



Understanding and Treating Depression in Multiple Sclerosis

Recognizing the Symptoms and Learning the Solutions

Written by Allison Shadday, LCSW

Edited by Susan Wells Courtney

Foreword by Dr. Jack Burks, MSAA Chief Medical Officer

MSAATM
MULTIPLE SCLEROSIS
ASSOCIATION OF AMERICA

Table of Contents

Foreword	1	Other Factors Increasing Susceptibility to Depression.....	15
Introduction	2	<i>Interruption of Routine</i>	16
Types of Depression and Diagnosis.....	2	<i>Winter Weather</i>	16
Risk Factors for Depression	6	<i>Changing Medications</i>	17
Depression's Impact.....	7	<i>Other Physical Conditions</i>	17
<i>Increased Risk of Suicide</i>	7	<i>Low Self-Esteem</i>	17
<i>Family Relationships are Often Affected</i>	7	Treatment Options for Depression.....	18
<i>Treatment Compliance and Health May be Affected</i>	9	Finding a Therapist.....	20
<i>Loss of Libido</i>	9	Types of Mental Health Providers	21
<i>Less Participation in Social Activities</i>	9	The Interview Process	21
<i>Losses in Employment</i>	10	Financial Considerations	23
Depression is Under-Reported and Under-Treated	10	Types of Therapeutic Approaches	23
Addressing and Evaluating Your Depression	12	Other Options When Traditional Therapies Fail	24
What Causes Depression in MS?	12	Family Involvement	24
<i>Disease Response</i>	12	Immediate Positive Steps	25
<i>Physiological Causes</i>	13	Resources for More Information	27
<i>Chemical Changes</i>	13	Suicide Hotline and Website	27
<i>Fatigue</i>	14	Recommended Reading.....	27
<i>Medication Side Effects</i>	15	References Used for This Booklet	28

Copyright © Multiple Sclerosis Association of America, 2007. All rights reserved.
This booklet is protected by copyright. No part of it may be reproduced, stored in
a retrieval system, or transmitted in any form or by any means, electronic, mechanical,
photocopying, recording, or otherwise, without prior written permission from MSAA.

Understanding and Treating Depression in Multiple Sclerosis

Recognizing the Symptoms and Learning the Solutions

Written by Allison Shadday, LCSW • Edited by Susan Wells Courtney

Foreword by Dr. Jack Burks, MSAA Chief Medical Officer

Depression is a common and disabling symptom of MS. It is a critical issue for MS patients, and is often overlooked by the patient, family, and healthcare providers. The information presented in this booklet is designed to increase awareness and understanding of depression in MS.

Anyone can experience depression at any time. For individuals with MS, depression is not only a symptom, but it can possibly be a silent signal of worsening disease, a side effect from medication, or another medical condition (such as a bladder infection) that is present but unrecognized. Additionally, suicide is a serious risk for extremely depressed MS patients.

The warning signs can point to a diagnosis, and all those who spend time with

an individual at risk should be aware of these sometimes subtle indications. The author of this booklet has outlined an effective protocol to increase the chances of early diagnosis and effective treatment, which may well lead to a better quality of life. Valuable tips for fighting the effects of depression have been highlighted throughout the pages of this booklet.

The combination of understanding the situation surrounding depression, taking advantage of the medical treatments available, and recognizing the important role of counseling, can often result in the successful management of this disabling symptom. This booklet is an invaluable resource for all those affected by depression in the MS population and their care partners.

About the Author

Allison Shadday, LCSW, is a medical clinical social worker, public speaker, and author, with several years of experience counseling chronically ill patients and their families. While counseling others, Allison could no longer deny her own symptoms,

and was diagnosed with MS in 1994.

Allison has written a book entitled, *MS and Your Feelings* (Hunter House Publishing, 2006). This “insider’s guide” provides strategies for dealing with the emotional changes that accompany MS.

Introduction

According to the National Institute of Mental Health, nearly one in 10 American adults suffers from a depressive illness during any given one-year time period. Over the course of a lifetime, the prevalence of experiencing a depressive disorder may reach to nearly one in five for women, and one in eight for men – and some sources give even higher estimates.

Despite being a fairly common condition, depression is still a widely misunderstood and “stigmatized” disorder – causing some to feel a sense of disgrace or embarrassment.

Providing accurate information to patients and their families is one of the best ways to help people recognize the symptoms of depression and to encourage treatment.

Depression often works its way quietly into people’s lives. The very nature of depressive symptoms impedes someone’s ability to realize that he or she is depressed. These same symptoms can even suppress one’s desire to seek treatment. Symptoms often creep up slowly over time, and those suffering from depression may have trouble remembering what it’s like to feel good.

Patients may describe depression as a black hole of despair, holding them down and shutting out any feelings of hope, excitement, or the possibility of future happiness. For many, joy disappears and everything is experienced as being bland or flat.

The prospect of continuing to feel this way day after day can be daunting. Many people who are depressed will find various

ways to escape this reality. Some may self-medicate with drugs, alcohol, and/or food. Others may sleep the days away, avoiding contact with others and the outside world.

Some may resort to suicide. Each year, approximately 500,000 Americans are treated for attempted suicide; each day, 85 die from these attempts.

Fortunately, depression is treatable. Once the illness is recognized and addressed, individuals with depression can rediscover the delights and pleasures of life.

Types of Depression and Diagnosis

Distinguishing between sadness and depression is important. Sadness is a normal emotion that everyone experiences at different points in his or her life.

Fortunately, depression is treatable. Once the illness is recognized and addressed, individuals with depression can rediscover the delights and pleasures of life.

We feel sad when we experience a loss or tragedy – and this feeling is usually an appropriate reaction to the situation that has occurred. Feeling sad is a natural coping skill that is required for growth and maturity. Experiencing sadness helps us to move through painful events.

When sadness manifests itself physically we may feel tension in our chest, or our hearts may ache. We may also experience an overwhelming desire to cry; and some are strongly compelled to talk with others about their sorrow. After expressing and letting out our emotions, we normally begin to feel a sense of relief. Unlike depression, sadness typically passes within a few days and one begins to embrace life again, enjoying normal daily activities.

In contrast to sadness, depression can seemingly come from “out of the blue,” and can last much longer. Someone may not even realize that he or she is depressed, and pinpointing any specific trigger for the depression can be difficult.

Different types of clinical depression have been identified. The first, which is commonly talked about, is “major depressive disorder” (also known as “major depression”). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), physicians will look for specific criteria when diagnosing a major depressive episode. These criteria dictate that five

or more of the following symptoms must be present for at least a two-week period (these symptoms are generally reported by either the patient or a family member who observes the patient):

- 1. A depressed mood for most of the day, nearly every day**
- 2. Loss of interest or pleasure in all, or almost all, activities for most of the day**
- 3. Significant change in weight or appetite**
- 4. Insomnia or excessive sleepiness**
- 5. Observable agitation or lethargy**
- 6. Fatigue and loss of energy, nearly every day**
- 7. Feelings of worthlessness, low self-esteem, or excessive guilt**
- 8. Difficulty concentrating or indecisiveness**
- 9. Recurrent thoughts of death or suicide**

Additional symptoms may also be present, but these are not typically considered when making a diagnosis. Among others, these can include: a reduced interest in personal appearance and hygiene; complaints of aches and pains, with the worry of these symptoms being an indication of a serious health problem or disease; an increased sensitivity to noise; and bouts of crying or sobbing.



TIP # 1

EXERCISE

Although participating in a physical activity can be difficult, exercise is proven to produce an increase in chemicals such as endorphins, which can make us feel less depressed. Exercises are available for individuals of all ability levels, and patients should discuss an appropriate exercise program with their doctor. (Specific exercise should only be done with a physician's approval.)

Another type of depression is known as “dysthymic disorder,” “dysthymia,” or “chronic depression.” Although this type of depression shares many symptoms with major depression, the symptoms tend to be less severe. These symptoms, however, are typically present for at least *two years* rather than *two weeks* (as with major depressive episodes). This form of depression sneaks up on patients, slowly becoming a part of everyday life, and eventually can be perceived as a person's normal mood, often appearing unhappy. At least two of the following symptoms must be present to confirm a diagnosis of dysthymic disorder:

1. Poor appetite or overeating
2. Insomnia or excessive sleepiness
3. Low energy or fatigue
4. Poor concentration or indecisiveness; memory problems
5. Low self-esteem
6. Feelings of hopelessness

Bipolar disorder (previously known as manic-depressive illness) is a disorder which also falls under a separate category of depression. In this case, the patient will experience severe depressive episodes as well as periods of extreme euphoria. Additional categories of depression include postpartum depression and premenstrual dysphoria.

In general, the symptoms of depression can be divided into three categories: physical, emotional, and mental. The physical symptoms include fatigue, poor appetite, insomnia, and agitation. The emotional symptoms include feelings of hopelessness, depressed mood, low self-esteem, guilt, and worthlessness. The mental symptoms include poor concentration, indecisiveness, and for some, thoughts of death or suicide. The severity of depression can vary from mild to moderate to severe. Regardless of how severe one's depression may be, it still affects us on all three levels: physically, emotionally, and mentally.

In all types of depression, symptoms typically impair daily functioning such as our ability to work or take care of household responsibilities. Doing simple tasks such as bathing or cooking a meal can seem overwhelming.

You may recognize several depressive symptoms that are also symptoms of MS. Examples of shared symptoms include fatigue, insomnia or excessive sleepiness, and cognitive difficulties, as well as restlessness or slowing down. Because many of these symptoms mimic typical MS symptoms, they may not necessarily indicate depression for someone with MS. The similarities in symptoms do in fact make diagnosing depression challenging in MS patients. A trained professional who is familiar with both MS and depression is

needed to make an accurate diagnosis of depression for an individual with MS.

One of the most commonly used tools for diagnosing and evaluating depression is the Beck Depression Inventory (BDI, BDI-II), which is a questionnaire aimed at measuring the severity of one's depression. The 21 multiple-choice questions allow adult patients to report on their depressive symptoms. Topics include: physical symptoms such as fatigue, loss of libido, and loss of weight; emotional symptoms, such as hopelessness and irritability; as well as mental (or cognitive) symptoms, reflecting any negative thoughts about the world, oneself, or the future.

The BDI is named after its creator, Dr. Aaron T. Beck, and was first developed in 1961. The questionnaire was revised in 1971 (BDI-1A), and has since been revised again in 1996 (BDI-II). All versions of this inventory for depression translate the degree of severity into specific numbers from one to three for each symptom. The self-reported ratings are added together to determine a total score, which gives physicians an exact number for the evaluation of a patient's depression.

The Goldman Consensus Group (a panel of experts who reviewed the issue of depression in MS) recommends that individuals with MS be routinely screened for depression using a tool such as the BDI. They also recommend

Understanding and Overcoming Depression in Multiple Sclerosis

individualized treatment plans (using therapy, medications, or an integrated approach), greater standardizations of treating depression in MS, as well as continuing clinical research.

Risk Factors for Depression

Individuals with MS have a greater risk of experiencing a depressive episode at some point in time. Fifty percent of individuals with MS will become depressed during their lifetime, compared to less than 20 percent of the American population. However, if you know you are at risk, you can be proactive: watching for signs and symptoms, and seeking help as soon as warning signs appear.

Women, who are twice as likely to have MS, are nearly twice as likely as men to experience depression. This is attributed to many factors. Hormonal fluctuations such as menopause, pregnancy, menstrual changes, miscarriage, and the postpartum period may trigger depressive episodes. Women who have multiple family responsibilities such as childrearing and caring for elderly parents are under tremendous stress, as are single moms. Mothers with disabilities face greater challenges and must wrestle with concern for their children, along with their own wellbeing. All of these challenges can make women vulnerable to depression as well as other illnesses.

CREATE A STRESS MANAGEMENT PROGRAM

Many strategies are available to manage stress, which in turn, can help to make you less susceptible to life's ups and downs. Meditation, yoga, guided-imagery, progressive relaxation, bio-feedback, and even regular napping are just a few options. Which technique you choose doesn't matter, but what is important is that you stay committed and practice the exercises that you find to be helpful.

**TIP
2**



One reason that fewer men are diagnosed with depression might be because they are less likely than women to seek appropriate treatment. As a result, they are more likely to self-medicate with drugs and alcohol, or develop a gambling addiction, rather than seek the help of a therapist and take prescribed antidepressants. Depressive symptoms for men may present as irritability or anger; for men who do seek therapy, these symptoms may be mistakenly treated as the primary issues, rather than the underlying depression.

Those who have a predisposition to depression prior to their MS diagnosis may be at an even higher risk for depression. Depressive disorders are one-and-a-half to three times more common among those whose parents suffered from depression. Furthermore, other factors such as a chronic medical condition, lack of social supports, and substance dependence, may also contribute to the onset of depression. Understanding these risk factors, recognizing depressive symptoms, and seeking treatment, may play a significant role with improving one's quality of life, and possibly prevent potential thoughts of suicide.

Depression's Impact

Increased Risk of Suicide

Suicide is one of the leading causes of death among MS patients. The primary

predictors of suicidal intent in those with MS include:

- 1. Severity of depression**
- 2. Abuse of alcohol**
- 3. Living alone**

In addition, a family history of mental illness, higher perceived levels of social stress, and anxiety also contribute to suicidal intent. Although fewer men are diagnosed with depression, they are four times more likely to commit suicide than women.

In a study of individuals with MS who had suicidal intent, one-third had not received any psychological help and two-thirds (all suicidal and with major depression) had not received any anti-depression medication. This research clearly points to the importance of seeking treatment for depression. When treatment is sought, the risk of suicide drops considerably.

Family Relationships are Often Affected

Similar to the way in which MS affects the family, depression also has a strong impact on relationships. Family members will often say that they can handle the patient's physical MS symptoms, but they cannot deal with his or her depression. Others may feel helpless as they watch a loved one succumb to the grips of depression. Sometimes family members believe that they are somehow the cause of their



**TIP
3**

TALK ABOUT YOUR FEELINGS

Confiding in a trusted friend or family member about difficult feelings or thoughts can often improve your mood.

loved one's unhappiness, but this is rarely the case, and this misperception puts an added strain on the relationship.

Since depression typically causes its victims to withdraw from others, family and friends can feel shunned or neglected. Similar to MS, the symptoms of depression are usually invisible, which can lead to misunderstandings. Unfortunately, when others cannot visibly see the cause of someone's pain, they may not be as sympathetic – as they may be unaware of how much the other person is suffering.

Many people still believe that depression can be overcome by willpower or religious

belief alone. They may have a “pull yourself up by your bootstraps” mentality, stemming from ignorance about the condition. These same people would never tell a cancer patient to just “try harder” or “snap out of it.” Education is the best way to combat these misconceptions.

Children are not immune to a family member's depression. In fact, a recent Swiss study of children who have a parent with MS and depression found that these children are at a high risk of mental health problems themselves. These children were found to be two-to-three times as likely to experience anxiety or depression. Parents need to be aware of the impact that their own psychological state is having on their children, and to watch for symptoms in them as well.

The symptoms of depression in children are more difficult to recognize. They may exhibit problems at school and with friends. They may be irritable and aggressive, or conversely, they may withdraw and isolate themselves from others. Children experiencing depression may not want to eat; they may also have trouble sleeping and have bad dreams, which may contribute to memory or learning problems that can also develop. When depression is present in one or more family members, seeing a family counselor as a group can help to bring about an emotionally healthy outlook.

Treatment Compliance and Health May be Affected

Depression can compromise one's willpower to follow his or her MS treatment plan. Even simple activities, such as getting out of bed in the morning, may become difficult. Bigger tasks, such as getting to a doctor's appointment, may feel impossible.

Following a treatment plan for MS includes taking medication on a regular basis. Taking the correct dosage at the scheduled times, especially with respect to injections, requires determination, discipline, and motivation. All of these traits are compromised when a patient is depressed. Other wellness strategies, such as following an exercise program, eating well, participating in support groups, and staying involved with positive people, may also fall by the wayside during depressive episodes.

Additionally, studies show that depression has been linked to many physical ailments. These can include (but are not limited to) such symptoms as: a lowered immune response, which could make someone more susceptible to colds and flu; an increased sensation of pain; mental and physical fatigue; weight gain or loss (according to changes in appetite and behavior); and an increased sensitivity to noise.

Loss of Libido

One of the chief complaints among individuals experiencing depression is a

lack of interest in physical relationships. When someone is feeling tired, withdrawn, or unlovable, he or she is much less likely to be interested in physical intimacy. Naturally, this has a negative impact on relationships. Loved ones will often feel rejected and unwanted when their partner withdraws from them sexually.

Since 25 to 50 percent of men and 50 percent of women with MS report having some type of sexual dysfunction, depression only makes matters worse. However, these sexual issues can often be resolved when the underlying depression is treated.

Some worry that antidepressants may decrease their sexual desire, however, medications have been improved over the years and this has become less of an issue. Anyone taking a medication and experiencing reduced libido should discuss the situation with a medical professional. He or she may be able to adjust the prescription to minimize or eliminate this potential side effect.

Less Participation in Social Activities

Depression often causes people to turn inward, withdrawing from family and friends, and declining to take part in social activities. The thought of picking up the phone to call a friend or to hold a conversation can seem overwhelming for someone who is depressed. As a result, individuals with depression will often



COMMIT TO ONE ACTIVITY EACH WEEK

**TIP
4**

Being accountable to a group can be a motivator to change one's environment and get social support – which can ultimately be uplifting.

discontinue social activities and commitments. Friends may eventually become discouraged and stop calling to urge the depressed patient to join them.

Severely depressed people may feel that they have very little to give others, as they are often using all of their energy just to make it through the next few minutes. The net result is that support systems tend

to crumble when they are needed the most. This is unfortunate, because connecting with others can often be of much benefit to the depressed patient.

Maintaining social contact is a necessity for both mental and physical health. According to the Centers for Disease Control and Prevention (CDC), a strong correlation exists between loving and supportive relationships, and the ability to cope with illness.

Losses in Employment

Although many mildly to moderately depressed patients are able to continue working, individuals who are severely depressed may have great difficulty going to the workplace, let alone being productive while there. In fact, the Journal of the American Medical Association estimates the annual cost of depression in the United States is \$43 billion. Of that, \$23 billion is lost through absenteeism or loss of productivity in the workplace. For the depressed individual with MS, the loss of employment and insurance benefits can have a devastating long-term impact.

Depression is Under-Reported and Under-Treated

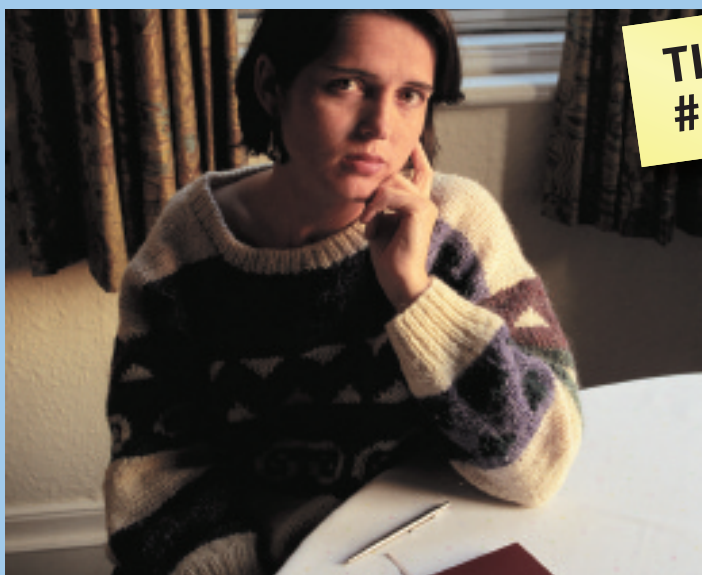
Despite all of the devastating implications of depression, this disease is still too often under-reported, and as a consequence, under-treated. Several factors contribute to this urgent situation.

One obstacle is the fact that depression, along with other psychological issues, is less tangible, especially given the relatively short times that a patient spends with his or her physician. Typically, both healthcare providers and patients may feel more comfortable discussing physical MS symptoms (which are easier to observe and evaluate), while ignoring the less obvious (and more sensitive) psychological issues.

This issue is further complicated by the demands placed on practitioners during a typical office visit. Most practitioners have good intentions, but they are challenged during office visits to complete a multitude of tasks. These include answering patients' questions, listening to their concerns, managing MS symptoms, tracking changes in the course of the

disease, educating patients, evaluating treatment approaches, managing medications, and making referrals to other specialists. With all of the things a doctor must do, one can easily understand how a problem like depression may be overlooked.

In addition, individuals – including MS patients – may not recognize the symptoms of depression, particularly if they are experiencing irritation and anger, rather than the more common emotion of a depressed mood. Some patients may automatically assume that their feelings of depression are MS symptoms, and that they must simply live with the sadness and other negative emotions. Finally, some patients may not realize that treatments are available for depression, so they do not pursue the issue.



**TIP
5**

JOURNAL YOUR FEELINGS

Take time to write down your feelings. This is a very safe outlet to release negative thoughts that may be building up inside.

Addressing and Evaluating Your Depression

Because our bodies are ultimately our own responsibility, we often must advocate for ourselves when addressing depression. Writing down your concerns prior to a doctor's appointment, including a list of all the depressive symptoms you are experiencing, can be very helpful. Such a list may be given to the doctor or nurse during your visit.

Patients and family members need to understand that depression is not a weakness or a moral short-coming that people can simply "get over." Depression is an illness, and just like MS, it deserves the time, attention, and treatment that any other illness would be given.

What Causes Depression in MS?

Why are MS patients at such a high risk for depression? The easy answer to this question is that living with MS in and of itself is depressing. Studies show, however, that those with other serious chronic medical conditions do not suffer from the same high rate of depression as do those with MS. By taking a closer look at what causes depression in MS, we can better target and treat its symptoms.

Disease Response

Experiencing a period of depression is not uncommon following the initial diagnosis of MS. Hearing the news that one has a chronic disease, which for now is incurable, has a tremendous impact on both the patient, as well as the family.

Psychologically "catching up" to this new information may take some time. One may initially assume that the prognosis will be the "worst case" scenario, at least until one has time to adjust to his or her

unique symptoms and disease course. Prior to developing the skills needed to cope with the diagnosis, one may be susceptible to having depressive episodes, especially if he or she is already prone to depression.

Many patients do not realize that most people do eventually adjust and adapt to the diagnosis of MS, but doing so just takes time.

Even after learning to cope with the initial diagnosis, patients will need to continually adjust to altered life circumstances. Some individuals may eventually experience losses which can occur as a result of disease progression. Examples include changes in physical abilities, employment, relationships, and plans for the future. During each of these losses, patients may be vulnerable to depression.

Depression is an illness, and just like MS, it deserves the time, attention, and treatment that any other illness would be given.

Additionally, recent research shows that depression may be experienced during disease activity. Three predictors strongly correlate to the level of depression the patient experiences. These include:

- 1. Present state of illness (if the individual is currently experiencing an exacerbation)**
- 2. Level of uncertainty about new symptoms and the future**
- 3. Poor coping skills such as “emotion-centered” and “escape-avoidance” reactions, rather than constructive problem solving**

The uncertainty a patient experiences during an exacerbation strongly influences the level of depression that may result. During the course of MS, people can feel as if they have lost control not only of their bodies, but their thoughts and feelings as well. Healthcare providers may be able to reduce the level of depression that patients experience by offering reassurance, answering questions, and working to reduce uncertainty whenever possible.

Focusing on what the patient still has control over can also help to reduce the feelings of depression. Studies show that when individuals have the perception that they can influence their environment, they feel a greater sense of engagement, energy, and happiness.

Physiological Causes

Damage to the central nervous system caused by physiological changes may impact mood. In some cases, depression is thought to be caused by lesions in the right frontal and temporal lobes of the brain.

The authors of *Comprehensive Nursing Care in Multiple Sclerosis* (second edition, edited by J. Halper and N.J. Holland, Demos Medical Publishing, 2002) note, “Both clinical depression and less severe emotional distress are common in MS... [occurring at] a rate much higher than in the general population or in other conditions with similar disabilities, e.g., spinal cord injury. In fact, the very high frequency of depression in MS has led many to theorize that it may be due in part to damage to parts of the brain concerned with the regulation of emotions.”

Chemical Changes

Chemical changes that occur within the body and the brain can affect mood. For instance, studies find that the expression of interferon-gamma (IFN-gamma) and other Th 1-type cytokines (pro-inflammatory protein molecules involved in cell-to-cell communications, shown to worsen MS) correlate with depression scores during an acute exacerbation. Another study showed that the level of depression, as well as IFN-gamma production, declined



**TIP
6**

DEVELOP A SPIRITUAL INTEREST

Defining spirituality is a very personal decision. Spending time in nature, prayer, meditation, or a religious setting, are all forms of spiritual practice. How you define spirituality does not really matter; the important thing is that you feel connected with something greater than yourself. When firmly grounded in a spiritual belief, one can come back to this centered place – especially during times of stress or sadness – and find great comfort.

significantly in MS patients over a 16-week treatment period using cognitive behavioral therapy. These studies suggest that chemical changes caused by MS attacks may in fact cause depression. This would also help to explain why patients are more prone to depression during exacerbations.

Fatigue

Patients report that fatigue is the most disabling of all their MS symptoms. Between 75 and 90 percent of the MS population suffers from fatigue during the course of their illness. When we are exhausted, we are much more likely to feel depressed. We simply do not have the emotional energy to fight depression; we are too tired to do the things we might normally do to ward off depressive symptoms – such as socializing or exercising.

Similar to depression, fatigue impacts every aspect of life. As fatigue robs us of our ability to work, to help others, or to care for our children, we can fall victim to a painful spiral of fatigue causing depression and then depression compounding our fatigue.

You must also take responsibility for pacing yourself and pay attention to what causes your fatigue. Using a journal to rate your fatigue can be a useful exercise. The “Rating Your Fatigue” exercise found on page 145 of this author’s book, *MS & Your Feelings: Handling the Ups and*

Downs of Multiple Sclerosis (Hunter House Inc., 2006), can help give you a structured way to begin monitoring causes of your fatigue.

Medication Side Effects

Some of the medications prescribed to MS patients may be linked to depression. Steroids top the list. These are often prescribed during exacerbations when patients are already vulnerable to depressive symptoms. Steroids tend to induce a short-term euphoric “steroid high” when first given, followed by a plunge into depression once the medication is stopped.

Some neurologists recognize the emotional roller-coaster which steroids can cause and they are prescribing medications to lessen the emotional effects often associated with the treatment. These might include anti-anxiety and antidepressant drugs given prior to starting a steroid treatment.

Many relapsing-remitting MS patients are now taking interferons (Avonex[®], Betaseron[®], and Rebif[®]) to help slow the progression of MS and reduce the number of attacks. Anecdotal reports suggest a possible association between this type of immunotherapy and increased depression. Recent follow-up studies, including data from SPECTRIMS and PRISMS trials, failed to show a

connection between these drugs and depression.

While this news is encouraging, the interferons have been shown to decrease the amount of serotonin formed in the brain. Decreased levels of this chemical in the brain may be linked to depression. Therefore, individuals who are taking an interferon and experience a change in their emotional state, are advised to talk with their doctor immediately.

Other medications given for MS symptom management may also cause depression. These include: baclofen, prescribed for spasticity; benzodiazepines, taken for dizziness, vertigo, or spasticity; and other sedating drugs. When taking any of these medications, patients, family members, and the treating physician should closely monitor any changes in mood, watching for the signs of depression listed earlier.

Other Factors Increasing Susceptibility to Depression

In addition to the potential causes of depression already mentioned, other factors can make a person more vulnerable to depressive episodes. By being aware of these situations, you can be extra sensitive to your mood changes during these high risk times and seek treatment if you notice yourself slipping into a depressive episode before it becomes too severe.

FIND YOUR BLISS

Along the same lines as spirituality, asking yourself, “Why do I want to get well?” is important. What is the one thing in your life that makes you want to get up in the morning and keep going even when your body wants to rollover and go back to sleep? What images can you think of that make you smile? This can be a loved one, a job, a hobby, or even a higher purpose. Your bliss can be a great motivator when you need an incentive to care for yourself.

**TIP
7**



Interruption of Routine

Some people find great comfort in sticking to a routine. They may believe that they have more influence over their MS symptoms when they are able to control their sleep, work, and exercise schedule, as well as having the freedom to choose when and what they eat. For these individuals, changing a routine can be a trigger for depression. Examples of changes that commonly affect routine include moving to another location, changing jobs, or traveling.

When someone clings to a routine and is forced to make a change, doing whatever is possible to maintain a normal schedule

will help with the adjustment to the new circumstances. For example, if you typically exercise for 30 minutes each day, continue to do this even if circumstances are quite different, such as being on vacation or beginning a new job. Try not to change your activities when in a new situation.

Winter Weather

For many people, the winter season can trigger depression. This phenomenon is known as “seasonal affective disorder,” also referred to as “SAD.” If you recognize a tendency to get depressed in the winter, the following suggestions may be of help (with a doctor’s approval):

1. **Vacation in a sunny location**
2. **Spend at least a half-hour outdoors**
3. **Use some type of bright visible-spectrum light**
4. **Talk with your doctor about your concerns and learn about additional strategies**

Changing Medications

Frequently when changing medications, one's mood is initially impacted. A few weeks may be needed to adjust to the new chemicals in your body. Informing your doctor of any mood changes when on a new medication is important to the success of a treatment as well as one's wellbeing.

Other Physical Conditions

One should not automatically assume that depression is caused by his or her MS. Individuals need to work with their doctor to rule out any other medical or physical issues that may be contributing to depression. Hormone or thyroid problems, changes in blood-sugar levels, and urinary tract or other infections, are among the types of medical conditions aside from MS that can cause depression.

Low Self-Esteem

Many people with chronic illness face challenges to their self-esteem. We may contend with issues such as poor body image, fewer social activities and friends, and the loss of a job or other responsibilities that made us feel worthy in the past. As our abilities change, we may begin to see ourselves as less valuable to both ourselves and others.

Feelings of low self-esteem can lead to

feelings of worthlessness and guilt – which can in turn lead to depression. One of the tasks that all people with MS must achieve in order to maintain mental health is the reinvention of a worthy self; despite

physical disability.

The responsibility is on each of us to find ways that we can still contribute our talents and skills, regardless of the changes that have taken place within our bodies. Fortunately, we get to choose our self-image. This means that regardless of what our abilities are or how they change, we can consciously decide to adjust our expectations of ourselves and, in turn, adjust what we value about ourselves.

One positive way to combat low self-esteem as well as depression is to

The responsibility is on each of us to find ways that we can still contribute our talents and skills, regardless of the changes that have taken place within our bodies.



HELP OTHERS

Volunteering is a great way to improve self-esteem and combat feelings of worthlessness.

**TIP
8**

volunteer. Research shows that volunteers actually experience a “helper’s high.” Frequently, volunteers report feeling physically, emotionally, and intellectually recharged after doing something for others. In fact, studies show that giving support to others can sometimes be more beneficial than receiving help.

Treatment Options for Depression

Seeking treatment for depression is just as important as getting help for one’s MS. Depression rarely improves on its own and without treatment, it often gets worse.

Fortunately, depression is one of the most treatable of all MS symptoms, although specific treatment therapies are not the same for everyone. Individuals may need to try a few different approaches before finding a treatment plan that works best for them.

Taking a prescribed medication along with participating in psychological counseling appears to be the most effective treatment plan to alleviate depression. Treating depression with medication alone is generally not as effective as working in conjunction with a qualified professional therapist.

Many advances have been made with the drugs used to treat depression. The most frequently recommended medications for depression come from a class of drugs known as “selective serotonin reuptake inhibitors” (SSRIs). These antidepressant medications inhibit the reuptake of serotonin (a chemical produced within the body which is known to elevate mood), allowing it to remain in the body’s system longer.

Some of the more commonly prescribed SSRIs include Celexa®, Lexapro®, Paxil®, Prozac®, and Zoloft®. Unfortunately, some

patients report experiencing side effects when taking these medications. Common side effects may include headache, nausea, sleeplessness, anxiety, drowsiness, and sexual dysfunction. These side effects may subside with time, or one's doctor may adjust the prescription or dosage. Newer antidepressants include "serotonin and norepinephrine reuptake inhibitors" (SNRIs), such as Cymbalta® and Effexor®, with side effects that are similar to the SSRIs.

Other drugs which are not SSRIs (belonging to other drug classes), such as Desyre1®, Remeron®, Serzone®, and Wellbutrin®, are options which may result in fewer side effects. Numerous other drugs are also FDA-approved for the treatment of depression, many of which either augment another antidepressant, or are used to treat specific behaviors found in various types of depression – including anxiety, mood swings, manic episodes, insomnia, and excessive eating (among others). The key is to work closely with your treating physician and therapist to determine the correct drug and dosage that will work best for you.

When starting a prescribed treatment for depression, understanding that many of these drugs can take up to six weeks before reaching maximum effectiveness is important. If after six weeks you are not seeing any improvement in your

symptoms, again consult with your doctor about adjusting your dose or switching to another medication.

Some patients find that monitoring their treatment progress by keeping a log of their symptoms is helpful. Since improvements may be gradual, this can be an effective way of documenting any changes you see in your mood. Suggestions include noting changes in appetite, energy, interest in activities, increases in



**TIP
9**

REWARD YOURSELF

Do something that makes you feel good. Ideas include getting a massage, renting your favorite DVD, spending time at the park, enjoying a delicious meal, and reading a great book, just to name a few.

socialization, increased sexual desire, as well as feelings of hope and optimism.

One note of caution, however, concerns the fact that patients often want to stop treatment once they start feeling better. Medications for depression usually need to be continued for at least four-to-nine months to prevent depression from quickly returning. For those with severe depression, medication may need to be continued indefinitely. Patients are advised not to alter the dose, stop taking medications, or combine a prescription with other medications, without first consulting their doctor. Of course, if a patient is experiencing an adverse reaction to the drug, a medical professional should be contacted immediately.

Some individuals may decide to try dietary supplements as a way to help improve their symptoms of depression. Examples of popular supplements which are promoted for depression include St. John's wort and ginkgo biloba. Anyone considering any type of supplement should first consult his or her physician, as these can cause serious side effects and/or interactions with other medications. Additionally, many supplements have not undergone the same rigorous studies as FDA-approved medications, which means that both safety and effectiveness may not be fully established.

Finding a Therapist

As mentioned earlier, the most successful treatment plan is to seek counseling in conjunction with a prescribed drug therapy. A variety of professionals are specifically trained to help those suffering from depression. Working with a psychiatrist, psychologist, social worker, psychiatric nurse, family therapist, or counselor can provide you and your loved ones with the guidance and support needed to help work through your depression.

These professionals can provide objective insight and concrete coping skills to help manage the symptoms of depression. A therapist may become one of the most important team players in assisting with the management of this debilitating disorder. Therefore, finding the right match for your specific needs is imperative. For those who have never worked with a mental health professional, one may feel a certain amount of anxiety over picking up the phone and beginning the process.

To follow are some points one should consider before starting the search for an appropriate therapist. Since a therapist may become a key player on one's treatment team, doing some research in advance may prove to be beneficial, before selecting the therapist that is right for you.

Your neurologist or physician should be able to give some referrals to mental

health providers. MS organizations, support group participants, and/or friends and family may also be able to offer recommendations. Understanding the differences between the types of professionals that offer counseling services is helpful as you begin the selection process.

The Interview Process

Ideally, patients should have the opportunity to interview potential therapists, just as they would when selecting other members of their medical team. As an empowered patient, you have the right to choose who treats you and to understand

Types of Mental Health Providers

Psychiatrists: These are medical doctors who are trained to treat psychiatric conditions. Because they are able to prescribe medications, psychiatrists are often a good choice for those who need special attention given to medication management. Most insurance companies pay for a portion of these services.

Psychologists: Generally, psychologists go through a four-year clinical training program after college. They often specialize in research and psychological testing. Many, however, also provide traditional “talk therapy.” They do not prescribe medications. Typically you would seek out a psychologist for neuropsychological testing. Most insurance companies pay for a portion of these services.

Social Workers: Usually social workers attend an additional two-to-three years of graduate training to obtain an MSW (Master of Social Work). Those who wish to continue into clinical private practice must complete two more years of supervised training to obtain an LCSW (Licensed Clinical Social Worker) designation. Traditionally, social workers take a holistic approach to treatment, considering environment, family, and psychosocial issues. Social workers do not prescribe medication. Most insurance companies pay for a portion of the services provided by an LCSW.

Counselors: Several types of counselors offering specific services are available. These include mental health counselors, marriage and family counselors, psychiatric



nurse clinicians, as well as addiction counselors. Psychological treatment approaches vary widely between these professionals. Often these practitioners have completed a master’s degree. They may not, however, consistently qualify for insurance reimbursement nor do they prescribe medication. Patients may discuss these issues with their counselor to ensure that both their financial and medical needs are being met.

Understanding and Overcoming Depression in Multiple Sclerosis

his or her treatment philosophy. If you don't click with the first person you speak with, meeting with more than one provider is reasonable when making this important decision. Some of the questions you might consider asking include:

1. Do you have experience working with MS patients?
2. What is your success rate in treating depression?
3. What is your psychological treatment approach?
4. What are your office hours?
5. Do you work closely with physicians?
6. How do you feel about using medications to treat depression?
7. Are your services covered by my insurance?

These questions will help give you the facts, but how you feel about the therapist at a “gut level” is the most important consideration. Does he or she listen to you? Do you feel that he or she cares about your concerns? Do you feel comfortable with the therapist? Does the therapist understand issues relating to chronic illness? The questions you ask, along with a certain amount of intuition, will help guide you toward the right match.

Once connected with the right therapist, a relationship can be established. This may ultimately help you to feel less alone as you gain a greater understanding of your emotions and how to feel better again.



**TIP
10**

ADOPT A PET

Although a pet can be hard work initially, owning a pet can help to take one's attention away from his or her despair. Pets provide the unconditional love that is so desperately needed during depressive episodes.

Financial Considerations

Therapy can be expensive. Fees can range from \$60 to more than \$200 per hour, depending on where the patient lives and the professional credentials of the practitioner. If the patient has medical insurance, the insurer should be contacted directly to determine if any of the costs are covered for the specific therapist selected. Questions to ask the insurer include: what is the yearly deductible, how much will the company pay per visit, and how many visits are allowed each year.

If finances are an obstacle to treatment, other options may be available. Individuals may talk with their church, the city or county public health department, social service agencies, or an MS organization, to see if any of these agencies have programs which provide financial assistance and/or low-cost counseling. Some therapists offer a sliding-scale fee based on income. If the patient has Medicare or Medicaid, a mental health benefit may be available to pay for therapy. Exploring these avenues can sometimes uncover more affordable options.

Types of Therapeutic Approaches

A variety of therapeutic approaches may be used during the counseling process. These include: (1) “talk therapy,” which helps the patient gain insight and



**TIP
11**

CREATE A GRATITUDE LIST

By consciously taking the time to shift the focus from all that is going wrong, to all that is going right in your life, you can create moments of pleasure.

resolve problems through verbal exchange with a therapist; (2) “behavioral therapy,” which helps an individual find reinforcement through rewards based on his or her own actions; (3) “interpersonal therapy,” which concentrates on issues arising in relationships with others; (4) “cognitive/behavioral therapy,” which works to change negative ways of thinking and acting into more positive approaches; and (5) “psychodynamic therapy,” which helps to resolve internal conflicting feelings, often stemming from past experiences.

Understanding and Overcoming Depression in Multiple Sclerosis

In addition to individual therapy, some clients benefit from family or couples therapy, while others find group therapy to be effective. Some less traditional, but increasingly popular therapy options also include phone therapy and therapy over the internet. Although these options have limitations, the methods used can be very attractive for clients who are home-bound or who live in remote areas, where finding qualified mental health professionals can be difficult.

Support groups and peer counseling are often particularly helpful for MS patients and a number of these programs are made available through MS organizations. These programs should not be substituted for professional therapy, but may be a nice adjunct. Talking to others who can relate first-hand to what it is like to live with MS and/or depression, helps to validate what you are experiencing.

Other Options When Traditional Therapies Fail

For a small number of individuals with significant depression who do not respond to the more traditional forms of therapy and medication, various procedures are sometimes performed. Examples include: transcranial magnetic stimulation (presently being studied); vagus nerve stimulation (used since the late 1990s for epileptic patients and has since been

approved for treatment-resistant depression); and electroconvulsive therapy (ECT), also known as electroshock treatment.

While this latter procedure (ECT) may sound extreme, patients may be reassured by the fact that this treatment method has been improved over the years. It is now considered to be safe and effective for many individuals. Patients receive anesthesia prior to treatment and each session lasts about 10 minutes. Individuals with MS must be cautious about this treatment course because ECT may have negative effects on the blood-brain barrier. MS patients must carefully weigh the risks and benefits of this treatment technique with their physician.

Family Involvement

Often families feel helpless as they watch a loved one suffer from depression. Many will ask, “What can I do?” Family members may be pleased to learn that they can help in several ways. One of the first things to do is to encourage the patient to seek treatment. As a family member or close friend, you may want to specifically describe the changes that you have seen take place in the patient’s life and explain the effect that this has on you. Doing research ahead of time, and having the names and numbers of therapists to call, can make that next step easier.



**TIP
12**

MAINTAIN A SENSE OF HUMOR

Laughing provides therapeutic value – even consciously smiling can help one feel better. You may cheer up by going to a comedy club, renting funny movies, and spending time with someone who makes you laugh. People shouldn't always take themselves too seriously.

If the patient agrees to the idea, you may want to accompany your loved one to the doctor's office to discuss the changes you have seen and to obtain a referral for a therapist. This can help get the ball rolling. You may also offer to attend the first therapy appointment with the patient. Let him or her know that you will provide support in any way you can as he or she seeks treatment.

Patients may be encouraged to participate in activities, helping to draw them out of their depressed state. Family and friends may make plans for social activities, inviting their loved one to come along. Provide these individuals with opportunities to do the things that they previously enjoyed. Let them know that you love them, no matter how depressed they may feel.

If your family member is prescribed medication, help to make sure that he or

she continues to take the drug(s). If you notice a change in personality after starting the medication, either positive or negative, talk with the patient and physician about those changes.

Finally, living with a depressed person can be extremely challenging, and quite frankly, depressing at times. Care partners (family or friends helping with the care of a patient) need to be sure to take care of themselves. As a care partner, you should try to keep balance in your life and to do the things that bring you pleasure. If experiencing depressive symptoms, a care partner should also seek professional help.

Immediate Positive Steps

While these tips have been highlighted throughout this booklet, to follow is a summary of these important positive

Understanding and Overcoming Depression in Multiple Sclerosis

steps. Although some of these suggestions may sound simple, many can offer immediate help to lift one's mood.

1. Exercise. Exercise is proven to produce an increase in chemicals such as endorphins, which can make us feel less depressed – and can help to lessen fatigue as well.

2. Create a stress management program. Many strategies, such as meditation, yoga, and guided-imagery, are available to manage stress, and can help with life's ups and downs.

3. Talk about your feelings. Confide in a trusted friend or family member.

4. Commit to one activity each week. Being accountable to a group can be a motivator to change your environment and get social support.

5. Journal your feelings. Take time to write down your emotions.

6. Develop a spiritual interest. Spend time in nature, prayer, meditation, religion, or some other form of spiritual practice.

7. Find your bliss. What is the one thing in your life that makes you want to get up in the morning?

8. Help others. Volunteering is a great way to improve self-esteem and combat feelings of worthlessness.

9. Reward yourself. Do something that makes you feel good (and causes no harm).

10. Adopt a pet. Pets provide unconditional love.

11. Create a gratitude list. Take the time to shift the focus from all that is going wrong, to all that is going right in your life.

12. Maintain a sense of humor. Laughing provides therapeutic value – even consciously smiling can help you to feel better.

Proven medications and therapy are now available to individuals who suffer from depression. Given the many resources that individuals with MS have to draw upon for support, we can see that this is a very hopeful time. By reading this booklet, you have taken an important first step toward healing your emotional pain. Having done so, you are greatly encouraged to take the next step... which is to seek treatment. Soon you will be on your way to a happier outlook in life.

Resources for More Information

The resources to follow offer support, advocacy, and information about depression (the first three can provide specifics on depression and MS). Many of these resources can assist with locating a mental health professional and treatment center in your area.

Multiple Sclerosis Association of America

Helpline: (800) 532-7667

Website: www.msassociation.org

Multiple Sclerosis Foundation

Phone: (888) 673-6287

Website: www.msfacts.org

National Multiple Sclerosis Society

Phone: (800) 344-4867

Website: www.nmss.org

Association for Applied Psychophysiology and Biofeedback

Phone: (800) 477-8892 or (303) 422-8436

Website: www.aapb.org

Depression and Bipolar Support Alliance

Phone: (800) 826-3632 or (312) 642-0049

Website: www.DBSEAlliance.org

Families for Depression Awareness

Phone: (781) 890-0220

Website: www.familyaware.org

International Foundation for Research and Education on Depression (iFred)

Phone: (410) 268-0044

Website: www.depression.org or
www.ifred.org

Mental Health America

Formerly known as National Mental Health Association (NMHA)

Phone: (800) 969-6642 or (703) 684-7722

TTY: (800) 433-5959

Website: www.nmha.org

National Alliance on Mental Illness

Phone: (800) 950-6264 or (703) 524-7600

Website: www.nami.org

National Institute of Mental Health

Information Resources and Inquiries Branch

Phone: (866) 615-6464 or (301) 443-4513

TTY: (301) 443-8431 or (866) 415-8051

Website: www.nimh.nih.gov

Suicide Hotline and Website

National Suicide Prevention Lifeline

Phone: (800) 273-8255

SuicideHotlines.com

www.suicidehotlines.com

Website visitors may scroll down to select the state where they live to find local CONTACT and crisis hotlines.

Recommended Reading

Allen J.G., *Coping with Depression: From Catch-22 to Hope*, American Psychiatric Publishing, 2005.

Burns D.D., *Feeling Good: The New Mood Therapy*, Avon Books, 1999.

DePaulo J.R., *How to Cope with Depression*, Ballantine Books, 1996.

Understanding and Overcoming Depression in Multiple Sclerosis

Henry A.D., et al, *Parenting Well When You're Depressed: A Complete Resource for Maintaining a Healthy Family*, New Harbinger Publications, 2001.

Kbat-Zinn J., *Full Catastrophe Living*, Bantam Dell Publishing, 1990.

Naparstek B., *Staying Well with Guided Imagery*, Warner Books, 1994.

Shadday A., *MS and Your Feelings: Handling the Ups and Downs of Multiple Sclerosis*, Hunter House Publishers, 2006.

Solomon A., *The Noonday Demon: An Atlas of Depression*, Simon & Schuster, 2001.

References Used for This Booklet

American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, DSM-IV, 1994.

Courtney S.W., "Recognizing, understanding, and treating depression," Multiple Sclerosis Association of America's magazine, *The Motivator*, Winter 2003, pp. 9-21.

Depression and Multiple Sclerosis, National Multiple Sclerosis Society brochure, 2003.

Haidt J., *The Happiness Hypothesis: Finding the Modern Truth in Ancient Wisdom*, pg. 93, Basic Books, 2006.

Halper J. and Holland, N.J., *Comprehensive Nursing Care in Multiple Sclerosis* (second edition), Demos Medical Publishing, 2002.

Harvard Mental Health Letter, Sept. 2004.

Jablow M.M., "On: depression and MS," revised from *InsideMS*, Vol. 11, No. 3, National Multiple Sclerosis Society magazine.

Kohn A., "Beyond selfishness," *Psychology Today*, October 1988.

Mann J., "The neurobiology of suicide," *Lifesavers*, 10, no. 4 (1998).

Ratliff C., "Mental health in children of parents with MS," Multiple Sclerosis Foundation's *MSFocus* magazine, Vol. 9, Issue 1, Winter 2007.

Scelfo J., "Men & depression: facing darkness," *Newsweek*, February 26, 2007.

Schapiro R.T., et al, "Sexuality and MS," web article previously found at: www.bluelif.com/ms/msi_sex_1.html, 2005.

"The changing rate of major depression," *Journal of the American Medical Association* 268, no. 21, 1992.

Various statistics and definitions confirmed through: Depression and Bipolar Support Alliance; National Institute of Mental Health; United States Department of Health & Human Services; and WebMD.



This booklet was made possible through a generous grant from The Horizon Foundation for New Jersey. The staff and Board members of MSAA would like to express much appreciation for this kind and purposeful gift.

The mission of the Multiple Sclerosis Association of America (MSAA) is to enrich the quality of life for everyone affected by multiple sclerosis. MSAA accomplishes its mission by offering many vital programs and services to members of the MS community.

MSAA's free programs and services include: toll-free telephone Helpline with trained consultants (English and Spanish); MSAA publications; Equipment Distribution Program; Cooling Equipment Distribution Program; MRI Institute and MRI Diagnostic Fund; Barrier-Free Housing Program; regional events and activities; Networking Program; Lending Library; and other programs. Please call the Helpline at (800) 532-7667 or visit MSAA's website at www.msassociation.org for information and assistance.

Help or support to MSAA in any way is truly appreciated. To inquire about volunteering, fundraising, or making donations, please contact MSAA at (800) 532-7667 or visit MSAA's website at www.msassociation.org for information and assistance.



National Headquarters

706 Haddonfield Road, Cherry Hill, New Jersey 08002

Phone: (800) 532-7667 • Fax: (856) 661-9797

Website: www.msassociation.org • Email: msaa@msassociation.org