

USEFUL LINKS:

[SOUTHONABIKE.COM](https://southonabike.com) (OUR SUPER-FUN TRAVEL PAGE)

[GOFUNDME](#) (FOR DONATIONS AND NEWS)

[CARINGBRIDGE](#) (FOR VOLUNTEERING HELP)

#3 | MARCH 3, 2023

PUSHING THAT BIKE HOME AGAIN? WE'LL FIX YOU UP AT

Keithbob's Village

CAREGIVERS!

Who gives a darn about me anyway? To my surprise, lots of people do. All are caregivers. And we have lots of needs they can help with. Caregivers can be professionals that come to the house and take care of me hands-on. Or they might be people who volunteer to help take care of the yard and house. Or maybe they drive me somewhere in the wheelchair van so I can make it to an appointment or the store, or up to the Providence ALS Center in Portland. Caregivers are often people I don't know. I have a quilted blanket for the wheelchair made by the mother of one of Jalene's best friends, and another given to me by a neighbor. Caregivers might be people I used to work with, or people who just dropped by to say hi. And there are an awful lot of caregivers who contribute money on our GoFundMe website.

My view of caregivers

My brain likes to think in pictures. Here is what my brain paints when I think of caregivers. I imagine myself with people around me. Family and close friends. A few of them have a firm grasp on me, hands and wrists, shirt, belt, ankles and feet. Each of them has a few of their friends and family holding on to them in turn. And so it radiates out, with more and more people, most of whom I don't know. They seize onto their friends who are gripping my friends who have a hold of me. Everyone has those they care deeply about, and so the web of people



EXPERT CAREGIVERS AT WORK ON
CONCRETE AROUND DRIVEWAY DRAIN

CAREGIVERS!

holding onto me eventually fades into the distance in every direction. An untold number of people are connected to me. Now ALS comes along, and suddenly the earth falls out from under me. As I look down I see something like the Grand Canyon open below. We all start to fall, and it's terrifying for a short while. But no one loses grip, no one stops caring about others, and soon our fall is brought gently to a halt. We all hang in space over the canyon, because there are so many more people along the canyon rims and on solid ground stretching back from the precipice. The webwork of people hangs in a gradual curve, a gentle bowl over the canyon below. We all have a grip on each other, we all love and trust each other, we are all safe. Not because everyone cares for me, but *because everyone cares for each other*. This mental image of an infinite web of loving relationships goes beyond caregivers. It also describes how I think about God and spirituality.

Meanwhile, back in reality...

Over the years, there have been occasions of bad news about a friend from school days, or maybe in Alaska or somewhere else long ago. It hits me in the gut, that sudden fear and the rush of recollection. "Should I call them?" I think to myself. "They must have so much on their plate, or their burden is so heavy that I would just be in the way, or annoying." Today I know that I was wrong, that I should have asked what I could do to help. No one that asks me how to help today is ever an annoyance, or somehow in the way. Even if there is nothing they can do for me, their presence is a comfort. Usually a great comfort.

Many friends wanted to donate financially, plus our good friend Justine Benson had organized four online auctions to raise money for us. We sat down with our banker and she immediately recommended we set up a GoFundMe page, because it was so easy for people to use. And what a response! Jalene and I were bowled over by the number of people donating. This taught us that there are a whole lot of people out there who want to help but don't know how. Maybe they live far away, maybe they're busy people. The GoFundMe page gave everyone a way to help, and proved to be a good way for me to update people. And as it turned out, GoFundMe was critically important to us. We needed to pay for the wheelchair van, and we also needed to convert the house to ADA standards, both big-ticket items. And now, we have the ongoing expense of in-home caregivers which insurance doesn't cover.

Jalene is my #1 caregiver

An ALS diagnosis has immense and severe shock value. Fear twisted my guts for about a month, as we began circling and sparring with this monster come to break our door down. Jalene immediately started planning for the largest immediate objectives: 1) get me retired from ODFW; 2) set up Social Security Disability; 3) Medicare (ALS patients qualify instantly regardless of age); 4) start modifying the house for accessibility; and 5) buy a wheelchair van. With her wonderful organizing sense, she helped me achieve all of these goals within about 9 months.

CAREGIVERS!

Modifying the house was a huge undertaking. We had wonderful help from our good friend Mark Hanrahan, a local contractor. He rallied help from carpenters, plumbers, electricians, and tile setters. George Moreland Plumbing and Liggett Flooring gave us incredible discounts on materials. Chris at Newport Fab did a superb job helping to build the overhead lift system, and Matt Blume installed it with my brother..

Special shout-out to Justine Benson (purple gloves, below) for organizing the online auctions. Her thoughtfulness and energy were truly inspirational. There are not enough Justines in this world. Also below, Dean Major, Erica Fruh, Lynn Mattes, and others take my ideas and make them happen, assembling the drain sections in prep for concrete. A few weeks later, asphalt was laid, and our driveway was "wheelchair-smooth."



THESE CAREGIVERS HOT-PATCHED A TUBE FOR US IN TOCOPILLA, CHILE.



COMING ISSUES:

WHAT'S WITH THIS "KEITHBOB" NAME?

EARLY TRAVEL ADVENTURES, SOME SUCCESSFUL

LIFE LESSONS IN COLD, MUDDY PLACES

I'll wrap up this newsletter with a request. If you are a person that could be a non-professional caregiver in Keithbob's Village, please email me. Also, the request in newsletter #1 for professional caregivers still applies.