

# More Than Walking



## Volunteer Welcome Packet

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[www.morethanwalking.com](http://www.morethanwalking.com)

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## Our Story

Jessica Bello Capote (right) grew up in Cali, Colombia and became a physical therapist because she enjoyed helping people live with chronic conditions that required new adaptive skills and tools. Valedictorian of her class at Universidad del Valle, she worked in Cali from 2013 to 2015, practicing neurological, aquatic, and musculoskeletal physical therapy in private rehabilitation centers and Clínica Fundación Valle del Lili, a large teaching hospital. The number of patients who needed physical therapy often outnumbered the available professionals, and access to assistive equipment and other medical services were limited, disrupting patients' recoveries and therapists' effectiveness.



Jonathan Sigworth (left) grew up in Connecticut, USA and became a documentary filmmaker and disability advocate in India after a 2006 bicycle accident there left him paralyzed below his arms and in his hands when he was 19. He subsequently returned to India, while completing his English degree at Wesleyan and then at Dartmouth University, to start India's first wheelchair rugby team and direct a short documentary "More Than Walking" (2009) – having witnessed the lack of opportunities that new spinal cord injury patients had to learn about pursuing independence again.

In November 2013, Jessica was treating a quadriplegic patient named Jaiber (center), who didn't believe that he could get out of bed and into his wheelchair on his own after becoming paralyzed in a motor-cross accident in 2011. In an effort to convince him otherwise, Jessica searched on YouTube and found Jonathan's documentary and bed mobility demonstration video. Jaiber believed that Jonathan was only acting paralyzed, so Jessica found Jonathan on Facebook and discovered that he had just moved to Delhi to start a transitional living and peer mentor program for quadriplegics with ESCIP Trust India. Soon after Jessica contacted him, Jonathan traveled to Colombia to visit her and mentor Jaiber in person. Not only did Jaiber begin pursuing independence, paragliding and wheelchair motocross, but Jessica and Jonathan married in 2016 and co-founded More Than Walking Incorporated on August 28, 2017 to improve global access to the knowledge and community that makes life with paralysis possible.

Go to the link below to watch Jonathan's 20-min. "More Than Walking" documentary.

[www.morethanwalking.com/story](http://www.morethanwalking.com/story)



## The World Needs Spinal Cord Injury Peer Mentors

500,000 people worldwide suffer a spinal cord injury every year and often face the inability to walk, bowel & bladder incontinence, social stigma, financial hardship, nerve pain, and depression. Patients often feel alienated, even with their own doctors and therapists, and return home without knowing how they can ever live independently again.



## How Your Videos Can Help Others



More Than Walking's Mobile Video Course Bridges the Gap from Hospital to Home



Connecting SCI Patients & Therapists



To Local Mentors & Medical Suppliers

When you share your story in a recorded interview and submit demonstrations of your independent living skills, More Than Walking (a non-profit organization) publishes them across social media and, eventually, in a mobile video course. When complete, the course will provide step-by-step guidance for every type of spinal cord injury on essential mobility techniques, introductions to local peer mentors, and a global resource map for finding support groups and disability-related services.



Every More Than Walking video serves as a means for others to learn and to contact our community for help. When a viewer clicks on a link to request peer mentor support, More Than Walking may contact you with details of the request in order to make an introduction, depending on your availability. Your personal contact information will never be shared without your permission.



***I'm not sure if I will get use of my legs back or not. If I don't... still good, because I'm not a pair of legs. I am more than that.***

- Joseph Newson Jr., C7/T1 Quadriplegic

## Our Injury Level Prognosis

### Cervical 1 – 3 Quadriplegia

Neck mobility intact, ventilator required for breathing. Motorized wheelchair. Total assistance for all activities.

### Cervical 4 Quadriplegia

Some shoulder movement, independent breathing. Motorized wheelchair. Total assistance for all activities.

### Cervical 5 Quadriplegia

Elbow flexion, can support sitting and lift hand to face. Motorized wheelchair. Total assistance for all activities.

### Cervical 6 Quadriplegia

Wrist extension, able to support and lift body while sitting. Manual wheelchair. Can perform wheelies.

### Cervical 7 – 8 Quadriplegia

Able to raise arm completely vertical. Manual wheelchair. Can transfer from floor to wheelchair.

### Thoracic 1 – 9 Paraplegia

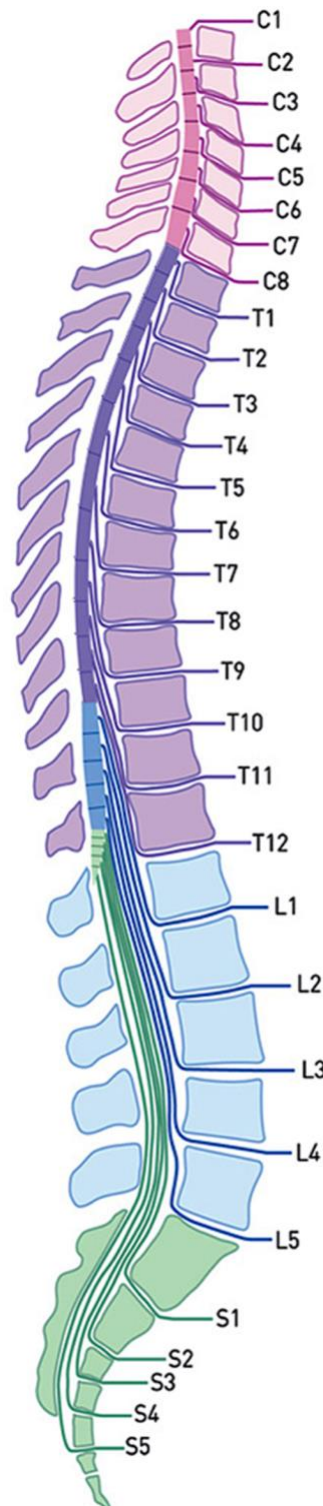
Full arm and hand function. Manual wheelchair. Total to some assistance with heavy house cleaning

### Thoracic 10 – Lumbar 1 Paraplegia

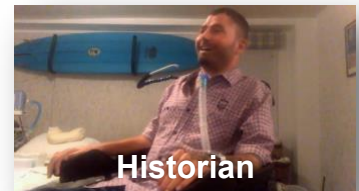
May walk with crutches, walker, or leg braces. Some assistance required with heavy house cleaning.

### Lumbar 2 – Sacral 5 Paraplegia

May walk with cane or ankle braces. Some assistance required with heavy house cleaning.



## Who We Are





## Our Global Community

More Than Walking surveys its 90+ participants several times a year in order to make sure that everyone has the resources and support they need, and to measure the impact we are making together. Please take the time to complete these surveys, whether or not you need any support or any major changes have occurred.

These surveys are also a way to share with you new opportunities to engage with the More Than Walking community. You can sign-up to:



Join our private Facebook group.



Be added to our mentor e-mail list serv.



Receive / give a monthly phone call from / to a fellow mentor participant for encouragement.



Participate in monthly published group video discussions on various social issues.

## Register to Volunteer and Get Your Free T-Shirt!

Register to become a peer mentor at <https://www.morethanwalking.com/connect.html>. Every volunteer gets 1 free shirt. By wearing it in public or when filming your next video, you can help share the path to independence after spinal cord injury!



Click below to choose size and color:

<https://forms.gle/WDoVk9g33JJ8JeUF6>



## Interview Guidelines



- If you have scheduled to do your interview over Zoom, download the application to either a smartphone, tablet, or computer at <https://zoom.us/>. At the time of your interview, click on the link emailed to you and the Zoom application will open automatically.
- Make sure your camera is on a stable surface that won't vibrate and that no one will touch.
- If using a smartphone, use landscape mode - the phone on its side instead of vertical.
- Look at the camera when talking, not at your face of the interviewer.
- Include the context of each question in your answer.
  - For example, if the question is: "What was life like before your injury?"
  - Do not say: "It was great..."
  - Instead, say: "Life before my injury was great..."
- Be specific and share details from your experience in each answer, remembering that the interview will be shared publicly. You can request to review the edited version before it is published or cancel its publication altogether.
- If you record your interview yourself, you can upload it at [www.morethanwalking.com/submit-videos.html](http://www.morethanwalking.com/submit-videos.html) or email [mentors@morethanwalking.com](mailto:mentors@morethanwalking.com).

## The Interview Questions

1. What is your name? What is something you care deeply about or love doing? Why?
2. What was life like before your injury?
3. How and when did your injury occur?
4. What barriers did you face afterwards to get back to life?
5. What helped you live again?
6. How have your relationships with people changed since your injury?
7. What have been your most surprising accomplishments since your injury?
8. What skills or experiences are you eager to have next?
9. Speaking to someone newly injured similar to you, what advice can you offer?
10. Are there other goals in your life that are more important than walking again?



## Independent Living Demonstration Guidelines

The following prompts are to help you think about what you might include in a demonstration for the listed 16 topics. You can submit demonstrations on topics not listed here. Please perform all demonstrations fully dressed. To submit a video, go to [www.morethanwalking.com/submit-videos](http://www.morethanwalking.com/submit-videos) or email [mentors@morethanwalking.com](mailto:mentors@morethanwalking.com).

### Basic Smartphone Filming

- Always record in landscape mode (the phone sideways, not vertical).
- Film with light on your face, not shining towards the camera from behind you.
- Make everyone and everything else quiet, silencing phones, fans, air conditioning, and closing windows. Speak loudly and clearly.

**1. Respiratory** - How is breathing now different from before injury, in terms of medical equipment, coughing strategies, singing, swimming underwater, complications in cold weather, assistance. How do you manage during travel?

**2. Bowel** - How is bowel management now different from before injury, in terms of adaptive devices/medicines/supplements / medical supplies used, bathroom setup, routine explanation (including prep and cleanup), assistance. How do you manage during travel? How do you prepare for emergencies?

**3. Bladder** - How is bladder management now different from before injury, in terms of adaptive devices/medicines/supplements / medical supplies used, bathroom setup, routine explanation (including prep and cleanup), assistance. How do you manage during travel? How do you prepare for emergencies?

**4. Bed Mobility** - How did you first learn how to get up from bed (with or without assistance)? How did you maneuver to lay back down? How did this change over time? How did the type of bed (hospital or normal) or mattress (spring, water, foam) make a difference, or any adaptive devices (pressure mattress overlay)? What precautions do you take?

**5. Transfers** - How did you first learn how to transfer to/from bed, wheelchair, tub, shower bench, car, floor, etc.(with or without assistance)? How did this change over time? How did the type of surface (soft or hard) or height (going up/down) make a difference, or any adaptive devices (slide boards, leg straps)? How do you manage during travel? What precautions do you take?

**6. Pressure Relief** - How did you first learn how to do pressure relief (with or without assistance)? How did this change over time? How did the type of surface (soft or hard, bed, seat, or ground) make a difference, or any adaptive devices (mattresses, overlays, cushions)? How do you manage during travel? What precautions do you take?

**7. Eating** - How is eating now different from before injury, in terms of positioning, utensils, adaptive equipment, carrying items to table, avoiding burns, cutting or serving food, assistance? Does your SCI influence your diet? How do you manage during travel?





**8. Dressing** - How did you first learn how to dress yourself again (with or without assistance)? How did this change over time? Can you dress both upper/lower body in a bed/wheelchair/standing? How do you manage buttons, zippers, knots, velcro? Do you use any dressing aids or custom clothing? How do you integrate leg bags, colostomy bags, etc? How do you manage during travel? What precautions do you take?

**9. Grooming** - How is brushing teeth, flossing, hairdressing, shaving, makeup, nail cutting, filing, nail painting now different from before injury, in terms of planning, positioning, adaptive equipment, timing, and assistance?

**10. Bathing** - How did you first learn how to bathe yourself (with or without assistance)? How did this change over time? How do you wash lower / upper extremities and back? What equipment or assistance do you use? How do you manage during travel? What precautions do you take?

**11. Chair Skills** - How did you first learn how to propel your chair yourself (with or without assistance)? How did this change over time? How do you manage doors, ramps, curbs, stairs, steps, hills, wheelies, falls? How does the floor or ground surface make a difference? What about the weather? What equipment or assistance do you use? What precautions do you take?

**12. Standing / Exercise** - How did you first learn how to exercise, stand, walk, or swim (with or without assistance)? How did this change over time? How do you manage low blood pressure, muscle soreness, nerve pain? What medicines, supplements, equipment, or assistance do you use? How do you integrate bowel or bladder needs (leg bags, colostomy bags, etc)? How do you manage during travel? What precautions do you take?

**13. Communication** - How is talking, listening, writing, typing, dictation, or using a remote / controller now different from before injury, in terms of technology, adaptive equipment, technique, and assistance? Is this affected by any medications? Have your methods changed over time?

**14. Transport** - How is traveling by car, truck, bus, train, boat, plane, or rocket now different from before injury, in terms of driving, riding, planning, wheelchair storage, adaptive equipment, timing, and assistance? What precautions do you take?

**15. Homemaking** - How is cooking, cleaning dishes, taking out trash, sweeping, vacuuming, mopping, dusting, doing laundry, changing light bulbs, household maintenance, organizing storage, moving furniture, mowing the lawn, raking leaves, shoveling, now different from before injury, in terms of delegation, adaptive equipment, timing, and assistance?

**16. Instructing** - How did you first learn how to manage your personal care with family, friends, or attendants? How did this change over time? How do you organize your personal care around your daily schedule? How do you maintain a positive relationship with those who help you? How do you approach and instruct strangers or neighbors for help (such as getting a wheelchair out of a car, getting up/down stairs)?