<u>Fact Sheet:</u> Depression and Caregiving

Introduction

Many people with symptoms of depression don't describe themselves as feeling depressed. Some people don't recognize the symptoms in themselves, while others may have a hard time admitting they feel depressed. It can be embarrassing to talk about. An individual may feel like a failure or that people will judge them. But here's what you need to know: for caregivers, depression is more common than you might think, and it's a normal response to a difficult situation. It is not unusual for caregivers to develop mild or more serious depression as a result of the constant demands they face while providing care.

Depression is an extremely complex condition with many research studies underway to pinpoint the cause(es). Known contributing factors include genetic characteristics, hormone levels, environmental triggers, certain medications, the effects of living with a major illness, grief and loss due to the death of a loved one, having experienced physical or emotional abuse, living with someone with serious depression, and other factors. Not everyone will experience the negative feelings that go with depression. But we know that in an effort to provide the best possible care for a family member or friend, caregivers often sacrifice their own physical and emotional needs. The complex and varied aspects involved with providing care can strain even the most capable person. Feelings of overwhelm, agitation, anxiety, distress, pessimism, isolation, exhaustion—and sometimes guilt for having these feelings—can exact a heavy toll.

Everyone has negative thoughts or feelings that come and go over time, but when these feelings become more intense and leave you drained of energy, tearful or irritable towards a loved one, it may well be a warning sign of depression. Concerns about depression arise when the emptiness 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 from others 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 classic symptoms, like sadness and hopelessness. Others

may have signs that you might not equate with depression, such as extreme fatigue or irritability. 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?

- Feeling sad, tearful, empty, hopeless
- Changes in eating habits—weight loss and no appetite or cravings with weight gain
- Changes in sleep—too much sleep or not enough
- Feeling tired all the time, difficulty being motivated to do anything
- A loss of interest in people and/or activities that once brought you pleasure
- Feeling numb
- Becoming easily agitated or angered
- Feeling that nothing you do is good enough
- Increase in alcohol or drug consumption
- Excessive time on the internet
- Trouble focusing, thinking, or planning—as if your head was filled with fog
- Neglecting your physical well-being and appearance
- Thoughts of running away, or escaping from the situation
- Thoughts of death or suicide, ideas of how to end your life
- Ongoing physical symptoms that do not respond to treatment, such as headaches, digestive disorders, and chronic neck and back pain

Special Caregiver Concerns

Caring for a person with dementia can be all consuming. 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. Not only do caregivers spend significantly more hours per week providing care, they report more employment problems, personal stress, mental and physical health problems, lack of sleep, less time to do the things they enjoy, less time to spend with other family members, and more family conflict than non-dementia 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 depression. Dementia-related symptoms such as wandering, agitation, hoarding, embarrassing conduct, and resistance or noncooperation from the loved one makes every day challenging and makes it harder for a caregiver to get rest or assistance in providing care. The more severe the case of dementia, the more likely the caregiver is to experience depression. It is critical for caregivers, especially in these situations, to receive consistent and dependable support and respite.

 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. If you think depression is all in your head, think again. Physical factors like menopause, childbirth, PMS, thyroid disease, and nutritional deficiencies in iron, vitamin D and Omega-3 fatty acids can all cause depression.

A Mental Health America study 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. Keep in mind that doctors have heard it all. It is important to both your mental and physical health to get a complete physical exam. Take time during the exam to bring up the subject of depression if you suspect you are experiencing symptoms of depression.

- 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 feelings of 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 to engage in outside the home. The mistaken assumption that depressive symptoms are a sign of weakness can make it especially difficult for men to seek help.
- Military and Veteran caregivers are at risk of depression. Military and Veteran caregivers experience

- depression nearly twice the rate of non-military caregivers. The more severe the mental and/or physical health conditions of the veteran, the more demands you face as a caregiver. Conditions like dementia, Traumatic Brain Injury, and Post Traumatic Stress Disorder (TBI and PTSD) can be particularly challenging for caregivers. Trying to cope with daily life in addition to watching out for the veteran's triggers, or helping them cope with their own stress, can lead you to feel overwhelmed and increase feelings of depression, particularly feelings of helplessness and hopelessness. As a military caregiver you may not have other people in your life who understand the experience of caring for a service member, particularly younger caregivers whose peers are unlikely to be facing the same kinds of challenges. You may have even moved to have better access to VA benefits, or to a region that is more supportive to your veteran's needs, which can make you feel even more isolated and less likely to have help from people you know and trust. That doesn't mean help isn't available. The first step is to talk to your doctor who can refer you to a mental health professional and can prescribe medications as appropriate.
- 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 or engaging a friend to be with your loved one while you take a nap, finding a day care center, or scheduling a stay over with another family member for a few nights are a few 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, the 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 some 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 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. Likewise, the best way to figure out what is causing symptoms is to talk to a qualified professional, like your doctor. If you feel uncomfortable using the term depression, tell your doctor that you are "feeling blue" or "feeling down," and describe your personal experience and symptoms. The more specific you can be, the better your doctor can help you. The important thing is

to make it a priority during your appointment and be as honest as possible so your doctor can help you.

It's not uncommon for a person receiving care to suffer from undiagnosed depression. Everything can feel worse than it is from their perspective adding to any daily caregiving challenges you may be experiencing. If you suspect this is the case in your caregiving situation, look for an opportunity to share your concern with them. 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 psychologist, social worker, or other licensed therapist. 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 should be evaluated by a physician. 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 a physician may prescribe antidepressant medication, medication alone is not the most effective treatment for depression. Concurrent guidance of a mental health professional is strongly recommended. The therapist or counselor will listen to your concerns, screen you for symptoms of depression, and assist you in developing ways to address your stress and build new coping patterns.

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 Employee Assistance Program (EAP). 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
- 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.

Treatment Options

Upon review of a physical and mental health evaluation, a course of treatment may be recommended. Primary treatment options are psychotherapy (also referred to as mental health therapy and talk therapy) and antidepressant medication. These treatments may be used alone or in combination with one another. The most frequent treatment for depressive symptoms that have progressed beyond the mild stage is antidepressant medication, which provides relatively quick symptom relief. Critical to treatment for depression is the concurrent use of psychotherapy along with medication. Discussing your situation with a therapist can open up new self-awareness for addressing a particular emotional concern

and provide guidance to address challenges in getting and staying healthy.

When choosing a therapist, be sure to ask about their experience working with family caregivers and their understanding of caregiving related stressors.

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

Many complementary medicines and alternative therapies are promoted for coping with depression. Some have been tested in scientific clinical trials, but many have not. Here is an overview of some of the most common therapies:

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. If that seems like a lot of time you don't have, then start with 15 minutes one-time a week. The important message is to get started with a regular exercise activity.

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.

Mind-Body Techniques: There is a growing body of research showing that our thoughts, beliefs and feelings can have a direct impact on our health, and our physical health can impact our mental state. Your mind and body are interrelated. Implementing mind-body techniques into your routine may help alleviate depression.

Even 5 to 10 minutes of any of these techniques may be beneficial. These are some to try:

- Meditation
- Prayer
- Deep breathing
- Acupuncture
- Yoga
- Massage
- Listening to music
- Creating art
- Guided imagery
- Journaling

Supplements: Herbal "over-the-counter" treatments such as St. John's Wart (Hypericum perforatum) and other supplements such as SAMe and omega-3 fatty acids are under study and/or in popular use in the US and Europe for treating depressive symptoms. At present, for nonprescription drugs in the US, 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. Effectiveness of a product is difficult to determine and the effects of a product can have negative side effects. For example, the US 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 any herbal supplements or considering taking them, talk with your health care provider to ensure they will not interfere with any other treatment you are receiving.

Light Therapy: 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.

Light therapy, 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.

Paying for Treatment

Private health insurance and Medicare may pay for some mental health care, and the Affordable Care Act (ACA) has increased insurance coverage for mental health benefits. Policies vary widely, so 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.

Professionals who don't accept insurance are called "out-of-network providers," and may be able to provide you with a receipt that you can submit to your insurance for partial reimbursement. Check with the professional to see if this is an option. If so, you'll have to contact your insurance company to make sure they'll cover some of the cost. They may require you to meet a deductible before they will start paying.

Caregivers without health insurance or who pay out-of-pocket for care will find that fees vary by professional and region, with psychiatrists and psychologists charging at the higher end of the fee scale, and

therapists and social workers offering services at a more moderate rate. Some professionals offer a sliding scale fee, meaning they may slide their fee down to meet your need. There may also be low-fee clinics that have a set low fee or will apply a fee based on your ability to pay. In these settings, you are often meeting with a mental health intern who is being supervised by a licensed mental health provider. 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. Below are guidelines adapted from The National Institute of Mental Health offering recommendations for dealing with depression. Set realistic goals in light of the depression. You may not be able to accomplish as much as you are accustomed to when you are feeling well.

- 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 you know and trust; it is often better than suffering alone.
- Participate in activities that may make you feel better, such as 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 can offer another view of your situation.

- People rarely "snap out of" a depression. People who expect you to do this are misguided in their understanding of your condition.
- Remember, positive thinking and the practice of new coping patterns will replace the negative thinking that is part of the depression. The negative thinking will be reduced as your depression responds to treatment.
- Say "yes" to offers of help and engagement by family and friends who you know and trust.

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.

Resources

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 <u>www.psych.org</u>
 Provides free information on depression and referrals to psychiatrists in your area.

Psychologist (PhD): 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 (LCSW.): Licensed to practice psychotherapy, with special training in addressing the person-in-environment. Has specialized training in human behavior, family behavior, psychology, and problem solving. Has a Master's degree in Social Work (MSW) with two years of

National Association of Social Workers

supervised post-graduate work providing

clinical treatment.

www.naswdc.org (800) 638-8799 Provides free information on depression and referrals to social workers in your area.

Licensed Marriage and Family

Therapists (LMFT): Licensed to practice psychotherapy and is trained to diagnose and treat mental health issues. Works with individuals, couples, families and groups. Has a Master's degree in Counseling Psychology with supervised postgraduate work.

 American Association of Marriage and Family Therapists

www.aamft.org (703) 838-9808

Visit their website to find a therapist 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.

National Institute for Complementary and Alternative Medicine nccam.nih.gov

Southern Caregiver Resource Center 3675 Ruffin Road, Suite 230 San Diego, CA 92123 (858) 268-4432; (800) 827-1008 (in CA) E-mail: scrc@caregivercenter.org Web site: www.caregivercenter.org

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions, and is for residents of San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial

consultation, respite care, education and training, and support groups.

Family Caregiver Alliance National Center on Caregiving

235 Montgomery Street, Suite 950 San Francisco, CA 94104 (415) 434-3388; (800) 445-8106 Web site: <u>www.caregiver.org</u>

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.

Recommended Reading

<u>The Caregiver Helpbook: Powerful Tools</u> <u>for Caregiving</u>, Vicki Schmall, Marilyn Cleland, and Marilyn Sturdevant. Published by Legacy Health System.

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

<u>Caring for Yourself While Caring for Your</u> <u>Aging Parents, Third Edition: How to Help,</u> <u>How to Survive,</u> Claire Berman. Published by Henry Holt and Company, Inc.

Updated by Family Caregiver Alliance. Reviewed by Beth MacLeod, Licensed Clinical Social Worker (LCSW) in private practice specializing in care consultation and psychotherapy. Clinical supervisor for professionals in aging and those working with family caregivers. Funded by the California Department of Health Care Services. © 2002, 2008, 2016 Family Caregiver Alliance. All rights reserved.

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