot of practice though! Be positive. Be yourself.

A good friend once gave me advice that he found to be so important that he tells everyone in a chair: It’s important to find someone who is caring. It’s important they are giving. But it’s important that they are not caregiving. When that person crosses the line into something a caregiver or nurse should be doing, the results can be catastrophic. So caring and giving, but not caregiving.

Peer Mentor and Inspiration
In Memorial of Glenn Bates

Surrounded by people who loved him, Glenn Bates passed away on July 1, 2014 at the age of 65. Glenn inspired people with his ever-cheerful attitude and with his ability to overcome the handicaps in his life. The countless number of dear friends he left behind are all better for having known him. He touched many people’s lives that also had SCI for many different reasons. He was the living embodiment that life isn’t over post-injury. Mr. Bates was an inspiration not only because he drove a beautiful car—not a van – but also because he often mentioned he wouldn’t change a thing about his past life. His SCI didn’t prevent him from pursuing happiness. He was and will continue to be an inspiration and will truly be missed.
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SCI Rehabilitation Program Group

The bi-annual meeting of the Spinal Cord Injury Rehabilitation Program Group took place on September 10, 2014. Topics included updates on clinical services, discussions about risk management, patient advocacy, and patient resources. This interdisciplinary team meets to improve continuity of care progress in the SCI rehabilitation program at the University of Michigan.

Top row: Rachel Hartwig, Claire Kalpakjian, Donn Hilker, Ed Chadd, Anthony Chiolo, Marty Forchheimer, Brad Trumpower, Denise Tate, Gina Jay, and Maggie Travin.
Front row: Lisa Konkol, Tom Hoatlin, Connie Pines, and Nancy Merbitz.

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