

Rehabilitating The Spirit

It takes a holistic focus to help patients restore their sense of self

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This year's mental health series has had a central theme: The body cannot be fully rehabilitated without engaging the spirit of a person.

This theme goes beyond the mind-body connection to address who the person is and his or her place in the world. A comprehensive treatment approach is essential not only in preserving the functionality of each patient but, more importantly, in restoring a sense of self.

Rehabilitating the spirit-restoring the sense of self-requires holistic support. Engaging the spirit involves different challenges for each patient: diagnosis, personality, emotional and physical resources, or lack thereof.

Treating the Mind, Body and Spirit

The compelling story of Dr. Jesse Lieberman distills the core ingredients of rehabilitation of the spirit. Profiled on the NBC *Today* show twice as an "everyday hero," Lieberman is a remarkable man of courage, hope and resilience. At 31, he is a physical medicine and rehabilitation physician who is currently a fellow in the Spinal Cord Injury unit at the University of Pittsburgh Medical Center. He and his wife, occupational therapist Michelle Lieberman, are the proud parents of 9-month-old twins, Saul and Gracey. Lieberman is also a C-5 tetraplegic.

In 2003, during his third year of medical school at Wake Forest University, Lieberman fell three stories from his balcony while helping a neighbor one floor below who was locked out of her condo. Lieberman's narrative is a remarkable account of how his own spirit remained intact through a life-altering disability and how he serves as an active source of inspiration to his patients. He knows both sides-the patient's and the practitioner's perspectives.

Recovery

For disabled patients, rehabilitation is a complex emotional journey. It is important to track not only patients' physical progress but their emotional progress as well. How they are coping? Where are they feeling stuck emotionally? Where are they in the stages of acceptance?

After his accident, Lieberman underwent twelve days of inpatient medical intervention, eight weeks of acute rehabilitation and four months of outpatient therapy. His early rehabilitation experiences were challenging.

"At first, it was frustrating. I had the assumption that I was going to be OK, that my function would come back. I was diagnosed as a C-5. I could not move anything other than shrugging my shoulders. I thought I would get better. I thought my injury was not permanent."

Lieberman's background as a personal trainer and bodybuilder fueled his commitment to his recovery. "I took my recovery as a new physical challenge. I would have been happy going to therapy 8 hours a day."

His work ethic helped him make valuable gains. "Now I am able to feed myself and brush my teeth, as well as be independent on my computer. I can direct my power chair and can direct others to transfer me. These small things have given me much more independence."

Lieberman has continued to gain strength in his upper extremities and uses a hand exercise bike twice a week. "I am a motivated person; I work hard regardless of the task."

Returning to Life

Lieberman returned to complete medical school immediately after discharge from inpatient rehabilitation.

"Now, I laugh when I think about it," Lieberman reflects. "I went right from the rehab center to the dean's office. My wife and dad were there and they supported me to return [to school]... I did a research project, studied for my boards and started a rotation [while also attending outpatient therapy]. I remember I was still very weak."

At the time, his doctors and rehabilitation team were advising that he take a year off, but Lieberman was intent on completing his studies on time. "I did not think staying home and taking a break would be good for me," he shares. "I would be bored and sad. I wanted see if I could go back to my life. I wanted to try to see what I could do."

Lieberman graduated medical school on time and married his wife, Michelle, a week later. Although he is not without his moments of frustration, the central quality in Lieberman's recovery has been patience.

"This was the most important quality that I had to learn." It is a daily effort, he adds, "when you are used to doing everything for yourself. I have to communicate, hand me my computer, hand me my file." It takes time to get dressed. I've learned to take a deep breath and remind myself it will get done. It is easier to go through life when you accept your situation and work with it-I try not to get upset about something I can't change."

In his emotional adjustment to life with a disability, Lieberman gained perspective from his work with ALS patients during his residency. "Although I had a lot less function than most of the patients I worked with, I knew where I was with my condition. Many of these patients did not know if they were going to be alive. Their decline is so rapid, they had more function at the time I saw them, and then one year later they have less function. This gave me perspective on my own disability, because I am stable."

Disability Accommodations

Helping patients return to work can be critical in the recovery of their spirits.

Lieberman was the first student to graduate from his medical school with C5 tetraplegia. At first, he had a difficult time finding residency programs that would accept him with his limitations. But East Carolina University accepted him for a one-year internal medicine internship and he then went on to do a three-year residency at the Charlotte Institute of Rehabilitation.

Lieberman's residency made "every accommodation without taking away from my experience," he recalls. "I was still held to high standards, had similar responsibilities and was still on call."

A nurse assistant helps him to examine patients, write notes and return phone calls. Lieberman, in turn, focuses on his observation and communication skills.

"I have learned to heighten my powers of observation during an exam, for example, observing how a patient moves, how they function. I take in the big picture. I work with a nurse assistant who conducts aspects of the actual exam for me, but I am talking through the entire exam each time."

Lieberman feels strongly about providing such opportunities to disabled health care professionals.

"We need practitioners who have been on the other side. The statistics tell us that 20 percent of the population has some type of disability. Finding ways to support disabled professionals to be part of the health care system helps to be more representative of the patient population."

Lieberman is aware of the challenges this may pose. "We don't want patients at risk either, but people with disabilities can make contributions and can operate as physicians." Lieberman emphasized that his disability accommodation model "is one example of a reasonable combination."

Patient to Practitioner: A Role Model

Lieberman's first-hand experience equips him with a unique sensitivity in his work with rehab patients. And although he has gained many insights on how to engage patients, he is not immune to challenges.

"It is difficult to tell patients their diagnosis. Some patients want to know the first day. Other patients have a harder time. I don't like it when patients come to the unit and they have been told something like 'you are never going to do able to do this.'"

He added that a health care provider's most common error is "not listening to patients, and treating each patient the same exact way. There is no blanket approach; you need to personalize your approach."

When Lieberman started his residency, a remarkable thing happened: patients began to look to him as a role model. "I went back to see patients right after my injury. I found that the patients got just as much out of talking to me. I saw the impact that I had on patients. And very few practitioners experience this."

Lieberman's experience gives patients a tangible vision of what is possible. "My disability gives a lot of hope and inspiration to my patients; I am able to challenge my patients: 'If I can do this, you can do this.' It gives me more leverage."

Early in his training, other practitioners also benefited from Lieberman's experience. Trauma surgeons asked him to see newly injured patients. "The main message I gave to the patients that were newly injured is that my life did not end with my injury and that each person needs to find what that life is going to be." Lieberman's wife Michelle also joined this effort and spoke to caregivers on what to expect.

Planting Seeds of Personal Value

Rehabilitating the spirit is not simply a matter of treating acute mental symptoms such as anxiety or depression; rather, it builds on the strengths of each individual. Since disability often requires reestablishing identity, all practitioners need to participate actively in helping a patient restore a sense of self.

"Patients need to find something that gives them value," Lieberman explains. "Going back to school and seeing patients gave me a sense of role and purpose. It was the best thing for me. By the time I realized that I was not going to get better, I had been seeing patients and seen the impact that I could have on them."

At the same time, Lieberman cautions against rushing through this process. Help patients find their goals organically, rather than impose goals on them, he says. "I remember one patient I worked with found value and a goal by rediscovering his role as a father, after his SCI injury. Previous to that, he was not there for his kids. And now he is home and spends time with them on their homework and that gave him a lot of value."

Cynthia Miller, MSW, MBA, is a psychotherapist and chronic illness specialist who helps patients formulate goals after a disabling condition. "Patients learn how to take care of their bodies in medical centers, but what about the rest of them?" she asks.

Miller offers the following question to guide patients who may not have well-formulated life goals: "What do you love, like or respect about yourself?"

Life after Rehab

In every domain of their lives, Jesse and Michelle Lieberman have learned to adapt and find solutions for all sorts of functional challenges. "I know I had a huge advantage with my wife who is an OT," he adds. "Michelle is an incredible problem solver. Each time we move, we try new things-how to set up the computer, how to set up our house."

Lieberman's daily adaptations include the use of dorsal wrist splints which keep his wrists in a neutral position and enable him to hold items and turn pages in books. On the computer he uses Dragon Naturally Speaking software and a trackball mouse.

Jesse and Michelle also adapt creatively in their role as parents. "It is challenging, but so much fun," Lieberman adds. "Michelle always made sure that I can hold [the twins] and spend time with them. I get out of my chair and onto the bed where I can hold them safely. When they were younger, we used bottle holders that wrap around them so I can feed one, with only nudging the bottle with my hand."

When Lieberman conducts his family meetings about discharge planning with patients, he is sensitive to guiding family members to think about their needs practically.

"I have an understanding of life afterward," he notes. "For example, even though after my own rehab I was returning to an accessible apartment, it was still challenging-designating the right room, making sure there is the right turning radius."

Michelle seconds this advice from her own perspective as both an OT and a caregiver. There is not a true appreciation of "what happens when the patient leaves you," she asserts. It is important to involve caregivers in the treatment and planning process. She also advises practitioners to be aware of the stressors that caregivers experience in negotiating the health care system.

"Unless you have lived with the challenges of SCI, you have no idea what the moment-to-moment challenges are," she says.

Refueling

No one is beyond needing ongoing support and frequent doses of hope and encouragement. Next February will be six years since Lieberman's accident; he admits that "anniversaries are still difficult. But at the same time, it is also fun for me to look back... I wonder how many people would imagine I would have completed medical school, residency and be in a spinal cord fellowship."

Miller stresses the importance of encouraging patients to seek ways of lifting their spirits daily. "Teach patients that keeping life in balance does not have to be left to chance," she says.

She defines four areas that patients can explore as resources: physical (activity), emotional (expressing feelings), spiritual (community) and intellectual (learning). Practitioners can guide patients in developing a list of possibilities in each area with the guiding question: "What would lift my spirits today? The answer can change frequently."

Lieberman refuels on hope through a myriad of sources, including his loving relationships and work. "My wife, kids and friends keep me hopeful. I am the breadwinner of the family."

After his current fellowship, Lieberman is hoping to work next year at the Charlotte Institute of Rehabilitation's Spinal Cord Injury unit. His story is a poignant example of the essential ingredients for rehabilitating the spirit and nourishing a meaningful life: individual will, family support, accommodations and medical care.

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Resources

• **NBC Today Show Segment: "Against All Odds":**

www.thehealingfundforjesse.org/todayshow.htm

• **Healing Fund for Jesse:**

www.thehealingfundforjesse.org

• **Spinal Cord Injury Association:**

www.spinalcord.org

• **Christopher and Dana Reeve Association:**

www.christopherreeve.org