

USEFUL LINKS:

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

[GOFUNDME](#) (FOR DONATIONS)

[CARINGBRIDGE](#) (FOR VOLUNTEERING HELP)

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SLOW DOWN BUSTER, YOU'RE ARRIVING AT

# Keithbob's Village

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## THE WAY FORWARD

I took the power chair down to Canal Creek this past August. There is a shallow concrete ford through the stream, and I was wondering if I could cross it in the wheelchair. Maybe a bad idea.

That picture illustrates life for me these days. ALS is presenting itself to me in new ways, and I'm searching for the best path and the best strategy for coping. The best way forward.



ALS is no longer just whittling away at me, it has started using a hatchet. Over the past few years, the degradation of my physical abilities means that I've lost the use of many of the skills that I've learned during my life, skills that I started to develop in my earliest years. The clearest example is this: after 57 years on bikes, I can no longer practice my skills of riding a motorcycle because I don't have the ability (strength in arms, legs, and abdominal core) to climb onto one and to work the controls. I'm not sure if my thumb still has enough strength to push a starter button.

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# THE WAY FORWARD

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The ability to breathe factors into every decision I make about what or how I'm doing something. My breathing capacity is down to about 30% of normal, due to my weakening diaphragm muscles. Any time I'm laying down, I require a ventilator to help me breathe. A second ventilator hangs off the back of the wheelchair, to help me when I get tired or after I've eaten a meal.

I no longer have the ability to walk or even stand. All day now I'm in the electric chair. We built an overhead lift system, used anytime I need to move between wheelchair, bed, toilet, or shower. I always carry a urinal bottle when I go anywhere because I can't stand up out of the chair. Sitting upright with nothing to hold onto or lean back against is dangerous, because my core muscles are so weak now I can easily topple sideways or backward. Any hope of 6-pack abs is forever gone.

Composing this, I am mostly talking to my laptop, because I am losing ability in my fingers and hands. So much for typing skills. I drop everything I handle, and leave many dropped items on the floor, because it's too dangerous for me to lean out of the chair to pick something up. If I fall on the floor out of reach of the ventilator, I can quickly suffocate.

Eating is getting tougher these days. To manipulate or even hold onto a fork or spoon is difficult because of the lack of strength in my hands and fingers (the menu is revealed on my shirt). Mostly I just sit with the bowl or plate in my lap, so I can tilt back a bit and breathe more easily.

Sometimes new tools help me out. I now use an Alaskan ulu knife for cutting things up because I can hold onto it and push straight down into things. I first learned of these knives when I lived in Alaska (magic for butchering or filleting). My mother used one for years after a stroke paralyzed the right side of her body. They look like an axe-head you hold in your hand, just push down and rock it.



**OH BOY, LET'S BUY SOME NEW TOOLS!**

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The green handled gizmo in the picture is a "Top-Off" jar opener from my mother's kitchen (older than me). You open the jaws, put it on top of the jar and twist the green handle. The jaws close tightly on the lid and you can twist it off. The harder you turn, the tighter it grips. I've never seen one like it in stores, and it still works better than anything I've ever tried. These days I need it just to get the cap off of a carton of milk. If you see one at a garage sale, just buy it.

I have methods, tools, and helpers for dealing with the big physical challenges that I face every day. But the toughest obstacles are inside, the psychological ones. Now more than ever attitude is everything. Attitude makes the difference. And attitude is a choice.

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## Coming Up Next Issue!

**Where DID you get  
that attitude?**



How does one live in a body where ALS is weathering it away, bit by bit? Sound coping skills, or are we just fooling ourselves? (and does it matter?)