

Hospice of Palm Beach County
Hospice by the Sea
trustbridge®



Caring for the
Caregiver



“ I appreciate all of you and your generosity and spirit. You are truly a gift to us. ”

Some facts about Caregivers

Caregivers - A Definition:

Unpaid caregivers are spouses, partners, family members, friends, or neighbors involved in assisting others with activities of daily living and/or medical tasks.

Magnitude:

- 65.7 million caregivers make up 29% of the U.S. adult population, providing care to someone who is ill, disabled or aged.

[The National Alliance for Caregiving and AARP (2009), Caregiving in the U.S. National Alliance for Caregiving, Washington, DC.]
- Updated: November 2012

- 43.5 million of adult family caregivers care for someone 50+ years of age and 14.9 million care for someone who has Alzheimer's disease or other dementia.

[Alzheimer's Association, 2011 Alzheimer's Disease Facts and Figures, Alzheimer's and Dementia, Vol.7, Issue 2.]
- Updated: November 2012

Gender and Age:

- More women than men are caregivers: an estimated 66% of caregivers are female. One-third (34%) take care of two or more people. The average age of a caregiver is 48.

[The National Alliance for Caregiving and AARP (2009), Caregiving in the U.S. National Alliance for Caregiving, Washington, DC.]
- Updated November 2012

Depression and Caregiving:

- 40% to 70% of family caregivers have clinically significant symptoms of depression with about a quarter to half of these caregivers meeting the diagnostic criteria for major depression.

[Zarit, S. (2006) Assessment of Family Caregivers: A Research Perspective in Family Caregiver Alliance (Eds.), Caregiver Assessment: Voices and View from the Field. Report from a National Consensus Development Conference (Vol. II) (pp. 12-37). San Francisco: Family Caregiver Alliance.
- Updated: November 2012

Impact on Worklife:

- Caregivers suffer loss of wages, health insurance and other job benefits, retirement saving or investing, and Social Security benefits losses that hold serious consequences for the "career caregiver." A reported 37% of caregivers quit their jobs or reduced their work hours to care for someone 50+ in 2007.

[AARP Public Policy Institute 2008: Valuing the Invaluable: The Economic Value of Family Caregiving]
- Updated: November 2012



Caring for the Caregivers

When a loved one is injured, ill, or recovering from surgery, as caregivers we spring into action. While we are busy taking care of their needs, we often forget about our own. As we take good care of ourselves, the loved ones we are caring for will benefit as well.

The demands of caregiving can put our health at risk, often resulting in:

- Stress
- Elevated blood pressure
- Anxiety and depression
- Physical exhaustion
- Alcohol and drug abuse
- Neglect of our own health and medical issues

There are many things we can do to preserve our strength and sense of well-being. The purpose of this guide is to provide information that will help you assess your situation, care for yourself and access important information.



Part 1: First, Care for Yourself

Research provided by the Family Caregiver Alliance



Part 2: Caregiver Self-Assessment Questionnaire

Prepared by the American Medical Association



Part 3: Practical Tips for Stress



Part 4: The Caregiver's Phone Guide for Palm Beach County and Broward County

Caregiver resources and important local phone numbers

“ It is hard to express the sense of relief that hospice provided. What was overwhelming is now manageable. ”



First, Care for Yourself

Provided by the Family Caregiver Alliance

On an airplane, an oxygen mask descends in front of you. What do you do? As we all know, the first rule is to put on your own oxygen mask before you assist anyone else. Only when we first help ourselves can we effectively help others. Caring for yourself is one of the most important—and one of the most often forgotten—things you can do as a caregiver. When your needs are taken care of, the person you care for will benefit, too.

Effects of Caregiving on Health and Well Being

We hear this often: "My husband is the person with Alzheimer's, but now I'm the one in the hospital!" Such a situation is all too common. Researchers know a lot about the effects of caregiving on health and well-being. For example, if you are a caregiving spouse between the ages of 66 and 96 and are experiencing mental or emotional strain, you have a risk of dying that is 63 % higher than that of people your age who are not caregivers. The combination of loss, prolonged stress, the physical demands of caregiving, and the biological vulnerabilities that come with age place you at risk for significant health problems as well as an earlier death.

Older caregivers are not the only ones who put their health and well-being at risk. If you are a baby boomer who has assumed a caregiver role for your parents while simultaneously juggling work and raising adolescent children, you face an increased risk for depression, chronic illness and a possible decline in quality of life.

But despite these risks, family caregivers of any age are less likely than non-caregivers to practice preventive healthcare and self-care behavior. Regardless of age, sex, race and ethnicity, caregivers report problems attending to their own health and well-being while managing caregiving responsibilities. They report:

- Sleep deprivation
- Poor eating habits
- Failure to exercise
- Postponement of or failure to make medical appointments for themselves

Family caregivers are also at increased risk for depression and excessive use of alcohol, tobacco and other drugs. Caregiving can be an emotional roller coaster. On the one hand, caring for your family member demonstrates love and commitment and can be a very rewarding personal experience. On the other hand, exhaustion, worry, inadequate resources and continuous care demands are enormously stressful. Caregivers are more likely to have a chronic illness than are non-caregivers, namely high cholesterol, high blood pressure and a tendency to be overweight. Studies show that an estimated 46% percent to 59% of caregivers are clinically depressed.

Taking Responsibility for Your Own Care

You cannot stop the impact of a chronic or progressive illness or a debilitating injury on someone for whom you care. But there is a great deal that you can do to take responsibility for your personal well-being and to get your own needs met.

Identifying Personal Barriers

Many times, attitudes and beliefs form personal barriers that stand in the way of caring for yourself. Not taking care of yourself may be a lifelong pattern, with taking care of others an easier option. However, as a family caregiver you must ask yourself, "What good will I be to the person I care for if I become ill? If I die?" Breaking old patterns and overcoming obstacles is not an easy proposition, but it can be done—regardless of your age or situation. The first task in removing personal barriers to self-care is to identify what is in your way. For example:

- Do you think you are being selfish if you put your needs first?
- Is it frightening to think of your own needs? What is the fear about?
- Do you have trouble asking for what you need? Do you feel inadequate if you ask for help?
- Do you feel you have to prove that you are worthy of the care recipient's affection?
- Do you do too much as a result?

Sometimes caregivers have misconceptions that increase their stress and get in the way of good self-care.

Here are some of the most commonly expressed:

- I am responsible for my parent's health.
- If I don't do it, no one will.
- If I do it right, I will get the love, attention, and respect I deserve.
- Our family always takes care of their own.
- I promised my father I would always take care of my mother.

"I never do anything right," or "There's no way I could find the time to exercise" are examples of negative self-talk, another possible barrier that can cause unnecessary anxiety. Instead, try positive statements: "I'm good at giving John a bath." "I can exercise for 15 minutes a day." Remember, your mind believes what you tell it.

Because we base our behavior on our thoughts and beliefs, attitudes and misconceptions like those noted above can cause caregivers to continually attempt to do what cannot be done, to control what cannot be controlled. This can result in feelings of continued failure and frustration and, often, an inclination to ignore your own needs. Ask yourself what might be getting in your way and keeping you from taking care of yourself.

Moving Forward

Once you've started to identify any personal barriers to good self-care, you can begin to change your behavior, moving forward one small step at a time. Following are some effective tools for self-care that can start you on your way.



“ With the support of hospice,
we were able to care for
Mom the way we hoped to. ”



Caregiver Self-Assessment Questionnaire

How are You?

Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have:

- | | | | | | |
|---|-----|----|--|-----|----|
| 1. Had trouble keeping my mind on what I was doing | Yes | No | 12. Felt strained between work and family responsibilities | Yes | No |
| 2. Felt that I couldn't leave my relative alone | Yes | No | 13. Had back pain | Yes | No |
| 3. Had difficulty making decisions | Yes | No | 14. Felt ill (headaches, stomach problems or common cold) | Yes | No |
| 4. Felt completely overwhelmed | Yes | No | 15. Been satisfied with the support my family has given me | Yes | No |
| 5. Felt useful and needed | Yes | No | 16. Found my relative's living situation to be inconvenience or a barrier to care | Yes | No |
| 6. Felt lonely | Yes | No | 17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. ____ | | |
| 7. Been upset that my relative has changed so much from his/her former self | Yes | No | 18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. ____ | | |
| 8. Felt a loss of privacy and/or personal time | Yes | No | | | |
| 9. Been edgy or irritable | Yes | No | | | |
| 10. Had sleep disturbed because of caring for my relative | Yes | No | | | |
| 11. Had a crying spell(s) | Yes | No | | | |
- Comments: (Please feel free to comment or provide feedback.)
-
-
-



“ When you walk into someone's room, their eyes light up and they perk up. Your presence can mean so much. We don't realize that we can do this in someone's life. ”



“ It was an extraordinary experience to see my mother let go and enjoy the last months of her life. ”

Practical Tips for Stress

We all feel the effects of too much stress in our lives. But nothing is quite like caring for a loved one who is injured, ill, or recovering from surgery. It can result in an overwhelming amount of stress and can last for a very long time.

While stress is an unavoidable consequence of life, not all stress is necessarily bad. To keep stress manageable, care for yourself by paying attention to the mind and body. Listen to yourself and what your body tells you. Think of your current habits: which of them are self-nurturing? How could you add to them with new habits? These will safeguard you against the physical and emotional toll of prolonged stress.

Below are Simple Stress Reducing Tips that are specific to caregivers. As you consider them, remember to introduce them gradually.

Change Breathing Patterns to Induce Relaxation

The Latin word, "Spiritus" means breath. Calming breath can refresh the soul and soothe the body. Breathing properly is one of the simplest ways of relieving stress.

Inhale slowly through your nostrils, taking in a very deep breath, filling your lungs and cheeks.

Hold that breath for about six seconds.

Exhale slowly through your slightly parted lips, releasing all the air in your lungs.

Pause at the end of this exhalation. Now take a few "normal" breaths.

Repeat the first three steps, two or three times and then return to what you were doing.

Take a "Stretch Break" and Stretch Away Your Tension

Stretching is one of the ways your body naturally releases excess bodily tension. Stretching exercises stimulate receptors in the nervous system that decrease the production of stress hormones.

Following are two tension-relieving stretches that are wonderful ways to discharge a lot of excess tension:

The Twist. This stretch is great for the upper body. Sitting or standing, put both your hands behind the back of your head, locking your fingers together. Move your elbows toward each other until you feel some moderate tension. Now twist your body slightly, first to the right for a few seconds and then slowly to the left. When you finish, let your arms fall to your side.

The Leg-Lift. This stretch is good for your lower body. Sitting in your chair, raise both legs until you feel a comfortable level of tightness in them. Maintaining that tension, flex and point your toes toward your head. Hold that tension for about 10 seconds then let your feet slowly return to the floor. If doing this with both legs is a bit uncomfortable, try one leg at a time.

Remember to stretch slowly and don't overdo it. Relaxation is the operative word!

Practice Mindful Eating with Healthy Foods

What you eat affects how you feel. Research has shown that food can increase or decrease stress in your life. Eating the right food gives your brain a better chance of getting what it needs to cope with stress.

Following are some guidelines to help you choose foods that will lower your emotional stress and help your body cope with it as well:

- Get plenty of potassium. Potassium is a mineral that helps relax muscles. Good sources of potassium are found in milk, whole grains, wheat germ, nuts and bananas.
- Eat proper amounts of protein. Foods high in protein enhance mental functioning and can help repair damage to your body's cells. Try eating more chicken, fish and other lean meats.
- Eat your vegetables. Feed your body the vitamins and nutrients it needs to resist the negative effects of stress. Keep your vegetable intake colorful with carrots, dark green leafy vegetables, squash and beans.
- Reduce “refined” simple carbohydrates such as cookies, white bread, doughnuts, candy etc. Foods with refined sugar feel good at the moment but will leave you feeling sluggish in the long run.
- Include, “unrefined” or complex carbohydrates such as whole grains, legumes, brown rice, most vegetables and many varieties of fruit. They enhance your performance.

Remember to bring your grocery list with you to the store and always shop on a full stomach. And don't stress over your diet, it's OK to have ice cream and pizza now and then. Bon appétit!

Smile

Did you know you can smile to improve your health and stress level? Research has found that you can even, “act as if” you are feeling an emotion—such as happiness—by arranging your face in a smile. By doing this, you are likely to feel that emotion. The physical benefits of a smile include:

- Reduced stress
- Reduced pain
- Increased relaxation response
- Increased endorphins and dopamine

You cannot entirely eradicate stress. However, you can make changes in small ways that will change your unhealthy habits and unconscious impulses in big ways. Remember to start with a smile and the world will smile back!

Quiet Your Mind with Meditation

People from both East and West have been practicing meditation for thousands of years as a means of relaxing your mind and body and turning off your inner thoughts. Many different faiths use it in a spiritual context, but it also has physical benefits aside from the spiritual.

Following are suggestions to help prepare for your favorite meditation:

- Find a quiet place where you won't be disturbed for a while.
- Find a comfortable body position. You are going to remain in one position for a few minutes.
- Maintain your focus and adopt a passive, accepting attitude.

Try a Breath-Counting Meditation

- Close your eyes and scan your body for tension. Let go of any tension you find.
- Begin to breathe in a relaxed way. Imagine a small balloon just under your navel. As you inhale through your nostrils, imagine that balloon gently inflating and as you exhale through your nostrils, imagine the balloon slowly deflating.
- Focus on your breathing. Your breath now becomes the object of your focus. When you inhale count this breath as 1. The next time you inhale is 2 until you reach 10. Then you start again at 1.
- If you find a distracting thought or image intruding—let it go and return to your count. Continue this for 20 minutes.
- The practice of meditation will refresh and invigorate. Remember, 1 minute of meditation is better than the 20 minutes of meditation you plan on doing, but don't!

Master the Art of Quality Sleep

Sleep can be a challenge in our hectic lives, but burning the candle at both ends leads to sleep deprivation leading to stress and fatigue. Unfortunately when you're tired, your perception of stress increases. It then becomes harder to sleep causing a cycle of insomnia that is difficult to break. Consider the following suggestions for breaking this cycle and help create a sleep ritual for many nights of blissful rest:

- Keep sleep time sacred and regular.
- Turn off the computer 2 hours before bed.
- Regulate room temperature.
- Make sure you have a comfortable bed.
- Maintain a dark, quiet environment.
- Avoid exercise 2-3 hours before bedtime.
- Do not go to bed hungry or thirsty. Try a warm cup of herbal tea with a light snack.
- Avoid alcohol and caffeine prior to bed.
- Use a natural relaxation technique. Apply a few drops of lavender essential oil to your temples for a soothing effect.
- After 30 minutes of tossing and turning, get out of bed until sleepy.

Remember to keep your room cool, comfortable, dark and quiet. Sweet Dreams!

“ Hospice lowered my stress level and helped distract me and it was tremendously appreciated. ”

The Caregiver's Phone Guide

Palm Beach County

GENERAL & EMERGENCY NUMBERS

Adult Day Care	211
Alligator Nuisance Hotline	(866) 392-4286
Animal Care & Control	(561) 233-1200
Caregiver Assistance	211
Elder Crisis Helpline	211
Elder Helpline	(866) 684-5885
FEMA	(800) 621-3362
Fire/Rescue (Emergency)	911
Fire/Rescue (Non-Emergency)	(561) 712-6550
Florida Abuse Hotline	(800) 962-2873
Florida Emergency Information Line	(800) 342-3557 TTY (800) 226 4329
Medicaid	(866) 762-2237
Medicare	(800) 633-2273
PBC Health Department	(561) 840-4500
PBC Insurance Commissioner	(561) 681-6392
PBC Sheriff (Non-Emergency)	(561) 688-3000
Poison Control	(800) 222-1222
Public Safety	(561) 712-6400
Social Security Administration	(800) 772-1213
US Postal Service	(800) 275-8777
Veterans Administration	(800) 827-1000
Veterans Crisis Line	(800) 273-8255, Opt.1

HEALTHCARE HELPLINES

Alzheimer's Crisis Line	(800) 394-1771
American Cancer Society	(561) 616-9370
American Diabetes Association	(800) 342-2383

American Heart Association	(800) 242-8721
American Lung Association	(800) 633-2273
American Red Cross	(561) 833-7711
Hospice by the Sea	(561) 395-5031
Hospice of Palm Beach County	(888) 848-5200
National Parkinson Foundation	(800) 473-4636

SPECIAL NEEDS

Agency for Persons with Disabilities	(561) 837-5564
Special Needs Shelters	(561) 712-6400
TDD (Hearing Impaired)	(561) 712-6343

TRANSPORTATION

Florida Traffic Information	511
Palm Tran	(561) 841-4200
Palm Tran Connection	(561) 649-9838
Palm Tran Connection Hotline	(561) 649-9848
Parks and Recreation	(561) 966-6600
Tri-Rail	(800) 874-7245

UTILITIES/ROADS

AT&T Residential	(877) 737-2478
FPL Outage	(561) 697-8000
PBC Water Utilities	(561) 493-6000
Roads, Drainage, Traffic	(561) 684-4018
Solid Waste Authority	(561) 640-4000
Water Emergency Line	(877) 429-1294

Broward County

GENERAL & EMERGENCY NUMBERS

Adult Day Care	211
Alligator Nuisance Hotline	(866) 392-4286
Animal Care & Control	(954) 359-1313
Broward Health Department	(954) 467-4700
Broward Sheriff (Non-Emergency)	(954) 765-4321
Caregiver Assistance	211
Elder Crisis Helpline	211
Elder Helpline	(866) 684-5885
FEMA	(800) 621-3362
Fire/Rescue (Emergency)	911
Fire/Rescue (Non-Emergency)	(954) 765-4321
Florida Abuse Hotline	(800) 962-2873
Florida Emergency Information Line	(800) 342-3557 TTY (800) 226 4329
FL Insurance Commissioner	(850) 413-3140
Medicaid	(866) 762-2237
Medicare	(800) 633-2273
Parks and Recreation	(954) 357-8100
Poison Control	(800) 222-1222
Social Security Administration	(800) 772-1213
US Postal Service	(800) 275-8777
Veterans Administration	(800) 827-1000
Veterans Crisis Line	(800) 273-8255, Opt.1

HEALTHCARE HELPLINES

Alzheimer's Crisis Line	(800) 394-1771
American Cancer Society	(954) 564-0880
American Diabetes Association	(800) 342-2383
American Heart Association	(800) 242-8721
American Lung Association	(800) 633-2273
American Red Cross	(954) 797-3800
Hospice by the Sea	(561) 395-5031
Hospice of Broward County	(888) 848-5200
National Parkinson Foundation	(800) 473-4636

SPECIAL NEEDS

Agency for Persons with Disabilities	(954) 467-4218
Special Needs Shelters	(954) 357-6385
TDD (Hearing Impaired).....	(954) 357-5608

TRANSPORTATION

Broward County Transit	(954) 357-8400
Florida Traffic Information	511
Tri-Rail	(800) 874-7245

UTILITIES/ROADS

AT&T Residential	(877) 737-2478
FPL Outage	(800) 468-8243
Roads, Drainage, Traffic	(954) 357-6410
Solid Waste Authority	(954) 765-4999
Water Emergency Line	(877) 429-1294
Water Utilities	(954) 831-3250

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