Six years ago, Heinz Ludke was diagnosed with amyotrophic lateral sclerosis, or ALS, a disease of the nerve cells in the brain and spinal cord that control voluntary muscle movement. It’s a progressive disorder that begins with muscle cramps and twitching and weakness in the hands, feet, legs or ankles, followed by difficulty swallowing or speaking. Three to five years after the first signs of the disease, the degeneration of motor neurons leads to death in nearly 90 per cent of patients. The cause of ALS, also known as Lou Gehrig’s Disease, is not known, and so far there is no cure. Every 90 minutes, someone is diagnosed with ALS. That’s more than 5,600 people a year.

When he was diagnosed with ALS, Heinz had no way of knowing whether he would be in the 10 per cent of patients whose life expectancy was closer to 10 years than five. We checked in on Heinz and Betty Ludke in July, and their schedule told us everything there was to know. They were home in Natomas for 22 hours between trips to Southern California visiting family, and upstate New York, for Betty’s 50th high school reunion.

“We’re here long enough to mow the lawn, pick some plums from the tree in our yard, and repack,” Betty said. “We went to Heinz’s 50th two years ago.”

Heinz and Betty are realistic about the future, and they have chosen to live their lives the same way they always have, prioritizing family and community, which has expanded to include the ALS community.
Betty: I’m lucky right now that Heinz is not completely disabled, so I don’t have to do a lot. He’s given up driving, so I’m doing all of that. He uses a cane, a walker or a scooter. I can offer him a hand if he needs it. He doesn’t write anymore so I do his signature. He still eats and drinks and we still travel.

Heinz: She does all the cooking, all the laundry. She does a lot more than she used to. She gets frustrated because I’m slow.

Betty: I’ve asked him to fix the sprinklers but they don’t get fixed. It’s time to call in help.

Heinz: We have lost a lot of friends to the disease because people normally live three to five years, and I’m at six and a half years. The doctor says I could live another five years because my breathing is ok, my eating is fine. One of the things with ALS, you lose your ability to swallow, so you need a feeding tube. The other part is you need help breathing, and an apparatus is key. Not yet for me.

Betty: I help him put on his clothes sometimes but if I’m not here he can do a lot himself; he can’t button buttons anymore.

Heinz: My manual dexterity is really limited. One of the reasons we choose cruising a lot is that the hotel is right on ship, and the ADA rooms on ship are wonderful. I can shower and use the restroom by myself. In the restaurant, when they ask if we need help, we ask them to cut up my steak for me, and they do it.

Heinz and Betty are very active in the ALS Association’s Sacramento chapter. Their many Natomas friends have turned out to support Heinz at the annual Walk to Defeat ALS, raising both funds and awareness.

Heinz: We serve from Oregon to Fresno, and Nevada to the Bay Area. There are five regional ALS groups in California, and Sacramento is the largest. We give grants to people who need support for transportation and medical needs. I’m lucky. We have good insurance. My medication could be $2,000 a month, but I don’t pay that.

Betty: But our copay is expensive. They have two medicines for ALS. One is $130,000 a year. Our copay for the two medicines is $2,000 every three months. They also found out that veterans are more susceptible to ALS, and once they’re diagnosed they are 100 per cent covered through the VA. Veterans are twice as likely to get ALS because they are 100 per cent covered. We have a registry at the Centers for Disease Control (CDC). We want to continue that funding. It’s up in the Senate now. We advocated for and got a waiver in Medicare rules for people diagnosed with ALS. Under Medicare, when you’re diagnosed with any disease, there’s a two-year waiting period for coverage for treatment. With the ALS waiver, that period is now five months, but we want them to knock that down to zero. That’s in the Senate now. There’s another bill that would change the process for paying for non-invasive respiratory treatment. Right now, it’s subject to bid, and we want them to waive that requirement because the respiratory therapist needs to be included. We’re afraid that in a bidding situation the therapist would make the bid more expensive, and contractors would eliminate the therapist.

We asked Betty and Heinz what they have learned from living with ALS.

Heinz: Having travel to look forward to is beneficial. I need more t shirts and hats.

Betty: I have planned our trips to Southern California for September, November and December.
January, and the whole family is going on cruise at the end of January. This will be our third cruise with the grandbabies. We have four grandchildren under five. Our two daughters each have a girl and a boy. They’re very supportive.

**Heinz:** That’s our pride and joy. Both graduated from Natomas High School and are doing very well. We try to see our daughter in Southern California every six to eight weeks. Our other daughter lives in West Sacramento and we see them often. In August we’re all going camping together, our children and grandchildren, at Mammoth. RV camping.

**Betty:** We don’t see his doctor but every six months. We go to Dr. Jonathan Katz at the Forbes Norris Clinic in San Francisco. It specializes in motorneuron disease and ALS. They have a clinic in Sacramento as well.

**Heinz:** There are 35 drugs in the pipeline. They’re discovering gene therapy and trying to find a drug to attack the gene protocol. I think they’ve found 18 genes so far that can cause ALS. A lot of my friends with ALS are in trials. I want to mention that there are a lot of quacks out there. Dr. Richard Bedlock from Duke University is in charge of a website that sorts fact from fiction. (See the web address below.)

**Heinz:** Get ahead of the disease. Don’t wait. Get ready. We have a hospital bed, an electric wheelchair, a shower chair – we don’t need them now, but we’re ahead of it. Don’t wait till you need it. Get good support of family and friends. You need a lot of help.

**Betty:** I walk every morning for exercise, and to get out of the house. We call on our daughter and son-in-law in West Sacramento to help when there are things Heinz can’t do.

**Heinz:** Spend time with friends, especially birthdays and weddings. I don’t like funerals.

**Betty:** We’re doing the best we can for as long as we can.