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COVER STORY
CELEBRATING TIM

For almost a generation, New Mobility has been guided by our beloved editor, Tim Gilmer. And now, as he retires, it is time to bid him farewell — although we trust he will not go far from these pages. This issue is dedicated to Tim, from tributes by staff and freelancers to excerpts of a few of his greatest articles.

18 THANKS, TIM
We rounded up the usual suspects to join us in sharing a word for the man who made us all look our best. SAM MADDOX, BOB VOGEL and more write for Tim one last time.

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How can such a small column have such a large impact? Perhaps because TIM GILMER’s formula is one part heart, one part soul, and two parts authenticity.

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In every significant national event, wheelchair users are involved. TIM GILMER and JOSIE BYZEK reflect on how New Mobility tells our stories.

28 LIFESTYLES OF THE WHEELED AND FAMOUS
Here are excerpts from three of TIM GILMER’s many profiles of well-known wheelers.

36 AN ANNOTATED MEDICAL COMPENDIUM
SETH MCBRIDE captures and collates TIM GILMER’s most useful health-related articles.
My first memory of New Mobility is wanting nothing to do with it. I was barely 18 and struggling on a ventilator in rehab a couple of months after blowing out my C5 vertebra in a rollover accident.

I had spent all my time surrounded by other people with spinal cord injuries, learning about spinal cord injuries, talking about spinal cord injuries and living with a spinal cord injury. When my parents offered me a copy of New Mobility, the last thing in the world I wanted was to read about spinal cord injury and the wheelchair life that awaited me beyond the hospital walls.

If you had told me that 20 years later I would be the editor of New Mobility, I feel pretty confident that I would have told you there was a better chance I’d be walking by then. But here I am, feeling out the Bully Pulpit and formally introducing myself to you, the readers.

I’ve had the pleasure of getting to know many of you over the last seven years. I started as a sporadic contributor to the website, then worked as the editor of sister publication Life in Action, and finally served as an editor and writer for New Mobility the last four years.

Whether via email, phone call or even the occasional fax, you’ve shared your honest responses and insights, and in doing so, helped to educate me and strengthen the magazine. I have grown to cherish the relationships I’ve made, that it’s hard for me to believe I almost closed myself off from them.

After I got out of rehab I focused on me. I went to college, learned to manage personal care attendants, negotiate government benefits and handle all the other fun stuff that comes with an injury. I didn’t have any wheelers in my inner circle, and I saw no need to change that.

If not for a fortuitous meeting with NM Executive Editor Josie Byzek in 2010, I might have stayed on that path. I met Josie at an advocacy event in Washington, D.C., and pitched myself as the answer to all the magazine’s writing needs. She gave me a chance to write an article for NewMobility.com, and, well, the rest is history.

Working with the NM staff under the aegis of United Spinal brought me into a rich world I feel foolish for having ignored. Much of my writing prior to New Mobility focused on sports. It was fun, but often left me feeling empty. Writing about other wheelchair users and the issues we all face every day proved more challenging but infinitely more rewarding.

I’ve learned so much about how little I knew about disability, and I’ve developed a deep appreciation for the strength of our community and the richness of our stories.

I’ve also seen how important it is that we tell these stories in an authentic way, not only for our own well-being but so others can begin to understand the complex lives we lead. For 29 years, New Mobility has been at the forefront of doing just this, and I’m honored and excited to keep forging ahead with you.
BEST WISHES, TIM. WELCOME, IAN.

Two big things are happening in this issue: We honor retiring editor Tim Gilmer and his legacy, and we officially welcome Ian Ruder to the editor’s seat.

It has been my pleasure to watch Ian grow as a journalist, and I am delighted to see him embrace his new role. I can assure you that as NM’s editor, he will advocate for you in ways both obvious and invisible. Not only will he continue educating legislators about SCI/D at United Spinal’s high-profile Roll on Capitol Hill, he’ll do 300 times as many jobs behind the scenes: reading manuscripts, assigning stories, nurturing writers, shaping copy, mining social media, brainstorming ideas and collaborating with the other editors and designers to craft a magazine that brings you information, resources, peer support and, we hope, meaning.

This is no small job — editorial decisions can deeply affect readers, writers and the larger community. Ian is ready for this. So please join me in welcoming him to his new post. Send him your ideas, your stories, your feedback.

As for Tim, much of this issue serves as a tribute to him and his stellar career. If you’ve been around a while, you may recognize a few of his great pieces of writing; he promises that there are plenty more where those came from, so stay tuned.

Welcome, everyone, to a new era.

Outgoing editor Tim Gilmer and incoming editor Ian Ruder live 20 miles apart in Portland, Oregon.

Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org
It Meant So Much

For the last 10 years there has been an unexplainable comfort knowing that Tim Gilmer was steering the ship of New Mobility. It is special to see somebody in his 70s living with and pushing through this ridiculous life of spinal cord injury. Tim has given this community a lot of wisdom in the last 17 years. I hope the wisdom is not lost in an attempt to appeal to the prototypical younger SCI person. So, tip a toast to Tim and keep his voice alive. Thanks.

Dan Nicholson

You were a worthy successor to Barry Corbet. Your writing is excellent — clear, concise and compassionate — and you have never been afraid to take a stand. I was in tears when Barry left the post, and history is now repeating itself. Congratulations on whatever adventures await you. I’m glad NM continues on.

Cindy Brown

I wish you the very best in whatever you choose to do or whatever path is shown for you to follow. You helped to guide me through the trying time when my son was injured back in the early 2000s. You helped give my frustration a voice, something for which I shall ever be grateful. Thank you, Tim.

John E. Smith

So many things Tim writes about really hit me in the gut. It’s just incredible.

Kirk Sketchley

Tim, I have followed your editorials since you began writing for NM. Your words have always had great meaning to me as a 71-year-old quad. Your article is always the first one I turn to and will be greatly missed. I hope you have a great retirement and good health to come.

David Coffield

Oh, Tim! I will miss your monthly adventures! Of course, I wish you all the best. I’m glad NM is in such capable hands, and I hope to continue to read your wheelchair wisdom for years to come.

Susan Scofield

Thank you for thoughtfully sharing your insights and experiences, Tim. I look forward to contributions from “retired” you. Keep being awesome, new editing team!

Brook McCall

I believe as you, and hope that whatever God is leading you into next brings the same kind of fulfillment.

David Keyes

Your sage words will be missed. It was an honor working with you for so many years.

Tiffany Carlson

I’m glad to read anything Tim Gilmer writes.

Marge Heatley

Hey, Tim. I remember vividly the day you, me, Barry and Jean met. Thank you very much for your many years as NM’s incredible editor! Enjoy retirement.

Jeff Leonard (former owner of NM)

Please, please, please find a way to keep sharing your thoughts, experiences and insights. You are a voice that still needs to be heard. Thanks for such a great career.

Mike Savicki

We want to hear more from you Tim, not less … sad that you are moving on … please keep us posted on your recovery from flap surgery and other experiences in life. Best wishes for your continued journey of life.

Madonna Logoz

Best of luck to Tim as he transitions into the next chapter of his life. I’ve always enjoyed his writing, which was (and still is) without exception informed and informative, relevant, clearly expressed, honest and heartfelt.

Stephen Feldman

I’m a better man — and a better writer — for having been a partner on this journey with you. All best!

Gary Karp

All the best to you, Tim! I so enjoyed working with you … and having the opportunity to contribute to a great publication. You will certainly be missed!

Linda Mastandrea

Sad for us but happy for you!

Lois West
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The insufficient supply of personal care workers to meet the demand of an American population increasingly in need of care has been the focus of a number of recent articles in major media outlets. The New York Times, Bloomberg, The Hill and The Washington Post are just a few of the platforms to tackle this emerging national crisis.

An aging baby boomer population, combined with chronically underfunded state Medicaid programs, low wages, lack of benefits and tough working conditions for home healthcare workers, is creating a dire situation for people who rely on all types of personal care. The New York Times reported in 2017 that "if nothing is done to draw more workers into the field, there will be a shortage of at least 350,000 paid care providers by 2040."

While much of the national concern about the home health labor shortage is focused on the impact for the growing elderly population, the shortage is already having a devastating impact on the disability community. From New York to Minnesota, people with disabilities who rely on personal care attendants are increasingly struggling to maintain sufficient care hours.

In May, the Minneapolis Star Tribune published a piece titled, "Shortage of home health workers forcing young Minnesotans with disabilities into institutions," which profiled three women who were stuck in nursing homes or assisted living facilities because of the difficulty of maintaining personal care assistance at home.

One of those women is Lauren Thompson, a writer, disability rights advocate and Ms. Wheelchair Minnesota 2016, who used the platform of the pageant system to warn of the impending home health care crisis.

Thompson moved out of her childhood home in 2011, and initially moved into a group home for people with disabilities. She then moved into her own home, but after being forced into a nursing home for a short period following a surgery, Thompson put herself on a waiting list for an apartment in an assisted living facility to ensure her care needs would be met. "Initially, it was a relief to be in assisted living care because managing home health care was a struggle," she says. "But I have no say in the staff who help me or their training, and I have decreasing control in my care."

In Minnesota, the home healthcare crisis is making it difficult for even those who have years of experience in PCA management to maintain sufficient, quality care at home.

"It's always been a problem finding good employees with longevity, but it's gotten more difficult to retain them," says Roxanne Furlong, who has been directing her own in-home care for years in Inver Grove Heights, Minnesota. "All of my good PCAs who've worked for me usually stay for more than three months, but move on looking for higher pay," adds Furlong, a contributing editor for New Mobility who has written about strategies for PCA management. "I talked to my social worker last year about how hard it is to find good quality help, and she said she'd recently called 39 agencies to find someone for one of her clients but none had anyone available."

For young people like Thompson who see the labor market for PCA services continue to tighten, the crisis is increasingly making for a terrible decision: try to live independently but risk being forced into a nursing home for an indeterminate amount of time if your care falls through; or move into an assisted living facility to guarantee your basic needs are met. As Thompson's experience in assisted living shows, the safer option might be better than a nursing home, but that's a life that no young person deserves.

— Seth McBride

My name is Lauren. I'm 30 years old and I live in Champlin, Minnesota. I am a writer and a disability rights advocate. In my free time, I like to watch movies, go arm-biking and to simply be with my friends and family. But, lately, what I feel like I've been doing most of all in my life, is waiting. I wait because I have cerebral palsy and rely on...
personal care assistance to survive.

At the assisted living facility where I now live, staff help me with everything from getting me out of bed in the morning, to getting dressed, cooking and cleaning. But I constantly have to wait for help, as the client to staff ratio is often 11 to one. To balance meeting the needs of many different clients at once, the aides are forced to prioritize their work.

This means the staff come to me whenever they have a free moment. Sometimes I have to get up earlier than I expected, but usually I have to get up later than I expected. Sometimes the wait is just a few minutes, sometimes it could be an hour or two. I just don’t know until they show up, so I need to be prepared either way. I’ve gotten in the habit of keeping my medication in bed with me so that I don’t have to worry about missing a dose while I’m waiting. There have been many times I have had to cancel my plans for the day because the staff haven’t been able to get me ready in time. At night, I have a set bedtime. If it’s in my control, I schedule events in the afternoon — if they’re in the morning or later at night, I can’t participate.

Constantly, there is a sense of urgency coming from the staff — they have 10 other people to think about helping besides me. Sometimes that means trying to get everything done as quickly as possible, sometimes that means doing my care by priority, in bits and pieces, coming and going, doing things when they can.

When my care is done too quickly, mistakes are made: My clothes are put on wrong, my hair is a mess, or the aides just forget to do something. Then they have to come back, and I never know exactly how long I’ll have to wait. I feel a personal obligation to simplify everything — I have very basic meal prep, simple cleaning routines and habits. The more complex or complicated the task, the longer I have to wait for it to be done, if it can be done at all. My apartment has gone weeks uncleaned, and I often miss my exercise routines.

I want to emphasize that the staff who are helping me now have the best intentions. But with the circumstances they’re put under, they’d need five hands to do all the work they’re expected to.

Advocacy, meeting with officials and my community is how I keep myself intact — it makes me hopeful and happy amongst all of this crap. Apart from my own needs, I wanted to help the PCA community of Minnesota, so in 2015 I started PCA Connections Minnesota. It’s a PCA services support network on Facebook where clients, PCAs, families and other stakeholders of this community in Minnesota connect to each other. People post want ads, share information, and support one another.

It has since grown to 2,000 members. I am grateful to be able to help people through this group, but I am even more grateful to have it there for myself. When I’m stuck at home and have nothing much to do, the group helps me break through the isolation, to see that I am not alone.

I see the magnitude of the crisis and, as an advocate, know that I have work to do. But, I haven’t been able to do as much work as I’ve wanted, in large part, because of this crisis. Life in an assisted living facility makes me feel like I’m on a broken assembly line. I absolutely feel stuck. Stuck in every way. Because, it is difficult to have a job, to be a contributing member of society, or to even visit friends when you can’t know what time you’ll be able to get out of bed in the morning.

— LAUREN THOMPSON

Resources

• “Shortage of home health workers forcing young Minnesotans with disabilities into institutions” Minneapolis Star Tribune, starttribune.com/shortage-of-home-health-workers-forcing-young-minnesotans-with-disabilities-into-institutions/481835481/
• “Americans Will Struggle to Grow Old at Home” Bloomberg, bloomberg.com/news/features/2018-02-09/americans-will-struggle-to-grow-old-at-home

Did You KNOW...

United Spinal Association produces more than 30 brochures and pamphlets on subjects like Disability Etiquette, Fire Safety for Wheelchair Users at Work and Home and Understanding the ADA. You can download them for FREE or order printed copies on our website at www.unitedspinal.org

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MEMBER BENEFITS

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- Accessibility Advocacy
- Local Chapters
- New Mobility magazine
- Informative and Educational Publications
- Ongoing Educational Webinars

Membership in United Spinal Association is free and open to all individuals who are living with SCI/D, their family members, friends, and healthcare providers. Visit unitedspinal.org or call 800/962-9629.

United Spinal has over 70 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive grassroots network that enriches lives.

NEW RESOURCES

UNITED ON THE AIR

A new podcast from United Spinal aims to provide the same SCI/D insight and resources the organization is known for in a more accessible and entertaining format. Launched in April, United on Wheels is produced under the aegis of United Spinal’s communications team and the United Spinal Resource Center, and is hosted by New Mobility Editor Ian Ruder. So far, episodes have featured a diverse selection of United Spinal employees and members discussing topics pertinent to wheelers, such as advocacy, travel and relationships, in a candid, back-and-forth dialogue.

“We’re really hoping to tap into the wisdom that our members and staff have, and distill that in a fun, approachable way,” says Ruder, a C5 quad.

With a panel of five staff members who brought more than 50 years of life experience with SCI, the inaugural episode dug into the difficulties of air travel with a wheelchair, and what you can do to make traveling with your chair easier.

“As someone who has never flown with my chair, the whole conversation was really helpful,” says United Spinal staff member Jose Hernandez, a C5 quad who contributed to the episode. “At the same time, I had a great time recording it.”

Episodes are available on the United Spinal website at unitedonwheels.blubrry.net, and on iTunes. Future episodes will focus on key topics such as employment and common misconceptions people have about wheelchair users. If you have a topic you’d like to see addressed, or would like to be a part of a future podcast, email iruder@unitedspinal.org.

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ADDRESS THE STRESS

Stress is a normal physiological reaction. In short bursts, it is beneficial to our health and survival. However, studies demonstrate that people with disabilities tend to experience more stress due to chronic physical pain, financial strain, difficulties with activities of everyday living and inaccessible environments. Prolonged stress wreaks havoc on our body, often exacerbating other disability-related health conditions.

The detrimental effects of chronic stress are due to an overabundance of stress hormones. Our adrenal glands, located on top of our kidneys, produce and release stress hormones in response to any kind of physical, mental or emotional stress. Cortisol is the most damaging hormone to our health when over-secreted into our bloodstream. So what does this have to with disability and nutrition? Lots.

Stress decreases our digestive function and our ability to break down and absorb nutrients. It lowers our production of stomach acid, which is critical to the breakdown and absorption of minerals and protein. Stress also makes our digestive enzymes less effective. These enzymes are required to help digest fats, carbohydrates, and proteins. However, cortisol can increase the acidification of our tissues, which in turn inhibits digestive enzyme activity, thus reducing enzymes’ effectiveness in digesting the nutrients we consume.

Many people with conditions such as traumatic brain injury, spinal cord injury, muscular dystrophy and cerebral palsy have compromised digestive systems and tend to experience nutrient deficiencies. Stress worsens pre-existing weakened digestive function, further diminishing nutrient levels and ultimately putting individuals at greater risk of developing multiple secondary health conditions.

Stress hormones can cause nutrients in the body to be used up more quickly. For example, magnesium stored in muscle tissue and calcium stored in bones is depleted, putting individuals with osteoporosis at risk for further bone loss. Vitamin C, necessary for immune health and skin integrity, is used to make adrenal hormones, and therefore is not as readily available to protect individuals who may be vulnerable to pressure sores or have a high risk of respiratory infections. Additionally, B vitamins are diminished as they are also used to create adrenal hormones, therefore negatively impacting energy levels of people at risk for fatigue, such as those with any kind of neuromuscular disease. Finally, nutrient deficiencies from stress contribute to weakening the immune system.

The good news is when you are under stress there are numerous nutritional strategies you can incorporate into your daily regime that can help combat its negative effects.

1. Increase intake of vitamin C. Foods like green/red peppers, kale, broccoli, and citrus fruits will help replenish what is lost through the production of stress hormones and support your immune system.
2. Increase intake of B vitamins. This will help replenish what is lost, support adrenal function and energy production. Try avocados, legumes, lentils and oats.
3. Reduce caffeine and alcohol, which stimulate your adrenal glands, contributing to adrenal stress/fatigue.
4. Increase intake of probiotics. These healthy bacteria play an important role in the digestion of food, facilitate the dissemination of nutrients and stimulate intestinal transit. Additionally, probiotics improve the absorption of B vitamins, help reduce the loss of vitamin C and strengthen your immune system. Try plain unsweetened yogurt, sauerkraut, fermented vegetables, miso and kombucha.
5. Take vitamin D supplements. It is well known that vitamin D plays a critical role in preventing osteoporosis, but research also reveals it plays an important role in supporting immune function.

NEGATIVE EFFECTS OF HIGH CORTISOL

Prolonged stress can contribute to obesity, diabetes, cardiovascular disease, depression and anxiety, memory and concentration problems, arthritis, reduced sex drive, osteoporosis and reduced immune function/increased risk of infection.

High cortisol levels can also lead to weight gain, increased risk of blood clotting, elevated blood sugar, worse premenstrual and menopause symptoms, breakdown of bone mass, disrupted sleep, mood swings and high blood pressure, among other health concerns.
ANTI-STRESS SIBERIAN GINSENG TEA*

This beneficial botanical is often referred to as “adaptogen” because it helps us adapt to, or cope with, stress. The anti-stress action is mediated by mechanisms that control the adrenal glands. Siberian ginseng delays the onset and reduces the severity of the “alarm phase” of the body’s short and long-term response to stress.

1 large pinch raw
Siberian ginseng root
2 cups water
1 tea ball
Bring water to boil, pour in large mug. Place Siberian ginseng root in tea ball and put in mug. Steep for at least 10 minutes. Enjoy hot or cold!

*Do not consume if you are pregnant, on blood thinning medications or have high blood pressure.

I SMILE

I smile when I’m happy, when I’m being polite or because I think someone is amazing. I also smile when my heart is broken, hoping no one will see past my teeth. Those kinds of smiles are hard. They take all the muscles in my face to sustain, and my throat contracts to keep my heart from escaping.

For a long time following my car accident and spinal cord injury, I observed my loved ones. I saw hurt in their eyes, but we all silenced it to protect one another from pain. “You are so strong,” people said. “She has such a positive attitude.” I did and I do. I was optimistic and determined, but that didn’t mean I wasn’t hurting or that I sometimes don’t feel pain and the loss of a life I once had. I felt I shouldn’t show sadness or anger because it would make others feel them too.

Many times I wished someone would just ask me how I was doing and wait long enough to hear the truth. But I was too scared and didn’t want to share my burden, so I’d quickly answer, “Great! How are you?”

In recent years the hurt I see in my family’s eyes is not as intense and fragile. We are allowing ourselves to talk even if it’s difficult. Moments where we recall the details of a wreck, hospital smells or coming back home in a wheelchair may lead to tears and even laughter in between.

It feels good to cry. I feel relieved — another reason to smile.

Joanne Smith is a nutritionist and co-author of Eat Well Live Well with SCI and Other Neurological Conditions. For more information on nutrition for neurological injuries, go to www.eatwelllivewellwithsci.com.
My wife and I recently bought a duplex with my sister, a three-story, 1916 craftsman with no hint of accessibility to it. Where we’ve lived previously, accessibility modifications have been minimal — a ramp to get in, a shower bench and a grab bar for the bathroom. As long as there aren’t a bunch of different levels and the doors are wide enough to fit my chair in, I can typically make do without a lot of specific accessibility features, or so I thought.

The main floor unit of the house, where we now live, has a tiny bathroom with a claw foot tub and an ill-designed kitchen with an island jammed in between an alley of cabinets. The rest of the house is beautiful and had exactly the kind of space and character we were looking for. So, I pulled some rose-colored glasses over my eyes, and we decided to go for it.

Once we moved in, I realized that, technically, I could make it work. But this didn’t factor in how much of a pain in the ass it would be to transfer into and out of a claw foot bathtub every day and do dishes in a space where Kelly couldn’t squeeze past me while I was at the sink. We knew we’d have to make some changes, but with a crazy local real estate market we didn’t have the money for a professional remodel. DIY to the rescue.

Claw Foot Shower Bench
Claw foot tubs are tricky. You can’t put a regular shower bench in one because of how the tub walls slope, but if you were to just secure some sort of seat across the top, you wouldn’t be able to get a shower curtain down into the tub. I put the problem to my dad, a retired heavy equipment mechanic, welder, amateur machinist and general do-everything kind of guy. After he let the problem marinate for a few days, his solution was a sort of hanging basket. Pieces of flat bar would hook over the rim of the tub — one on each side and one in the back — then angle down into the tub before flattening out to create trusses to which a seat could be attached. Because the seat would sit just below the rim of the tub, I’d be able to get the shower curtain down into the tub, thereby avoiding soaking the bathroom every time I showered. “Brilliant,” I said after he told me the idea.

“I guess we’ll find out,” he shrugged.

At first, my dad was planning to make some sort of seat. Then he found an extra shower bench in our work shed. The seat and backrest are self-contained, secured to the legs by a couple of screws. Why fabricate a new one when you can just adapt what you already have?

After taking the measurements, cutting, welding and bending the frame to fit our particular tub, he secured the shower bench seat to the frame with a couple of spacers and the bolts that originally had attached it to the legs. The finishing touch was to spray the steel frame with some Flex Seal, a rubberized paint, so that it wouldn’t rust or clank too much on the cast iron tub.

I happen to have a dad-of-all-trades, but a handy chair user or just about any machine shop could easily weld and bend a similar frame. Attaching a shower bench to the frame with a couple of spacers and the bolts that originally had attached it to the legs. The finishing touch was to spray the steel frame with some Flex Seal, a rubberized paint, so that it wouldn’t rust or clank too much on the cast iron tub.

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bench seat is as simple as drilling a few holes and screwing it on. The setup works as both of us had hoped. The transfer still isn’t easy. I have to throw my legs into the tub first to get decent leverage. But it’s a hell of a lot easier than going down to the floor of the tub and back out. And all the water stays in the tub. As my dad said when he finished, “I guess it’ll work.”

**Kitchen Remodel**

There’s nothing easy about a DIY kitchen remodel. Ours took six adults — two of whom built their own houses — 10 days of work. But we did the whole shebang, as we figured we might as well do it all at once. Some of the goals were aesthetic, as everything was old, grimy, and “in a state of deferred maintenance” as our home inspector put it. My main accessibility concerns were opening up the layout and changing out the sink, as it was a deep, double-bowl cast iron sink that was difficult for me to use.

To open up the layout, we ripped out the island and put a peninsula perpendicular to where it had been. Behind the peninsula was the only place to put a kitchen table, so we decided to install a built-in table that would be supported by some beefy shelving brackets so I could roll under it without having to worry about running into the table legs. We chose butcher-block style counter tops for looks, price (they’re less than half the price of stone) and for adaptability. Because they’re made of actual wood, anyone with some basic carpentry skills can modify them, whereas stone or concrete take some serious skills and specialized tools. We made the table out of the same butcher block as the counter tops.

An unexpected bonus with putting a table set lower than the countertop height is that I can use it as a food prep area. It’s still central to everything in the kitchen, but I can roll under it and it’s at a height that is functional from a chair. I’d never had anything like this, but as soon as I started using it for food prep, it made everything — cutting, stirring, grating, mixing — much easier and less time-intensive.

We used the same shelving brackets to support a narrow countertop next to the stove instead of putting in a cabinet. This allows me to roll under it, right next to the stove and have easier access to items cooking on that side’s burners. We also have a Breville toaster oven on that counter, which operates as well as a normal electric oven, just smaller. Considering that my baking repertoire consists of nachos, pupusas, fish sticks and quiches, it works perfectly (yes, it fit and cooks a 9 inch pie crust quiche with no issues). And it’s much easier to use than lifting pans in and out of a regular oven.

For the sink, our dads cut a countertop hole, and we chose a large, stainless-steel rectangle that is only 9 inches deep. The large single bowl and shallow design are key for me. The large single bowl and shallow design are key for me. There’s enough room for me to get my elbows in there for leverage. This is important, as my hands are pretty weak, and not having to reach down a couple extra inches is huge when you’re coming at dishes from a seated position. Sometimes simple is best.

Do you have any DIY home modification tips or stories? Share them with us — online, social media, email, old-fashioned letter, however you want — and we’ll put up a blog post on Newmobility.com with your best ideas for making your home functional without breaking the bank. Happy hacking.
ON THE GO

Karen Roy

This fall, for the first time in 24 years, Louisiana member Karen Roy will have her Baton Rouge home all to herself. Her youngest son will be off to college, and his two older siblings have already moved out. With her three little dogs in tow, Roy is unfazed by the prospect of empty nesting. “That’s what you want,” she says, laughing. “I saw something on the news today where the parents of a 30-year-old were taking him to court to evict him, so, I guess it’s a sign you’ve done your job well.”

A Stand-Up Woman

Roy, a T10 para, won’t lack for things to do with her new freedom. She travels all over the Southeast for her job with Numotion, serves as a board member for the Brain Injury Association of Louisiana, which serves as the state United Spinal Association chapter, and is the reigning Ms. Wheelchair Louisiana.

After a 20-plus year career as a hospital social worker, Roy is enjoying the freedom that comes with her new job, even if it means she spends long hours on the road. “I was stuck inside of a hospital for so long, and it was just crisis after crisis. And even if it’s not, it’s fax after fax, and you are in the same place every single day,” she says. “Now, granted, when it’s 110 degrees down here and I’ve gotten in and out of my car with my wheelchair six times, I’m doubting my choices. But for the most part, I like the freedom and the flexibility. I like being able to listen to an audio book or whatever music I want to while I’m on the road.”

Looking back on her career as a social worker, Roy says it was difficult to watch the length of rehab stays for people with spinal cord injuries continually get shortened.

“The length of stay when I got injured in ’87 was like three months,” she says. “It got progressively to the point where you could have a spinal cord injury, and if you were lucky, you’d get four to six weeks, and they may try to kick you out sooner.”

Roy always emphasized how critical mastering the basics of SCI — bowel, bladder and skin care — is when she worked with people with new injuries. She worries that shortened rehab stays are sending many people out of the hospital without the knowledge they need to lead full lives.

That is one of the issues she educates the public about in her role as Ms. Wheelchair Louisiana. The state’s program wasn’t active, so Roy didn’t have any competition, but she saw an
opportunity to do more than just wear a crown.

“I decided to volunteer to run the program,” she says. “So that will be my responsibility after my reign, to promote the organization for women with disabilities, and try to get a real pageant organized for the following year, for 2019.”

Roy is enjoying the challenge and taking advantage of speaking opportunities across the state to spread her platform about the importance of standing and exercising after SCI. She uses braces, a TekRMD standing frame and a FES bike to make sure she stays in shape. “I definitely credit that with a lot of my health for the last 30 years,” she says. “I’ve never had a wound, a fracture, contracture — any of that.”

“They say that sitting is the new smoking,” she says. “And for those of us who cannot stand on our own it’s not any less important. I’m just glad to tell people all about it.”

WEARING IT WELL

The Gift of Garb

Clothes are one of my only vices. I have a gigantic walk-in closet full of clothes. It’s an enormous amount — and slightly embarrassing — but I am a bargain shopper, and definitely not a hoarder.

I love clothes and I think they can be a real confidence booster. I like the idea that people see me and not the chair. That really was my whole point: ‘Yes, I’m in a chair, but I would prefer you see me.’

I remember when I first got hurt and I went back to school at LSU. I was in the center of all these people, parking and getting out, and I vividly remember thinking to myself ‘if everyone wants to stare at me, I’m gonna look good, and I’m having a really cute outfit on. And I’m just gonna pretend like they’re all looking at my outfit.’

Because I do intermittent cathing, I really don’t wear pants. I’m always out and about, so I wear dresses for the ease of using the bathroom. The skirts and the dresses have to be form fitting because even with clothes guards they get in the way of the chair, get dirt rubbed into them and they get ruined.

CRAZIEST PLACE I’VE BEEN:
Getting to the top of the Acropolis was pretty cool. I had to get some help pushing up the hill, but they had a lift to the top.

WHEELCHAIR FASHION DO’S AND DON’TS:
Do: Boots and pencil skirts — they always look cute and they stay on.
Don’t: Bangle bracelets — they get in the way of pushing and make noise.
Thanks, Tim

TRIBUTES FROM NM STAFF AND FREELancers

For almost a full generation, our editor Tim Gilmer has guided and mentored us, making our words more relevant and powerful. Now it’s our turn to tell him how much we appreciate all he’s done for us, and for our readers.

Living Life to the Fullest

As the member of the editorial staff who lives closest to Tim’s Oregon home, I have had the great fortune to get to spend the most time face-to-face with him over the six years we’ve worked together. Our rendezvous usually take one of two forms. Either I drive down to his walnut/tomato farm for a lovely afternoon watching swarms of hummingbirds feed on his deck while his grandson builds elaborate structures and plays in the fields, or I find myself navigating a full hospital parking lot in search of an accessible spot so I can check in on him after his latest medical adventure.

It’s a stark contrast, but probably one many of our readers can identify with. One day things are hunky-dory, the next everything is upside down. Having had my personal share of medical adventures and knowing how difficult it can be to remain positive, I am continually impressed by Tim’s unfailing determination to return to his beautiful home and get back to his life.

There are a number of reasons why Tim has been able to so deftly guide New Mobility over the last 17 and a half years — his writing and editing skills obviously, his people skills, and his candor and willingness to share his experiences — but first and foremost is that he literally personifies the magazine’s underlying ethos: refusing to let a disability get in the way of living life to the fullest.

In each of the 211 issues of New Mobility Tim edited, he invited readers onto his porch and candidly chronicled his journey to stay there. He leaves an unparalleled body of work that will help future readers and allow them to get to know the man that I am so honored to call a friend.

— Ian Ruder

Just the Kick I Needed

As the newest staff member for New Mobility, I can think of no better tribute to Tim than to say that he helped turn me into a writer. Of course, I thought I was a writer before I first contacted Tim in 2010, looking to do some freelance work for the magazine. I’d sent him a memoir-ish piece of text that I’d used in my application for MFA programs and was quite proud of. I’d carefully crafted the prose and spent countless hours refining descriptions, mostly of the forest near my Alaska home. I’d never thought to consider the story I was telling, or who I might be telling it to.

After buttering me up with a few compliments about my “command of the language,” he let the hammer drop. “What you sent me is too much about too little. There is no story. It is almost like a writing exercise in description, and the reader is asked to supply the theme and story. Magazine writing is different. Space is valuable, literally. You can assign a dollar value to each square inch, and readers have short attention spans.”

He went on, but the message was clear — if you want to write for us, write something that is worth its space rather than waxing on about squawking crows and decaying conifer stumps.

It was just the kick in the ass I needed. Over phone calls and emails, he helped guide me through the process of magazine writing. Wrestling my often-florid prose into something tight and interesting to the readers of New Mobility was a process, one that Tim undertook with a great deal of patience and understanding.
Looking back, I realize that before Tim shook some sense into me I wasn’t actually a writer. I wrote, but it was primarily for my own amusement. Actually being a writer, instead of just saying you’re one, is about putting the reader first and telling stories that offer something to the world outside of yourself.

It’s something I’m still working on, but I can’t thank Tim enough for starting me along the path.

— Seth McBride

The Heart and Soul of NM

Who knew Tim Gilmer before he arrived at the top of the New Mobility masthead, back in late 2000? Barry Corbet had retired but by reputation and myth still embodied the post. I guess I’d heard Tim had 35 years on the gimp trail and that he taught writing at a college, and that he had a little organic farm outside Portland. Is he the guy to carry forward the vision?

Well, yeah. Apparently he was.

At some point I started writing a few features and a monthly column for Tim called Uncle Spine. He was forced to be patient with deadline indulgences, but we hit it off just fine — we both cared about getting it right, about entertaining and informing the NewMobe hive.

I came to appreciate Tim as a nosy reporter in 2002 when
he flew to New York to interview Christopher Reeve — set up by Random House to flak Reeve’s new book, Nothing is Impossible. I had been to visit Reeve a few years earlier at his Pound Ridge home and told Tim how I had left behind a brand new linen jacket that no one in the fairly chaotic household could ever locate. Tim said he’d look for it, sure enough he reported in his piece that when left alone he snooped through Reeve’s closets looking, but with no luck.

Writers love good editors. They can make your rocks into gems. Tim was decisive with language arts, weeding out tropey journalism and sloppy syntax but not so lapidary as to dull the patina of style. Tim was what you want in an editor. Collegial and encouraging. He always justified changes and was always transparent. He never made any attempt, as some editors do, of presuming any ownership of a piece.

So now it’s time to look back at the heart and soul he’s left in the magazine. A formidable body of work, man. Thanks, Tim.

— Sam Maddox

Fighting the Good Fight

Tim’s Bully Pulpit column encourages us to fight the good fight. It’s the first place I turn every month. No inspirational cripple stories for Tim — just real people engaged in interesting activities or frustrated with the status quo. No cheap tricks. No exploitation. Just truth and its consequences. Thank you, Tim, for informing the world that life using a wheelchair is challenging, nuanced and fulfilling.

— James Weisman

A Resounding Voice

For the past 17 years, Tim hasn’t just been the editor of New Mobility, but, through his role, a resounding voice of living with disability in the most genuine sense. Under Tim’s stewardship, NM has dared to tackle not just the feel-good, but the tough stuff, too. What Tim shows is that there’s ultimately no such thing as “disability experience.” Rather, we’re all in the same trenches of finding our way through “human experience.” Tim leaves a legacy of improving the lives of countless individuals with his work, wisdom and heart. I wish him the absolute best in retirement, and extend our deepest gratitude for all that he has given to us, his readers — touching so many lives far beyond any printed page.

— Mark E. Smith

My Old Buddy Tim

Tim is the best editor I’ve ever dealt with. A lot of people in his position are anxious chain-smokers, tyrannical chain-smokers, or both. Tim used another time-honored tactic: smarts. I never fought a change in a story that he suggested. If not always right, he wore you down with calm logic. This is a lost art in this day of bullies and screamers and specious provocateurs. Rational, adult compromise — what a concept!

I came to admire and appreciate Tim even more when my wife and I visited him and his wife, Sam, at their home outside of Portland. They live on a beautiful, sylvan truck farm, surrounded by fields of tomatoes, in a slightly modernized version of the clapboard farm-house that my Great-Uncle Alfred lived in outside of Carney, Oklahoma. If, in that old saw, “The best revenge is living well,” I figured Tim and Sam had pulled off the best revenge possible for becoming paralyzed in your 20s. It may have not been Valhalla — running a farm is crazy hard, frustrating, and rarely profitable — but at least from my tired urban eyes, it could sure as hell pass for it.

Here’s hoping Tim leases his farm land to a young couple deserving of living their dreams, enjoys his grandkids, and writes whatever he damn pleases. He sure gave his heart and soul to this magazine.

— Allen Rucker

His Caring is Genuine

I met Tim in 2003 when he flew to California to speak with me and my family for a New Mobility story. Tim was so warm and easy to talk to that sharing came easily. He asked all the right questions and got me to divulge details about my life I hadn’t shared publicly before. I was so impressed with his authentic charm, clear intellect, and his ability to not only get my story, but get me.

In 2007 Tim contacted me to write a story of Kristina Ripatti, a police officer and mom about my age who had sustained an SCI. I had never written a profile piece, let alone a cover story. Tim was so warm and easy to talk to that sharing came easily. He asked all the right questions and got me to divulge details about my life I hadn’t shared publicly before. I was so impressed with his authentic charm, clear intellect, and his ability to not only get my story, but get me.

In 2007 Tim contacted me to write a story of Kristina Ripatti, a police officer and mom about my age who had sustained an SCI. I had never written a profile piece, let alone a cover story, but Tim had faith in me. He guided and supported me through the interview and execution. I was so nervous I had my sister look the piece over before sending him my first draft. Tim was not pleased. But, instead of scolding me, he urged me to trust him. He assured me that he believed in my abilities and that as my editor, he would bring out the best in my writing. And he did. His wisdom and advice are always spot-on, and his caring spirit is genuine. Like countless others, he has not only changed me for the better, he has changed me for good.

— Ellen Stohl

Editor, Farmer, Friend

Writing for a new editor can be intimidating. Fortunately, Tim followed up Barry Corbet’s deft editing with his own deft editing and words of encouragement. Although there were
The Day I Got Out of Tim’s Way

When I was telling my husband that June would be Tim’s last month as editor, I started to cry. At first I wasn’t sure why because when I described his retirement, it’s the one we all want: He did high-quality, heartfelt work over a long, admirable career — and he’ll continue to be involved with the magazine in new and exciting ways, unburdened by the demands of a full-time job.

But still. We won’t speak as often, younger editors will fill the void, and NM will take on a new persona. While possibility hangs on the horizon, wistfulness steals under the radar.

During the early days, Tim and I struggled to find our own rhythm after Barry Corbet retired. We probably broke every Human Resources rule about avoiding religion in the workplace — Tim wanted to talk about his faith in Bully Pulpit and elsewhere; I wanted to quash those conversations. (By then I felt like NM was my baby, and my baby was raised a secular Buddhist!) We hashed it out more than once in awkward phone calls in which I was tempted to play the boss card. There were many reasons I resisted that inclination, but the most important was that Tim needed to be free to authentically inhabit the editorship.

I don’t recall exactly when it transpired, but one day I decided to trust Tim with NEW MOBILITY. He wrote beautifully, he edited passionately, he lived fully — so what if I just let Tim be Tim, faith and all? A wonderful thing happened. He found his NM voice, the one that includes his Christian perspective but also illuminates the quirky nooks and crannies of lived experience. And we are all the better for it.

Tim softened toward my agnosticism, too. It’s hard to convey how all the weird email chains and unexpected conflicts on a tiny staff end up informing the magazine. Perspectives shift. Ideas are tried and trashed. Some days you figure out a better way to understand the world. On really good days, you figure out a better way to share it.

Tim, Josie and I had been collaborating in this way for about five years when Utne Reader — which curated “the best of the alternative press” — honored NM as one of its Top 15 Magazines of the Year. New Mobility had won awards before, but frankly this one meant more. A respected publication beyond the disability echo chamber had recognized our purpose, our point of view, and our unique place in the media universe:

Times when we disagreed on the direction of a story — sometimes really disagreed — we would exchange information and find a direction that worked for both of us, ending up with better information for the reader.

I enjoy talking on the phone with Tim, especially in those rare times when I’m not past a deadline. We’ve shared “life and disability hacks”; stories from his hippie days, to the latest news from the Gilmer organic farm (“It’s a farm, not a garden!” he would rather sternly remind me); and highlights of raising our daughters. Perhaps the most powerful thing Tim enabled me to see is that aging with style, with a disability, is possible. When I hit my early 50s, I ran into a mental cloud, becoming a bit too focused on peers that passed too soon and how disability accelerates the aging process. Tim pointed out that although aging with a disability is no picnic, it can be full and long. He led by example, despite having to battle severe...
health challenges, and provided a list of quite a few people, many of whom NM has profiled, that are thriving in their late 70s and beyond. The key is to keep pushing.

Farmer Tim, I wish you and Sam a long “semi-retirement” overflowing with friends, family and grandkids, and look forward to sharing more stories. And since you have retired from farming, I look forward to hearing about life in the garden!

— Bob Vogel

Mentor, Friend

In 2005, I was asked to join the magazine full-time as associate editor. It just so happened that this coincided with Tim recuperating from quintuple bypass surgery, and a cover story he was working on about injured Iraq veterans was passed on to me. I felt the story was taking a different route than what he had planned. I went with my gut, sent in my piece and waited by the phone for the sweeping accolades that I was sure Tim would bestow.

Within the hour, Tim called and though it was really hard to tell, boy, was he steamed. As this soft-spoken man quietly chewed me out for not getting the story that he assigned, I learned a huge lesson that day that would help me grow as a writer. I found out that I could always count on his support and direction and knew this guy would become a great mentor and good friend.

— Roxanne Furlong

That Silly Little Thing

For many years now the lovely and talented Tim Gilmer has let me do the silly little thing I do for New Mobility, not only with little interference but with great support and encouragement. And he loves jazz, too! What more could one ask of a human being? Gracias, crippled comrade.

— Mike Ervin

NM Quality Controller

As a freelance writer who has been lucky enough to be paid for sharing my thoughts on a broad variety of subjects related to disability, I know the value of having editors with kindred thoughts and experiences to review my work before it is available for the scrutiny of our readers. New Mobility and its predecessors Spinal Network and Spinal Network Extra have employed a string of such qualified professionals throughout their existence, and everyone living with paralysis has benefited from their work. To do that job takes intimate knowledge of the covered subject matter and a great idea of what will interest and inform readers. I’m extremely fortunate that during 17 of the 27 years I have been writing for these publications that I have had Tim Gilmer editing my draft submissions. While I was proud of my work, it turned out to be even better once it made it through the editorial process. Tim has encouraged me to cover some interesting subjects, and I received frequent feedback from someone who has endured many of the challenges that my paralysis brings; in Tim’s case, he has often faced even greater challenges. His willingness to share them with readers in an open discussion of causes, potential cures and the frustrations of trying to deal with the medical/industrial complex that passes for healthcare in this country are usually humorous and informative at the same time. While Tim has certainly earned retirement, I hope he will keep contributing to this magazine and to others who seek quality, insightful writing on subjects that interest us all. Thank you, Tim!

— Michael Collins

Doug Davis has illustrated Tim several times over the years. Here Tim goes on a mythical road trip with staffers Douglas Lathrop, Roxanne Furlong and Josie Byzek. Jean Dobbs is gassing up the van.

Our Captain

Look at the ships also, though they are so great and are driven by strong winds, are still directed by a very small rudder wherever the inclination of the pilot desires.

— James 3-4

I want to share a staff secret: Even more than his brilliant editing and writing, it’s Tim’s passion for our readers that makes him especially wonderful, and that has moved me the most. Whether it’s encouraging a newly injured young person wondering what the future will hold or calling a reader concerned about a health issue, Tim cares deeply for people living with SCI/D and their families. This manifests in these personal phone calls and emails as well as in his willingness to share his own SCI journey, from the hospital stays to the joy of grandchildren climbing up in his lap.

In his first Bully Pulpit he used the metaphor of himself as a sea captain. “This wheel will fit my hands,” he wrote, and so it has. Tim is retiring, but not going very far. We will call on him for ideas and expertise as long as he lets us, and I have high hopes he’ll keep his newfound taste for blogging. And thanks to Tim’s steady hand at the helm, New Mobility is in shipshape, once more ready to set sail for lands both charted and unexplored by a new captain. That is quite a legacy.

— Josie Byzek
Tim Gilmer has a thing for the poetry of Walt Whitman, and for Christian scripture. He became spinal cord injured in 1965 when a plane his friend was flying crashed; his friend did not survive. Afterward, he spent years dazed, self-medicating with drugs and alcohol to deal with so much loss. Yet in the fullness of time, he reemerged and went about the business of crafting a life.

He married his wife, Sam, whom he loves with all his heart. They were organic farmers in Oregon and for a while had a U-pick tomato field frequented, for some reason, by an awful lot of Russian immigrants. Those organic tomatoes were also featured on a national TV show, PBS’ Chefs A ‘Field because they were that good.

But you probably already know this, as Tim opened his life to all in his monthly “Bully Pulpits.” In the column, he raged at those who discriminate against us — especially medical professionals who think they know best but ought to know better — and mourned the early deaths of so many of us and shared what he learned about longevity and SCI. He’s learned a lot. Heart disease, amputation, pressure wounds and flap surgeries are all part-and-parcel of his own SCI story, and he has been generously vulnerable with the answers he’s unearthed.

Following are three columns that capture some of the depth and breadth of Tim’s “Bully Pulpit” canon.

**Peelio and Oochie’s Getaway**

June 2001

Remember Oochie? She’s slim, 25, with wavy red hair flowing down below her waist. Mood-sensitive eyes — hazel when smiling, dark when angry. She’s agile, a good dancer, wears tight-fitting bellbottoms, eats fried potato sandwiches and listens to Joni Mitchell (did you guess it’s 1974?). Peelio’s 29, a little thick around the waist, a passionate but flawed lover, likes to wear worn-out blue denim shirts and take his knobby-tired chair into the woods. He eats anything that comes within reach and listens to jazz and regional accents.

Peelio and Oochie’s relationship is built around escape. Oochie has escaped a bad marriage and Peelio has escaped death, but that’s another story. Now they spend time together escaping Bakersfield. At night they escape into music and ice cream. When people stare at them, they do their best to escape stereotypical assumptions.

One day, hearts set on escape, they drive north in Peelio’s ‘69 Chevy Malibu, snaking up the Kern River Canyon, flanked by white-water and granite walls. They stop for lunch at a secluded restaurant overlooking the river. The waitress smiles as if to say, “How special — the young man in the wheelchair has found a lovely companion.” Peelio, attuned to such condescension, stifles an impulse to run over her toe.

They continue driving with no destination in mind. Peelio turns west and they start climbing. Patches of snow appear on the roadside. Soon they have reached the snow-covered summit of Greenhorn Mountain. They start down the other side — snow patches dwindling — and Peelio remembers the cabin that friends of his parents own. Yes — the perfect getaway. No one will be there this time of year.

He turns into the red-earth drive and parks next to the cabin.

“Sure,” says Peelio. “The Three Bears won’t mind. There’s a key hanging above the woodpile next to the window.”

Oochie helps Peelio in his wheelchair up the steps into the musty cabin. In the sleeping porch a huge pine grows through the floor and out through the roof. Peelio starts a fire in the old woodstove.

The old phonograph cabinet stocked with vintage 78s is still there — Count Basie, Benny Goodman, Duke Ellington, Frank Sinatra with his young crooner’s voice. For the next few hours the old music takes them far away, far from Watergate, the tired tale of Vietnam, the energy crisis, discrimination. Nothing matters but pine aroma, crackling fire and timeless lover’s music.

For a moment, asleep in each other’s arms on a blanket in front of the woodstove, Peelio and Oochie disappear.

“Oh my,” says Peelio, waking. “Time to go.” Oochie blinks, her eyes the color of bright acorns.

Back in Peelio’s Malibu, retracing their path through the canyon, they approach the secluded restaurant again. “Dinner?” asks Peelio.

“Sure.”

They sit at the same table. The same waitress comes to take their order, smiling the same smile, the one that bothered Peelio earlier. But something has changed.

The waitress waits, still smiling. What seemed like condescension now seems generous. Oochie beams from across the table. Their journey to a timeless getaway has tweaked Peelio’s heart. “How special,” he thinks. “The young man in the wheelchair has found a lovely companion.”

**I celebrate myself, and sing myself.**

I too am not a bit tamed, I too am untranslatable, I sound my barbaric yawp over the roofs of the world.

I exist as I am, that is enough. — Walt Whitman, “Song of Myself”

Tim Gilmer has a thing for the poetry of Walt Whitman, and for Christian scripture. He became spinal cord injured in 1965 when a plane his friend was flying crashed; his friend did not survive. Afterward, he spent years dazed, self-medicating with drugs and alcohol to deal with so much loss. Yet in the fullness of time, he reemerged and went about the business of crafting a life.

He married his wife, Sam, whom he loves with all his heart. They were organic farmers in Oregon and for a while had a U-pick tomato field frequented, for some reason, by an awful lot of Russian immigrants. Those organic tomatoes were also featured on a national TV show, PBS’ Chefs A ‘Field because they were that good.
During the first few minutes of nearly every conversation I have with a new nondisabled acquaintance, the question invariably surfaces: “So, what do you do ... I mean, do you work?” Implicit in the question is our ever-present nemesis, The Shadow: What kind of job could he have, being confined to a wheelchair? Not only is he wheelchair-bound, he may even be a shut-in.

Confined, bound, shut-in. These words, like shadows cast across our lives, obscure the truth of who we are. Even a figure as well-known as John Callahan must tolerate them. On a Dutch website describing a recent documentary about Callahan, the translation came across this way: “Callahan, a quadriplegic chained to a wheelchair ...”

The assumption that disability has the power to imprison us knows no boundaries. But disability’s power to diminish our lives is nothing compared to these entrenched stereotypes themselves. For myself, I decided to attack the persistent mindset long ago. “I’m a professional tightrope walker,” I used to tell questioners with a straight face. “And you?”

Back then, my pat answer was absurd and mildly amusing, but today I couldn’t get away with it. You can bet that right now someone somewhere is rigging up a wheelchair that will balance and roll on taut cables.

These days, when I tell someone I’m an editor, I see feigned interest: “Oh, really, exactly what do you do?” When I try to explain, I see they don’t quite get it. They need an easy image. So I change the topic: “I also own and operate a small organic vegetable farm.” Then comes a barrage of pre-packaged questions: “What do you grow? How many acres? Do you actually sell what you grow? How do you, well, get around?”

So I’m back to square one, stalked by The Shadow again: “How can a wheelchair-bound person actually farm?”

Once I establish that I ride an all-terrain vehicle and have tractors outfitted with hand controls and toss in a few hints on how to get rid of harmful bugs without chemical poisons, I take another run at explaining what New Mobility is all about: “The magazine I edit is about active lifestyle wheelchair users.”

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This month’s cover story is about the out-of-the-box practice of commemorating the onset of paralysis — 10 stories of readers who celebrate the day that changed their lives forever. It has helped me appreciate, once again, the power that our individual stories hold.

But soon after I finished writing the stories, I realized my own date, July 11, was upon me, and I had no plan for celebrating the 52nd anniversary of my plane crash.

In my early post-injury days, I would party, even if alone, a kind of private rebirth day, feeling fortunate to be alive. Later I would invite friends, who were always happy to have an excuse to celebrate anything. In time, the celebrations became a symbolic ritual involving launching and crashing various flying objects — paper airplanes; rubber-band propelled models; larger, more aerodynamic hand-thrown replicas.

This year, due to a time crunch, it would have to be paper airplanes again. At the last moment I invited my daughter, son-in-law and two grandsons to join my wife and me on the deck for guacamole and chips, margaritas, and barbecued burgers. But first I had some deck repairs to do.

My faithful worker-friend, José — who comes each growing season from Mexico to our farm in Oregon to live and help — 28 years and counting — assisted me with the deck repair. When we were half done, I explained to José in my best Spanish that we needed to hurry to finish for the celebration. He looked up, puzzled. “Today’s the day of my accident,” I said. He looked blank. “I’ve told you, right? About the plane crash in California? My friend, the pilot, died?”

“Nooh,” he said. “California? I thought you were in a war.”

Twenty-eight years and I had never told him. Out of respect for employer-employee personal space, he had never asked. So for the first time I told the full story in a foreign language. José listened, rapt, his eyes large. When I reached the part where the pilot, my friend Jim, dies in the plane wreckage, I detached, looked away and stared at a rough spot in the deck.

We completed the repairs and the party began.

The grandboys played in the yard with their dad while I sat with my wife and daughter, now 30, on the deck. My daughter asked if there was an article about my plane crash. “Article?” I said. “Haven’t I … have I ever told you the full story of that day?”

“It’s not with any details, just that you crashed,” she said.

I had told the full story countless times, but never to my own daughter. So I began the detailed, unadulterated version in English. This time, when I got to the part where I heard Jim take his last breath, I stopped, hearing it again, as if for the first time. Then came real tears. Fifty-two years and the emotion still surprises me.

Later, amid laughter, my wife broke out the rocket-copters she had secretly bought for the occasion. We took turns launching them, especially the boys, watching as they catapulted into the sky, then floated safely to the grass.
As editor, Tim Gilmer knew sometimes a story would break so big that we should respond as quickly as possible — not an easy task for a magazine that plans articles a year in advance. Our staff would pore over story budgets to see if a feature could wait a month or so, or cajole the publisher to give us a few extra pages, and work overtime to get the info to our readers as quickly and thoroughly as possible.

“What I really liked about those times was the sense of excitement and energy we felt because we knew it was important and our community had a place in the larger story,” says Tim. “Like with 9/11. You and I realized it at the same time … what about our community? Where are our people? We realized we have a place here, let’s get it in the magazine.”

He’s referencing our coauthored piece, “Sept. 11, 2001: A Day to Remember,” [Nov. 2001] where we told the stories of two men, both quads, caught in the twin towers the day they fell. Tim told the heartbreaking story of Ed Beyea, a high-level program analyst for Blue Cross/Blue Shield who worked on the 27th floor. Beyea and his personal assistant/friend, Abe Zelmanowitz, perished for lack of appropriate rescue options. I told the happier tale of John Abruzzo, an accountant for the Port Authority who worked on the 69th floor. Abruzzo got out on the 69th floor. He lived because he had access to emergency evacuation equipment and coworkers who were able to use it to save him.

After telling that story, we told another one, “Unsafe Refuge: Why Did So Many Wheelchair Users Die on Sept. 11?” [Dec. 2001]. We looked at rescue equipment pros and cons, and ever since then have delivered strong reporting on emergency preparedness. Jean Dobbs’ “Eye of the Storm” [Dec. 2005] about how wheelchair users fared during Hurricane Katrina told harrowing tales of people separated from their wheelchairs, their service dogs, their homes and, yes, their lives. It shined a white-hot spotlight on the gaping holes in existing emergency preparedness plans that wheelchair users fall through.

Those holes still gape, and we still tell the tales, yet some progress has been made, and we tell those stories as well.

“I like to think we saved some lives,” I say, and Tim tells me just the other day he saw a sign for an EVAC+CHAIR in a building he was visiting — that’s the product Abruzzo escaped in, way back in 2001. So maybe we have.
All People are Our People

“My kind of advocacy has been in writing and information gathering, and communicating with my community,” says Tim. “But sometimes it breaks out into the broader community.”

That’s true, and it stretches beyond disaster relief. On the day Baghdad fell in 2003, Tim scored a coveted interview with anti-war activist Ron Kovic, of “Born on the Fourth of July” fame [see “Lifestyles of the Wheeled and Famous,” page 28].

“What made that topical was we were entering into a war with Iraq that was controversial — many of us didn’t want to — and one of the main voices against the war was Ron Kovic’s,” recalls Tim. “I remember I tried to reach out to him and he had never responded. But the day I got him was when our forces finally invaded Iraq. I left a message and I said, ‘Well, I guess all your efforts are for nothing and this is the way I’m going to write the story unless you get back to me.’ I baited him, and he called right away and he was impassioned and said, ‘No, this is only the beginning.’” And he was right.

Lots of big news organizations had tried unsuccessfully to get an interview with Kovic, and Tim’s story became one of the few places Kovic’s words entered the public record. “CNN, people writing books got in touch with me to find out how we reached Kovic, it went on for years, mainly because the story jumped from NM to Al-ternet,” says Tim. “It was exciting because it was a big stage and one of our people was important to the idea our people shouldn’t be part of that war.” That’s our people — wheelchair users — and our people — Americans. All are our people.

“Just recently you wrote the story about how movies like Me Before You dovetail with real life when we saw that teenager Jerika Bolen took her life [‘2016 People of the Year: The Resis-ters,” Jan. 2016], and also how ADAPT got involved in Medicare last summer, the whole legislative mess going on [Disabled Americans Saved Health Care, Oct. 2017],” says Tim. “Those are the kinds of stories that are exciting — when we break through the barrier and aren’t just preaching to the choir anymore.”

Correcting the Mainstream

My story on Bolen and Me Before You followed the NM tradition of asserting disabled lives are worth living. Tim nurtured that tradition, and his reporting on Christopher Reeve’s post-injury life and death comes to mind. “When he had a breakthrough and they were show-ing him in the swimming pool standing, I just had to go there. That was exciting because I got to travel and meet him [see story, next page].” But when he died, the media blew it,” Tim sighs heavily.

“We have always been keen to follow coverage of our community by the main-stream because they’ve rarely gotten it right,” says Tim. “There was something screwy about how Reeve’s death was covered because I heard on my own local ABC channel, ‘In the end, quadriplegia was too much for him.’ But he was only 50-some-thing and was in good shape, had the best care. After digging and finding my way to his actual nurse, I verified he died of shock, an allergic reaction. I tell people that’s what he died of, not of being a quad, because prior to his quadriplegia he had allergic re-actions to a lot of things. He died from an antibiotic he’d taken before.”

Tim was the first, and one of the only, journalists to report Reeve’s death accurately. And why was that so important? “Mainstream media coverage furthered the myth that people are better dead than quadriplegic,” he says.

unless you get back to me.” I baited him, and he called right away and he was impassioned and said, ‘No, this is only the beginning.’” And he was right.

It’s All of Us Together

In 2000, when Tim and I were both new to New Mobility, he mentioned his love of The Atlantic Monthly and a few similar magazines known for long, beautifully-written articles. I started picking up copies of Atlantic and then a variety of mags different from my usual choices so I could see what he meant. To this day, even in the world of clickbait, NM strives to deliver substantive well-written articles in print as well as expand our online offerings.

“We do a good job, and I mean we,” Tim says, when I shared this with him. “We’ve kept the long form alive while at the same time realizing the importance of the shorter form and online platforms. It all goes together.”

I tease Tim, calling him Mr. Internet, an inside joke since our stalwart champion of print has only recently embraced blogging and some aspects of social media. “It’s been difficult for me because for a while I thought it took away from print rather than adding to it,” he acknowledges. “Think of all the print mags that have gone down.”

We are one of the very few print magazines for people with disabilities left, but that doesn’t mean we can slack off. “There’s competition,” says Tim. “We need to stay up with everything online, it’s so critical now.”

But that’s really just an aside, since Tim has crafted us into a strong voice for the disability community’s place in our broader community — and that won’t change. After all, he says, “We have a collective consciousness on staff. No one takes off and does it on their own. It’s exciting, that process, when we all think it’s something we should cover.” It is all of us together — that interplay between our staff, readership and broader communities.

But for me, I believe I will probably always judge a breaking story’s merits by the principle of WWTD — What Would Tim Do?
Tim Gilmer is a master at assigning, editing and writing profiles of wheelers worth knowing – from everyday moms and dads to superstars like Teddy Pendergrass.

“First off, interesting is key, more important than well-known because it is more inclusive, and truthfully, there aren’t that many well-known wheelchair users,” says Tim about how he chooses who will be profiled. When there is a famous wheelchair user, “we like to get them in the magazine if they are a good fit with our readers and their needs. But we don’t really consider them as role models per se, because being famous doesn’t automatically translate into that category. Sometimes, though, the famous factor is very alluring because we know our readers would like a kind-of-inside peek into the lives of the rich and famously disabled.”

Tim’s interview with Christopher Reeve is a textbook example of this. “Reeve had just written his second book, and someone at Random House, his publisher, contacted me with an offer we couldn’t refuse. So I flew cross-country from Oregon to New Jersey, rented a regular minivan with hand controls — in 2001 it was easier to do that, believe it or not — drove to his estate three hours north of New York City, and spent the day with him. I was surprised at the unfettered access I was given.”

In addition to his masterful profile of Reeve, Tim wrote or assigned stories spotlighting wheelchair athletes Marty Ball and Randy Snow, Shakespearean actor Regan Linton (penned by Richard Holicky) our own satirist Mike Ervin, jazz singer Lisa Thorsen, Vancouver Mayor Sam Sullivan, Christian minister Joni Eareckson Tada and pornographer Larry Flynt (delivered by Allen Rucker).

Following are excerpts from profiles of three famous wheelers written by Tim: Reeve, anti-war activist Ron Kovic and cartoonist-turned-singer John Callahan.

**The Missionary Reeve, November 2002**

This excerpt takes us with Tim to Christopher Reeve’s house, where he wanders around, speaks with Reeve’s young son Will, and allows readers to peek behind the curtain and see how the great man lived. For the full profile, including a long Q-and-A that hints at what would become the Reeve Foundation’s The Big Idea, see newmobility.com/2002/11/the-missionary-reeve/.

Christopher Reeve’s New York home is fairly new — built in 1990 and remodeled for accessibility in 1996 after his return from rehab. At first glance it appears
modest but is actually quite large, comfortably se-
cluded in woodsy Pound Ridge opulence. For some reason
I expected to be greeted by snarling Rottweilers and gray-
suited men with walkie-talkies. Instead, a thirtyish woman
with red hair emerged from the house with a warm smile.
“You’re welcome to look around to your heart’s content,” she
said. “Christopher will be ready shortly.”

My curiosity led me straight to his exercise room, where
the magic happens, we are told. I expected to find futuris-
tic equipment spaced around a large indoor swimming pool.
What I saw was a modest rumpus room. In the corner near
a sliding glass door stood a tilt table much like the one I re-
membered from my rehab days. On the wall nearest the slid-
ing doors sat a functional electric stimulation bike — the Er-
gys 2, made by Therapeutic Alliances. On the opposite side of
the room sat a similar machine — the StimMaster. Framed
freehand calligraphy hung on the walls — “You are Every-
thing You Choose to Be,” and a timeline entitled, “Progres-
sion of Recovery.” The timeline ended about a year after his
accident, in May 1996.

A doorway led to a hall that gently sloped up to a kitchen area.
To the right of the door was a smaller standard exercise bike. I
entered the hallway and to my left was an open closet. Sam Mad-
dox’s jacket [see Tributes, page 19]? Maybe a dusty red cape?
No, nothing but sports equipment — soccer balls, basketballs,
hockey sticks, helmets
and protective masks, equipment bags, enough stuff for a
small team. To my right a shorter hallway was clogged with
coats and shoes, maybe a dozen pair. So how many people
lived here?

I wheeled up the gentle slope, into the area adjoining the
kitchen. “I see you made it OK,” came a familiar voice from
my left. There sat Reeve in the kitchen-dining area, tilted back
slightly in his power chair, attended by three people, light
streaming in from a south-facing window, in the early stages
of being made up for the photo shoot. He smiled and reiter-
ated what I had been told earlier — make yourself at home.
He would be ready in about 45 minutes. We would shoot first,
then he would take off his make-up for the interview.

I felt a little awkward, as if I had walked in on someone in a
bathroom. Reeve’s make-up artist would earn $775 for trans-
forming her famous client from a middle-aged man with no
eyebrows and alopecia areata, a pre-injury hair loss condition
(testosterone supplement therapy is promoting new growth),
into a camera-ready face that looked a decade younger. Not
bad for an hour’s work. Random House would pick up the tab.

I wheeled back into the exercise room and there was Will,
Reeve’s 10-year-old son, exercising on the small bike. He smiled
and talked freely, clearly at ease: He liked to work out with his
dad, they often biked two miles together, all of the sports equipment and most of the coats and shoes were his, his brother Matthew was in England working on the documentary, his sister Alexandra was away at Yale, he was getting in shape for hockey season, hockey was his favorite sport, he would go to his first practice of the season that night, you can go anywhere you want in the house, really you can. I was beginning to feel a little like a house guest.

The interview took place in the living room, windows looking out on a spacious circular driveway. I waited and snooped: A music stand held a handwritten composition for beginning saxophone entitled, “Not the Prettiest Song in the World” — food for the other side of Will’s brain. In the corner of the living room sat a glossy black piano which held more serious fare — Mozart, I believe. Perhaps Alexandra or Reeve’s wife, Dana, played. Reeve himself used to, of course. And then an absurd notion surfaced, no doubt from watching too many made-for-TV movies: Maybe no one had dared touch the music, or the piano, since the day of his accident. Maybe Mozart patiently awaited Reeve’s return, as did his sailboat, his airplane, his love of riding horses, his sex life, his career as an A-list actor. It occurred to me that those of us who have had fewer opportunities may have difficulty truly understanding the depth and breadth of what Christopher Reeve has had to give up.

He appeared suddenly, a changed man from only minutes before, seemingly vulnerable now, cleansed of makeup.
Ron Kovic Reborn, June 2003

Although penned 15 years ago, Tim's profile of anti-war activist Ron Kovic feels more relevant than ever — perhaps because the wars du jour, Iraq and Afghanistan, have not fully ended, or perhaps because many of Kovic's prophecies have been realized. For the full profile, see newmobility.com/2003/06/ron-kovic-reborn/.

The day Baghdad fell, Ron Kovic was back in the Veterans Affairs hospital. Not the shameful Bronx VA of Kovic's 1976 book, Born on the Fourth of July, and later, Oliver Stone's academy award-winning movie of the same name — which was condemned and torn down — but the Long Beach, California, VA hospital. Kovic, 56, had gone in for a checkup at the spinal cord injury outpatient clinic, only to find his doctor expressing worry over potential cutbacks, a situation reminiscent of spending priorities at the close of the Vietnam War.

“We're putting all of these millions of dollars into warfare when the disabled of our country, disabled veterans and disabled citizens, are in need. Many of them live below the poverty level,” says the man whose life was portrayed onscreen in 1989 by Tom Cruise. “This policy of aggression, this policy of arrogance, of blindness, of recklessness, I don't think this is going to help America. I think that this behavior, which I abhor, this policy, which I strongly disagree with, is leading this country in the wrong direction.”

Kovic was not always this eloquent. His voice has been shaped by war, its destructive aftermath and decades of fearless commitment to protesting governmental policies that support war. To Kovic, war is not an abstraction, not a neatly packaged television graphic — The War with Saddam — not a map bristling with colored pins. It’s blood-and-guts reality, and he owns it. He's a streetwise activist who speaks like a polished politician — the cadence, the repetition, the dramatic diction, streams of words pouring forth, demanding attention: “I think this policy is so wrong, and so misguided, and I may be one of the few Americans saying that right now, but I believe strongly in what I'm saying, and I'll say it today, even on this day — [the day Baghdad fell]. This is a terribly misguided policy that will backfire, this will not stand, this will not work, this will work only against us. This will not lead us to peace and this will not lead us to justice, and this will not lead us to a safer world but a more dangerous world, a more dangerous and unstable Middle East. I think this is going to hurt America.”

THE ROAD TO RAGE

He first spoke out in public against war at Levittown High School on Long Island, New York, in 1969. He was 23 years old, still adjusting to the T4-6 spinal cord injury he had sustained in combat in January 1968, still feeling conspicuous in his wheelchair. It was baptism by fire. For a Vietnam veteran to speak out against the war at this time was tantamount to sacrilege, and dangerous: “All week I had not wanted to go because I had never spoken in public before, I was very hesitant, and Bob Muller, who later became the founder of the Vietnam Veterans of America, had finally convinced me to come down and join him that day, and I went out on the stage and there was this bomb threat. We had to evacuate the auditorium and go out to the grandstands on the
football field. That was quite a beginning for me."

And an even more dramatic turnaround. Kovic had been a gung-ho Marine who had volunteered to serve a second tour of duty in Vietnam, a young man whose parents had both served in World War II, whose uncles had been Marines, who had been deeply disturbed by growing protests against the war and who had not hesitated to volunteer for a dangerous mission the day he was shot. But his experience in the Bronx VA Hospital opened his eyes. “They used to call it the Bronx Zoo. It was there that I began to wonder why I and the others had gone to Vietnam in the first place. And whether we had lost our bodies for nothing. It was in that place going through the sometimes-abusive conditions that I was slowly becoming aware and recognizing what had happened. And I remember seeing all the wounded around me, getting a full picture, which you never saw, for instance, during the recent war coverage on CNN or Fox News. You’ll never see what I saw.”

What he saw was an understaffed, outdated veterans hospital teeming with paralyzed bodies, amputees and head injuries. And why were they being treated like disposable parts of a machine instead of heroes? The questions yielded no satisfactory answers, and anger and bitterness grew in the vacuum. “I’m not ashamed to admit that I felt enraged,” he says. “God, I gave so much.”

Not long after leaving the Bronx VA for the second time, he moved to California, where he was influenced by author/screenwriter Dalton Trumbo. “I remember reading his book — Johnny Got His Gun — a powerful antiwar novel [set in World War I and published in 1939]. I had just become involved with the vets against the war, just hesitantly beginning to oppose the war in 1970-71.” Kovic attended the opening of the movie based on the book, where he met Trumbo and actor Donald Sutherland. “It was an extraordinary evening, and I thanked them that night and it was thrilling to meet Trumbo. He was one of the Hollywood 10, definitely a man of his conviction, someone I respected.” Trumbo, suspected of having communist ties, was imprisoned for nearly a year in 1950 for refusing to testify before a congressional committee, then blacklisted by Hollywood until the late 1960s. “I really think his book influenced the very heart and soul of my writing of Born on the Fourth of July.”

The year prior to the release of the film version of Johnny Got His Gun, National Guardsmen opened fire on a crowd of Kent State University students protesting the Vietnam War, killing four and wounding nine. To this day Kovic maintains a close connection with Kent State students. In the late 1970s he was arrested for protesting the desecration of the site of the massacre and has spoken on campus a number of times, primarily on the anniversary of the shootings. “I was deeply affected by what happened on that date,” he says, referring to May 4, 1970 — one of the darkest days of the Vietnam era, on a par with the infamous My Lai massacre.

As if witnessing this kind of government-sanctioned madness wasn’t enough, Kovic had to deal with his own personal My Lai — his platoon had killed innocent villagers. Babies. And then there was the young corporal from Georgia, who Kovic accidentally shot and killed in a chaotic firefight. Add to this the allure of fate: The most important dates in Kovic’s life coincided with two of his country’s most important historic dates. Most people know the significance of his birthdate from his book or Stone’s movie, but many do not know that he was shot and paralyzed, in effect reborn as a paralyzed vet, the same day Martin Luther King Jr. celebrated his last birthday. He would later choose King as his model for nonviolent protest in the streets. …
Callahan’s Long Reach, April 2007

There is renewed interest in the life and works of famed cartoonist John Callahan thanks to Don’t Worry, He Won’t Get Far on Foot, a movie based on his life and works starring Joaquin Phoenix that will be released on July 13. Here at New Mobility, we have a special relationship with Callahan as Tim Gilmer befriended him toward the end of his life, supporting his endeavors and providing him with encouragement. Following is an excerpt of Tim’s story about how Callahan reached beyond his crooked-line cartoons to become a singer. Read the rest at www.newmobility.com/2007/04/callahans-long-reach/.

The playbill for the January 19 taping of Oregon Public Radio’s Live Wire! — an old-time radio show modeled loosely after National Public Radio’s Prairie Home Companion — gives John Callahan top billing. For most everyone at Portland’s Aladdin Theater, it is the first time they have seen Callahan’s name paired with the words “singer/songwriter.” The crowd, 650 strong, is standing room only.

When Callahan is introduced, the Aladdin erupts with applause and cheers. He rolls to center stage, dressed grunge/casual. Beneath his worn jacket is a faded T-shirt with one word subtly visible: “Trash.” Callahan’s wheelchair armrests are liberally wrapped with black electrical tape. His accompanist, Chris Hubbard, settles in behind a shiny black grand piano. After an embarrassing moment when he has to ask a stage hand to adjust his microphone for him, Callahan looks around, squinting at the balcony seats, sizing up the crowd. “I thought they were supposed to have a little mark here,” he deadpans, gesturing toward a spot on the stage floor, “where I could throw up.”

Laughter. Tension released. This is the Callahan everyone knows, the cartoonist with the dark wit. “My first song is titled ‘Suicide in the Fall.’” A few people titter, then an uncomfortable silence settles in. “It’s not as uplifting as it sounds,” he says. More laughs.

After a simple medium-tempo piano intro, Callahan launches into the lyrics:

There’s trouble in the steeples
And the crows are set to fly
But there’s apples in the baskets
And a dead moon in the sky.

His voice, innocent, unadorned, creates a mysterious contrast with his often dark lyrics. The effect is suspenseful, as the audience waits for the song to declare itself. Will he make a joke of suicide? Is he serious? You can almost feel a sigh of relief from the audience when the lyrics reveal the artist’s intent:

Well, there’s something about the softness
Of the colors on the wall
That keeps me from committing
Suicide in the fall.

When the song ends, there is generous, respectful applause. The crowd is catching on. They are witnessing the evolution of Callahan the musical artist. His single-frame gags have somehow given way to a CD of

songs — “Purple Winos in the Rain” — that at times seems almost uncomfortably honest and melancholy, yet somehow charming, and always melodic.

When the applause dies down, emcee Courtenay Hameister sits next to him for an interview, drawing upon his past cartoons for comic relief, gently probing about his new artistic venture, and making entertaining chit-chat. After the interview, Callahan closes with his signature song, “Touch Me Someplace I Can Feel”:

Life is hard but death is worth it
Nothing’s certain, nothing’s real
Give me something cheap but perfect
Touch me someplace I can feel.

Callahan lives in a Northwest Portland apartment a short power-chair jaunt off NW 23rd — known locally as “trendy-third” — a 19-block run of bustling boutiques, natural foods restaurants, kosher delis, inner-peace-love-tarot-card-reading-art-sy-shoppes and anti-Bush signs in sash windows. Callahan, 56, whose eight books of cartoons have established him as a master of political incorrectness, lives smack dab in the middle of liberal Americana, two blocks from the local abortion clinic. There are at least four Starbucks within easy rolling distance.

I drove there on a snowy day in January. Once on busy NW
23rd, I began worrying about finding a parking space, but first I had to find Callahan’s apartment building. Bingo — a perfect set of power chair tracks embedded in the sidewalk snow traveled up Lovejoy from NW 23rd.

After parking and transferring into my manual chair, I aligned my wheels in Callahan’s tracks and followed the trail he had blazed to a side door on an older three-story brick building next to a debris-filled dumpster. I knocked and waited a full four minutes for his attendant to respond. He had been busy getting Callahan ready to meet me at 2 p.m. in the afternoon — one of three attendants who rotate off and on. Callahan lives independently but needs help part of each day, which costs a pretty penny. His income from royalties disqualifies him from assistance of any kind.

I was surprised to find his twin bed just inside the door in what I assumed was his living room, with almost no furniture other than an upright piano. The one-bedroom apartment was small, dark, stripped to essentials. Sitting in his older power chair next to a too-tall breakfast bar, Callahan told me he no longer owns a computer — he had thrown it away — “but I’m getting a lot of pressure to get one again, since the CD came out.” His mammoth fluffball of a cat, Biggie, eyed me from the comfort of Callahan’s bed.

I tell Callahan that people are surprised when they hear of his CD, but I’ve recently re-read his autobiography, where just before his accident, at age 21, he describes himself as having a “creative artist, poet, and songwriter hidden within.”

“It’s something that’s always been growing in me,” he says. “I’ve always wanted to be a songwriter. The points just never connected back then. I was playing guitar very well at 18, 19, 20, and I’d try to write songs but I was such a little alcoholic, and I could never get the words together right. Took me until I was older, in my 30s and 40s, to start writing songs, and then I had to learn how, with my fingers, to play the piano a little bit again, and play sort of open tuning on the guitar. I could always play harmonica. I didn’t have to learn that, it was just natural.”

Does this mean he’s de-emphasizing cartooning now?

“No, no,” he says. “Just doing music and stuff in addition. But I wouldn’t mind developing my music and becoming more of a performer and traveling around. But in an easier way than a plane. I don’t like planes because they can wreck your wheelchair. Every time I ride in a plane they smash it, they always somehow damage the wheelchair or send it to the wrong place. I don’t feel like dealing with that stress. And a train I don’t know about. Maybe having one of those big rock-and-roll buses or something would be cool. I could just stay in bed. Each town I could just sing out the window of the bus and go to the next town.”

And then I ask the question that’s been nagging at me. I’ve read elsewhere that he lives off his royalties, but his apartment is, well, basic. “How are you doing economically?”

“Oh, doing OK. It’s sometimes big, sometimes not. It varies so much with me. I don’t even pay much attention to money. I just
do what I want to do creatively, and the money always follows. I’ve always been lucky that way. I just never look down from the high wire and I’m OK.”

WHERE HIS SONGS COME FROM

There’s a hint of “Purple Winos in the Rain” in his autobiography as well. In the concluding pages, after he has faced down his alcoholism six years following his accident, he describes what he sees while rolling past St. Mary’s Cathedral one evening: “It looms high above me in the night with its sculpted saints and the peaceful face of the Blessed Virgin above the ten broad doors. … I can hear the bell sounds, broken by the wind, and the rain is stinging my face. … The winos are crouching in the little shelters that the doors and buttresses of the church provide …”

References to street life are sprinkled throughout Callahan’s songs. In his daily rounds in his power chair, especially whenever he ventures as far as “Old Town,” where Portland’s homeless people, drunks, addicts and prostitutes hang out, Callahan must literally swerve to avoid running over people sprawled on sidewalks. The rest of us roll up our windows as we drive by, safely insulated.

Callahan’s focus on street people seems part of a deeper connection. “Yeah, I think that’s true,” he says. “I don’t have any lines of delineation between classes and people. I feel it internally. It’s an illusion to think there are lines. It’s all one thing.”

Callahan’s egalitarian worldview may come from an awareness that he might have been a homeless drunk himself, had he not hit bottom, wrestled and reconciled with his Higher Power, and stopped drinking. “It was a touchstone,” he says. “I had a bottoming out experience, a dramatic reckoning with God, but then years later I had another experience, nine or 10 years ago, more of a self-realization kind of thing. Long story short, they messed up a surgery and I got a staph infection. It almost killed me and I had to be put under, kept down on machines and alive for about a week, it was terrible. But a couple months after that I woke up in my home and I just sort of moved into this space where there was just nothingness and bliss, maybe just for a few minutes. I mean, once you have an experience like that, it’s almost like having what they call ‘free samples.’ And you just have a very easy time believing.”

The Callahan Biopic

Will director Gus Van Sant and nondisabled actor Joaquin Phoenix pull off a worthy version of Don’t Worry, He Won’t Get Far on Foot? Tim Gilmer will weigh in with his review of the film this month on newmobility.com, where he plans to be a regular contributor to the NM Blog.
Over the course of his tenure at New Mobility, Tim received an on-the-job education in SCI research and medical issues. Publisher Jean Dobbs, who hired Tim, recalls how he had little interest in “cure” at the time. “He wasn’t up to speed on hot topics like stem cell research when he started,” she says. “But he put in the time to really grasp the science, and now he’s our resident expert on everything to do with restoration of function.”

In some ways, the fact that his knowledge was tied to his personal experience was a good thing. He started in the same place as many of NM’s readers, and unfortunately, more than a few of the doctors and therapists who treat them. After all, finding specific, sound medical advice on how to manage the secondary complications of living with a spinal cord injury is like searching for an accessible cab in New York City.

Armed with the connections and resources of NM, he compiled the best available knowledge on a host of medical subjects — pain, infections, bladder management, pressure sores, functional recovery, sleep-issues and depression, just to name a few — and made it available to readers in clear, easily-understandable language.

Tim’s natural skepticism, when combined with his methodology — giving equal space to the medical professionals who advance disability care and actual wheelchair users’ real-life medical strategies — helps readers to see past the typical medical model, where the doctor’s word is beyond reproach. In Tim’s world, doctors are only worth listening to if they truly know what they are talking about.

A 2005 article, “Bladder Matters,” opens with a scene that is a microcosm of Tim’s approach:

“Once upon a time, in a hospital far far away, a urologist appeared to me all dressed in white. “How would you like me to give you an injectable,” he said, “that will prevent urinary tract infections for the rest of your life?” At the time I had been stuffed away in isolation for three weeks and was gradually descending into paranoia. The magical gift bearer had on a sterile mask and gown and wore the relaxed look and condescending attitude of a doctor who thought too highly of himself. All I wanted to do was go home.

“No,” I said, and that was that.

Why did I refuse? Because it was 30 years ago, I’d never heard of a UTI vaccine and I trusted nobody — especially not wise men in white gowns.

Tim understands an essential truth of magazine writing: To inform readers, often you first need to tell a story people can relate to. And Tim is unafraid to use his own experiences, trials and complications — and he has plenty — as the hook to pull readers along, while keeping the medical information as practical and easily understandable as possible. Exactly the opposite of doctor-ese.

Breaking down the wall of medical knowledge and jargon while constantly advocating for better care is one of Tim’s contributions to rectifying a medical system that so often fails people with disabilities. Most of us who live with SCI/D know the helpless feeling of realizing our doctor doesn’t know the first thing about our disability, but nevertheless is going to be making decisions that directly affect our health and well-being. Tim’s medical writing disseminates the most up-to-date medical knowledge and best-practices from the people who do understand disability so readers are armed with enough knowledge to direct their own care. Whether detailing the specifics of bladder augmentation or excoriating the medical establishment for systematic inaccessibility, advocating for better care is at the heart of everything he writes.

“He created something that wasn’t there and was incredibly valuable to people,” says Dobbs. It’s not an overstatement to say that the medical writing in New Mobility during Tim’s stint as editor has saved lives. It’s hard to ask for more than that.

Below is some of Tim’s most impactful medical writing that remains relevant to current readers.

This profile of Rob Summers, the first participant in the groundbreaking epidural stimulation trial designed by renowned researcher Reggie Edgerton, Ph.D., and conducted at the University of Louisville, details the science behind epidural stimulation and activity-based therapy. It chronicles what was extremely invigorating news for the SCI community, an excitement Tim shared in. But Tim takes us beyond the "Paralyzed Man Stands!" headlines, giving space for researchers to explain the fledgling science as best as they could, showing the amount of work Summers put in before and after getting the stimulator implanted and how individualized the whole concept of “recovery” is.


Following the success of the epidural stimulation trial that Rob Summers was involved in, the Christopher Reeve Foundation announced The Big Idea, essentially an expanded, 36-person epi-stim trial to further test the procedure’s ability to produce functional recovery. This piece takes a broad view as Tim talks with Sam Maddox, the founder of New Mobility, to place The Big Idea within the context of SCI “cure” stories that have been popping up since the ’60s without ever producing practical results. With epi-stim, the name of the game isn’t “cure,” but improving quality of life by recovering functional ability. That’s something that has already been demonstrated. Now, the disability community is waiting to see how far they can push the concept of recovery and when the procedure could become widely available.

When Rehab Becomes Recovery (April 2015) newmobility.com/2015/04/when-rehab-becomes-recovery

This article is a look into the evolution of epi-stim trials, including the case of Mark Pollock, a blind SCI survivor who underwent the trials while using a robotic exoskeleton. Tim talks with Reggie Edgerton, the man behind most of this research, about how his team targets epi-stim to improve specific functional improvements, including arm, hand and lower-limb movement.

Overcoming Recurring Depression (June 2015) newmobility.com/2015/06/overcoming-recurring-depression

Here, Tim recounts his own battle with depression and the long journey to escape its hold. The story is at once intensely personal and outward looking. He shares the things that helped him the most — music; physical, outdoor activity; connecting to something greater than himself; and rediscovering purpose — as a way of lighting a path for those caught in a similar situation. With estimates of depression affecting anywhere from 11 percent to 37 percent of the SCI population, it’s important for those in its throes to know that they’re not alone.

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Equal Healthcare: If Not Now, When? (July 2013) newmobility.com/2013/07/equal-health-care-if-not-now-when

“Why is it taking so long for the health care industry to begin to comply with the Americans with Disabilities Act?” It’s a simple question, but one that takes a few thousand words to even begin to get a handle on. Tim looks at the appalling lack of accessibility within the medical establishment, much of which can be traced back to the medical model of disability, which he describes as “the long-held bias that a person with a disability is not as valuable to society as a nondisabled person,” how it affects wheelchair users across the country and the various types of pressure being used to try and slowly bring about more widespread compliance.


In this piece, Tim recounts his experience with coronary artery disease, the lifestyle decisions that led to it, the multiple bypass surgery that followed, and the changes he’s made to ensure he doesn’t just clog his new pipes back up. Like the rest of his medical writing, it’s filled with practical information, so anyone dealing with similar issues comes away with a broad understanding of the disease and how it affects wheelchair users.


Sleep is an often-neglected process, both in our lives and in medical writing. But the more science studies it, the more we learn how vitally important quality sleep is to our health. This piece digs into sleep issues as they relate to people with disabilities, with everything from expert mattress and positioning recommendations to pain management, bedtime strategies for those with trouble falling asleep and a host of tips from wheelchair users.

The Pain That Never Stops (March 2017) newmobility.com/2017/03/neuropathic-pain

This article is a look into the maddening world of neuropathic pain, a condition prevalent within the SCI community that is not subject to easy fixes. Tim relays his personal experience with pain and talks with a number of wheelchair users about how it affects them and what they do to manage it. While the medication strategies vary from Neurontin to cannabis and everything in between, almost all agree that staying both mentally and physically active is the key to not being swamped by pain.

Journey to the Far Side of Tomorrow (February-June 2018) newmobility.com/2018/06/tim-gilmers-journey/

Tim’s first foray into blog writing, in which he recounts his lead up to and the aftermath of a flap surgery to heal a stage IV ischial pressure sore, struck a chord with readers, many of whom have been on similar journeys. Tim tells a multi-part story in serial form, intertwining personal experience with medical facts, analysis of insurance margins, profit-driven healthcare and the need for change, concluding his journey with a story of “complete healing.”
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Peripherals are the components that make it possible for drivers with disabilities to ride in and operate adaptive vehicles. Downsizing, consolidations and ever-changing business models mean more and more European-made peripherals are being installed and distributed by mobility equipment dealers in the United States. The perfect example is the BraunAbility corporate group, which includes Autoadapt, Bruno, Unwin, Permobil and Foca-Braun, as well as other brands.

The availability of so many different types of accessories and features may seem confusing, but it's easier than ever for potential customers to pair themselves with the best product. Mobility equipment dealers are trained to evaluate needs and recommend solutions that work best, and thanks to the internet, everyone can shop around.

**Getting Aboard**

Wheelchair lifts remain the most common method of entry into full-sized vans for drivers or passengers who use mobility devices. BraunAbility recently introduced a new lift, the BraunAbility A-Series cassette lift, as an international public-use wheelchair lift. At 287 pounds, Braun claims it's the lightest lift on the market that can do a stable lift of 770 pounds. All Terrain Conversions makes another lift for pickups and SUVs [see April 2018 Motorvation] that offers locking mechanisms that allow it to raise, swivel and secure a driver or passenger from a ground level wheelchair to a seated position in the vehicle.

AMF Bruns offers a line of adjustable aluminum ramps that deploy from the rear or side of a vehicle. The company also offers power and manual side steps for people with some, but limited, mobility who may not be able to step higher up into a vehicle.

For wheelchair users who might need assistance pushing their chairs up the incline of a ramp, Q'Straint has an updated product to assist with loading called the Incline Loader. The winching device can be used on side or rear-entry ramp vehicles to help pull the wheelchair up the ramp safely, with the operator using the directional "steering" capabilities of the Incline.

For drivers or passengers who are able to transfer into a vehicle's standard seating, but still need to load and unload their mobility devices, there are a variety of lifts and rear-mounted carriers available for loading and hauling wheelchairs in vans, sedans or pickup trucks. One option for loading, stowing and hauling wheelchairs is the former BraunAbility Chair Topper. Production was moved to Sweden, where Autoadapt updated the design under the name Autoadapt Chair Topper. A redesigned carrying case mounted on the roof of the vehicle houses a mechanism that loads and stows the wheelchair for travel at the touch of a remote control. With less interior space in many newer vehicles, the Chair Topper lets you avoid disassembling and reassembling a wheelchair when you enter a vehicle.

Autoadapt has also launched an all-new Carony transfer wheelchair that, for the moment, is only available in Europe; this wheelchair allows the user to transfer to the car seat without any lifting. The company will soon launch an app that allows swivel seat users to use their smart phone as a hand control for their swivel seat.

Adapt Solutions, a Canadian company, offers several products to assist with transferring into a vehicle. There's the Power-Pull that pulls a wheelchair up the incline of a ramp; powered seat bases that swing the vehicle seat users to use their smart phone as a hand control for their swivel seat.
side and lower it to the desired level for transferring from a wheelchair; and the Speedy-Lift device for loading an empty wheelchair into the back seat of a vehicle.

**Securement**

Q’Straint has developed a wireless remote release the size of a key fob for its QLK-150 docking system that eliminates the need to reach to the dashboard to release a wheelchair from the floor-mounted docking device. The similar EZ Lock Wheelchair Docking System has been on the market for 30 years, and the company continues to design and manufacture custom brackets to fit the latest models of wheelchairs so tiedown bolts can be securely attached to the chairs.

AMF Bruns offers a full line of securement devices. Its Protektor system provides stabilization for occupants or passengers in wheelchairs in the event of a collision. It claims the design prohibits any wheelchair from being improperly secured. Its FutureSafe head and backrest is adaptable to a variety of in-vehicle positions, with an integrated certified shoulder belt.

**Driving Controls**

As discussed in the last column, the requirement for all vehicle manufacturers to install knee bolster air bags beneath the steering wheel area is proving challenging in many types of new vehicles. According to some hand control installers, the new electronic Suregrip Featherlite requires minimal space for routing because the brake rod is tucked out of the way, offering a work-around for dealing with the knee bolster airbag problem. Other options exist as well.

Maine-based Electronic Mobility Controls continues to offer its AEVIT 2.0 “drive by wire” technology that accommodates inputs from a broad variety of sources and can eliminate the need for hand control brake rods.

Kempf-USA continues to update its Darios digital accelerator ring, and main hand brake for a broad variety of vehicle types — from small Chevrolets to an Aston Martin. The steering wheel and dashboard of each new vehicle is measured in 3-D, and specific parts are designed for that particular model.

Guidosimplex USA offers a similar line of hand control options, including accelerator rings that mount above or below the steering wheel and electronic accelerators that can be programmed for sensitivity depending on the traffic situation. Guidosimplex is distributed in the U.S. and Canada by MPS Driving Aids, which also offers its own line of reliable hand controls.

There are options for drivers who cannot use a steering wheel as well. Driving Specialties is still building the Scott Driving System on a Chrysler minivan base. The Scott system allows drivers to rest their arms in a steering yoke that also operates the throttle and brakes with minimal effort, similar to the movement of a wheelchair joystick, while an adjacent touchpad gives him the ability to operate all auxiliary controls. The company works with evaluators nationwide, builds vans in Los Angeles and ships them throughout the country.

**Resources**

- Adapt Solutions, 866/641-0419; adaptolutions.ca/products
- AMF Bruns America, 877/506-3770; amfbrunsamerica.com
- ATC, 855/324-3085; atconversions.com
- AutoAdapt, autoadapt.com
- Bever Car Products, bevercarproducts.nl/en
- B&D Independence, 618/262-7117; bdindependence.com
- BraunAbility, 800/488-0359; braunability.com
- Bruno, 800/454-4355; bruno.com
- Carospeed Menox, autoadapt.com/en/products/independent-driving/carospeed-menox
- EMC/AEVIT, 207/512-8009; emc-digi.com
- EZ Lock, 888/952-5625; ezlock.net
- GuidoSimplexUSA, mpsdrivingaids.com/guidosimplex-us
- Kempf, 888/453-6738; kempf-usa.com
- MPS, 800/243-4051; mpsdrivingaids.com/mps-products
- National Mobility Equipment Dealers Assn, 866/948-8341; nmeda.com
- Q’Straint, 800/987-9987; qstraint.com
- Scott Driving System, 818/782-6793; drivingsystems.com
- Sure Grip, 888/370-5050; suregrip-hvl.com
- Unwin, unwinsafety.com/new-unwin-products
- Veigel North America, 800/488-7688; veigel-na.com
- Wells-Engberg, performancemobility.com/hand-controls/wells-engberg

**The Impact of Self-Driving Cars**

While still in the early stages of development and acceptance on public streets, vehicles that drive themselves could have huge benefits for drivers who are unable to use their hands or feet. The age of autonomous driving may soon move beyond the testing stages to become available in all types of vehicles.

In the meantime, vehicle manufacturers are devising new ways to meet customers’ needs. A shift to electronic steering and braking assistance in newer vehicles reduces the need for supplementary systems like power assistance for steering and braking used by many drivers who have diminished arm strength or dexterity. Other exciting trends include:

- Electronic ignition, which eliminates the dangers of dropping a key while fumbling to start a vehicle after dark.
- Backup cameras, soon to be required on all new vehicles, reduce the need for mirrors mounted on the upper rear corners of many full-sized vans.
- Lane proximity warning devices reduce the risk of accidents and are becoming more common.
- A hands-free and feet-free driving system, which may be publicly available sooner than you’d think. See the January Motorvation for more on the Arrow Electronics system used by quad race driver Sam Schmidt.
NON-SURGICAL RECOVERY OF FUNCTION: NOT A FANTASY

“Improved voluntary hand function occurred within a single session in every subject tested.”

That’s the killer sentence from a new study soon to be published in the Journal of Neurotrauma. The principal investigator is our old friend, Professor Reggie Edgerton, who has been looking for ways to help people with chronic spinal cord injury since the late 1960s. I’ve met him a number of times in my own efforts to get my head around the difficulty of restoring function. In the small, intense universe of SCI research, he’s a sort of godfather — having mentored and trained a great many of the students currently on the hunt for therapies.

Until the first epidural stimulators were implanted in volunteers back in 2009 and 2010, no substantial functional recovery was happening with chronic injuries. You got back what you got back in the first year or two post-injury, and then you lived with it. Even the breakthrough moments of trials involving different kinds of cells were questionable, because they were invariably aimed at people with very new injuries.

The epidural stimulation work that I covered in my last column originated in Edgerton’s lab, but his new study is about what his team has christened tEMC, short for transcutaneous enabled motor control, also called transcutaneous stimulation.

There is no surgery, nothing implanted, no wires snaking through the body to a device embedded under the flesh. Instead, there are a couple of electrodes taped right onto the skin, not unlike the functional electrical stimulation units a lot of people use to ride stim bikes. The difference is that FES units are designed to push current directly into targeted muscle groups, while tEMC units push current toward the spinal cord itself. In that way, tEMC is just like epistim, and like epistim, it seems to work — in the sense that people do regain volitional movement.

In the fall of 2016, Edgerton published a report based on this question: If putting a stimulator into the lower back epidural space results in voluntary movement of feet and legs, would putting one into the cervical area result in the same for hands and fingers? The report included this line: “Herein we show that epidural stimulation can be applied to the chronic injured human cervical spinal cord to promote volitional hand function.”

Volitional hand function means successfully willing the hand to move. We went from reports of epistim working on the lower limbs to studies showing epistim worked on the hands, and now we have tEMC working on the hands. I got to see this for myself in May. One of Edgerton’s collaborators, Chet Moritz, Ph.D., runs a lab for SCI research at the University of Washington. He invited me to visit during one person’s tEMC session.

What a tEMC Session Looks Like
The session participant, Joe, a 60-something C3-4 quad, was undergoing follow-up work from an earlier tEMC study he’d done with Moritz. It’s the first documentation of tEMC helping a person with limited hand function regain a measure of independence.

Joe was a genial person working with a small team of grad students engaged in setting him up, monitoring his blood pressure, helping him move from place to place, giving him specific tasks to perform and measuring every scrap of data associated with the process. The electrodes were placed in the center of the back of his neck a few inches apart, one above the other.

One of the grad students operated a tablet that controlled the amount and nature of the current being sent to his cervical cord. Joe said it did not hurt at all. Did it feel like those FES units from the stim bikes? He said it was nothing like that. “It doesn’t tingle on your skin. It’s like you can feel the current moving through your spine and all the way down your legs.”

The session lasted for about an hour and a half, with plenty of rests and adjustments. Joe seemed to enjoy it, though I could see that he was getting tired by the end. In a video of Moritz discussing the initial study with Joe, you can see that while he’s not in any sense “cured,” Joe is able to do things independently that were impossible before the study. And as it turned out, Joe wasn’t an anomaly.

Edgerton’s team recruited a total of eight people with SCIs ranging from

“Finger dexterity also improved. Some could pinch a debit card and get it into an ATM, use a cell phone or turn a key in a lock.”

By Kate Willette
C3-4 to C7 who were 13 months to 21 years post-injury. None were vent users. Their hand function covered the range from barely a trace to measurable, but weak. The study began with three sessions of testing designed to locate a baseline function for each person. That was followed by four weeks of intervention with the tEMC, twice a week for an hour or two at a time. By the end, two of the subjects had to drop out, both for reasons unrelated to the study.

During each session, with their wrists in neutral positions and arms stabilized to prevent compensating, the subjects worked on maximizing grip strength and rhythmically opening and closing their hands. Electrodes were attached to the appropriate forearm and bicep muscles to measure the exact amount of energy their efforts were generating. All of them got stronger immediately under the influence of the tEMC — and those gains stayed with them. With each new session, their baseline grip strength improved from the previous time. Because the strength was retained, the improvements from week to week were also cumulative.

Finger dexterity also improved. Some could pinch a debit card and get it into an ATM, use a cell phone or turn a key in a lock. One of them was able to twist the cap off a water bottle. Their average maximum grip strength had more than tripled by the end of the study, but also — just as in the epistim trials — they enjoyed improvements in other quality of life measures. Sensation was better. Trunk control was more reliable. They even made gains in bowel and bladder control.

Understanding How It Works

It turns out the spinal cord is not just a collection of individual neurons all wired to other individual neurons; it’s more like a collection of wired-together collections. In my imagination, these collections of neurons that function all together — called neural networks — are sort of like the clumps of jigsaw puzzle pieces you put together off to the side when you’re building a big puzzle. They lock on to one another, and they form part of the picture, but until you find at least one place where your small clump connects to the larger puzzle, they’re just floating, useless.

The neural networks are intact in the undamaged parts of the cord below the injury, but they’re useless without a sufficient connection to the brain. The tEMC and the epistim units light them up in such a way that whatever slender link exists becomes enough.

But what if there’s no link at all? Isn’t that exactly what we mean by “complete injury?” When I was writing Don’t Call It a Miracle in 2014, I asked Lyn Jakeman, Ph.D., about this. As program director, Repair and Plasticity, at the National Institute of Neurological Disorders and Stroke, her job is to oversee research funded by the National Institutes of Health that’s aimed at finding therapies for us. She told me that it’s possible the conventional wisdom is wrong — that there’s no such thing as a complete injury. There seems to exist in every cord, no matter how badly damaged, a way to restore some connection.

I call that good news. As Edgerton’s paper puts it: “The increasing number of examples of regained/improved supraspinal control after ‘complete’ paralysis suggest that the basic biology of a spinal lesion that is presently clinically defined to be motor complete must, at least, be challenged.”

What’s even better is these gains were not only quick, they were lasting. Combined with a few months of therapy, stimulator-enabled changes didn’t go away once the study was over. We’re entering a time, at long last, when there is reason to think that even years after injury, some recovery is possible. As Edgerton said, “We have no evidence that the intervention here has been developed to its optimal potential.”

The next task is to work out what that optimal potential might be. It is too early to know for certain. It will take time and a lot of dedicated effort, but we are definitely going to be hearing a lot more about transcutaneous stimulation.

Resources

- Edgerton Neuromuscular Research Laboratory, edgertonlab.ibp.ucla.edu
- Moritz Lab, depts.washington.edu/moritlab/
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WHAT MAKES TIM HAPPY

In his December 2015 article “What Makes Us Happy,” Tim wrote:

If I have learned anything over the past 70 years, 50 of them as a wheelchair user, it is that what brings happiness changes with the seasons of your life.

At first, as a young man, it was all about the chase — the emotional rollercoaster of pursuing and being pursued by girls. That was the name of the game, and happiness rose and fell daily with the tide. Later, still young but nearing middle age, the lure of good times won me over. Smiling faces, thumping music, food and drink, drugs — if something felt good, it was instant proof that you were happy, at least until you woke up the next morning.

At some point I began to feel the need to leave a mark, to know that my life counted for something. Working and succeeding, doing something worthwhile was the path to happiness and fulfillment. Funny, how I look back now and think that all of it, no matter how memorable and valuable it may have been, is fading fast.

Change rules our lives, and time pushes us onward on our journey. What is really important? What is lasting? What do we leave behind?

Friends. People. Relationships. Memories. Love. Now I know, as time becomes more precious with each passing day, what really makes me happy.

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