



Faith Hunter, MBA, practices yoga and meditation, while also teaching it to those in the bleeding disorders community.

PAIN RELIEF

How alternative therapies
can help reduce or manage
bleeding disorders pain.

BY CHERYL ALKON, FREELANCE WRITER

For Rick Starks, who has lived nearly seven decades with severe hemophilia B, learning to manage pain has been a lifelong pursuit.

"When I was a young child, I was given no pain medications at all," said Starks, 68, of Haiglar, Nebraska. "My form of pain management was counting the dots in the ceiling tile at the hospital while I got the full gamut of treatments for my hemophilia, including factor IX," he said.

"I realized, after counting the tiles every time, that each tile all had the same number of dots. I think the exact number is 1,241 dots. That's when I quit counting. I was probably around nine years old."

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Starks turned to reading to take his mind off the pain. “It became my next big thing—anything in children’s literature,” he said. “The Tarzan novels by Edgar Rice Burroughs were my favorites.”

Time passed, and Starks, at 17, went with his uncle to watch the martial arts film “Enter the Dragon.” The 1973 kung fu action movie featured Bruce Lee. Starks was intrigued by kung fu, a style of Chinese unarmed fighting, but his parents forbade him to try it because they feared he would get hurt. But once he turned 18, he began training—first with kung fu and later, tae kwon do, a Korean martial art that focuses on power and kicking.

Practicing martial arts helped Starks strengthen his body and become more flexible—both of which helped build his confidence. “With martial arts, you always get hurt, but I would know it was coming,” he explained. “It was the same kind of pain [like a sprain] that would cause the same bleeding as hemophilia would, but the biggest form of pain relief was that I’d heal up and I’d begin training again.”

Starks eventually earned his black belt in tae kwon do and incorporated meditation more formally in his life. It was a long way from counting ceiling tile dots.

“When you meditate, you focus on breath, and follow it so intensely so no other thoughts or feelings or emotions fall into that space,” he said. “It’s an incredible part of pain management for me. For that period of time [when I was meditating, the pain] just disappeared. It was probably still there, but my attention didn’t notice it.”

By his 40s, Starks needed two hip replacements due to joint damage and later, had two ankle replacements. By his 50s, he moved on to tai chi, a Chinese style of incorporating gentle movements and controlled breathing.

“Because of the slow movements, it’s also very meditative,” he said. “It helped with my pain. With both my ankles, I would meditate and my respiration would slow to four breaths per minute. Normal is around eight to 12 breaths per minute.”

Starks became a tai chi instructor and now speaks around the U.S. about the benefits of tai chi for those with bleeding disorders.

“It’s my passion, and I like trying to help those in our community,” he said. “I’ve seen what it does for me. In moments of crisis, I stop and take a breath before acting—I’m not going to say ‘reacting.’ I’ve found that by doing so, your whole life turns around. You start looking for the good things in life. If you focus on negative things, the pain becomes your main focus. The what-ifs end up taking over your life. Living in the present moment is what I try to do now.”

As Starks shows, finding useful ways to alleviate pain from a bleeding disorder can be an ongoing process. Pain can be acute—caused by a short-term issue such as a fall or injury or joint bleed—or chronic—a long-term problem due to ongoing joint damage and arthritis from multiple bleeds over time, said Tyler W. Buckner, MD, MSC, associate professor of hematology at the University of Colorado School of Medicine Anschutz Medical Center and the Hemophilia and Thrombosis Center in Aurora, Colorado.

And yet, no matter what kind of sensation a person experiences, “pain is a very personal experience,” said Angela Lambing, MSN, ANP, GNP, a hemophilia and pain management expert and consultant and retired adult nurse practitioner and geriatric nurse practitioner. “Therefore, the treatment or management of pain is also unique. There is no one right answer on how to best treat pain. Treatment has to be personal.”

Being open to what is called “alternative” or non-Western ways of pain management can be helpful, many patients and providers say. Known as complementary or alternative medicine, or CAM, such treatments can work together with or in place of conventional medicine to treat pain, Lambing said. CAM treatments include but aren’t limited to modalities such as meditation, hypnosis, acupuncture, physical exercise, yoga, cannabis and more



Rick Starks, left, with his first tai chi instructor, David Dorian Ross.

Understanding Pain and Hemophilia

Hemophilia pain primarily involves joint pain. Acute pain, which can be caused by spontaneous bleeding or an injury that leads to bleeding into the joints, is more common with severe hemophilia.

“Blood in the joint takes up space, which causes pain and inflammation, which is also painful,” Buckner said. The primary treatment, of course, is clotting factor to treat the bleeding and get it to stop. RICE—rest, ice, compression and elevation—can also help.

“We try to emphasize non-pharmacological ways to treat chronic pain, such as physical therapy, activity modifications and exercise,” Buckner said. All can be effective.

Chronic pain occurs when arthritis, or prolonged joint damage, develops in people with hemophilia, typically at a younger age than the general population experiences arthritis. Damage can also cause a loss of cartilage between the bones and the structures of the joint. The loss of the joint can lead to muscle and tendon weakness.

Since the 1990s, prophylactic factor infusions—often called “prophy”—starting in early childhood have helped reduce the incidence of uncontrolled bleeding. This has helped younger

generations of people with hemophilia to have fewer cases of chronic pain as compared to those born earlier, in general. However, despite the use of ongoing prophylaxis, young adults still report pain episodes for reasons that remain unclear, Lambing said.

Newer Pain Research

At the 2022 HFA Annual Symposium and at various chapter events, Lambing has presented her findings of literature reviews of how CAM methods treat pain, noting for each modality whether there was research on people with bleeding disorders.

For Buckner, whose research addresses how pain is measured in populations both living with and without hemophilia, and how they compare, measuring pain is a good way to start a conversation about how to manage it.

“It’s been well-demonstrated that pain has an impact on people’s quality of life and their ability to go to work and to school,” he said. “We get a lot of interesting stories about disconnects—someone may not be in pain at all but will still avoid certain activities because they know the activities will cause pain,” he said. “That differs from someone who has pain all the time and continues

to function in spite of it. You really have to ask all the questions to get all the story.”

Other research has tried to bring more attention to pain for people with hemophilia. Nathalie Anne Roussel, PhD, a professor at Belgium’s University of Antwerp, focuses her work on pain management, neuroscience education and how to empower people to treat their pain. Her findings on pain and hemophilia, published in the January 2023 journal *Haemophilia* and based on a survey of 185 adult men, concluded that “pain is a major issue amongst people living with hemophilia, even those with mild hemophilia. Pain interferes with activities, emotions, sleep and health-related quality life.” In her study, she called for more comprehensive research into how to approach pain treatment and management for people living with hemophilia.

Moving More

For Faith Hunter, MBA, hemophilia has been a family affair. She is a carrier, and her grandfather and two brothers had hemophilia. Now a wellness expert focused on yoga, meditation and general healing, Hunter once developed programs as the HFA FitFactor coordinator.

Hunter began practicing yoga while studying for her MBA and dealing with stress after her older brother, Michael Hunter, MD, contracted HIV from bad blood; he died in

1994 at 27, shortly after graduating from medical school. Hunter also incorporated meditation and physical exercise to help cope, often working out with her younger brother, Mark Hunter, PhD.

“Mark and I were living near each other in Washington, DC, and we would do bike rides together, between 10 to 20 miles each weekend, and he would do lightweight strength training and stretching,” as a way to deal with pain, she said.

Hunter’s advice: Try movement, yoga and/or meditation to alleviate pain. “Stand as much as you can,” she said. Set a timer to get up and stretch every 20 minutes while working at a desk or computer. “It activates the body and resets the brain as well.”

When people are in pain, they have a tendency to stop moving, she added. “Even some light subtle movement can get the blood pumping and moving through the muscles.”

People in pain shouldn’t avoid motion; easing into it can help with any fear about discomfort. “Most people don’t move, especially when they have blood disorders and are in pain,” she said. “The main thing when you are in pain is to breathe. Our natural reaction is to hold our breath, but having a breathing practice is so important.”

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To try it, close your eyes or gaze at a fixed spot in front of you. “Use your breath as your first tool to help you relax or reduce the pain,” she said. “It’s a slow process, but it helps you over time. Then you can move into doing meditations or practicing yoga as one of three methods to help deal with pain.”

For people who are new to yoga or meditation, “if you are in mild pain or discomfort, take 10 to 15 minutes to start,” she said. “Don’t feel you have to do more at first.”

Yoga as a Foundation

Growing up with hemophilia A, Corey Pierce, now 36, was often in pain, especially in his left ankle. At 22, just before he graduated from Oregon State University, he had surgery to fuse his left ankle joint together.

“Getting to that point, the pain had eroded my self-confidence and limited where I thought my life could go,” he said. Recovering at his parents’ house in Eugene, Oregon, took about six months as Pierce also worried about the then-stagnant economy and how he would find a job with health insurance. Tentatively, he turned to hot yoga as a way to strengthen his atrophied muscles. “My whole calf muscle was like a piece of floppy Jell-o,” he said.

The hot yoga practice, which is a series of poses done in a room heated between 80 and 100 degrees Fahrenheit, helped him grow stronger. “It was physically demanding even if I was not moving around terribly much,” he said. “I had started to build some confidence about my abilities, physically. I had a better body image as well through that process. Many yoga poses are power poses. In the years prior to my surgery, I had so many little pains and bleeds throughout my body. It took a toll on my sense of self and sense of what I was capable of.”

Pierce also considered himself a bridge between younger people with hemophilia who had access to life-sustaining medications and older generations who did not. “I saw a lot of death and physical limitations in the people who came before me, and I had thought, ‘This is what it is like to have

a bleeding disorder.’ It was depressing. If you’ve spent your life as I had, constantly taking a step forward and then a step back in terms of physical health, it was rare for me to be taking steps forward. Part of that is the yoga practice byproduct of feeling better about myself.”

Ultimately, Pierce grew confident and strong enough to try rock climbing in an indoor gym, which he found helpful for improving arm strength, thus reducing painful bleeds in his elbow joints.

Eventually, Pierce took up running. During the COVID-19 pandemic, many indoor studios shut down, so he turned to running outside. “I never thought I’d be able to do it, as my ankle doesn’t move right, but I’m still able to run,” he said. “It’s been a long process, but it blows my mind, as I was walking with a cane in my later college years.” In November 2022, Pierce completed the Silver Falls Half Marathon in Portland, Oregon.

For those interested in getting started in yoga or any other physical exercise, Starks recommended finding an instructor or studio where you can try something short-term. Ensure the instructor listens to you and understands where your body is.

“Adapt their techniques to you,” he said. “A good instructor will always get you to where you are. If an instructor makes you try to conform, run [away].”

For Pierce, finding yoga has helped him get where he is today. “I didn’t see myself 15 years down the road as being as healthy as I am at the moment,” he said. “My joints are stable and are not going to get worse. That’s a big deal for me. Without question, when I couldn’t find a job, while dealing with the tenor of the early 2010s, the economy and being unsure about my sense of self and place, yoga was a foundation for me to rebuild myself physically and mentally and reform how I felt about my body.” ♦

Note: While this article shares information about alternative pain relief methods, it is not intended as medical advice by HFA. Speak to your hematologist or medical provider when considering any new physical activity or pain relief method.