

# Health Self-Management: A Self-Advocate's View

Mitchell Levitz

Self-advocacy means speaking up for myself by sharing my ideas and thoughts with people about what is important to me. One way I advocate for myself is to speak up about my health. As a self-advocate, I would like to share with you some of my personal experiences related to how I advocate for my own health.

## A Circle of Support

We need to consider the decisions we are capable of making on our own, and the kinds of decisions we should get help in making. I don't need help deciding what to eat for lunch or what to wear for work. But I do ask for advice when making financial or legal decisions, and dealing with medical problems.

I have family and friends who I trust and can give me good advice. Putting together a circle of support was a very important part of person-centered planning for me. I decided who I wanted in my circle of support to help me to make important decisions in my life.

My circle includes the people who know me very well. They each have knowledge in particular areas to support me in making decisions. Of course, I wanted my family to be a part of my circle of support, including my parents, my sister, an aunt who lives nearby, and a cousin who is an accountant. And I also invited some family friends (especially a few my own age) including a lawyer, a doctor, and a nurse. As other people come into my life in the future, I might ask them to join my circle of support to play certain roles.

## Health Self-Management and Taking Charge of My Health and Wellness

I created a computer document to keep track of all of my medical appointments. This reminds me when I need to make appointments with my doctor and specialists. Before going to appointments, I find out if I need to bring any information.

I also check my records to see if I will need to get new prescriptions while I am at the doctor's office. When I go I bring my health insurance information, and I am prepared for how I am going to pay.

Sometimes my parents drive me to the appointments and help me fill out forms such as my medical history. They also help explain information that is hard for me to understand. But the final decisions are for me to make after getting their input and having the information I need to know.

And if someday, if something major happens to my health and if I am not able to make medical decisions myself, my circle of support will be there to determine what is best for me. That is why I have a health care proxy and a living will. I keep a copy of my health proxy card with me in my wallet for emergencies.

## Transportation

This is sometimes a challenge for me. But my primary care doctor and my dentist are close by so I can walk there on my own.

I take a bus into town to go to appointments with my foot doctor, so I can set up these appointments according to my own schedule.

I also see some specialists. But I have to coordinate getting a ride from one of my parents to go for my gum care and to my appointments with the eye doctor and ENT. Last year, I had an infection that needed to be removed by a surgeon. When I went to see her, she recognized me because we had been neighbors, so I had a very easy time speaking with her. I had one of my parents go with me during the procedure but I was able to handle the aftercare on my own.

## Communication is a key to health self-advocacy

I am very comfortable speaking with the doctor and the other office staff who are very friendly. But before I go, I write down questions to ask the



Mitchell Levitz enjoying kayaking

doctor and I take that list with me to my appointment. Some people I know ask the doctor to draw a picture or diagram to help explain a medical problem.

Sometimes, if I am having a more serious health problem, I ask one of my parents to go to the appointment with me, but I make sure that the doctor speaks directly to me, even though I brought my parents along for support.

When I have my annual physical I usually go by myself. Last year, my doctor suggested that I have my heart checked at the hospital, so I made an appointment for a special test. I walked there early to give myself plenty of extra time. People on staff showed me where to go and helped me register. I had a backup plan and a cell phone in case I needed to reach my family.

## Taking Medicines

It is important for me to remember to take my medicine and vitamins every day. I use a special pill box marked with each day of the week. I do a lot of traveling, sometimes for work and sometimes to visit with my family. I plan ahead and I count out the right number of pills to take with me.

I go to the drug store to buy supplies that I should keep on hand. A few times each year, I go through my medical supplies and check the expiration dates. That way I can tell what I need to throw out.

## Prevention

This is another part of healthy living. I put on sunscreen as part of my daily routine after taking a shower in the morning. I always wear my bike helmet when riding. Since I walk all over the place, I always try to pay close attention to traffic, especially when I am crossing streets.

## Eating Right

Healthy eating is a good way to maintain the right weight. For me, losing weight is very hard. I usually only eat when I am hungry. I plan out a weekly menu so that I know what foods I need to buy.

On work days, I make my lunch to bring to the office. But on my days off, I love going out to eat at restaurants. I eat vegetables and fruits, low fat milk and whole wheat bread every day.

When cooking, I am careful about cutting with a knife and using a frying pan. I always make sure to turn the oven off when I leave the house, and make sure that I have enough money or a credit card to do my shopping. When I am at the supermarket, I check the last day of sale on the food items. I also check the food in my refrigerator before eating something by checking for mold and for foods that smelled spoiled. I also check the prices to make sure nothing is overpriced and I try to buy foods when they are on sale. Sometimes I go food shopping with my father when he is going to a supermarket.

My mother often prepares home-cooked meals for me that I keep in my freezer, and that I can just microwave. When I do cook, I make something that is easy to cook like eggs, pasta, a sandwich or salad.

## Getting Good Sleep

Just like me, many people have sleep problems. I have learned that to get a good night's sleep, it is important that I do not stay up too late.

I have sleep apnea so I sometimes get drowsy during the day and start to fall asleep during meetings and workshops. This is only when I am not active and physically moving around. Two strategies that I figured out are to have a drink with me or to stand in the back of the room.

I have had a sleep problem since I was young. I had a sleep study done and surgery to help with this problem. It only helped a little. One treatment recommended was to use a "c-pap" machine at night. It worked for one of my friends, but I found it very uncomfortable. I also tried a tongue-guard. Through these experiences, I learned a valuable lesson. It is important to know myself and realize what works for me and what doesn't. I also learned that I can figure out strategies when I need to.

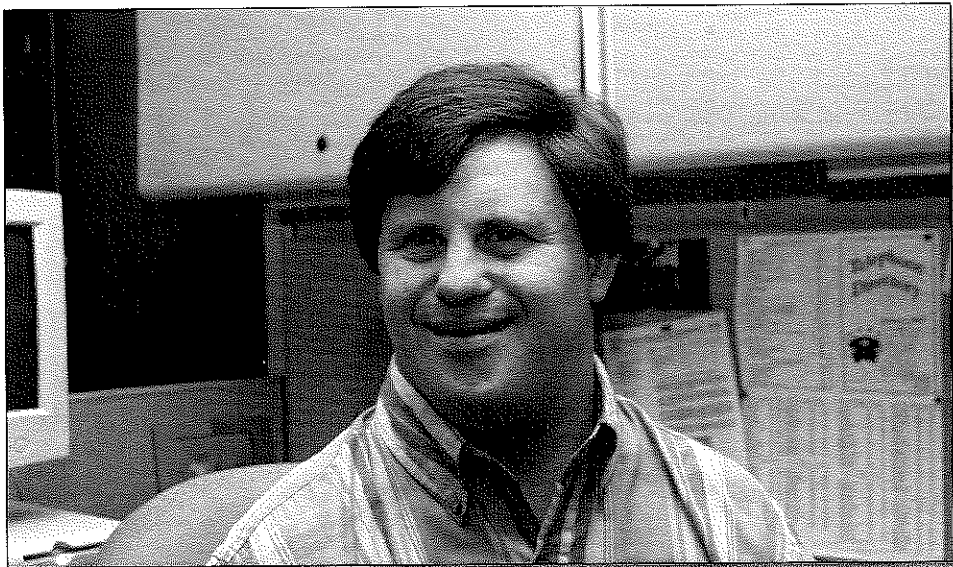
## Final Thoughts

My message is that having a healthy lifestyle can have a good impact on your life. It can help you feel better about yourself. I realize that each person has his or her own way of doing things and choosing how to be healthy. For me, I hope that being in charge of my own health and making good health decisions will help me live a long, active and healthy life.

*Mitchell Levitz is the Self-Advocacy Coordinator at the Westchester Institute for Human Development, a University Center for Excellence in Developmental Disabilities, in affiliation with New York Medical College. He is the co-author of the book, Count Us In: Growing Up with Down Syndrome.*

# Key Points: A Self-Advocates View of Managing Your Health

1. Self-advocacy means speaking up for yourself with doctors and other health professionals.
2. A good circle of support—family and friends—can help you make good medical decisions.
3. Taking care of your health means keeping track of appointments, taking your medications, and learning what to bring to the doctor's office.
4. If you can, learn how to travel to your medical appointments. Family, friends, and support staff can help you learn how to do that.
5. Whenever possible, choose doctors and other health professionals who listen to you and make you feel comfortable.
6. Practice how to talk with your doctor and ask questions. You should understand what to do to get and stay healthy before you leave the office—how to take a new medicine or care for an injury at home.
7. Eating right, exercising, and getting enough sleep are important ways you can take charge of your own health.
8. Preventing illness before it starts is the best way to stay healthy.



Mitchell Levitz at work at WfHD