

# Duty

# of



# Care



Caregiving can be overwhelming and may feel never-ending. But it's important to take care of yourself and ask for help.

BY PRISCILLA BLOSSOM,  
FREELANCE WRITER

**B**eth Stewart never could have imagined how a simple shower would become her greatest form of self-care when she first gave birth to her son Joey. Her eldest child was only five and a half months old when he was diagnosed with severe hemophilia A, after some suspicious recurring bruises raised red flags for her and his doctors.

Thirteen years later, Joey, who is non-verbal, has received several additional diagnoses: attention-deficit/hyperactivity disorder, attention deficit disorder, an intellectual disability, and most recently, Phelan-McDermid syndrome (PMS), a rare genetic condition that causes developmental and speech delays.

Facing page, bottom left, Kendall Fitzpatrick with her husband, Brad; her son Jared, far left; and her stepsons, Elijah and Gabriel. Facing page, top, Beth Stewart's children, left to right, LilliAnn, Joey and Daniel. Above, Randy and Jackie Curtis.



Because of this, Stewart spends most of her time as Joey's primary caregiver, managing his medicines, taking him to and from medical appointments, educating herself on his conditions and advocating for him every step of the way. All of this leaves little time for self-care.

"My role as a caregiver is much different than the typical family," said Stewart, who lives in Dexter, Maine. "[Self-care] is something I struggle with, honestly, every day. Showers are my go-to where I'm fully relaxing, taking care of me."

She isn't alone in this struggle. According to a study by AARP and the National Alliance for Caregiving, there are an estimated 53 million unpaid caregivers in the U.S. alone, including many within the bleeding disorders community. Caregiving can take a toll. New caregivers don't always know where to begin seeking help for their loved ones, much less for themselves, while long-time caregivers might go years putting their needs aside in order to care for others before they recognize that they, too, could use a hand. Additionally, caregiving for people with hemophilia, von Willebrand disease (VWD) and other bleeding disorders can be even more isolating given the lack of education outside the community. And for those, like Stewart, whose loved ones have multiple co-occurring conditions, self-care can be even harder to make time for.

### No Two Caregiving Situations Are Alike

For Kendall Fitzpatrick, caregiving has become a way of life. Her eldest son, Trey, was diagnosed with hemophilia B as a toddler, and she was diagnosed with hemophilia B and VWD a couple years later. But Fitzpatrick said her journey toward becoming a caregiver for individuals with bleeding disorders was also inspired by her late father.

"My father had hemophilia but was never diagnosed," said Fitzpatrick, whose father died by suicide when she was just 13. Fitzpatrick said she grew up hearing stories about her father that told how he was "bleeding to death" and that he was believed to be schizophrenic. "Once I had Trey's

diagnosis, everything fell into place. Like, 'This is what my dad had.' And he just hadn't known of his diagnosis."

Putting those things together prompted Fitzpatrick to go to school to become an infusion nurse. Over the years, she has not only remained a caregiver for Trey, who is now 28, but also for her patients and others in the community.

"I'm on call for anybody who knows me, whether they're patients or not, if they have immediate questions. And with my nursing license, I provide responsible answers," she said. "Some things you can't assess unless you're there in person, so you might need to go back to [a hemophilia treatment center]."

Fitzpatrick said it feels a bit like mentoring. She also spent years making herself available around the clock to the hemophilia community via a Facebook group called Helpful Hemo RNs, but recently shut the group down to set healthy boundaries for herself.

While Fitzpatrick isn't quite as hands-on with caring for her son as she once was, she said she is still regularly reminding him about appointments,

medications and generally educating him about things such as the genetic aspects of hemophilia for the day he might want to start a family of his own.

For community member Jackie Curtis, caregiving for her husband, Randy, is actually a lot more hands-off. In fact, Curtis is reluctant to even call herself a caregiver.

"I'm his wife; we take care of each other," she said. The couple have been together since the early '90s, and she said Randy's always been fairly independent.

"I don't do much [active caregiving] on an ongoing basis," said Curtis, pointing to the ways in which caregivers of children need to handle things such as intravenous infusions. "There's only been about five episodes in our 30-plus years where I really had to step up and actually be a caregiver for a while."

One of those episodes was when her husband needed to get surgery on his right elbow, one of his target joints. But

most of the caregiving Curtis deals with is about being educated on what Randy needs at any given time. While some of it is simple reminders for him to take his pills, it also involves knowing what to do in emergencies.

"I have a list. If there's a crisis, [I need to know] who should I call? Who's the primary contact? Which hospital do I take him to?" she said.

### The Pandemic's Effect

The COVID-19 pandemic certainly changed the way many of us lived for the past two years. Stewart said it made life "crazy and chaotic" at times for her family.

"It was hard to be able to focus on just Joey's appointments doing Zooms because there were other kids around and a lot going on," she said. While some families returned to school within months of the early shutdowns, her children did remote learning for two years, which meant a constant full house. In-person visits for Joey's various conditions were also limited during that time, in part because urgent patient cases were prioritized while others had to wait.

"I would say that returning back from the pandemic, we're a little bit more shy, a little bit more timid because we kind of stayed back," she said. "There's been a lot that we've had to catch up on."

For Curtis, the pandemic wound up coinciding with Randy's liver transplant surgery, which he needed due to damage from a previous hepatitis C infection. The surgery meant flying to Missouri from their home just east of San Francisco. "We flew out to St. Louis, and because of COVID, I was terrified to go on an airplane," she said. She'd been especially worried looking at the COVID maps and seeing how much higher the cases were in Missouri versus California.

Because it was still early in the pandemic, neither she nor Randy were able to get vaccinated before the surgery. "Their vaccines were allotted only for the hospital staff, and they couldn't bend the rules," she said.

Due to the number of reduced flights from the West Coast (which made it difficult for them to fly to and from

appointments), Curtis said they decided to move to the St. Louis area for six weeks so Randy could get his transplant. Once they returned to California, Curtis was able to get vaccinated as Randy's caregiver. "It all worked out," she said.

Others, like Fitzpatrick, said they've found some silver linings when it comes to the pandemic, especially when it comes to accessibility to resources and information for the hemophilia community.

"All of a sudden, these different nonprofits had Zoom meetings and it was now accessible," she said. "And they did a better job on social media of advertising that, so everyone kind of started with equal access to get this information."

Alfredo Narvaez, MSW, LMSW, a hemophilia social worker at the Louisiana Center for Bleeding and Clotting Disorders, said treatment centers like his had to pivot to using new technologies and methods due to the challenges of the pandemic.

"We did use virtual visits for a lot of our patients during that time and continue to use them as necessary to continue to provide care," he said.

### What Caregivers Struggle with Most

No matter how much active or visible work is involved, all caregivers experience their own set of struggles. "I think the biggest struggle is the complexity of the impacts on their loved ones," Narvaez said. "Bleeding disorders are rare, require specific therapies which are very expensive, and can lead to a number of secondary conditions that are just as difficult to treat. It can feel like you're fighting multiple issues all at once."

And then there are other aspects that you might not even think of initially. "Compassion fatigue can also be an issue," says Mosi Williams, PsyD, a clinical social worker at the University of California San Francisco Hemophilia Treatment Center. "If you care for somebody over time, it wears you down and you may not be as empathic."

The financial burden can also be great for many individuals with bleeding disorders. Williams, who also



Beth Stewart and family.



Randy and Jackie Curtis.



has hemophilia, said that while people in California have access to in-state insurance via the Genetically Handicapped Persons Program (which covers adult patients with bleeding disorders as well as other genetic diseases), programs like this aren't the norm.

"We're lucky in that sense, but it can be challenging for other people that don't have that where they live," he said.

Fitzpatrick's greatest challenge had to do with accessing her son to give him his infusions. "He had a lot of anxiety around it. ... The emotions that go along with infusing, I think, caused a lot of issues for him in his teenage years," she said. "Me going to school to do that was definitely me trying to gain a better perspective, or a healthier perspective, that this was just the norm, having needles in our life."

Stewart's greatest challenges have involved learning how to advocate for her family and standing up when she knows something is wrong. "When you see a fever of 101, [we] have to take [Joey] to the hospital to have cultures done and a whole workup to make sure that that port is not infected," she said. "With Joey, we've learned the reason why his temperature gauge runs so low is because he has Phelan-McDermid syndrome."

This has caused issues when he's in the emergency room. Because his temperature will read low, hospital staffers don't always understand that there can still be an infection present.

"They were making me feel as if I was a crazy helicopter mom, not listening. So I had to learn how to appropriately advocate for Joey without being too aggressive and assertive that they wouldn't listen."

### How HTC's Can Help

There are 149 federally funded hemophilia treatment centers (HTCs) around the U.S. where people with bleeding disorders can obtain a slew of services ranging from physical to emotional and psychosocial needs. And while these HTCs are there to serve the patients first and foremost, they also offer resources and benefits for the caregivers as well.

"We try to ensure that caregivers are as informed and provided with the same connections to community and other resources as our patients," Narvaez said. This can entail connecting them with state and federal resources and nonprofit agencies, as well as assisting them with obtaining services when they are finding access barriers.

He recommends people seek out their local hemophilia chapters also. "Organizations like this, run by people who live, advocate and provide care and support for patients, their caregivers and families, are the backbone of this community," he said.

Finding time to get everything done can be especially difficult for some caregivers. Some HTCs can also assist in offering respite to caregivers by way of finding day programs for people with developmental disabilities. Williams said he had a patient who aged out of a school program, so he sought out a new program for that person to attend during the day.

"Being able to find activities, for example, we found an art program for that patient; that does kind of give a break to the caregiver," he said.

Additionally, there are other programs around the country for people to attend, such as inhibitor summits, retreats and bleeding disorder camps. Some of these spaces offer tracks for caregivers, while others may simply offer respite if the person with the bleeding disorder attends alone.

Sometimes, HTCs also offer more immediate assistance to families. Stewart said her local HTC has helped her family numerous times. If the HTC knew of a financial need, it would offer her a gas card to get to and from Joey's appointments. At Christmas, the HTC has offered gifts and gift cards to her family.

"Recently, we had to do some investigating with the new diagnosis [of PMS]. The clinic helped point me in the direction of a patient advocate that could help make sure that all the I's and T's were dotted and crossed before we went to the appointment out of state," she said. "So for me, I think the clinic helps in the family sense, not just for the patient."



Kendall Fitzpatrick with her mini Aussie named Buddy.

Curtis said HTCs are priceless. She recounts a day when she and Randy were in their RV in a remote area of Arizona when she realized Randy was having a crisis. The immediate challenge for her was convincing Randy they needed to turn around and go to the nearest HTC. That's when Curtis decided to call their HTC for help, despite it being after hours.

"They were wonderful. They just coached us through the whole thing," she said. The HTC staff member quickly gave her information on their nearest HTC and set everything up so that upon arrival, Randy would be treated immediately without needing to wait in the emergency room.

### Advice for New Caregivers

Fitzpatrick advises new caregivers not to expect to take it all in at once. "There's stages of learning, and you reposition yourself with every bit of new knowledge you get."

For Stewart, it's all about finding a community of people who understand what you're going through. "Having the hemophilia community that I have, I don't have to explain anything. They understand the worry that I go to bed with

every night. I don't have to question their sympathy or their empathy for the situation at hand," she said. Stewart said she found her community by attending a family camp through the New England Hemophilia Association.

Curtis recommends new caregivers get involved in any educational symposiums to understand more about bleeding disorders and their loved one's diagnoses. She also reminds people to be open to accepting help from others.

"Learn to make things easier that can be made easier," she said. "If someone offers to bring you a casserole, just say, 'Oh wonderful, thank you!'" The same goes for friends and others who offer to pick something up for you at the store or provide other bits of help, she added.

Most importantly, it's vital that caregivers remember to also care for themselves.

"The adage of 'putting your own oxygen mask on first' exists for a reason," Narvaez said. "Providing care is important and good, but caregivers need not forgo their own care to give to others. Caring for oneself is not being selfish. It's ensuring that they can give that support that their loved one needs." ♦

## Reach Out to Helping Hands

HFA's Helping Hands program consists of several programs that offer financial support to community members and their families, including:

### Emergency Assistance

Provides help with one bill once a year for urgent living expenses such as housing, transportation and utility bills if a community member is facing a short-term financial emergency caused by or directly affecting their bleeding disorder.

[www.hemophiliafed.org/resource/emergency-assistance](http://www.hemophiliafed.org/resource/emergency-assistance)

### Items Assistance

For medically recommended items community members cannot afford out of pocket.

[www.hemophiliafed.org/resource/items-assistance](http://www.hemophiliafed.org/resource/items-assistance)

### Inhibitor Support

Helps cover medical travel (assistance for travel for medically necessary procedures, surgeries or

second opinions) and tutoring/educational supplies (assistance with the cost of tutoring or education-related expense for K-12 and college students) if applicants cannot afford these needs.

[www.hemophiliafed.org/resource/inhibitor-support](http://www.hemophiliafed.org/resource/inhibitor-support)

### Disaster Relief

Supports community members in areas affected by natural disasters, as declared by the U.S. Federal Emergency Management Agency or the National Weather Service. The program provides assistance by covering temporary housing, replacement of necessary home items, household bills and/or necessities such as food and clothing.

[www.hemophiliafed.org/resource/disaster-relief](http://www.hemophiliafed.org/resource/disaster-relief)

The Helping Hands team also maintains robust resource lists for financial assistance, mental health, drug manufacturer assistance programs, hepatitis C and HIV, financial planning, employment rights and job search.

[www.hemophiliafed.org/resources](http://www.hemophiliafed.org/resources)



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