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Preparing

A wrong turn, a dangerous river, and an absent partner

Rachel Curtis



THIS MORNING, AS I WAKE, THE LIGHT IS ALREADY CREEPING AROUND the edges of the motel curtains. My alarm still has 30 minutes to sleep before it will ring at 5:30. I have chosen one of the longest days of the year to hike Owl's Head Mountain, my second to last hike of the New Hampshire 4,000-footers I climbed at least half of them with my partner Scott over the past seven years, but he's not climbing this one with me today. He can't. His hiking days are over. Soon he won't be able to sit up on his own anymore.

A few years back, when Scott finished summiting all 48 of the mountains, I was already well past the halfway point and figured it would be fun to finish them too. Scott said he would happily retrace his steps to accompany me on many of my remaining mountains, with a few exceptions. Owl's Head was one. It was neither interesting nor enjoyable enough for him to do it twice. All the bad press made me put off Owl's Head till nearly the end. It is now one of only two hikes I have left to finish all 48. My last hike will be the North and South Kinsman Mountains. They boast a ridge walk and views hikers gush about.

Now, Scott would do anything to hike this slog with me, but he simply can't. Three years ago, he was diagnosed with amyotrophic lateral sclerosis (ALS). He had to stop hiking last fall. These days a half-mile stroll is more challenging for him than this hike ever was.

Scott is dying. Some days his dying seems much too fast. Other days it feels excruciatingly slow. Ninety percent of ALS patients die three to five years from the date of diagnosis. He was diagnosed early so had two good years when he chose to live large. He explored our country's national parks, hiking all the most beautiful peaks, checking things off his bucket list as he crisscrossed the country in a van he had transformed into a camper. I joined him whenever I could. He took care of me, served as my front man, scouting out local libraries—and the occasional ski area—with Wi-Fi where I could work remotely. And I played hooky every chance I got.

In a few weeks, he will give up walking, resigning himself to sitting—in a wheelchair, a recliner that rises up to eject him, a bed—for the rest of his life. Soon after that he will replace the bed we have shared, the place of our greatest comfort, connection, and intimacy, with a bed built for one that comes with a remote control. It raises, bends, and folds in ways that Scott used to be able to do himself. And in the middle of all of that, a Hoyer Lift will be

White Mountain stream crossings like this one create big challenges for hikers. S. L. LIVINGSTON

introduced into our household, giving us time to get used to this contraption that reminds me of a stork carrying a baby in a blanket from its beak. Soon, we will use it to scoop Scott up in a sling to lift and transfer him from bed to wheelchair, wheelchair to toilet, toilet to shower when he can no longer facilitate any of that for himself.

When we can bear to talk about the specifics, we guess he will die in the next six to twelve months. I am losing the person who knows me the best and loves me the most. He is my friend, my lover, my guide and companion in interpreting life's events. He is the person who can lead me to myself, wrestle me from myself, and invite me beyond myself. When I lie curled up against him my thoughts, my breath, my need to know slow down and whatever needs to surface—the truth beyond the noise—does. His physical presence helps me find the deepest, clearest, truest part of myself. Every time. To me, it feels like magic.

Now, as I lie in bed alone, waiting for my alarm to catch up with me, I am reminded that sleep has become unpredictable. It's no longer something I can count on. Sleep has often been a state in which I sort things out, make sense of them, waking to clarity. Yet now, awake in the middle of the night, I think maybe there is too much to process some nights. It can't all happen in my sleep. I sometimes stop tossing and turning, lie on my back, limbs stretched long, surrendering to the reality that the issue is not my physical comfort. It's something more psychic. It seems I need to be awake for some of the processing, more fully aware of it, rather than just waking up with it done and me none the wiser. I need to get wiser. I'm running out of time.

This morning, sleeping in the shadows of the early morning light, in the bed across the room from me is Jemma, my hiking companion. She is the daughter of my best friend in college, 30 years my junior. At this time last year, she was somewhere in Virginia, making her way north on the Appalachian Trail, a thru-hiker headed to Maine. Jemma loves the outdoors and playing in it as much as I do. In a few minutes when she wakes, while I am in the bathroom, she will open the motel room window, inviting in the cool morning air, wanting to feel it in anticipation of stepping out into it.

When Jemma and I hit the trail, it's still early, so we have it to ourselves. The first three miles are a stroll down a wooded boulevard. Owl's Head is characterized as an out-and-back eighteen-mile traipse through the woods with multiple stream crossings punctuated by a midpoint, two-mile, 1,500-foot vertical gain over rocks, some prone to slide around under your feet. The wooded summit offers none of the views that are hikers' usual reward. Aside

from the ascent, it is not hard; it is just long. Having Jemma with her quick steps, easy conversation, and unbridled enthusiasm as my companion will make it seem shorter.

We're hiking in June after a depressingly wet spring and rain earlier in the week. We expect the trail to be wet and the streams to be high. We've brought water shoes to change into for the stream crossings and I have reread the tips on crossing streams that Scott sent me via email. I smiled when I opened the link. I wanted to be offended that he thought I needed to be reminded of how to stay safe. Scott's kids nicknamed him Safety Officer Scott 15 years ago when he was their church youth group leader, homage to the care he takes with children. Even now, when he can't hike with me and has so many struggles of his own, he is still taking care of me. I read the reminders with the awareness that he won't be with me on the trail now or ever again, and I have to learn how to take care of myself.

While Jemma and I are planning our crossing of the Pemi, Scott is at home, starting his day, navigating what has become the unfamiliar wilderness of his body.

Jemma and I hit mile three in the hike. We are looking for the turnoff to our next trail. It is elusive. We finally realize that when we started the hike, we misread the arrows of a sign and walked down the east side of the river whose banks we're now standing on rather than the west side. In our excitement and chatter we missed a big, hard-to-miss bridge over the Pemigewasset River that was less than 100 yards away from the sign where we'd turned. I suddenly long for Scott's preternatural sense of direction, realizing that Jemma is as spatially and directionally challenged as I am. We have a map that clearly indicates what side of the river we should have hiked along and yet, three miles in, we are on the wrong side. I can't even call it a rookie mistake. Most rookies would have caught it.

After considering our options, we decide to cross the river. We begin scouting up and down the edge of the wide river for the easiest place to cross. The view from the riverbank is deceptive. The river appears lazy and shallow on its edges, shrouding the volume and speed of the water in the middle. Along the path we choose there are places where we can hop from rock to rock, using

our hiking poles to make us stable four-legged creatures. And then there is the heart of the river where the water runs fast and high. I have changed into my water shoes for the crossing, slinging my hiking boots around my neck, my socks jammed deep into the toes in hopes of keeping them dry. Jemma has decided to cross wearing her new, low hikers—the shoes she’s hiking in—wanting to test how quickly they dry. It strikes me as a risky proposition three miles into an eighteen-mile hike, but then again, she’s not wading into a river with boots hanging off her neck.

While Jemma and I are planning our crossing of the Pemi, Scott is at home, starting his day, navigating what has become the unfamiliar wilderness of his body. My friend Susan is his companion. She left her family overnight and drove an hour to our apartment so I could leave Scott in good hands while I hike. I can see their morning unfolding. With his still-somewhat-functional left hand and arm he struggles to pull shorts on over boxers, a plan we concocted to ensure he could dress the most private parts of himself. Susan helps him put on a T-shirt, socks, sneakers, and his braces—one for his right leg, others for each shoulder. They enjoy breakfast sandwiches of eggs, sausage, and cheese on English muffins that Susan makes. With effort, Scott is able to feed himself, weary at the end. Susan brushes his teeth, washes his face, and combs his hair.

AS JEMMA AND I PICK OUR WAY ACROSS THE RIVER, SCOTT’S RIVER-CROSSING tips run through my head: Face upstream as you cross, avoid areas where the position of rocks underwater makes the water run with greater force and volume, and don’t cross in water higher than your waist. As I look down from my perch on top of a rock, dry above the rushing water that surrounds me, assessing my next move, I am reminded that the rule about it being safe to cross in water waist high is one many deem too risky. From where I stand, I have no idea how deep the water is. What is clear is how fast it is moving. With apprehension running through my veins, I realize that the key to a safe river crossing is not to get psyched out by all the water rushing around me. Its volume and speed remind me that in any contest of me versus nature, I am bound to lose.

I employ the water-crossing variation on a trick Scott taught me when driving on the left side of the road in a foreign country. He told me to keep my eyes on the white line down the middle of the road up ahead to help me stay in the middle of the lane. It’s the same technique I employed when we hiked in Nepal and I had to cross long, swaying suspension bridges that

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hang across wide rivers with enough rushing water to generate power. Here it translates into keeping my eyes on the next rock, letting the rushing water between it and me recede into the background rather than flood my head with worry. The water comes and goes but the rock is more steady, elemental. It reminds me of trying to focus on my breath when I meditate, letting the thoughts in my head float by, resisting the urge to grab onto them, trusting that the breath that courses through me is the thing to follow to find the truth beyond the noise.

Watching my hiking poles vibrate fiercely against the force of the flowing water as I set them in the river threatens to distract me from my focal point, as I wonder how quickly we could be swept downstream. There is a moment in the river crossing when Jemma has no choice but to step deeply down into the water to a lower rock. She's bracing her steps with her poles when one of them shakes loose and she tumbles into the river. She falls face-first into the cold spring water, taking in a mouthful.

In the seconds it takes her to upright herself and signal to me that she is OK, it hits me that I am hiking with the daughter of one of my dearest friends—someone I held as a newborn. I think of Jemma's mother, who she talks with every day on her way to and fro. And I think of her mother and me as college students, rowing in a shell up the Connecticut River, running along country roads—our common sense often shrouded by our desire to challenge ourselves. Jemma is her mother's daughter, and although she has the experience of months on the AT, the fact that she did it with a shredded ACL and had stretches where she averaged more than 30 miles a day rings in my head.

I realize I have to be the voice of reason. No one who knows me would likely describe me as the voice of reason on matters of physical challenge and stamina. This is a role reversal. Scott, my personal safety officer, has always been the voice of reason when we hike. He would be dumbfounded at how we missed the trail we were supposed to be on and the circumstance we have gotten ourselves in. It would never have happened if he was with

me. And if, by a bizarre twist of fate he was with me and it had happened, he probably would have insisted on us retracing our steps on dry ground. I would definitely have fought him on it, trying to convince him of a straight shot across the river. He would not have been moved.

As I watch Jemma struggle to regain her footing, gasping for air, I feel this clear sense of responsibility for our safety. I feel a pang of longing for Scott and his sense of direction. Jemma, wet nearly from head to toe, stands up and reclaims her hiking pole before it has the chance to rush downstream with the current. She smiles the hopeful, slightly battered smile of someone trying to reassure her hiking buddy that all is well after falling into a cold river. We are nearing the far bank of the river. I scan for the easiest place to scramble up the riverbank, knowing we need to get Jemma warm and dry as quickly as possible. In crossing the river, we have run the risk of being swept downstream in cold water and tempted hypothermia.

As we make our way up the steep slide of the riverbank, safe after what was the unplanned, unnecessary, trickiest part of the hike, I picture Scott and Susan heading out on a walk. They are walking behind the enormous apartment building we now live in, a place we would never have chosen before Scott's diagnosis. It sits at the end of a divided highway on the edge of Cambridge, Massachusetts, on a site that once housed a hip nightclub. We were wooed by the accessible unit at the very back of the building that boasts a wheel-in shower, wide doorways, a balcony built for two, and a bank of windows that look out on conservation land we never knew was there. Deer periodically prance by our windows, and we count rabbits by the dozen on our ten-minute walk to the train station. Finding this home was such grace.

As Susan and Scott walk, his shortened steps—a hack against the loss of various muscles that motor his legs and anchor his knees—set the pace. I imagine Susan standing close to him, trying not to hover but wanting to be close enough so he can grab her to steady himself if need be. They rest at one of the benches, the ones we used to barely notice that we now rely on for respite.

After Jemma munches on an energy bar, balls up the wrapper and shoves it in the pocket of her pack, she declares herself warming up and her new hiking shoes surprisingly quick to start to dry out. It's a short bushwhack to the trail. As we step onto the trail, we discuss which way to head down the path, chastened by our early mistake. I am deeply aware of the river now to our east and am listening for the sound of an upcoming stream to our west, the one I confirmed when we unfolded our map, soggy and fraying at the seams

from Jemma's dunk in the river. I step forward, ahead of Jemma. I am on the lookout for the trail crossing up ahead. This is something I need to practice, finding my way in the woods without Scott.

The rest of the hike is filled with stories of Jemma's AT adventures, oohing and aahing over nature's delights, snacks, lots of mud, and a few wet feet as we navigate the much smaller stream crossings. We find the not-well-marked turnoff to the summit with ease. Someone has accessorized a rock by the turnoff with mirrored sunglasses, which makes it hard to miss the cool dude inviting us along. When we summit, we sit on a fallen tree in the woods eating our avocado on a long-ago toasted bagel, chatting with a guy who put off Owl's Head until he'd hiked the other 47. I don't envy him his final summit: wooded and viewless.

Jemma and I tread gently down the slide of loose rocks with water running through them, chastened by our earlier misstep, and we hit the flat section with momentum. We end the hike crossing that big, hard-to-miss bridge across the Pemi that had been so elusive nine hours before. We marvel at how we missed it and can laugh about our river crossing now that it is firmly behind us and all has ended well. We have found our way to the summit of Owl's Head and back to our car in the parking lot. And in the process Jemma and I have become friends in our own right, no longer simply connected through her mom. We will hike together again. Thrilled to find cold water and a bathroom, we splash water on our faces, fill up our water bottles and head home happy, both refreshed and weary, and pleased by our accomplishment. On this hike I found my way, inexpertly to be sure, but along the eighteen miles of trail and wetness I was reminded of all I know and am capable of even without Scott's trusty guidance I so depend on.

IN THE COMING WEEKS, BACK AT HOME, SCOTT AND I WELCOME, WITH HEARTBROKEN, weary resignation the ubiquitous wheelchair, the lift, and the new twin bed, its made-for-one size a nod to the space required for all the other equipment. Our landscape shifts again, the terrain becoming increasingly challenging. In the three years Scott has lived with ALS, he has led himself through it and guided us both with the same sure-footedness he had when we hiked. But now, simply being here is getting harder for him.

We regularly retreat to his new, cramped bed or gently settle him into the big bed in our guest room where I now sleep. We cuddle as we try to wrap our heads and hearts around the latest loss or decision. I am generally the cuddler these days, taking up the role Scott assumed for years, trying to hold him

through it all. Sometimes sleep offers a respite. Other times we lie together, entwined, trying to be fully conscious, as much as anyone could be, of what is unfolding in front of us.

When I struggle to be fully present, wanting to run ahead or away, I remember how Jemma and I missed the bridge across the Pemi river and our risky crossing. We could have avoided it with a little more attention in the moment. And when I fail to be present in the tumble of moments, I comfort myself with the memory that even without conscious awareness and after stepping off the path and into harm's way, Jemma and I made it to the summit and back. It will be OK. I will be OK.

The losses are piling up, and the decisions Scott needs to make are growing more existential and unbearable. The current dilemma is whether to get a feeding tube or to roll the dice and see if he dies of malnourishment before his respiratory system is paralyzed and he dies because he cannot take a simple breath. At times I watch Scott get overwhelmed, feeling pressure to figure things out about his care or his mortality. They are things no one should ever be expected to sort through but which he does because he wants to die with the same consciousness and authenticity he's always brought to living.

The decision of how to die is a scary river crossing of its own. There will be no celebration at a summit or satisfying sense of accomplishment. He will ultimately be swept away in the current. What sustains me in this darkness is the idea that when Scott makes his final crossing it will be into lightness, and the views will be magnificent.

Before I have to live without Scott, I have the chance to help him find his way, returning the favor of all the ways he has cared for me. Standing beside him and guiding him as he needs help is more demanding than any hike, and there is no greater privilege. It is what will prepare me to find my way when he is gone.

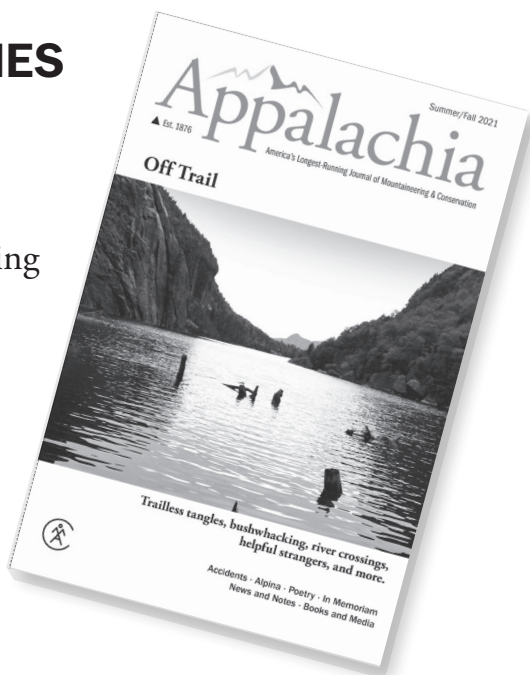
RACHEL CURTIS finished hiking the New Hampshire 4,000-footers in 2020. She lives in Arlington, Massachusetts. Her partner Scott Hamilton died in 2019.

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