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Depression and Caregiving

Introduction

Could the sadness, loneliness or anger you feel today be a warning sign of depression? It's possible. It is not unusual for caregivers to develop mild or more serious depression as a result of the constant demands they face in providing care.

Caregiving does not cause depression, nor will everyone who provides care experience the negative feelings that go with depression. But in an effort to provide the best possible care for a family member or friend, caregivers often sacrifice their own physical and emotional needs and the emotional and physical experiences involved with providing care can strain even the most capable person. The resulting feelings of anger, anxiety, sadness, isolation, exhaustion—and then guilt for having these feelings—can exact a heavy toll.

Everyone has negative feelings that come and go over time, but when these feelings become more intense and leave caregivers totally drained of energy, crying frequently or easily angered by their loved one or other people, it may well be a warning sign of depression. Concerns about depression arise when the sadness and crying don't go away or when those negative feelings are unrelenting.

Unfortunately, feelings of depression are often seen as a sign of weakness rather than a sign that something is out of balance. Comments such as “snap out of it” or “it's all in your head” are not helpful, and reflect a belief that mental health concerns are not real. Ignoring or denying your feelings will not make them go away.

Early attention to symptoms of depression through exercise, a healthy diet, positive support of family and friends, or consultation with a trained health or mental health professional may help to prevent the development of a more serious depression over time.

Symptoms of Depression

People experience depression in different ways. Some may feel a general low-level sadness for months, while others suffer a more sudden and intense negative change in their outlook. The type and degree of symptoms vary by individual and can change over time. Consider these common symptoms of depression. Have you experienced any of the following for

longer than two weeks?

- A change in eating habits resulting in unwanted weight gain or loss
- A change in sleep patterns—too much sleep or not enough
- Feeling tired all the time
- A loss of interest in people and/or activities that once brought you pleasure
- Becoming easily agitated or angered
- Feeling that nothing you do is good enough
- Thoughts of death or suicide, or attempting suicide
- Ongoing physical symptoms that do not respond to treatment, such as headaches, digestive disorders and chronic pain.

Special Caregiver Concerns

What do lack of sleep, dementia and whether you are male or female have in common? Each can contribute in its own way to a caregiver's increased risk for depression.

Dementia and Care

Researchers have found that a person who provides care for someone with dementia is twice as likely to suffer from depression as a person providing care for someone without dementia. The more severe the case of dementia such as that caused by Alzheimer's disease, the more likely the caregiver is to experience depression. It is critical for caregivers, especially in these situations, to receive consistent and dependable support.

- **Caring for a person with dementia can be all consuming.** It is different from other types of caregiving. Not only do caregivers spend significantly more hours per week providing care, they report more employment problems, personal stress, mental and physical health problems, less time to do the things they enjoy, less time to spend with other family members, and more family conflict than nondementia caregivers. As stressful as the deterioration of a loved one's mental and physical abilities may be for the caregiver, dealing with dementia-related behavior is an even bigger contributor to developing symptoms of depression. Dementia-related symptoms such as wandering, agitation, hoarding and embarrassing conduct makes every day challenging and makes it harder for a caregiver to get rest or assistance in providing care.
- **Women experience depression at a higher rate than men.** Women, primarily wives and daughters, provide the majority of caregiving. In the United States, approximately 12 million women experience clinical depression each year, at approximately twice the rate of men. A National Mental Health Association survey on the public's attitude and beliefs about clinical depression found that more than one-half of women surveyed still believe it is "normal" for a woman to be depressed during menopause.

The study also found that many women do not seek treatment for depression because they are embarrassed or in denial about being depressed. In fact, 41% of women surveyed cited

embarrassment or shame as barriers to treatment.

- **Men who are caregivers deal with depression differently.** Men are less likely to admit to depression and doctors are less likely to diagnose depression in men. Men will more often “self treat” their depressive symptoms of anger, irritability or powerlessness with alcohol or overwork. Although male caregivers tend to be more willing than female caregivers to hire outside help for assistance with home care duties, they tend to have fewer friends to confide in or positive activities outside the home. The assumption that depressive symptoms are a sign of weakness can make it especially difficult for men to seek help.
- **Lack of sleep contributes to depression.** While sleep needs vary, most people need eight hours a day. Loss of sleep as a result of caring for a loved one can lead to serious depression. The important thing to remember is that even though you may not be able to get your loved one to rest throughout the night, you can arrange to get much needed sleep. Hiring a respite worker to be with your loved one while you take a nap or finding a care center or scheduling a stay over with another family member for a few nights are ways to keep your caregiving commitment while getting the sleep you need.
- **Depression can persist after placement in a care facility.** Making the decision to move a loved one to a care center is very stressful. While many caregivers are finally able to catch up on much needed rest, loneliness, guilt and monitoring the care a loved one receives in this new location can add new stress. Many caregivers feel depressed at the time of placement and some continue to feel depressed for a long time after.

People assume that once caregiving is over, the stress from providing hands-on care will go away. Yet, researchers found that even three years after the death of a spouse with dementia, some former caregivers continued to experience depression and loneliness. In an effort to return their life to normal, former caregivers may need to seek out help for depression as well.

What to Do If You Think You Have Depression

Depression deserves to be treated with the same attention afforded any other illness, such as diabetes or high blood pressure. If you feel uncomfortable using the term depression, tell the professional that you are “feeling blue” or “feeling down.” The professional will get the message. The important thing is to seek help.

Those with chronic illnesses also may suffer from depression. If you suspect this is the case with your loved one, look for an opportunity to share your concern with him or her. If they are reluctant to talk about it with you, encourage a trusted friend to talk with them or consider leaving a message for their doctor regarding your concern prior to their next appointment.

How is Depression Treated?

The first step to getting the best treatment for depression is to meet with a mental health

professional such as a psychiatrist, psychologist, or social worker. At the same time, schedule a physical exam with your doctor. Certain medications, as well as some medical conditions such as viral infection, can cause the same symptoms as depression, and can be evaluated by your physician during an exam. The exam should include lab tests and an interview that tests for mental status to determine if speech, memory or thought patterns have been affected.

Although it's not unusual for a physician to prescribe antidepressant medication, medication alone may not be the most effective treatment for depression. The guidance of a mental health professional throughout your treatment is strongly recommended. The therapist or counselor will listen to your concerns, screen you for symptoms of depression and assist you in setting up an appropriate course of treatment.

One way to find a professional is to ask a friend for the name of someone they know and trust. You may also find someone by asking your minister or rabbi, your doctor, or, if you are employed, you may check your employer's health insurance provider list or EAP program. In addition, national organizations can provide contact information for mental health professionals in your community. (See "Finding a Professional in your Area" in this fact sheet.)

It is important to trust and feel comfortable with the professional you see. It is not uncommon to request a free introductory phone or in-person meeting to help determine if the professional is the right match for your particular needs and style. It is appropriate to clarify what the cost will be, how much your insurance will pay and how many scheduled sessions you should expect to have with the mental health therapist. Any treatment should be evaluated regularly to ensure that it continues to contribute towards your improved health and growth.

Questions to Expect in a Mental Health Exam for Depression

1. Tell me why you think you may be experiencing depression.
 - When did you first notice these symptoms? How long have you experienced them?
 - How do they affect you? Are there things you don't or can't do anymore?
 - Have you ever experienced these feelings before?
 - If you have, did you receive treatment? What type?
2. How often do you use alcohol or drugs (both prescription and nonprescription) to help during the week?
3. Have you had any thoughts about death or considered suicide?
4. Do you have any family members who have experienced depression?
5. If so, did they receive treatment? What type?
6. Have you experienced any serious loss, difficult relationships, financial problems or other recent changes in your life?
7. Is there anything else you'd like to add to help me understand your situation better?

Treatment Options

Upon review of the physical and mental evaluation, a course of treatment will be recommended. Primary treatment options are **psychotherapy** (also referred to as mental health therapy) and **antidepressant medication**. These treatments are used alone or in combination with one another. (**Electroconvulsive therapy** or shock therapy is used for severe cases of depression and is recommended **only when other approaches have not been effective**.) The most frequent treatment for depressive symptoms that have progressed beyond the mild stage is antidepressant medication, which provides relatively quick symptom relief, in conjunction with ongoing psychotherapy, which offers new strategies for a more satisfying life. Following are the most common treatments used today:

Psychotherapy

- **Cognitive and Behavioral Therapy** — The therapist will focus on identifying and changing persistent, self-defeating thinking and behaviors. The ultimate goal is to help caregivers recognize and enjoy positive events in their lives and learn practical skills to deal with the problems they are facing.
- **Interpersonal Therapy** — The therapist helps the caregiver self-evaluate problems in their communication, or lack of communication, with other people. The caregiver will come to better understand his or her own communication style and learn how to improve relationships with others.
- **Psychodynamic Therapy** — Although sometimes used to treat depression, this therapy is thought to be less effective than the other two therapies already mentioned. Its goal is to surface deeply held conflicted feelings to better experience and understand them.

Medication and ECT Therapy

- **Selective Serotonin Reuptake Inhibitors (SSRIs)** (Examples: Prozac, Zoloft, Paxil) — Medications that work by stabilizing levels of serotonin, a neurotransmitter. Low levels of serotonin have been linked to depression. Fewer side effects than tricyclic medications.
- **Tricyclics** (Examples: Norpramin, Pamelor, Sinequan) — An earlier family of antidepressant drugs, tricyclics increase levels of neurotransmitters in the brain. May cause more side effects.
- **Monoamine Oxidase Inhibitors (MAOI)** (Examples: Nardil, Parnate) — These therapies are not often used today. MAOIs are drugs that increase the level of neurotransmitters in the brain. They are most often used when other medication isn't effective or tolerated.

- **Electroconvulsive Therapy (ECT)** — A brief pulse of electricity is delivered through electrodes on the scalp over a period of several days to produce changes in the brain function. ECT is used only for serious (possibly life-threatening) depression and when medication doesn't work.

If drug therapy is recommended, a certain amount of trial and error is necessary to find the right type and dosage of medication for each individual and it may take several weeks before effects are felt. Good communication between patient and doctor is important. Older adults should be especially careful to watch for medication side effects caused from too high a dosage or interactions with other medications.

Complementary and Alternative Therapies

St. John's wort. One of the most studied alternative treatments for depressive symptoms is St. John's wort (*Hypericum perforatum*). It is an herb used extensively in the treatment of mild to moderate depression in Europe and is now undergoing studies in the United States. St. John's wort extract is sold "over the counter" in the U.S. as a nutritional supplement.

It is promoted as a "natural" way to improve mood, and as a treatment for mild to moderate depression. Researchers are studying it for possibly having fewer and less severe side effects than antidepressant drugs.

Yet, questions remain regarding whether St. John's wort really does what its promoters claim. For nonprescription drugs in the U.S. there are no established criteria for determining the amount of active ingredient a company puts in their product or what dose is right for a given person. The Food and Drug Administration issued a warning stating that St. John's wort may affect the metabolic pathway used by many prescription drugs prescribed to treat a number of conditions, including heart disease, depression, and HIV infections. *If you are taking St. John's wort or considering its use, talk with your health care provider to ensure it will not interfere with any other treatment you are receiving.*

Seasonal Affective Disorder. Caregivers who feel "the blues" when confined indoors or in response to winter's gray days may suffer from Seasonal Affective Disorder (SAD), also referred to as "winter depression." As seasons change, there is a shift in our biological internal clocks or circadian rhythms, partly in response to the changes in sunlight patterns. This can cause our biological clocks to be out of sync with our daily schedules. People with SAD have a difficult time adjusting to the shortage of sunlight in the winter months. SAD symptoms are most pronounced in January and February, when the days are shortest. SAD is often misdiagnosed as hypothyroidism, hypoglycemia, infectious mononucleosis and other viral infections.

Phototherapy, using specially designed bright fluorescent lights, has been shown to reverse SAD's depressive symptoms. Experts believe that the light therapy works by altering the levels of certain brain chemicals, specifically melatonin. Antidepressant medication along with other treatments, including exercise, may be helpful as well. If you experience mild depressive symptoms seasonally, experiment with increasing the light in your surroundings, using lamps or other sources. If the symptoms are strong enough to impair your day-to-day functioning, seek out a mental health professional with expertise in treating SAD.

Physical Exercise. Exercise has been found to reduce the effects of depression. Walking three times a week for 30 to 45 minutes has been linked to reducing or alleviating symptoms of depression. It is unknown whether physical activity prevents the onset of depression or just helps modify the effects. Arranging time for exercise is sometimes difficult for caregivers. It is often seen as a “value added” activity—something to do when everything else is done. You might consider adding it to your “to do” list, asking a friend to give you a “walk date” each week as a gift, or requesting that your doctor write a prescription for walking or joining an exercise class. All the research shows that for a healthier life, it makes good sense to make time for exercise.

Paying for Treatment

Private health insurance and Medicare will typically pay for some mental health care. It's best to call the mental health professional directly to find out if they accept your insurance for payment. Health insurance providers will usually list mental health professionals in the same insurance material that lists health plan medical doctors. Medicare recipients will find the booklet titled, “Medicare and Your Mental Health Benefits” a helpful source of information. See the “Resources” section of this Fact Sheet to find out how to obtain a copy.

The “covered services” of the insurance plan will specify mental health coverage for inpatient (hospital, treatment center) and outpatient (professional's office) care, how many visits are paid for, and at what rate of reimbursement. Employed caregivers may also have access to an Employee Assistance Program, where licensed professionals (usually psychologists and social workers) are available for confidential sessions to discuss personal or professional problems.

Caregivers without health insurance or who pay out of pocket for care will find that fees vary by professional, with psychiatrists charging at the higher end of the fee scale and psychologists and social workers offering their services at a more moderate rate. In some instances, a mental health center will apply a fee based on your ability to pay. In any case, find out what the fee is up front to avoid any misunderstandings later on.

Strategies to Help Yourself

Depressive disorders can make one feel exhausted, helpless and hopeless. Such negative thoughts and feelings make some people feel like giving up. It is important to realize that these negative views are part of the depression and may not accurately reflect the situation. The National Institute of Mental Health offers the following recommendations for dealing with depression:

- Set realistic goals in light of the depression and assume a reasonable amount of responsibility.
- Break large tasks into small ones, set some priorities, and do what you can as you can.
- Try to be with other people and to confide in someone; it is usually better than being alone and secretive.

- Participate in activities that may make you feel better, such as mild exercise, going to a movie or ballgame, or attending a religious, social or community event.
- Expect your mood to improve gradually, not immediately. Feeling better takes time.
- It is advisable to postpone important decisions until the depression has lifted. Before deciding to make a significant transition—change jobs, get married or divorced—discuss it with others who know you well and have a more objective view of your situation.
- People rarely "snap out of" a depression. But they can feel a little better day-by-day.
- Remember, positive thinking will replace the negative thinking that is part of the depression. The negative thinking will be reduced as your depression responds to treatment.
- Let your family and friends help you.

Direct assistance in providing care for your loved one, such as respite care relief, as well as positive feedback from others, positive self-talk, and recreational activities are linked to lower levels of depression. Look for classes and support groups available through caregiver support organizations to help you learn or practice effective problem-solving and coping strategies needed for caregiving. For your health and the health of those around you, take some time to care for yourself.

Source for online depression screening checklist:

University of Michigan Depression Toolkit

www.depressiontoolkit.org/depressed

Mental Health Screening.org

screening.mentalhealthscreening.org/Military_NDSD

My HealtheVet

myhealth.va.gov (search depression screening)

Finding a Professional in your area:

Psychiatrist (MD): A psychiatrist is a medical doctor who specializes in the diagnosis, treatment, and prevention of mental illnesses, including substance abuse and addiction.

- **American Psychiatric Association**

www.psych.org

Provides free information on depression and referrals to psychiatrists in your area.

Psychologist (Ph.D.): Licensed to practice psychotherapy and has special training in psychological testing. Although referred to as "doctor," a psychologist cannot prescribe medications.

- **American Psychological Association**

www.apa.org

(800) 964-2000

Visit APA's website for more information about depression or call the toll-free number to be referred to a psychologist in your area.

Licensed Clinical Social Worker (L.C.S.W.): Has specialized training in human behavior,

family behavior, psychology, and problem solving. Has a Master's degree in Social Work (M.S.W.) with two years of supervised postgraduate work providing clinical treatment.

- **National Association of Social Workers**

www.naswdc.org

(800) 638-8799

Provides free information on depression and referrals to social workers in your area.

Note: Additional professionals may be licensed to practice psychotherapy in your state or county. Check with the local mental health department or hospital in your community for more information.

Other Resources:

Medicare

www.medicare.gov

Call 1-800-MEDICARE (1-800-633-4227) to request a copy of "Medicare and Your Mental Health Benefits."

National Institute of Mental Health

www.nimh.nih.gov

(800) 421-4211

Provides free information on depression and other mental illnesses in English and Spanish.

Websites:

American Geriatrics Association

www.americangeriatrics.org

National Institute for Complimentary and Alternative Medicine

nccam.nih.gov

National Institute of Mental Health

www.nimh.nih.gov

National Alliance for the Mentally Ill

www.nami.org

National Mental Health Association

www.nmha.org

National Library of Medicine

www.nlm.nih.gov

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Schultz R., O'Brien A.T., Bookwala J., et al. (1995) *Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates and causes*. Gerontologist. Vol. 35, 771-791.

Recommended Reading

The Caregiver Helpbook: Powerful Tools for Caregiving by Vicki Schmall, Marilyn Cleland and Marilyn Sturdevant. Published by Legacy Health System. Accompanies a class by the same name. Class information and the book are available by contacting Legacy Caregiver Services, 1015 NW 22nd Ave., Ste. N300, Portland, OR 97210, (503) 413-7706.

Caregiving: The Spiritual Journey of Love, Loss, and Renewal by Beth Witrogen McLeod. Published by John Wiley & Sons, Inc., New York, NY.

Caring for Yourself While Caring for Your Aging Parents, Third Edition: How to Help, How to Survive by Claire Berman. Published by Henry Holt and Company, Inc. 115 West 18th Street, New York, NY 10011, (212) 886-9200.

Resources

Family Caregiver Alliance National Center on Caregiving

785 Market Street, Suite 750

San Francisco, CA 94103

(415) 434-3388

(800) 445-8106

Web Site: caregiver.org

E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating disorders that strike adults.

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