

How to Live Longer

Not just one or two years
but fifteen or twenty!



and other amazing discoveries
from the life of Ed Roberts,
as told by himself

At our first CIL, on campus at Berkeley, we had a whole bunch of people with progressive disabilities like multiple sclerosis, muscular dystrophy — people whose disability was ‘terminal.’

They got involved in the politics of independent living and they lived longer. Not just one or two years, but fifteen or twenty!

If you’re independent, and you fight, you live longer.

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of polio that they’d put big
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My first life and death battle

I got polio when I was fourteen, in 1953. That was my first time fighting for my life. This was before the vaccine.

Polio was a scourge, you know. It was a terror. People were just terrified that their children might get it. It was a virus that spread like the flu or a cold. One of my friends died, then I got it.

People were so afraid of polio that when someone at your house got it, they’d put big red signs on the front of your house and warn everybody away. When I got polio, my whole family was quarantined, my whole high school emptied.

Some people got out of it with just a limp. But

I got it pretty good. I was put in an iron lung within three days. Polio is a voracious fever, you're running a fever of 106, so you're really going through a lot of dreams and a lot of hallucinations.

I was fighting a symbolic war, and it came complete with *rat-a-tat-tat, bang-bang-you're-dead* sound effects. One of the nurses told me to stop the fighting, that I had to sleep, but she had no consciousness about what was going on. It was life-and-death struggle, and I was right on the edge.

I won the war, and I lived.

‘He Will be Nothing But a Vegetable’

The doctor told my mother, ‘Well, maybe you should hope he dies, because if he lives he’ll be nothing but a vegetable.’ To have a doctor say it’s better that he should die than live as a cripple — well, he doesn’t know!

True: early in my rehabilitation days, I think I was trying to kill myself — by not eating. It wasn’t a conscious effort, and the anorexia may actually have been a result of the disease. But the day they took my last special-duty nurse away, I started to eat again.

Talk about symbolism! All of a sudden I was on my own, and I had to make my own choices. Again, I chose life.

Still... I stayed inside for five years. I was terrified that if I went out, people would stare at me. I wanted to die. You’re 14 and you’re paralyzed from the neck down and you’re in an iron lung — you have all these people around you, doctors and nurses, and their job is to save life. You have to be pretty creative to commit suicide.

But I was just totally depressed and not knowing what the hell my life was going to be all about.

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Spotting My First Freak

I had totally accepted the whole idea that being crippled was terrible, the worst thing.

I remembered being on my father's shoulders, at the State Fair or something, when I saw a woman in a wheelchair who had cerebral palsy. She was just moving about in her chair, and I was fascinated by this person.

I'd never seen anybody like that. I was really *looking*, and all of a sudden my father reached up and yanked me back and said, 'Don't stare!'

I thought, 'Well, my God, if you can't even look at it, what must it be? Something really to be afraid of! It's terrible!' But she was fascinating! She was different!

After the polio, I didn't want to go out. I went to high school by radio/telephone. I was terrified that people would stare at me; I didn't like myself very much. As I said, I accepted all those old stereotypes.

I did very well in school, I didn't have a lot of distractions. I mean, I didn't have that teenage social rating and dating and all that stuff, so I could concentrate on my studies.

A swift kick in the butt — I believe in that. We're too gentle sometimes. We don't teach people to take risks; people have to learn how to take risks. Whether we're young or old, that's the only way we can learn, by taking that next step, that risk.

My mother came to me and said, 'If you don't begin to get out of here, you're going to be here the rest of your life!' She said, 'I want my life, too.' Nothing cruel, just a kick in the butt.

So I decided I'd physically attend the high school. They got me in the car, and drove me to this courtyard where about 200 students were. I went, 'Oh, no!' That feeling... and everyone turned

to stare at me. When I'd look up at them, they'd look away.

Here I was, sitting in the middle of my worst fear! And something remarkable occurred to me: It didn't hurt! It didn't *hurt* for people to stare at me. Then I thought, 'Whoa, this is kind of like being a star! Hey, it's not so bad.'

Then I also thought, 'Hmmm, you know something? I have a choice here. I can decide it's because I'm ugly, or I can decide, I'm a star! I'm different.' I could *enjoy* being stared at.

That day was very important to me because that's the day I realized, 'Hey, I'm going to separate what's my problem from what's somebody else's problem.' Those things happened to me all through my life, the 'Aha!' moments. Why do we build self-hatred around this stuff, and actually be the people, become the people, who put us down?

Today I try to teach that you make choices about how you feel — whether people stare at you or not.

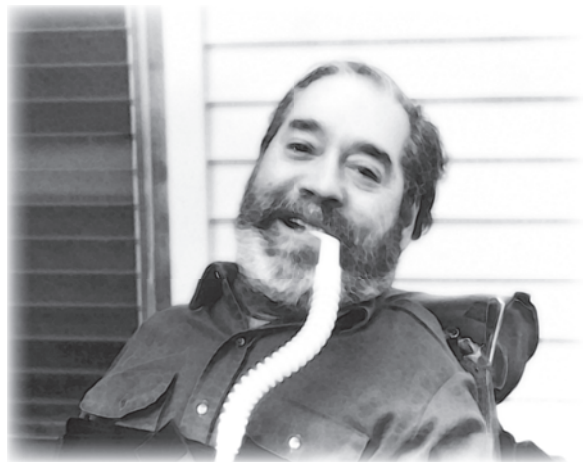
Misery is optional.

I want to talk to you about strength

I don't have to tell you, or anybody else, about disability and weakness. I want to talk to you about strength. I want to talk to you about what people can do when they're motivated and when they're clear about who they are.

I've become a very strong person over the years, not only because of life in general but because I have a disability.

It forced me to do things and learn things that many young people never have to learn. I have come to terms with death, for instance. I'm not afraid of that. And I learned about the staring thing that it's totally their problem. I'm not going to internalize



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that and feel bad about how I am. I learned, too, that when people look at me as so different that they want to feel pity, I can probably get anything I want out of them. I can manipulate the hell out of them.

While they see me as weak and unable — well, I'm not. I can come on strong and capable when they're staring at my wheelchair and my respirator and feeling entirely sorry for me. I can use that, tactically. It's a very powerful tool and it's something we should teach people to use in practical ways.

I learned this, interestingly enough, from the women's movement. I watched women in the self-support groups [consciousness-raising groups] in Berkeley teaching each other how to manipulate the stereotypes of weakness in women. And I thought, 'Wow! That could work real well for disability.' I began to use it tactically.

You see a lot of people who take that role as part of their whole life. That's a whole different thing. When you use that sick role all the time, it's toxic.

Parents may see their disabled kids try to manipulate them. The kids may not be aware of doing it, but there's always a very natural tendency. Hopefully, we can recognize it, and encourage people to use that for a tactic, but also be clear with them about what's going on there.

The most important person in my life

My mother, Zona Roberts, was probably the most important person in my life. She would believe in me. Together we had to learn to fight [discrimination] because there were so many people with their little narrow rule books who were always willing to say 'no.'

One of our first struggles was to get me a high

school diploma. This school guy came out to our house to tell me that I couldn't graduate because I didn't have driver training and phys ed. But I was the number two student in school!

The guy looked right at me and said: 'You wouldn't want a cheap diploma, would you?' Feeling so humiliated, working so hard and feeling like I'd earned it, at the same time both my mom and I feeling like we wanted to kill the guy...

So first we threw the guy out of the house. Then Mom and I said, 'How can we change this decision?' We went to the school board. It was very important for me and my mother, fighting together. It was a landmark for me. I don't think I could have done that alone, at all. Both of us were terrified. Oh boy, were we afraid — not that we'd lose, but *it is scary* going up against authority. It is! It takes a lot to be able to do that.

There was no question, though, once they heard. They gave me my diploma.

I learned from that fight. You don't let people walk all over you. You fight for what you believe is right. The fight for my diploma taught me that. That is the model I've followed ever since.

The other thing I figured out is that while people often see the sickness, the weakness of disability, disability can make you real strong. It was a bitch at the beginning. It was real hard, but over the years as I've felt better about myself, disability has made me strong.

Later on, I began to discover how—while everybody else is concentrating on disability — how little disability matters! Sometimes disability was irrelevant. It didn't even matter. That's funny. Ø



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*For Ed's tales of being the first man on
the moon, see page 28.*