

SELF ADVOCACY FOR FAMILY CAREGIVERS

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What does it mean to be a happy person when you are a family caregiver? How do you stand up for yourself, take care of yourself and find a balance between your own needs and those of your loved ones? These are heady questions, and ones that we have discussed often at the National Family Caregivers Association (NFCA) because they are at the core of our search for meaning and our need to have a code to live by as caregivers.

We've now given form to the many ideas we have discussed, and I want to share them with you. We call them NFCA's Principles of Caregiver Self-Advocacy. They are the fundamental tenets by which we now try to live, and we hope you too will use them as guideposts, as you seek to come to terms with your life as a family caregiver.

We caregivers often feel like victims, as if all choice has been taken away from us. We often ask: Why did my spouse\parent\child get sick, have an accident? Why did this happen to our family? Why did it happen to me? We so often feel out of control.

Having a sense of control, or choice, is a relative thing and depends as much on our attitude as it does on our circumstances. As long as you are alive and mentally competent, you have the freedom to choose. You may not be able to control the course of a disease or the effects of an injury, but you can control how you live with it. You can let it take over your life, or you can let your life progress and incorporate your loved one's disability into it. You may not have all of the choices you once did, or you may have to make choices now that you don't like, but if you recognize that you do have the power to choose, and you consciously act on those choices, you won't feel quite as much like a victim any more. **CHOOSE TO TAKE CHARGE OF YOUR LIFE** is the first of NFCA's principals of caregiver self-advocacy.

The second principal is **HONOR, VALUE AND LOVE YOURSELF**. If you are like most caregivers, you are probably worn out and are questioning yourself all the time, but don't for a minute doubt how good a job you're doing. You're doing a great job! And you owe it to yourself to take very good care of yourself, to love yourself.

Are you familiar with the safety message that airline stewardesses give during take off? "If the cabin loses pressure, an oxygen mask will drop down from the bulkhead. If you are traveling with a small child, or someone else that needs assistance, put your own mask on first. "

They are right. You can't help someone else if you are gasping for air, but that's what caregivers are always trying to do. You can't give and give without renewing your energy. We fill our cars up with gas when they are on empty. Can't we be at least as good to ourselves? After all, we're worth it!

Are you aware that over 76% of the family caregivers that responded to an NFCA survey last year don't get consistent help from other family members? Perhaps part of the reason is

because we don't ask for it, or don't accept it when it is offered. There is nothing wrong in asking for, or accepting, help. There is no reason to martyr yourself.

SEEK/ACCEPT AND AT TIMES DEMAND ASSISTANCE from others to lighten your load. That's NFCA's third principle of caregiver self advocacy. You have a right to ask for help, and you have a right to be angry when you don't get any. Don't be afraid to stand up for yourself. It might actually make you feel good.

Often friends want to help, but they don't know how. We've all heard people say: "Call me if you need me," and it doesn't sound like they mean it, but what do you have to lose by finding out? The worst thing anybody can do is say no. In fact those people who do want to help sometimes need a concrete suggestion on how they can benefit you the most. The next time someone says: "Call me if you need me", try responding "I need you right now. Would you be willing to stay with Jack while I go get a haircut on Saturday morning?"

The last, and perhaps most valuable part of NFCA's Principles of Caregiver Self Advocacy is the strength that comes from knowing you are not alone, and the belief that there is power in numbers. Caregivers represent more than 10% of the adult population of this country. Nobody knows exactly how many family caregivers there actually are, but estimates suggest that there are more than 25 million. We are everywhere, but we are invisible.

At NFCA, we believe there needs to be a caregivers' movement in this country, a movement to gain recognition for caregivers, to broaden services, to educate caregivers and to provide us with more support. There is a wonderful feeling of empowerment that comes from standing up for yourself. There is a wonderful feeling of empowerment that comes from recognizing your own worth, from knowing you are not alone, and that millions of others share your same concerns and feelings.

Family caregivers can be a powerful force for change in their own lives, and in the lives of their loved ones, if they are willing to be their own advocates. **STAND UP AND BE COUNTED**, that is NFCA's fourth principle of caregiver self advocacy.

We hope you will use these principles to take control of your life, to honor, value and love yourself, and to find the help you need. Together we can gain recognition and benefits for ourselves and for all caregivers across this great land. Stand up and be counted. It will make you feel great.

The National Family Caregivers Association is a not-for-profit membership organization reaching out to all family caregivers regardless of relationship or their loved one's medical condition. For information on the National Family Caregivers Association call, 800/ 896-3650 or visit our website at www.nfcacares.org