

Taking Care of the Caregiver

Caregiver Information Booklet

Support for those
who care for others



An Area Agency on Aging

Family Caregiver Support Project

Northwest Regional Council/Area Agency on Aging

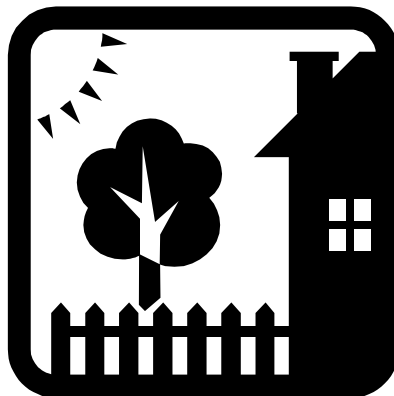
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Caregiver's Bill of Rights

As a caregiver, I have the right...

- To take care of myself—to rest when I'm tired, to eat well, to take breaks from caregiving when I need them.
- To recognize the limits of my own endurance and strength.
- To seek help from family, involved parties, and the community at large.
- To socialize, maintain my interests, and to do the things I enjoy.
- To acknowledge my feelings, whether positive or negative, including frustration, anger, and depression; and to express them constructively.
- To take pride in the valuable work I do, and to applaud the courage and inventiveness it takes to meet the needs of my care recipient.



Principles of Caregiver Self-Advocacy

Reprinted from the National Family Caregivers Association

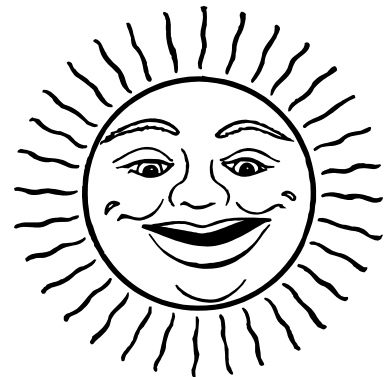
What does it mean to be a happy person when you are a family caregiver? How do you stand up for yourself, take care of yourself, and find a balance between your own needs and those of your loved ones? These are heady questions, and ones that we have discussed often at the National Family Caregivers Association (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 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 come to terms with your life as a family caregiver.

1) Choose to take charge of your life.

Caregivers sometimes 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.



2) 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.

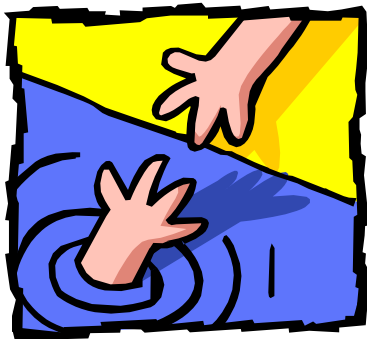
Are you familiar with the safety message that airline flight attendants give during take-off? "If the cabin loses pressure, an oxygen mask will drop down from the bulkhead. If you are traveling with a small child, or someone else who needs assistance, put your own mask on first."

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!

3) Seek, accept, and at times DEMAND assistance.

Are you aware that 76% of the family caregivers who 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 we question whether they mean it. 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 help," try responding, "I need you right now. Would you be willing to stay with Jack while I go get a haircut on Saturday morning?"

4) **Stand up and be counted.**

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 we need a caregivers movement in this country 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 the 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.

Caregiver Stress Test

(To be completed by the primary caregiver)

Instructions

The following is a list of statements which reflect how people sometimes feel when taking care of another person. There are no right or wrong answers.

	0 Strongly Disagree	1 Disagree	2 Neither Agree nor Disagree	3 Agree	4 Strongly Agree
1. My relative asks for more help than he/she needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Because of the time I spend with my relative, I don't have enough time for myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I feel stressed between caring for my relative and trying to meet other responsibilities for my family or work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I sometimes feel embarrassed by my relative's behavior	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I sometimes feel angry when I'm around my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I feel that my relative negatively affects my relationships with other family members and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I am afraid of what the future holds for my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I feel that my relative is dependent upon me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I feel strained when I am around my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		0	1	2	3	4
		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
10.	I feel my health has suffered because of my involvement with my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	I feel that I don't have as much privacy as I would like because of my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	I feel that my social life has suffered because I am caring for my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13.	I feel uncomfortable having friends over because of my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14.	I feel that my relative seems to expect me to take care of him/her as if I was the only one he/she could depend on	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15.	I feel that I don't have enough money to care for my relative in addition to the rest of my expenses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16.	I feel that I will be unable to take care of my relative much longer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17.	I feel that I have lost control of my life since my relative's illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	I wish I could just leave the care of my relative to someone else	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19.	I feel uncertain about what to do about my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20.	I feel I should be doing more for my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21.	I feel I could do a better job in caring for my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22.	I feel burdened caring for my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

TOTAL SCORE _____

Ways to Cope

When the Caregiving Burden Becomes Too Heavy

- Unload a little—even if it's on someone else's shoulders.
- Do that one thing you love, even if it's not timely.
- Remind yourself it's okay to cry—crying releases more than tears.
- Walk!
- Stop everything you're doing—go find a quiet spot and begin writing down all those things that make you happy.
- Turn things over to someone else. Get free, even if only for an hour.
- Make sure you get enough rest, even if it means having someone stay to take care of the one you care for.
- Take things as they come—don't think too far ahead on things.
- Let things go if you're too weary to do them. Dishes can stay in a sink for days, if necessary.
- Breathe! Take long, slow, deep breaths. It's amazing how often caregivers hold their breath without knowing it. Breathing deeply releases stress.
- Keep things in perspective:
 - Know you cannot make life perfect for the one you care for—life is not perfect.
 - Realize that things will not always work out the way you'd like them to.
 - Recognize you can't do everything.
 - Have someone you can trust and share your feelings with—and allow them to be honest with you.
 - Let things go that don't need to be held onto.
 - Don't lose sight of your blessings.
- Here are some special things I do when I'm having trouble coping:
 - I sort my jewelry (nothing spectacular, just old favorites)
 - I read old cards and letters—how quickly I am whisked away to another time.
 - I have a foot bath—first very warm water for 3 minutes, then plunge them into cold water for 1 minute.
 - I call someone I haven't talked to for years—maybe an old grade school friend.
- One sure way to improve your ability to cope with your burden of caregiving—**do something for another caregiver.**

"It's Time"

When should I give up my loved one to another's care?

When I no longer have the privacy of the bathroom.
When he sits in front of me and objects when I talk on the phone.
When I am too tired to wash hair or bathe.
When he doesn't remember the use of the bathroom.
When he gets out of bed and runs into the night.
When he thinks people are "after" him.
When medication acts in reverse and he cannot sleep.
When he wants to go "home" and raves when not taken.
When he runs away and I'm *glad* to have a few minutes to myself.
When I *do* fall asleep and I am too tired to respond to his needs.
When I feel I might die first.

Yes! It's time!

by Dorothy Hessell

Florida Panhandle Chapter, Alzheimer's Disease and Related Disorders Association



A Mixed Bag of Feelings

From “Choosing a Nursing Home: A Guidebook for Families”

by Marty Richards, MSW et al (University of Washington Press)

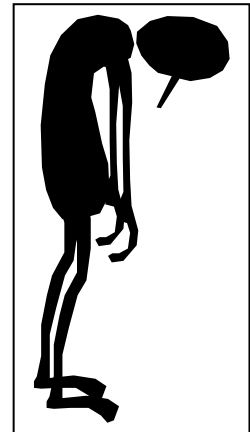
When a relative becomes physically or mentally impaired because of age or illness, the family’s “sense of balance,” which has developed over a period of many years, is changed. This change involves the need to make decisions together, to examine the feelings and emotions of all persons involved, and to develop new relationships within the family and outside of the family. This transition has the potential for being a positive experience for all members of the family, but it requires a continuing effort. The best place to start toward a positive experience is to look honestly and closely at what is happening to you and your older relative.

Facing the decision of placing your relative in a nursing home undoubtedly causes many mixed feelings within each person involved. You may be experiencing all or only a few of the following feelings. The important thing to realize is that you are not alone. These reactions are normal and shared by many others.

What are you feeling?

Sadness

Often, placement is associated with a deep sense of sadness. You remember this person as she was before her strength failed. You recall the relationship you had before she became dependent. And perhaps you feel grief for the inevitable passage of life and for your loss of both the individual person and of the tie to your cultural heritage.



Fear

Another very common feeling at this time is fear. Will my relative receive good care? Will the care be as good as the family would provide if they were able? Will I, too, become dependent on others? When I am older, will I become frail and incapacitated by illness?

Frustration and Helplessness

Many people express helplessness in the face of aging and illness. They would give anything to be able to reverse time and events, or to forestall the end of their relative's productive years.

Anger and Resentment

Along with feeling fearful and helpless, many persons experience a mixture of anger and resentment. You may feel angry that an independent person is relegated by age or illness to dependency. You may also feel angry that this person is no longer able to provide the emotional and physical support you need. You may feel resentful that the burden being placed on you is unjust and unfair. Many families have one or two "dependable" members. If you are one of those members, you may have accepted a huge burden of responsibility to the point that you are finally feeling sorry for yourself. At the same time, you have started to feel envious of others who are free of such responsibility.



Loneliness and Fatigue

Perhaps you have been trying to provide care without depending on anyone else. You are now just too tired to carry the load alone any longer. You have emptied yourself. There are not enough resources to keep yourself going and take care of your elderly relative too. If fatigue has reached the point that you wish the dependent person would die, you undoubtedly also feel some measure of guilt.

Embarrassment and Shame

If your relative has been behaving in a confused manner or socially unacceptable ways, you may feel embarrassed. Drooling, swearing, dressing strangely, or exposing the body can occur with some diseases. But if you have felt ashamed because a member of your family has done such things publicly, you have probably also felt guilt, because you "ought" to be more loving and kind.

Guilt and Uncertainty

Guilt comes from within and without. You may feel guilty that you have not done something in the past or will be able to do so little in the future. The high cost of services may have required some compromises that you don't feel good about. Uncertainty concerning whether you have done the right thing opens up the possibility of guilt. Friends, work associates, relatives, and well-meaning persons may give you advice about what you "ought" to do, without knowing details or considering the whole situation. If you

feel relief after you have placed your relative in a nursing home, that sense of relief also may be mixed with guilt feelings.

Feelings are Okay

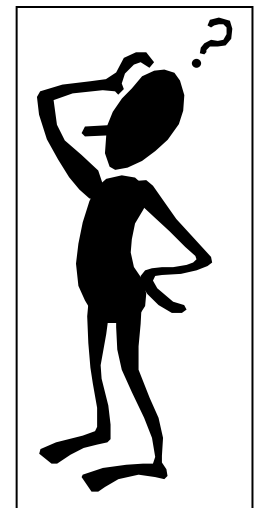
All of these feelings are natural and okay. When a person who is important to you becomes infirm and dependent, you are likely to experience most, or all, of them. Pushing down such feelings does not help. You are going through a type of grieving process, which is very normal. We all begin to grieve long before a chronically ill relative dies—grief for the way she used to be or for the past that she represents and that is now gone.

Unfinished Family Business

Along with dealing with your relative's physical or mental changes and the feelings that these changes arouse, you also have work to do regarding your own role and relationships within the family. What has been this person's role within the family? Matriarch? Father confessor? Tyrant? Child? How does her illness or incapacity affect the family? How does it change your position within the family? What have been the past relationships between various family members (brother/sister, spouses, parent/child)? What is the role of "long distance" family members?

Who among family members has been dependable and close? Who has shared the load and who has participated only when it has been convenient? Who has substituted money for more personal involvement? Has the family as a unit ever learned to handle major changes and crises (relocation, childbirth, marriage, retirement, illness, or death)? Would the method of coping with previous events be appropriate and acceptable in the current situation, or would earlier feelings of fear, anger, frustration, or personal slight be brought up again?

Do you find yourself in a position of having to care for someone with whom you have never been close? Someone you hated? Do you feel guilty because of the way some family members have treated this person? Does anyone in the family feel the need to "make up for past wrongs"?



If a great deal of "unfinished family business" remains from the past, acting together now in the best interest of all concerned may be quite difficult. It is often helpful to step back and identify which "old business" is coming up in the present in order to anticipate future

conflicts or frictions. Realistically, your family will probably respond to this crisis in much the same way that it has to previous problems.

It is best to give everyone an opportunity to be involved. If possible, sit down with siblings and others to express your feelings and concerns. Often a counselor who specializes in the needs of families can help you sort out the “old business.” After a family meeting, it may become easier to devise a plan which includes an appropriate division of labor in the care of your relative.

Working Through Mixed Feelings

Peace of mind is more than a feeling. It is a state enjoyed by those who have accepted life, illness, and death and who have made thoughtful decisions with their relatives. They consider both their own and others' needs, make the best possible choices from the available resources, and then go on with the business of living. Because it can be hard to work through mixed feelings, you may find it helpful to ask yourself the following questions.

What is happening to my relative?

How does my relative feel about what is happening?

What is happening to me?

How do I feel about what is happening?

What is happening within the family?

How do family members feel about what is happening?

You may want to share your responses to these questions with another family members and then try to identify what all of this means in terms of the actions that you could take. In fact, just the process of talking about these feelings may help to resolve difficulties you are facing.