



**TAKE** *A Guide For Caregivers  
On How To Improve  
Their Self-Care*  
**CARE!**

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## PREFACE

This booklet is written out of respect and appreciation for all of you who provide care for a family member or friend who is chronically or terminally ill, disabled, or otherwise impaired. Yours is a special and important role that involves more than compassion, dedication, commitment, and service. It can also involve repetitive physical care and feelings of resentment or isolation. Caregivers need people who understand their role and can share the load. Some caregiving days may be routine; others may require skills, tact, and strength beyond measure.

We wrote this booklet to encourage and support you who "give care" to also "take care." Taking care is a necessity for your health and well-being, not an idle luxury.

Use this booklet like a friend; refer to the sections as needed. The booklet is set up in eight major sections:

1. [Who Are Caregivers?](#)
2. [Challenges And Stresses](#)
3. [Thriving, Not Just Surviving](#)
4. [Self-Care](#)
5. [Living With A Mix Of Feelings](#)
6. [Getting The Support You Need](#)
7. [Utilizing Help That Is Available](#)
8. [Afterword](#)

Within each section there are exercises for you to do. Work and re-work the exercises. Return to the booklet as frequently as you need to. Use whatever information specifically meets your needs to sustain your well-being.

We sincerely hope this booklet is helpful. Best wishes to you in your caregiving and in your "taking care."

*--Sheryl Niebuhr and Jane Royse  
Amherst H. Wilder Foundation*

## WHO ARE CAREGIVERS?

Caregivers are the people who, through their effort and tenacity, make it possible for a family member or friend who is ill, disabled, or frail to get the help they need. If you provide ongoing assistance to someone who is ill or otherwise impaired, then you are considered a family caregiver.

Some caregivers assist with daily activities such as household management, personal hygiene, and health care. Others manage services such as home health care, homemaker/chore services, or nursing home care. Regardless of the type of caregiving assistance, all caregivers encounter their family member's needs for encouragement, understanding, and a sense of belonging, purpose, and hope.

- ❖ As a group, caregivers have the following characteristics:
- ❖ Seventy percent are the primary caregiver.
- ❖ One third are the sole caregiver.
- ❖ Seventy-two percent are women.
- ❖ Among men, husbands and sons are the most common caregivers.
- ❖ Most caregivers are spouses. When a spouse is not available or able, a child--usually a daughter or daughter-in-law--becomes the caregiver.
- ❖ Among older caregivers who are spouses, nearly half report that they are concerned about their own health.
- ❖ One third of family caregivers are employed and have work and parental responsibilities in addition to their caregiving responsibilities.
- ❖ Eighty percent of caregivers provide care seven days a week for an average of four hours per day; in instances of severe impairment (for example advanced Alzheimer's Disease) many caregivers provide over 40 hours per week of assistance.

Most people think nurses and nursing homes are the primary providers of care for frail, ill, or disabled people. In reality, the vast majority of all long-term care is provided by family members. Of the 4.4 million older Americans who needed long-term care in 1982, only 1 million lived in institutions; of those living at home, 85 percent were aided by their families. Even many living in institutions continued to receive support and assistance from their families.

*Evidence suggests that family caregivers provide approximately 80 percent of all personal and medically related care and about 90 percent of all home help services.*

You are "head, heart, and hands" of most ongoing care within your family and within our society. Your role is extremely important to the life and well-being of your family member and to the capacity of our society to provide dignity, comfort, and assistance to those with significant health concerns.

## CHALLENGES AND STRESSES

**C**ertainly one of the biggest challenges you face is managing your caregiving tasks along with the other demands on your time, attention, and energy. This challenge is intensified when the demands are many or emotionally draining. In addition to your other responsibilities, you may provide several kinds of assistance to more than one person.

### SYMPTOMS THAT SIGNAL TOO MUCH STRESS:

**Physical:** headache, muscle ache, sleeping and eating problems, worsening of chronic conditions and illness susceptibility

**Emotional:** guilt, anger, loneliness, depression, and anxiety

**Mental:** forgetfulness, difficulty making decisions, poor attention

**Interpersonal:** withdrawal, blaming, irritability, impatience, and sensitivity to criticism

**Spiritual:** feelings of alienation, loss of hope, purpose, and meaning

While caregiving can be very satisfying, especially when it is an expression of love and care for someone important to you, it can also be psychologically and physically exasperating. When demands become overwhelming, your energy, good humor, and coping capacity can be taxed and you can feel stress.

The stresses you face will vary from day to day because caregiving responsibilities shift according to your family member's health and outlook and your own energy and optimism level. You may feel increased stress if your circumstances are undesirable, unchosen, uncontrollable, or uncertain. Chances are your stresses include:

- ❖ General demands and responsibilities associated with your various roles.
- ❖ Adjustment to changes and losses you have experienced (for example, changes in personal time, future plans, lifestyle, well-being, social life, and friendships).
- ❖ Hassles--those routine and unexpected inconveniences and frustrations that inevitably crop up.

As a caregiver you will experience stress. Managing stress requires balancing the demands in your life with the resources that can help you cope. Learn to recognize, anticipate, and offset the demands and stresses in your life with positive self-esteem, coping skills, and adequate social support. This booklet reviews a number of self-care strategies that can help you cope and relieve stress. Practice and incorporate them into your daily life.

### Check Which Of The Following Kinds Of Caregiving You Currently Provide:

- Household management (cooking, shopping, cleaning, housekeeping)
- Transportation
- Personal care (bathing, grooming, toileting, ambulating)
- Medical care (assistance with medication, dressings, oxygen)
- Supervision for safety
- Emotional support and companionship
- Financial management and decision-making assistance
- Coordination and management of care provided by others
- Regular assistance to another family member--grandparent, in-law, child, etc.

## THRIVING, NOT JUST SURVIVING

**W**hat does it take for you to thrive, not just survive, especially in difficult circumstances? Your sense of vitality and fulfillment are greatly affected by your hardiness under stress. Self-care involves sustaining your hardiness by practicing steps to reduce harsh and negative thinking, nurturing your self-esteem, and including enjoyable activities in your life.

### Avoid Harsh Self-Criticism

Do you blame yourself when things go badly and credit someone else when things go well? Do you whisper words of encouragement to yourself or mutter harsh criticism? Your answer to these questions may indicate whether or not you are too self-critical.

Even if you don't tend to be self-critical, stressful situations like caregiving can increase your tendency to slip into this type of negative thinking. Negativity can generate anxiety or depression and diminish your functioning capability. It erodes your ability to use your coping resources.

### Balancing Demands And Resources

<i>Demands</i>	<i>Resources</i>
Tasks/responsibilities	Self-esteem
Adjustment to change/loss	Coping skills
Hassles	Social support

- ❖ If you are ever harshly self-critical or feel immobilized and unable to function, try following these general guidelines:
- ❖ Pay attention to what you say to yourself. Are you whispering gentle encouragement or are you muttering harsh criticism?
- ❖ Watch for self-critical statements like: I should have . . . ; I'm too . . . ; I should be . . . ; I'm never . . . .
- ❖ Stop thinking negative thoughts about yourself.
- ❖ Replace negative thoughts with more reasonable ones that acknowledge the realities of your situation, recognize your strengths and limitations, and identify possible alternative actions or perspectives.
- ❖ If you catch yourself feeling self-doubt or self-criticism, get an objective view from a friend, advisor, or counselor.

*Make a list of what you like about yourself and what you have to offer others.*

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

### Nurture Your Self-Esteem

Self-esteem is knowing in your heart that you are a capable and lovable human being. This "knowing" helps you believe in yourself. Without it, you can feel helpless, uncertain, isolated, and anxious.

Research indicates that positive self-esteem is vital to well-being and the capacity to cope with stress. Three strategies to help build and sustain your self-esteem as a caregiver are:

1. **Spend time with your "fan club."** It is important to spend time with the people in your life who like you, help you believe in yourself, recognize your capabilities, and trust your opinions.

How often do you see and talk with these people? Have you actively kept these people in your life since becoming a care-giver? What keeps you from seeing them? What could you do to reduce the barriers? Make a point to talk to and see these people often. Spending time with members of your fan club is an important part of building and sustaining your self-esteem.

2. **Give yourself a pat on the back!** Give yourself permission to see the positive attributes that others see in you. Absorb the appreciation from others. Take it to heart. Appreciate your talents and focus on your inner strengths and unique capabilities.
3. **Avoid "poisons" that lower your self-esteem.** No one thrives on harsh, demanding input from others. People lead satisfying lives in spite of, rather than because of conflict, negativity, disrespect, or harassment from others. Such destructive input tends to impede rather than empower.

Avoid those around you who erode your positive self-esteem. Instead, follow these do's and don'ts for sustaining positive self-esteem:

- ❖ Do spend time on a regular basis with people who believe in you and like you.
- ❖ Do avoid discounting, negating, or minimizing another person's appreciation of you.
- ❖ Do acknowledge your inner strengths and how they have served you in the past.
- ❖ Do recall every day at least one thing you and others appreciate about you.
- ❖ Do ignore unfair or unhelpful criticism of yourself rather than taking it to heart.
- ❖ Do learn to honor and respect yourself as much as you do others.
- ❖ Don't seek the company of those who sap you of your positive self-esteem.
- ❖ Don't minimize what you have to offer others or the value of your own capabilities.

***List ten activities that revitalize, energize, and lift your spirits.***

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_
8. \_\_\_\_\_
9. \_\_\_\_\_
10. \_\_\_\_\_

***Was it easy to think of ten uplifting things?***

***When was the last time you enjoyed any of these activities?***

### Enjoy Yourself

As a caregiver you have experienced an increase in the hassles in your life. Simple tasks like shopping, cooking, or taking a bath may no longer be routine. You may no longer take part in activities which energize and nurture your spirit. These pleasures may have become infrequent luxuries rather than regular occurrences because the demands and hassles make enjoyable activities seem to cost too much time, energy, and money.

If naming ten activities was difficult for you, it's probably not because you don't like doing many things, but that you haven't paid much attention to what enlivens and revitalizes *you*.

Plan to make at least some of the activities you enjoy a regular part of your daily life. Be intentional -- avoid putting all your energy into managing the demands and hassles at the expense of enjoying leisure activities. Incorporating leisure activities into your life will improve your coping capacity; by not doing so you risk depression and discouragement.

### Change Unrealistic Expectations And Unhelpful Thinking

Research shows that how you think influences how you feel. When you have negative thoughts, try to look at your situation from a different perspective. Doing so helps you minimize feelings of distress, enabling you to solve problems more effectively.

#### What Roles Do You Play?

Check all the roles you currently play.

- |   |  |
|---|--|
| <input type="checkbox"/> caregiver            | <input type="checkbox"/> husband/wife  |
| <input type="checkbox"/> mother/father        | <input type="checkbox"/> aunt/uncle    |
| <input type="checkbox"/> grandma/grandpa      | <input type="checkbox"/> son/daughter  |
| <input type="checkbox"/> son-/daughter-in-law | <input type="checkbox"/> lover         |
| <input type="checkbox"/> friend/acquaintance  | <input type="checkbox"/> best friend   |
| <input type="checkbox"/> organization member  | <input type="checkbox"/> church member |
| <input type="checkbox"/> home maintainer      | <input type="checkbox"/> employee      |

#### What are your idealized expectations of your three most important roles?

(For example, some commonly held expectations for a spouse include: always knowing how your partner feels; always being kind, patient, passionate, and supportive; always being committed to your partner.)

**Evaluate your role expectations.** You probably have idealized expectations of yourself. Although you know these images and expectations are unrealistic, you still feel disappointed when you don't meet these standards. Learn to let go of these idealized expectations. Make sure your expectations are yours, not ones placed on you by others. Practice the art of compromise and recognize your limits. Replace your idealized expectations with acceptable and realistic compromises.

**Break habits of unhelpful thinking.** Over time you may have developed a tendency to exaggerate your problems, minimize your resources, jump to conclusions, think in absolute terms, or over-generalize situations. You may automatically practice these unhelpful thinking habits. Learn what your unhelpful thinking habits are, watch for when they occur, and replace them with a positive perspective that can help you cope better.



Unhelpful thoughts associated with depression and anxiety include:

- ❖ Exaggerating the actual threat, loss, or undesirable aspects of a situation--the proverbial "making a mountain out of a mole hill."
- ❖ Minimizing the resources available for coping with the situation.
- ❖ Jumping to dismal conclusions without waiting to collect all the relevant information.
- ❖ Casting situations in absolute terms such as "never" or "always."
- ❖ Over-generalizing situations.

When you feel upset because of unhelpful thinking, use the following process to change unhelpful thoughts into helpful ones:

1. Recognize and identify your feelings. Use your upset feelings as signals to let you know you're engaging in unhelpful thinking.
2. Look at what is upsetting you. Identify the thoughts you're having about the situation.
3. Clarify the situation. What are your opinions, interpretations, or judgments? Look for exaggerations, over-generalizations, and premature conclusions.
4. Replace your unreasonable, upsetting thoughts with more realistic ones, such as:
  - This is hard, but I do have some options for coping with it.
  - I need to stop speculating and assuming things and find out what is really going on.

### **Set Limits**

Do you know your own limits of time, energy, and capabilities? Do you accept them, or do you consistently ignore them and push well beyond them? How are you at saying "no" to yourself or to others?

You may have a hard time saying "no" because you care so much, see no other options, feel obligated and guilty, want to please or prove something, or simply have never learned to say "no." It's hard to set limits, but not setting them is ultimately self-destructive.

Let go of some of the things that don't have to be done. Anticipate your needs to cut back or to set limits and pace yourself. Get comfortable with letting others help you. Talk things over with someone who understands you and your situation. Let others help you see things in perspective and find ways to manage your situation without going beyond your limits or making yourself sick.

Remember, you are "response-able" only to the extent that you are able to respond. Sustain your ability to respond by honoring and working within your own limits of energy, time, and know-how.

*List some times when you have pushed yourself beyond your limits as a caregiver.*

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

Ask yourself these questions:

Am I comfortable acknowledging my limits? What keeps me from setting reasonable limits? How can I change those barriers and set limits I can live with?

## SELF-CARE

**E**xercise, good nutrition, and relaxation are the basis of good health and well-being. Balancing these factors recharges your body and mind and keeps you in the best possible working order.

### Exercise

Excuses for not exercising are many: "I'm too old," "I get enough exercise lifting and caring for my spouse," or "I just don't have the time or energy for that."

The benefits of exercise are endless, yet fitting it into your schedule is never easy. Research shows that you're never too old to exercise; that giving physical care to another person is not the kind of exercise you need; and that you may be experiencing stress, fatigue, and depression partly because you don't exercise. So read on.

**Choose the right exercise for you:** It doesn't have to be what everyone else is doing. It does have to be something you'll enjoy, benefit from, and continue to do. Some exercises to consider include walking, swimming, or bicycling. If you haven't been regularly exercising, consult your physician before beginning.

**Make exercise fun:** Choose an activity you enjoy rather than one you dread. The more you enjoy the activity, the greater the chance you will stick with it.

**Don't expect too much too soon:** Your results will be greater if you set short-term goals and begin slowly. Gradually increase your participation in your chosen activity to at least three times a week.

**Reward yourself:** Reward yourself for every positive step you make. Whether you accomplish your goal or not, do something special to reward yourself for what you did accomplish. Treat yourself to a massage, a bouquet of flowers, or a movie.

**Believe in taking care:** Finding time for your caregiving responsibilities is easy. Finding time to take care of yourself is hard. Adequate self-care lessens and may even eliminate the constant feelings of being overworked and overtired. Make time to take care.

### Eating Habits

#### *Your Personal Exercise Chart*

Date:

What kind of exercises do I currently do?

What excuses do I use to keep myself from exercising?

What exercise goal do I want to achieve six months from now?

What short-term goals can I set to achieve my six-month goal?

What are some rewards that will keep me going?

*Complete this chart every other month and compare your progress. It should get easier to set goals and think of rewards. Exercise is an important part of self-care.*

This section does not discuss nutrition in the usual sense of the word but rather the certain self-destructive eating behaviors common to caregivers. Our society is flooded with information on cholesterol, sodium, and vitamins. As a caregiver, you need to not only know about those topics, but you also need to know how to maintain healthy and nurturing eating habits.

There are alternatives and solutions to poor eating habits. Try the following and add ideas of your own.

- ❖ Arrange to have certain meals during the week with someone special--your granddaughter, a neighbor or a close friend.
- ❖ Graciously accept their offer to bring the meal or take you out. Company makes any meal taste better.
- ❖ Don't serve yourself until your family member is finished if it's impossible to eat while feeding them.
- ❖ Take your meal to the bedroom if the person you care for eats in bed.
- ❖ Pick up the phone when you feel alone instead of those cookies. Look for companionship somewhere other than the candy dish.

List your ideas for alternatives to poor eating habits.

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

### Give Your Mind A Break

Reading, walking, or window shopping are all ways to relax--unless you continue to fret. To relax you need to learn ways to clear your mind of work and stressful thoughts.

Try the following relaxation techniques. By incorporating them daily into your life, they will help you manage stress.

**Deep breathing:** Deep breathing takes only a few minutes and can be done any time or place without disrupting your schedule. This deep breathing exercise focuses your physical and mental activity to give your body and mind relief from prolonged tension.

Read through all the steps first, then do the exercise.

1. Get in a position that is comfortable and convenient for you.
2. Close your eyes.
3. Take a breath, then exhale. Repeat three times.
4. Inhale deeply through your nose as you slowly count to five.

5. Hold this breath for five seconds.
6. As you slowly count to seven, exhale through your mouth.
7. As you inhale, imagine you are bringing energy into your body; as you exhale, feel your body releasing and blowing out tension and stress.
8. Repeat steps 4 to 7 four to six times, inhaling energy, exhaling tension.
9. Return your breathing to normal for the balance of your quiet time.
10. Concentrate on your regular breathing--putting aside all stress-producing thoughts or feelings.

*Suggested practice techniques:*

- ❖ Take four or five deep breaths every time you start to feel tense, focusing all your attention on your breathing.
- ❖ Get in the habit of practicing deep breathing.

**Imagination, memories, and relaxation:** Visualization and guided imagery are techniques to help you use your imagination to create a state of relaxation. By using visualization and guided imagery, you can create a heightened sense of positive feelings while minimizing tension, depression, and restlessness.

*Visualize colors:* Close your eyes and imagine your whole body being filled with the colors red and green. The green represents relaxation and the red, stress and tension. Imagine the red in your body turning to green. Keeping your eyes closed, feel your whole mind and body becoming completely calm and relaxed as the green washes the red totally out of your body.

*Creating your own guided imagery:* Close your eyes and imagine yourself going on a journey, leaving your troubled world behind. As you walk down a path, the sunshine is warming your back and shoulders while a cool breeze blows through your hair. You decide to sit and examine the tensions and hassles of your life. After looking at each one carefully, you put them by the side of the path, stand up, and continue your journey hassle-free! As you walk, you look around and become aware of your surroundings--the sights, smells, and sounds. Spend the next few minutes breathing deeply and enjoying the complete relaxation that comes with imagining your special place.

Now end your journey by taking one last look around at your special place. As you open your eyes, stretch and remember that the picture you have just created can be revisited whenever you need to relax.

*Your own bag of tricks:* Develop your own "bag of tricks" that you can use to take care of yourself and relieve stress. Some ideas you might try include: enjoying a good laugh, writing in a journal or diary, or listening to your favorite music.

### My Bag Of Tricks

*List your own ideas for relieving stress:*

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

## LIVING WITH A MIX OF FEELINGS

**A** mixture of conflicting feelings is found in every caregiving situation. That's normal. By looking closely at your emotions you can better understand them and how they affect you.

To understand your feelings you must first identify them. Once identified you can confront and work with these feelings rather than ignore or bury them. Thinking your emotions aren't real, hoping they will go away, or feeling guilty are not healthy reactions and only serve to increase stress.

**List all the feelings you can have so far during your time as a caregiver.**

(For example: guilt, loneliness, anger, love, hope) Remember, there are no right or wrong, good or bad answers—just normal responses to difficult situations.

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

6. \_\_\_\_\_

7. \_\_\_\_\_

8. \_\_\_\_\_

9. \_\_\_\_\_

10. \_\_\_\_\_

Although writing down your feelings is difficult, this is the first step toward living with the mix of feelings most caregivers experience. Don't stop here. Now that you recognize your emotions, you must learn to deal with them.

**Grief:** Most people associate grief with the feelings you have when a loved one dies.

Because of the finality of death, you give yourself permission to grieve. However, you do not always give yourself this same permission when you lose someone to aging or disability. Grief is a natural response to any loss; therefore, you should also grieve the losses that accompany disability or illness.

To cope, talk about your feelings with other caregivers. They are struggling too, and can understand. Be as patient and understanding with yourself through this grieving process as you would be with others. And give yourself time and permission to grieve each individual loss as it happens.

**Anger:** There have probably been times as a caregiver when you've been angry at everything and everybody. Being angry is okay; letting the anger take control isn't.

Looking at your anger objectively will help you deal with it and with the guilt that surrounds it. Direct your anger at the disability rather than at the person you're caring for; realize that other caregivers get just as upset as you do; and try to deal with the pent-up energy that accompanies anger by cleaning your house or taking a brisk walk.

Learn how to vent your anger in healthy ways. Bottled up anger can be physically and emotionally detrimental to your own well-being and can lead to abuse of the person you are caring for.

**Loneliness:** When the one person with whom you have shared years of love and memories is no longer capable of sharing, you may feel lonely and alone. To deal with these emotions you must first accept that neither you nor anyone else can bring back the relationship you once had. To ease the pain of your loss, look for nurturing relationships with others who care about you. You will feel less alone surrounded by other caregivers who understand, and by family and friends you love.

**Inadequacy:** During your time as a caregiver, you've probably experienced feelings of inadequacy. Feeling inadequate often stems from three reasons:

- ❖ You are unable to meet the expectations placed upon you by yourself and others.
- ❖ Daily you see pain and suffering and are unable to relieve them.
- ❖ You're faced with accepting your human limitations.

To deal with feelings of inadequacy, accept yourself and appreciate the strengths and talents you possess.

**Hope:** Often your hope is focused on the sick, disabled, or elderly person, and you forget to have hope for your own dreams and desires. There are two of you in this situation, and neither of you can afford to live without hope. If you do lose hope, you need to talk to someone who can help you regain a positive perspective.

Hope can:

- ❖ Prevent you from being held captive by the disability.
- ❖ Encourage you not to settle for survival, but to thrive.
- ❖ Inspire you not to get stuck in the worst of what is, but to work toward the best that can be.

Learning to live with your feelings is easier if you let others help. Don't try to cope by yourself--find support options that work for you.



## GETTING THE SUPPORT YOU NEED

### Drawing On Social Support: Friends Can Be Good Medicine

**W**e can't thrive and may not even be able to survive without a sense of connection to and support from others. In difficult situations such as widowhood, job loss, unemployment, complicated pregnancy, heart attack, and family caregiving, people who have a support network fare significantly better than those who don't. People need people who care, especially during life's difficult times. Supportive relationships are one of the most important resources you can have to help you sustain and manage difficult demands.

Because of the pressing demands on them, many caregivers find it difficult to sustain long-standing relationships. Over time, their support relationships become fewer and weaker. As a result, their coping resources become more fragile and they feel more vulnerable and alone. If your support network is becoming weak, strengthen it. Don't take it for granted. Take steps to include the people you most want to be a part of your life.

#### Know Your Support Needs

The type of support you need will vary. To determine what type you need, use these five categories:

**Emotional support:** Someone who recognizes, understands, and conveys appreciation for what you are experiencing; a confidant who is willing to listen to you and help you with acceptance and understanding.

**Esteem support:** Someone who helps you know and remember your strengths and capabilities and how likable you are; a member of your fan club who believes in you and helps you believe in yourself.

**Informational support:** Someone who helps you get the accurate and timely information you need to cope with your caregiving needs--insurance, medical systems, available services.

**Tangible support:** Someone who helps you get tasks done, for example, home maintenance, food preparation, shopping, transportation, respite care.

**Companionship:** Someone who shares your leisure time and activities, conversations and meals.

#### Identify Your Support Resources

Who are the people you can count on for support? What type of support do they each provide--emotional, esteem, informational, tangible, or companionship? How adequate is your support system?

If your resources are low for any type of support, consider building people into your life who can be helpful in those areas. They may be family, friends, and spiritual advisors; or they may be a counselor or members of a

#### Where to find counseling and support groups:

- Mental health agencies
- Aging and/or social service agencies affiliated with a church or association
- County Public Health Nurse
- County Extension Services
- Hospitals
- YMCAs and YWCAs
- Illness and disability associations
- Information and referral services

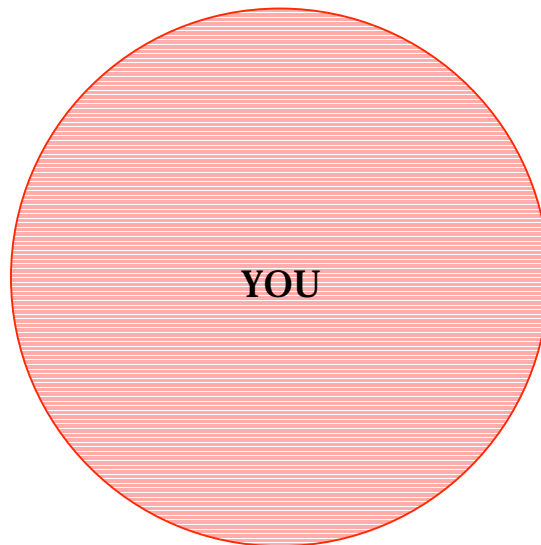
support group.

**One-to-one counseling:** Your situation and problems can seem overwhelming and unsolvable when you look at them from the inside out. A counselor can help you break down your problems into small, manageable parts that can be addressed one at a time. A counselor provides an objective, understanding ear that helps you cope and solve problems, thus improving your emotional well-being. Family and friends can lend additional support, but they too can be affected by their emotional involvement and might not be as objective as an outside person trained in this area.

**Support groups:** A support group is a safe, non-threatening environment where everyone has experienced similar feelings and situations. At support group meetings you can meet with other caregivers to share your feelings and exchange coping strategies. Now is the time to seek the support a group can give. You deserve it.

### SUPPORT WHEEL

Use this exercise to determine the strength of your support network.



1. On the outside of the wheel write the names of the significant people in your life.
2. Draw lines like the spokes of a wheel, connecting you to each of the people in your life.
3. Indicate the strength of the relationship by the strength of the connecting line:

Strong relationships with a \_\_\_\_\_

Weak relationships with a .....

Intermittent relationships with a - - - - -

4. Note the direction of giving and getting support in each relationship with an arrow on the line:

- ❖ If you give the primary support draw the arrow pointing toward the person's name.
- ❖ If you primarily receive support draw the arrow pointing toward you.
- ❖ If it is an equal give and receive relationship draw the arrow pointing in both directions.

5. Note any conflict in a relationship with a jagged over the connecting line.



**Now answer these questions:**

1. Judging from your spokes, what is the strength of your wheel of support? Do you have many or few support relationships? How many strong relationships do you have?
2. In how many relationships do you give the primary support? Is there a balance between the number of giving and receiving relationships?
3. Does conflict disrupt the supportiveness of any of your relationships?
4. If one or two of your strong relationships ended by death, illness, divorce, or relocation, how would that affect your support wheel?
5. Do you want to change the number, strength, or reciprocity of your support relationships? Are there weak relationships you want to build? Are there relationships you would like to add?

### Utilize Your Support Resources

The people in your life are most effective when the support they provide fits their capabilities. Avoid expecting people to give what they cannot. Match your needs with the people who can best meet them.

Also remember that even the best support system will not be useful to you if you don't give it a chance to work. Let others know what your needs are and how they can help. Get comfortable asking for support!

But when should you ask for help and support? Anytime. Don't wait until you've turned to food, alcohol, or drugs for your support. Don't wait until all of your other relationships are suffering because of your caregiving pressures. And, especially don't wait until your own health suffers. No matter what stage of caregiving you're in--just beginning, a long-timer, or anywhere in between--NOW is the time to seek support.

## UTILIZING HELP THAT IS AVAILABLE

**W**hile most caregivers feel that they can, should, or must provide all the care to their family member, carrying the total burden is not only self-destructive but ultimately impossible. Finding additional care may be difficult. It might upset the care-receiver if you entrust their care to someone else. It might mean making repeated attempts to find a service that can help you. And it might even mean using some of your reserved financial resources to pay for the help. But before you dismiss the idea, consider these three points:

### Fill In The Blanks To Determine Your Help Needs

What is it I need help with?

Whom will I ask to help?

When could I use this help?

When will I ask them? *Right Now!*

1. Additional help allows you to be a more effective caregiver by giving you time away from the care-receiver.
2. The care-receiver benefits by seeing and being with someone other than you.
3. Community-based services often postpone institutionalization because they allow more difficult and/or more skilled care to take place in the home.

### Where To Look For Services

Try your local information and referral service for specific names and numbers of agencies. Your county social service agency, county health nurse, and social service agency affiliated with your religion are also good sources of information. If the person you care for has a specific disease-related disability, contact that particular organization, such as the Alzheimer's Association or the M.S. Society.

When you're looking for a service, be persistent. If the place you call can't help you, ask them for ideas on where to look. Remember, there is someone out there to help; set your goal on finding them.

### Resources Available

**Informal services:** Religious organizations, community centers, or other family members, friends, and neighbors--these sources of help are obvious but under-used by most caregivers.

**Adult day health programs:** These programs are in centers where an elderly and/or disabled person can go for recreational activities, socialization, rehabilitation therapy, and some medical monitoring. Supervision is provided by trained staff who work with your family member and encourage them to participate in activities appropriate for their abilities.

**Chore services:** A handyman can perform such tasks as yard work, minor home repairs, and home winterization.

**Housekeeping service:** A housekeeping service can do your cleaning, laundry, shopping, or meal preparation.

**Home health services:** These services range from skilled nursing care to assistance with bathing or dressing. Depending on the care required, the assistance may be delivered by a trained home health aide or a registered nurse.

**Home delivered meals:** A hot, nutritious noon meal is delivered to the home of an elderly or disabled person.

**In-home respite care:** This service gives you a break from your caregiver role and allows the care-receiver to be assisted by a new face--adding a different perspective to the situation.

**Out-of-home respite care:** In this type of respite the care-receiver goes to a nursing home or similar setting to be taken care of for a short time (3-30 days). It allows you to take a vacation, handle an emergency, or just be at home without the responsibility of another person. Reservations for out-of-home respite are usually required, so plan ahead.

## AFTERWORD

**B**ecause taking care of yourself is an ever-changing and ongoing process, there is more to be said than what we have here. It is important to address the thoughts and feelings you have, that we haven't. Ask others in your life to share their reflections and wisdom. Use this booklet as just one source of support among the many available. We wish you well.

For more than 90 years, the Amherst H. Wilder Foundation has been providing health and human services that help children and families grow strong, the elderly age with dignity, and the community grow in its ability to meet its own needs.

The Medtronic Foundation is the primary channel for charitable contributions from Medtronic, Inc., a leading developer and manufacturer of devices for improving cardiovascular and neurological health. The Foundation allocates a significant portion of its funds to innovative programs that assist older people in maintaining healthy, independent, and productive lives.

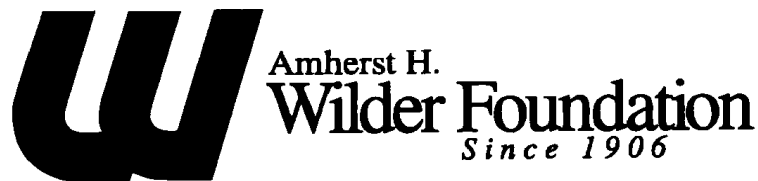
Jane Royse, M.S., has devoted more than a decade working on behalf of family caregivers—locally, regionally, and nationally. In addition to her support group, program development, and training activity, Jane is a consultant to the National Council on Aging's Family Caregiver Program and co-chairs the Minnesota Coalition for Caregiver Support Services.

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Printed copies of the 1989 publication TAKE CARE! are no longer available. The publication's text is provided free of charge to World Wide Web users at: <http://www.wilder.org/>.



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