

Caregiver Kit



Support for those who care for others

Taking Care of the Caregiver

NorthWest Senior & Disability Services
Created in partnership with Northwest Regional Council/Area
Agency on Aging

Taking Care of the Caregiver

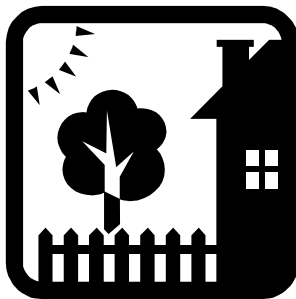
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Caregiver's Bill of Rights

As a caregiver, I have the right...

- To take care of myself, which includes resting when I'm tired, eating well, & taking breaks from caregiving when I need to. **This is not an act of selfishness.** It will actually help me take better care of my loved one.
- To recognize the limits of my own endurance and strength and to realize that I don't have to do it all by myself. I can ask for help from family, friends, and my community, even if the one I am caring for objects.
- To socialize, maintain my interests, and to do the things I enjoy.
- To acknowledge my feelings of frustration, anger, and depression and to express them in constructive ways.
- To take pride in the valuable work I do and to applaud the courage and inventiveness it takes to meet the needs of my loved one.
- To not allow my loved one to manipulate me through guilt, anger, nor depression.



Principles of Caregiver Self-Advocacy

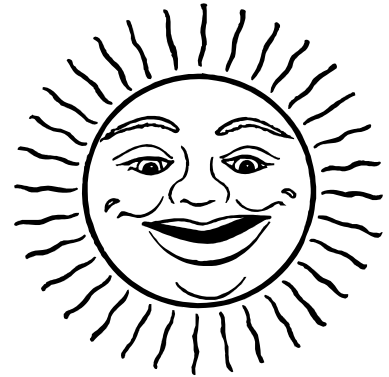
Reprinted from the National Family Caregivers Association

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.

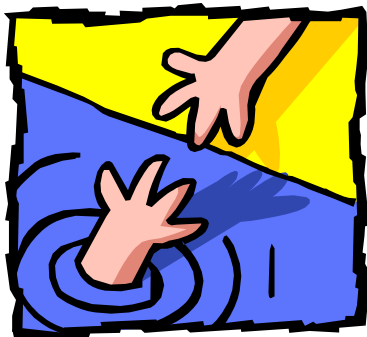
Are you familiar with the safety message that airline flight attendants give during take-off? "If the cabin loses pressure, an oxygen mask will drop down from the bulkhead. If you are traveling with a small child, or someone else who needs assistance, put your own mask on first."

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 Fatigue Timeline



1-18 Months

- **Anxious to provide best possible care for loved one**
- **Manages the person with dementia**
- **Maintains house, garden, car, etc.**
- **Attends to family relations**
- **“Keeps up appearances”**
- **Remains optimistic, caring, & supportive**
- **Operates as a “superwoman/superman”**
- **Attends to personal care**


At 21 Months

- **Begins to take medication, usually for sleep/headaches**
- **Becomes harder and harder to keep on top of things**
- **Some help from family still available**

24 - 32 Months

- **Emotional & physical resources drained**
- **Less & less contact with personal doctor, dentist, minister, friends**
- **Experiences feelings of powerlessness**
- **Caregiving consumes the whole day & night**
- **Outside help dwindles**

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<p style="text-align: center;">At 32 Months</p>	<ul style="list-style-type: none">• Stress becomes harder to conceal• Caregiver begins taking tranquilizers• Begins using medication for musculoskeletal pain• Sleep is continually disturbed• Less & less contact with others
<p style="text-align: center;"> By 38 Months</p>	<ul style="list-style-type: none">• Caregiver feels unhealthy• Finds it harder to get up• Never feels rested• May have hypertension or colitis• Symptoms of chronic fatigue• Caregiver loses the will to take care of self• Unable to manage the household• Rarely socializes with others• Feels helpless; guilty; a failure
<p style="text-align: center;">After 50 Months</p>	<ul style="list-style-type: none">• Chronic state of fatigue• Caregiver is in a state of “unwellness”• Is unable to ask for help• Is unable to access resources for information or help• Becomes isolated

10 Warning Signs of Caregiver Stress
*Taken from the Alzheimer's Association publication: Caregiver
Stress: respect your well-being*

1. **Denial** about the disease and its effect on the person who's been diagnosed.
I know Mom is going to get better.
2. **Anger** at the person that you're caring for; that no effective treatments or cures currently exist; and that people don't understand what's going on.
If he asks me that one more time, I'll scream!
3. **Social withdrawal** from friends and activities that once brought pleasure.
I don't care about getting together with my friends anymore.
4. **Anxiety** about facing another day and what the future holds.
What happens when he needs more care than I can provide?
5. **Depression** begins to break the spirit and affects the ability to cope.
I don't care about anything anymore.
6. **Exhaustion** makes it nearly impossible to complete necessary daily tasks.
I'm too tired for this.
7. **Sleeplessness** caused by a never-ending list of concerns.
What if she wanders out of the house and falls and hurts herself?
8. **Irritability** leads to moodiness and triggers negative responses and reactions.
Leave me alone!
9. **Lack of concentration** makes it difficult to perform familiar tasks.
I was so busy, I forgot we had an appointment.
10. **Health problems** begin to take their toll, both mentally and physically.
I can't remember the last time I felt good.

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The Warning Signs of Stress

- | | | | |
|-----|----|-----|---|
| Yes | No | 1. | Do you feel a loss of energy or zest for life? |
| Yes | No | 2. | Do you feel out of control? |
| Yes | No | 3. | Do you lack interest in people or things that were formerly pleasurable? |
| Yes | No | 4. | Are you becoming increasingly isolated? |
| Yes | No | 5. | Are you consuming an increased amount of sleeping pills, medications, alcohol, caffeine, or cigarettes? |
| Yes | No | 6. | Are you having increased health problems (e.g., high blood pressure, ulcers, or difficulties with digestion)? |
| Yes | No | 7. | Do you have difficulty falling asleep at night, awakening early, sleeping excessively? |
| Yes | No | 8. | Are you experiencing appetite changes? |
| Yes | No | 9. | Do you have problems with concentration or memory? |
| Yes | No | 10. | Are you increasingly irritable or impatient with others? |
| Yes | No | 11. | Do you have thoughts of suicide? |

A YES answer to even some of these questions can indicate stress that has become debilitating. Recognizing the source of this stress is the next step in dealing with its destructive effects.

The Causes of Stress

- | | | | |
|-----|----|-----|---|
| Yes | No | 1. | Are you experiencing multiple demands on your time, energy, or money? What are they? |
| Yes | No | 2. | Do you feel that your responsibilities conflict? Which ones? |
| Yes | No | 3. | Is there a difference in expectations among your family, your boss, your dependent relative, yourself? What are they? |
| Yes | No | 4. | Do you feel a lack of understanding about the older person's mental or physical condition? |
| Yes | No | 5. | Do you have difficulty meeting your relative's physical or emotional needs? |
| Yes | No | 6. | Are you pressured by financial decisions and a lack of resources? |
| Yes | No | 7. | Do you feel a loss of freedom and a sense of being "trapped"? |
| Yes | No | 8. | Is there disagreement among family members? |
| Yes | No | 9. | Do you feel that other family members aren't doing their share? |
| Yes | No | 10. | Does the older person place unrealistic demands and expectations on you? |
| Yes | No | 11. | Is there a lack of open communication? |
| Yes | No | 12. | Do other family members have negative attitudes that you have trouble contending with? |
| Yes | No | 13. | Is there an observable deterioration in your family member that is painful to watch? |
| Yes | No | 14. | Are there other problems with children, marriage, employment, or health? What are they? |

A Checklist of Stress Symptoms



Physical Symptoms of Distress Involving Skeletal Muscles

1. Tension headaches
2. Frowning
3. Gritting or grinding of teeth
4. Jaw pain
5. Stuttering or stammering
6. Trembling of lips or hands
7. Muscle tenseness, bracing, and aches
8. Neck aches
9. Back pain
10. Aggressive body language

Physical Symptoms of Distress Involving the Automatic Nervous System

1. Migraine headaches
2. Increased sensitivity to light & sound
3. Lightheadedness, faintness, or dizziness
4. Ringing in ears
5. Enlarged pupils
6. Blushing
7. Dry mouth
8. Problems swallowing
9. Frequent colds or bouts with the flu

Automatic Nervous System (cont.)

10. Hives
11. Rashes
12. “Cold chills” or “goose bumps”
13. Heartburn, stomach cramping, or nausea
14. Uneven or rapid heartbeat without exercising
15. Difficulty breathing
16. Sudden, suffocating panic, as if you are about to die
17. Heart and chest pain
18. Increased perspiration
19. Night sweats
20. Cold, sweaty hands
21. Painfully cold hands & feet
22. Gaseousness or belching
23. Frequent urination
24. Constipation
25. Nervous diarrhea
26. Lowered sexual desire
27. Difficulty with sexual orgasm

Mental Symptoms of Distress

1. Anxiety, worry, guilt, or nervousness
2. Increased anger and frustration
3. Moodiness
4. Depression
5. Increased or decreased appetite
6. Racing thoughts
7. Nightmares
8. Problems concentrating
9. Trouble learning new information
10. Forgetfulness
11. Disorganization or confusion
12. Difficulty making decisions
13. A sense of being overloaded or overwhelmed by problems
14. More frequent crying
15. Suicidal thoughts
16. Fear of getting close to people
17. Loneliness

Behavioral Symptoms of Distress

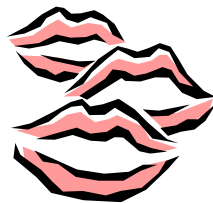
1. Inattention to dress or grooming
2. More frequent lateness
3. A more “serious” appearance
4. Unusual behavior
5. Nervous habits, such as finger or foot tapping
6. Rushing around or pacing the floor
7. Increased frustration & irritability
8. Edginess
9. Overreaction to small things
10. Increased number of minor accidents
11. Perfectionism
12. Reduced work efficiency or productivity
13. Lies or excuses to cover up poor work
14. Fast or mumbled speech
15. Defensiveness or suspiciousness
16. Strained communication with others
17. Social withdrawal
18. Constant tiredness
19. Sleep problems
20. Frequent use of over-the-counter drugs
21. Weight gain or loss without diet
22. Increased smoking
23. Recreational drug use
24. Increased alcohol use
25. Gambling or overspending

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Positive Self-Talk

An important step in managing stress and improving our mood is to stop and listen to the things that we say to ourselves. Are we saying positive, uplifting things or do we berate ourselves? We tend to be our own worst critic and we don't always have realistic expectations for ourselves. Have you ever thought that you had to be the perfect caregiver?

The next step is to tear that negative statement apart and separate fact from fiction. You may not even realize that the negative things that you are saying to yourself are not true! We just believe that they are true, when in fact, they are thinking errors (cognitive distortions). The following is inspired by Feeling Good: The New Mood Therapy by David. D. Burns, M.D. Examples have been added to help you change negative self-talk to more positive statements.



It's Either All Bad or All Good: You see yourself as a failure if you make even a small mistake.

Negative	Positive
<i>"I was late making dinner for Mom. I'm such a lousy daughter."</i>	<i>"I'm a good daughter whether dinner is late or not."</i>

I Always, I Never: You see a single negative event as a never-ending pattern of defeat.

Negative	Positive
<i>"I never get dinner ready in time. I'm always messing things up!"</i>	<i>"I'm sometimes late with serving dinner, but most of the time, dinner is right on time." "It's impossible to mess up all the time. Sometimes I make mistakes just like anyone else."</i>

Nit-Pick: You criticize your mistakes and dwell on them and you filter out anything positive.

Negative	Positive
<i>“I made this big Thanksgiving dinner, but the turkey was dry.”</i>	<i>“The family enjoyed getting together for our Thanksgiving meal. We had a lot of fun.”</i>

It Doesn't Count: Instead of celebrating your successes, you tell yourself and other that it was just a fluke.

Negative	Positive
<i>“She wouldn't compliment me if she really knew me.”</i>	<i>“It was nice that she noticed how well that I take care of Mom. I try really hard.”</i>

Just the Facts: You see things as being negative, even when there are no facts to support it. This includes:

Mind Reading: Even though you don't have super powers, you know what people are thinking and it's all about you and it's all negative.

Negative	Positive
<i>“I know that she thinks that I'm a horrible caregiver.”</i>	<i>“It's impossible for me to know what she is thinking. I have no proof that she is thinking that.”</i>

Look Into My Crystal Ball: You can foretell the future and just know that things will not work out.

Negative	Positive
<i>“I know that I won't be able to give Mom a shower the right way.”</i>	<i>“The more I help Mom with showering, I will learn what works best for the both of us.”</i>

Mountains Out of a Mole Hills: You magnify your mistakes and shrink you successes and positive qualities.

Negative	Positive
<i>“I was late giving Mom her medications today. I've made a horrible mistake & everyone will know that I'm a terrible daughter.”</i>	<i>“Being late with Mom's medications isn't the end of the world. It's really helping Mom that I'm here to give her medications to her.”</i>

I Feel it, So it Must Be True: You think that your negative emotions reflect the way things really are.

Negative	Positive
<i>“I feel guilty. I must have done something wrong.”</i>	<i>“I may have wanted to do something differently, but I didn’t do anything wrong or harmful.”</i>

I Should, You Should: Should statements only lead to guilt, anger, frustration, and resentment.

Negative	Positive
<i>“I should be able to take care of Mom & keep the house as clean as mom used to.”</i> <i>“I should be doing more. I shouldn’t take a break.”</i> <i>“My sister should be doing more to help.”</i>	<i>“I’m doing the best that I can. The house may not be as clean as Mom kept it, but she is comfortable and safe.”</i> <i>“It’s important that I take breaks so that I can take better care of Mom.”</i> <i>“I know that my sister is helping when she can. At least she visits Mom once a week.”</i>

Name Calling: When you make a mistake, you label yourself as a loser and failure. When someone’s behavior rubs you the wrong way, you call them names, too. These names can be explosive.

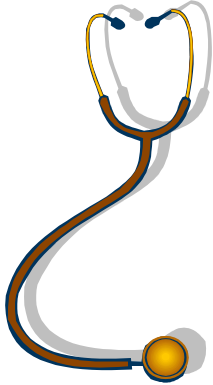

Negative	Positive
<i>“I’m such a loser!”</i> <i>“My brother is such a jerk!”</i>	<i>“I’m being too hard on myself. I made a mistake. It doesn’t make me a loser.”</i> <i>“I don’t always agree with the decisions that my brother makes. I know that he cares about Mom.”</i>





Everything’s My Fault: You carry the weight of the world on your shoulders & feel guilty for things that you have no control over.

Negative	Positive
<i>“It’s my fault that Mom is in a nursing home.”</i>	<i>“I didn’t cause Mom to have a stroke. She is in a nursing home so that she can receive all of the help that she needs.”</i>

Practicing Self-Care

In order to be an effective caregiver, you must maintain your own health and spirit and nurture yourself. Remember, it is only when we love and nurture ourselves that we are able to love and nurture another. Taking care of ourselves is not a luxury. It is an absolute necessity, especially if you are in it for the long haul. Practicing self-care means that you:

<p>Attend to your own health care needs</p> 	<p>This means:</p> <ul style="list-style-type: none">◆ Getting regular check-ups◆ Following your doctor's orders for medications & treatments◆ Eating nutritious meals◆ Limiting your caffeine intake◆ Exercising regularly◆ Not relying on drugs or alcohol to reduce stress◆ Getting enough sleep (even if it means taking naps during the day).
<p>Seek & accept the support of others</p> 	<p>Refusing help does not make you a better caregiver. You don't have to do it all! Caregivers caring for their spouses often say that taking care of their loved ones is part of their wedding vows...for better or worse, in sickness & health. However, there is nothing in the vows that says you have to do it alone!</p> <ul style="list-style-type: none">◆ Tell people what you need. Don't assume that they should know.◆ Keep a list of chores & tasks that you need help with. Then, when someone says, "Let me know if there is anything I can do," you can hand them the list and let them pick.◆ Seek counseling or attend a support group.

<p>Take time off without feeling guilty</p> 	<p>It is important to the well-being of your loved one that you take breaks. Not taking time off leads to caregiver burn-out, which can put your loved one at risk for abuse and/or neglect. If your loved one protests that you are leaving, acknowledge his/her feelings, but state that it is important for the both of you that you take a break.</p> <ul style="list-style-type: none"> ◆ Contact the Family Caregiver Support Program and Lifespan Respite Care Network in your area. ◆ Ask friends, family, or church members if they would be willing to stay with your loved one, even if it is only for a few hours. ◆ Hire a private home-care worker or use an agency to provide in-home care. ◆ Find an adult day respite program in your area. ◆ Contact local Adult Foster Homes & Residential Care Facilities to see if they offer overnight or day respite services.
<p>Know your limits</p> 	<p>This means learning to say “NO.” Knowing your limits & reaching out for help before you are beyond your limits is an important characteristic of a strong individual, not a sign of helplessness, inadequacy, or failure.</p>
<p>Set goals & prioritize</p> 	<p>It is alright to take “baby steps.” Break tasks into small, manageable pieces. Remember, the world won’t end if you don’t get the dusting or dishes done. What’s important is that your loved one is receiving good care & is safe. Be flexible. Life happens, even when you have other things planned. Learn some effective time management techniques.</p>
<p>Have fun</p> 	<ul style="list-style-type: none"> ◆ Find humor in your caregiving situation & life in general. Studies show that laughter helps to stimulate breathing, muscular activity, & heart rate, which in turn, helps to reduce stress & strengthen the immune system. ◆ Do the things you love to do that help you “recharge your batteries.” ◆ Reward yourself. You have definitely earned it!

Manage your stress



You can do this by:

- ◆ Recognizing your warning signs early. We don't always pay attention to the red flags. Examples of red flags may be: irritability; anxiousness; snapping at others; eating too much; muscle tension; difficulty sleeping..... (Also see "A Checklist of Stress Symptoms.")
- ◆ Identifying the sources of your stress. Ask yourself, "What is causing stress for me?" Is it trying to do too much? Difficulty saying no? Your loved one asking the same question over & over?
- ◆ Identifying what you can & cannot change. Too often, we try to change things that we don't have any control over. The only thing that we can change is ourselves (how we perceive things, how we respond, our attitudes, & our self talk). We cannot change, nor do we have control over, other people or the disease process. We may need to accept that the person we love, as well as our lives, has changed.
- ◆ Having **realistic** expectations about what you can do & what you think you should do. This may mean challenging your thoughts & beliefs (Also see "Positive Self-Talk.")
- ◆ Educating yourself about your loved one's disease so that you can be realistic about what they can & cannot do.
- ◆ Reframing the way you look at a situation. If you choose to look at a situation in a more positive light, you can ease much of the stress associated with it. What are the hidden treasures of caregiving?
- ◆ Keeping things in perspective.
- ◆ Learning & using relaxation techniques, such as deep breathing, stretching, meditation, guided imagery, or aromatherapy.