

# CHAPTER 1

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## PREPARATION: ARE YOU READY TO HIRE A PERSONAL CARE ATTENDANT?

*I miss the me  
I used to be  
Standing on my own.  
But now wheels go round.  
Freedom found.  
Independence shown.*

### Issues to Consider When Hiring an Aide:

- Personal dependency
- Personal acceptance
- Time management
- Becoming an employer

Before you begin the process of hiring an agency or your own personal care attendant (PCA), several major issues must be considered. Living with a disability is scary. It can be frightening, because you don't always know who will walk through your door to assist you, whether it is a prospective aide applicant or a mystery

aide from a home health agency. There is a good chance that many of us will face this type of dependency. For example, the Baby Boomers (those born following World War II, the generation from the late 1940s to the early 1960s) are quickly approaching the age at which assistance from others is going to be needed.

Asking for help and accepting it goes against our free will. It is human nature to want to do things on your own. However, if you do need the help of others, you are not a weak person. So get that chip off your shoulder, if you have one, admit that you need help, and go on with the rest of your life. Do I like depending on others to help me every day with my most intimate needs? No, I don't! But not getting my bladder emptied or not taking a shower sound like pretty painful and stinky options!

People with disabilities are the largest minority group in the United States. When I became a member of this population in 1990, the estimated number was around 38 million. As I write, the current number is 58 million. The 1990 Americans with Disabilities Act recognizes two types of disabilities: physical and mental. But I see the breakdown as physical, sensory, cognitive, and emotional disabilities.

- *Physical Disabilities:*

Physical disabilities affect a person's ability to move; they include:

- Spinal cord injuries
- Cerebral palsy
- Spinal bifida
- Muscular dystrophy
- Bodily injuries

- *Sensory Impairments:*

Sensory impairments affect a person's visual and auditory senses.

- *Cognitive Disabilities:*

Cognitive disabilities affect a person's ability to mentally process information. These disabilities include:

- Developmental and learning disabilities
- Mild or severe mental retardation

- *Emotional Disabilities:*

Emotional disabilities affect a person's ability to interact with others and society, such as:

- Depression
- Anxiety
- Bipolar (manic-depressive) disorder

There is no such thing as an "easy" disability. They all force limitations on the people who have them, although some people who have an emotional disability can be more paralyzed than I am. My wheelchair and I can go anywhere I want to, provided the terrain is smooth. But I have heard of people with anxiety disorders who don't leave their home for days. (Appendix F, on page 131 of this guide, has a list of disability-related agencies and organizations that offer information and resources on some of these disabilities.)

Living with a disability requires two forms of acceptance. The first is the acceptance of who you are. I am now a person with a disability, but I am still basically the same person I was before I became disabled. However, my disability has educated me in so many wonderful ways. I've learned all about patience. I've also learned that life isn't always fair. Bad things happen everyday and to everyone. But the trick is to see the beauty in the bad and the value of all experiences. I've slowed down—well, my wheelchair made me slow down—and I now see the bonuses of my paralysis. A lot of good has come my way since becoming a "woman on wheels." (You can

read more about my personal journey in Chapter Nine, *This Wasn't What I Expected.*)

Disabilities can happen to anyone, at any time, including those disabilities that occur at birth. There is an interesting debate on this very subject: People who are born with a disability have told me that they feel they may have it easier because they've never experienced life without a disability. On the other hand, I feel that being born with a disability would be harder because those folks have never experienced full abilities. Regardless of how you became a member of the disability culture, you are still a human being. If you incurred a disability, your body may not function the way it used to, but try to remember your inner being—your soul's essence can still be the same.

I must admit here that, even though I accept who I am, anger over loss is an issue I continually deal with and probably will for the rest of my life. But after 19 years of therapy and counseling, I have discovered that if I do not constructively deal with my anger, I pay a heavy price. I get headaches, I have stomach problems, my sleep suffers, and my ability to concentrate during the day is affected. Also my personal relationships with those I love suffer as well. So if you need help, ask for it or find it. Many self-help books, doctors, and counselors are out there to help you overcome difficult and stressful feelings. Get psychiatric help if you need to. I quickly learned that before I could fully invite others into my life to care for and help me, I had to know, understand, and accept who I am and my given circumstances. It is essential to deal with your anger and then put it aside in order to have healthy relationships with your personal care attendants.

The second form of acceptance is learning to accept the dependency upon others that you need to help you with your personal care needs. Prior to my paralysis, like most people, I was a fully independent person. I made a modest living, paid my bills, and had fun with my friends and family. Anyone who knew me before my paralysis will attest to the fact that I never sat still! I've

always been fiercely independent and a woman on the go (probably going too fast). Paralysis not only showed me that I needed to slow down, but it taught me how to ask for help every day for the rest of my life. These two things are not easy to do, but I've learned how, and you will see how I do it throughout this guide. If I can do it, so can you. Have faith in yourself. You are more powerful than you think you are. Please remember and remind yourself that what you think creates your reality.

Something I discovered in my early days of independent living is that it's hard to function at full capacity in other areas of my life while looking for a personal care attendant. The process of looking for an aide is engaging and extremely time-consuming. I must allow myself adequate time to focus on this daunting task, and I can't commit to doing too much until I find someone to assist me. I have to balance finding an aide with the other activities of daily living. Balance is important. I can't be "on the go" while I'm looking for help because I have to stay home, answer phone calls from prospective aides, conduct interviews, check references, and train new hires.

My lifestyle is a part-time job, so when I'm looking for help, the rest of my life goes on hold. Susan, my therapist, helped me to acknowledge this issue. I deal with this aspect of independent living on a continuing basis. The alternative is living in a nursing home and, for me, that is a last resort. My independence is worth the time and effort it takes to maintain it.

Like it or not, as a person with a disability, you have become an employer. This will include all the duties that any employer undertakes—hiring, firing, scheduling, payroll, taxes, advertising, record keeping, and managing others.

A person cannot afford to have a casual approach to finding caregivers; you can't sit back and wait for an aide to magically appear. It's hard work. If you are the one who needs an attendant, you must be the person in charge of this process. Others can help you investigate options and possibilities, but you should

have the final say, not family members or other caregivers. Be proactive. You might consider training yourself to be a good employer through reading books, taking a human resource management class, or talking to other people with disabilities about how they manage their attendants.

If the person who needs a caregiver is unable to make decisions about his or her own care, the person with the utmost concern for the individual who needs personal care should be the one looking for the attendant.

My final words of advice on preparing yourself to bring personal care attendants into your life are: Be a person who others want to be around. This doesn't mean you have to always be "up" or "happy." If you are down one day, that's fine. We all have bad days. But snap yourself out of the "disability pity party." No one wants to hang out with someone who brings them down 24/7. If I'm sad, I cry, find someone who'll listen, and then I move on.

Crying is so important but it isn't easy for some people. I grew up hearing "Quit crying or I'll give you something to cry about." That was my father's way of coping with sad feelings. But those 19 years of therapy helped me to realize the value of a tear. Whenever I'm really mad and so angry that I want to explode about everything, Susan would ask me, "Katie, have you been grieving?" My answer used to be "No" because grieving is hard work. Who wants to be sad? Society offers us all kinds of ways to avoid and mask our true feelings; substances like alcohol, tobacco, sugar, caffeine, and other drugs—prescription and nonprescription. But now I've learned to mourn my losses. Now, I cry with pride. But I still can't walk, and I'll always miss that ability. And that is something to cry about.

So, now having cried your eyes out, blown your nose, accepted your given situation and your dependency on others, you can now begin looking for a personal care attendant. I've made the process easy to follow with step-by-step instructions. You can do this. Really, you can. Read how I find my help, copy the easy-to-use forms in the back, and enjoy the stories from both caregivers and people who hire them. I use humor and my personal experiences in the hope that it will help you understand this interesting relationship and work environment.

When looking for your aide, remember this familiar saying: "Minds are like parachutes, they only function when open." Attendants come in all forms. There isn't an "attendant mold" out there. Caregivers must be helpful and dependable, but that aside, I've had attendants who were Asian, Muslim, African American, Jewish, Catholic, Mexican, Jehovah's Witness, Bosnian, married, single, athletic, conservative, independent, liberal, older, younger, simple, confused, shy, outgoing, co-dependent, messy, on-time, forgetful, nervous, insomniacs, exotic, petite, tacky, really tall, freckled, and people who were takers and many givers.

My point is, when looking for a caregiver, be open to all types of people. Let go of the prejudices and barriers that seem to set us apart from each other: religion, color, size, sexual orientation, political affiliations, and ethnicities. Life would be so boring if we were all alike. So—viva la difference!

All right, you are ready for the next step. Now go out there and find your attendant!

