

Depression: What You Should Know

A Guide for People with Spinal Cord Injury



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**American Association of Spinal Cord Injury
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**American Association of Spinal Cord Injury
Psychologists and Social Workers**

American Congress of Rehabilitation Medicine

American Occupational Therapy Association

American Paraplegia Society

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Association of Rehabilitation Nurses

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Eastern Paralyzed Veterans Association

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This guide has been prepared based on scientific and professional information found in *Depression Following Spinal Cord Injury: A Clinical Practice Guideline for Primary Care Physicians*. Users of this guide should periodically review this material to ensure that the advice herein is consistent with current reasonable clinical practice.

Depression: What You Should Know

A Guide for People with Spinal Cord Injury

Important:

Depression is often related to a medical condition like spinal cord injury, and **it can be treated**. Depression can ruin lives. Don't let it ruin your life or the life of someone you care about!

Some signs of *depression* are listed below. If you have any of these signs, don't wait for a scheduled checkup. Call your *primary care physician* right away. If you know someone with a spinal cord injury who has any of these signs, encourage that person to see a primary care physician and get a referral to a *mental health professional*. These include *psychologists, social workers, psychiatrists, psychiatric nurse practitioners, and family therapists*.

Some Signs of Depression

Having one or more of these signs doesn't necessarily mean that you're depressed. But they could mean that something is wrong.

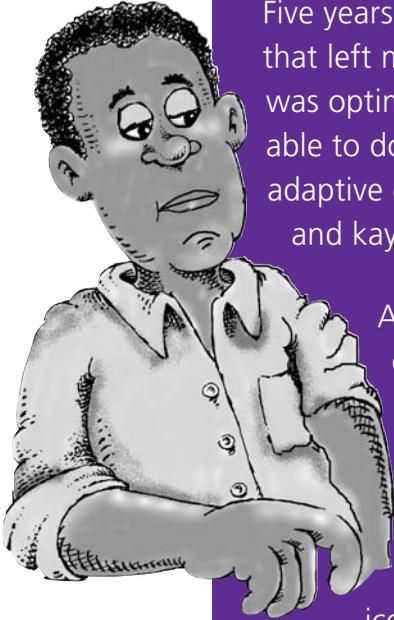
- You think about killing yourself or have tried to commit suicide
- You feel sad, or empty, or cry often
- You feel worthless, hopeless, or guilty often, or all the time
- You have trouble sleeping **or** sleep much more than you usually do

- You don't care much about activities you used to enjoy
- You've gotten careless about personal habits like bathing, brushing your teeth, changing your clothes
- You're tired a lot or have much less energy than you used to
- You have problems concentrating or making decisions
- You have much less or much more appetite than usual (people may have noticed that you have either gained or lost weight)
- You feel slowed down, heavy, or sluggish
- You have so much nervous energy that it's hard to relax or keep still
- You avoid your friends and people you care about
- You turn to alcohol or drugs when feeling angry or sad
- You have less interest in sex than usual
- You feel irritable or get mad more easily



**Words in italics are explained in the glossary on page 15.*

Cliff



Five years ago I had an accident in my all-terrain vehicle (ATV) that left me with a T7 complete spinal cord injury. At first, I was optimistic about my future and looked forward to being able to do the things I loved to do before I was hurt. I got adaptive equipment so that I was able to go camping, fishing, and kayaking.

After a while, I didn't feel much like doing anything or seeing anyone. I kept thinking, "No one really understands what my life is really like." My body felt like lead and I often stayed in bed until the middle of the afternoon.

One day I wheeled out to my garage to get some ice cream from the freezer and I happened to glance up at my kayak hanging from the wall. Cobwebs had taken it over. I felt like someone had knocked me over the head.

Something was definitely wrong, but I didn't know what it was or how to fix it. I decided it was time to call my doctor. I felt comfortable talking to my primary care physician and told him about how I just didn't feel like doing the things that I used to do.

Being able to talk openly about my emotions helped me deal with them.

The doctor was very understanding and told me I was showing signs of being depressed. He suggested that I seek some counseling before he prescribed any kind of antidepressant. He gave me the name and number of a mental health professional who accepted my insurance and told me to call.

I thank goodness every day that I made that call. Counseling has really made a difference in my life. Being able to talk openly and not feel like I'm being judged gave me the opportunity to deal with my emotions. Right now I'm planning a weekend whitewater rafting trip. I'm really looking forward to life again.

Contents

Who Should Read This Guide	1
Why Is This Guide Important	2
What Is Depression	2
What Causes Depression	3
Table 1. Checklist: Some Signs of Depression	4
What Are Some Signs of Depression	6
Why Do Feelings Matter	6
Where Can I Get Help	7
How Is Depression Treated	7
Suicide: Untreated Depression Can Kill.....	8
What Is Psychotherapy	9
What Is Psychopharmacology	10
Are Side Effects a Problem	11
What Are Alternative Medications	12
Will My Insurance Cover Treatment	12
Get Involved	13
You're Not Alone	13
Help Is Available	14
Glossary	15
Appendix A. Resources for People with SCI	16
Medical History	17
Acknowledgements	19

Bridget



Three years ago I had a spinal cord injury at C6. They sent me home from the hospital too fast. I wasn't given enough time to accept what had happened to my body or how my new injury would affect my life. At 24 years old I was devastated!

At a time when I thought I'd be out on my own and independent, I was back living with my parents. My mother was doing all my attendant care. This caused many conflicting emotions in our relationship.

I was feeling very depressed and down. I didn't want to get up in the mornings. It seemed pointless for my mother to bother getting me dressed. I was over-eating and this caused problems with my bowel routine. I was in a deep, dark, downward emotional spiral. I began thinking about ending my misery.

In desperation, I shared my thoughts and feelings with my home health nurse. She understood the hopelessness I felt. She had seen my symptoms of depression before in people with spinal cord injury and she knew to refer me to my primary care physician.

My doctor told me that I had a major depression and that I should talk to a mental health professional about my hopeless feelings. She immediately started me on an antidepressant medication and referred me to a psychiatrist.

I started seeing a psychiatrist weekly. Talking about my problems has helped me and my family cope with my disability. I am now planning for my future with a positive outlook on life.

I was feeling very depressed and down. I shared my thoughts with someone who understood the hopelessness I felt.

Who Should Read This Guide

- People with spinal cord injury (SCI)
- Family, friends, personal care attendants, and other caregivers
- Health-care professionals, especially primary care physicians and mental health professionals who treat people with SCI
- Health-care educators

Mood disorders like depression are common among people who have chronic health conditions. That includes SCI. After an SCI, a person experiences major life changes. Adjusting to those changes can take time and often requires help. However, depression can strike at any time in life—whether the person is able-bodied or disabled.

For people with SCI, depression can contribute to:

- Pressure ulcers
- Urinary tract infections
- How easily they get sick
- Chronic pain
- Longer or more frequent hospital stays
- Problems with personal relationships
- Problems with caregivers
- Substance abuse
- Higher medical expenses

People with SCI also have a higher risk of suicide as a result of depression. (See **Suicide: Untreated Depression Can Kill** on page 8.)

Special Note For Family, Friends, and Caregivers

Depressive changes in behavior and mood can be gradual. Sometimes it's easier for others to see such changes first. If you care for a person with SCI, learn about the signs of depression (see table 1 on pages 4-5). If you see any of those signs:

- express your concern, and
- encourage the person to see a primary care physician or mental health specialist right away.

It's a good idea to watch for signs of depression in yourself, too. Although you can't "catch" depression from someone else, it can be depressing to be around a depressed person. If you're feeling down or blue or helpless about helping someone you care about, talk with someone you trust: a counselor, your primary care physician, a friend. (See **How Is Depression Treated** on page 7.)

Why Is This Guide Important

Depression can ruin lives. But it doesn't have to. People with SCI are at special risk for depression and its effects, some of which are listed on page 1.

There are three things that everyone should know about depression:

1. It's a common condition. Depression affects 7 percent to 12 percent of all men and 20 percent to 25 percent of all women at least once in a lifetime—not just people with SCI.
2. It's a serious problem. If you're depressed, it can affect your physical and mental health, your quality of life, and the well-being of people around you.
3. **IT CAN BE TREATED effectively.** The vast majority of people who are treated for depression have good results.

Depression can affect every part of a person's life. It can also affect the lives of those around a depressed person. It's hard to be with someone who's always down or blue. Proper treatment can benefit everyone. It can improve or overcome the depression. Treatment helps the person feel better and function better. That, in turn, helps family, friends, and co-workers.

Too many people have wrong ideas or impressions about depression. That misinformation causes needless misery by preventing people with depression from getting help.

What Is Depression

Depression is a condition in which a person feels sad, hopeless, or powerless. It can be brief or long term. And it can range from a mild sense of feeling blue to more severe forms in which



Myths About Depression

"It's all in your head."

"You're just feeling sorry for yourself."

"People who talk about committing suicide never really do it."

"There's nothing you can do."

"Once you're depressed, you're always depressed."

it completely disrupts a person's life. Depression can feel like a cloud that darkens everything and takes the joy out of life. Fortunately, in most cases it can be improved or cured.

What Causes Depression

Many things can cause or contribute to depression. These include the effects of SCI, life events, personal circumstances, other medical conditions, some medications, alcohol, and drugs.

- **Effects of SCI.** Fatigue, loss of appetite, loss of energy, sleep problems, chronic pain, pressure ulcers, other secondary conditions of SCI, grief or blame related to the injury, loss of self-esteem, changes in body image, change from independence to depending on others for care, loss of hobbies.
- **Life events.** Divorce; loss of a loved one, a job, a home; retirement.
- **Personal circumstances.** Financial problems, inability to work, wheelchair access problems at home or at work, transportation problems, lack of support from family or friends, loneliness and isolation, personal (or family) history of depression or *bipolar disorder*.
- **Other medical conditions.** A chemical imbalance in the brain, which may be caused by heart conditions or stroke, migraines, mild brain injury, renal dialysis. These are only some of the medical conditions that can be related to depression.
- **Medications.** Many medications that people with SCI take for other conditions, such as spasticity or pain, can affect their moods. If you're taking any medications—nonprescription or prescription—make sure your primary care physician knows what they are, how much you take, and when.

WRONG! Depression is a real illness with real symptoms that can cause very real problems—in your health, at home, and at work. Because depression relates to mental health, many people are ashamed to discuss it. Even well-meaning family and friends may tell you to get a grip, pull yourself together, tough it out, or learn to live with it.

For all these reasons, many depressed people don't know they can be helped. Or they think they shouldn't need help.

We can all do our part to dispel these myths about depression. We can learn to recognize the signs of depression. We can seek help if we're depressed. And we can encourage loved ones to get the help that can improve—even save—their lives.

TABLE 1.**Checklist: Some Signs of Depression**

Use this checklist to help identify if you have any signs of depression. Take this with you when you visit your health-care provider.

Check all that apply.

- I've thought about killing myself.
- I worry about being able to control my thoughts about suicide.
- I've tried to commit suicide.
- I'm unable to cope with daily activities.
- I feel more tired than I used to.
- I seldom leave the house.
- I feel especially tired in the morning, after I wake up.
- I feel like a burden on my family.
- Being dependent on others for my care makes me feel sad, empty, and worthless.
- I have trouble falling asleep at night (*insomnia*).
- I often wake up early in the morning.
- I'm eating more than I used to.
- I've gained weight recently: about _____ pounds.
- I'm not hungry very often anymore.
- I've lost weight recently: about _____ pounds.
- I've lost weight recently, even though I'm hungry and eat as much as I used to.
- I don't care much about things I used to enjoy, like hobbies.
- I've gotten careless about personal habits, like:
 - taking a bath or shower
 - using deodorant
 - brushing my teeth
 - changing my clothes
- I just don't feel motivated to do much.

I have other medical problems now or have had them before (such as heart disease, epilepsy, fibromyalgia, cancer). Those problems include:

I'm taking nonprescription (over-the-counter) medicine now. Here's what I take:

Drug Name	How Much	How Often
_____	_____	_____
_____	_____	_____

I'm taking prescription medicine now. Here's what I take:

Drug Name	How Much	How Often
_____	_____	_____
_____	_____	_____

I'm having problems in my marriage. My examples:

I'm having problems in my family. My examples:

I have trouble concentrating and making decisions:

- sometimes
 - all the time
- I feel like my body is made of lead; life seems to be in slow motion.
- I feel restless; I have so much energy that it's hard to relax.
- I feel helpless; I can't seem to get used to being in a wheelchair.
- I feel angry a lot.
- I feel worthless a lot.
- I'm hard on myself.
- I feel hopeless; it seems as if things won't ever get better.
- I live alone.
- I don't have many friends.
- I don't have any family members nearby.
- I worry a lot about money.
- I've had a mood problem before:

- depression
- bipolar disorder (*manic depression*)
- other _____

Mood disorders seem to run in my family. These are my relatives who've had a mood problem and the problem they had:

Relation	Problem
<i>example: father</i>	<i>Uncontrolled crying</i>
_____	_____
_____	_____
_____	_____

I'm having problems at work. My examples:

I'm having problems with my personal care attendant. My examples:

I've had some terrible things happen the past few months (such as divorce, death of loved one, loss of job). My examples:

I drink, but I don't think I have a problem with alcohol. I drink:

What Kind	How Much	How Often
_____	_____	_____
_____	_____	_____

I recognize that I have a problem with alcohol.

I use drugs:	How Much	How Often
What Drug	_____	_____
_____	_____	_____

More complete lists of medical conditions and medications that can have a role in depression appear in *Depression Following Spinal Cord Injury: A Clinical Practice Guideline for Primary Care Physicians*. The guideline is available free from PVA (phone: (888) 860-7244, website: www.pva.org). You may want to give a copy of the guideline to your primary care physician.

What Are Some Signs of Depression

Table 1 on pages 4 and 5 lists many signs of depression. Having any of these signs doesn't necessarily mean that you're depressed. But you should discuss the signs with your primary care physician and/or mental health professional anyway. They're good indicators that something may be wrong. And if something is wrong, you should find out so that it can be treated.

Bring the checklist with you when you see your primary care physician or any mental health professional. You can make copies to take with you.

Why Do Feelings Matter

There's no one "right" emotion for every person in every situation, whether it's the shock of SCI or the loss of a loved one. In fact, there's no such thing as a right or wrong way to feel.

But feelings have a lot to do with mind and body health. Your mind and body are all connected. Studies show that depression can play a big role in many health ailments. Similarly, feeling upbeat about life can improve your health.

Depression changes the way people feel about themselves and their lives. When you're depressed, it can seem as if everything is wrong and you can't fix it. It's important to pay attention to your feelings. Feelings are signs that something in your life needs to be understood, addressed, and potentially changed. That means:

1. recognizing what you're feeling
2. understanding why you feel that way
3. trying not to be too hard on yourself for feeling down
4. taking steps to address the source of your feeling

Talk to people you trust: family, friends, counselors, health-care professionals. Don't wait for people to call you; reach out to them. Even a friendly word with a neighbor can brighten your day. The more involved you become in fulfilling activities, the less you'll focus on the problems in your life. And remember: **Help IS available.**

Where Can I Get Help

A good place to start is with your primary care physician. He or she can help you figure out if your problems are related to depression. (Be sure to fill in Table 1 on pages 4 and 5 and bring it with you to the doctor's office.) Your primary care physician can also refer you to someone who specializes in treating depression.

If you don't have a primary care physician, talk to staff at your rehab center. They can help you with treatment or find a specialist in your area. Or see if the phone book lists a mental health center in your community. Other places to get help include the clergy, PVA, and national hotlines such as the National Spinal Cord Injury Hotline at (800) 526-3456.

How Is Depression Treated

There are two basic types of professional help for depression. *Psychotherapy* is the treatment of mental and emotional conditions using talk therapy and counseling, without the use of medications. *Psychopharmacology* is the use of medications to treat these conditions. These two types of treatment may be used alone or together.

There's no one standard treatment for depression. Treatment is based on each person's needs. Your treatment will take into account many things. They include what may be causing your depression, your personal situation, and aspects of your personality, such as how you cope with problems. Your doctor will then suggest one or more forms of appropriate counseling.

One form is individual counseling, which is just you and a mental health professional. Other forms of counseling involve other people. For example, family problems can cause depression, and depression can create family problems. When that happens, marriage or family counseling may be suggested. If

Suicide...

Untreated Depression Can Kill

People with SCI are at much higher risk for suicide. The risk is highest in the first five years after the injury.

Depression is the biggest risk factor for suicide. Other risk factors include:

- Dependence on alcohol or drugs
- Lack of a spouse or close social network for support
- A previous suicide attempt. People who've tried to kill themselves before are likely to try again.

The most important factors in preventing suicide are spotting depression early and getting the right treatment for it.

If you're thinking about suicide, get help! Remember that depression casts a shadow over everything. Your whole world will look different when your depression is treated and your spirits improve.

And if you think your family will be better off without you, you're wrong. Suicide puts a huge burden of guilt and grief on loved ones. They never get over it. Ask anyone who has lost a loved one to suicide. **If you're angry with someone and are thinking of suicide as a way to get back at them, think again!** There are better ways of expressing your anger and resentment.

If you or someone you know is suicidal, seek help right away. Help is available through:

- 911 for emergency assistance
- Suicide hotlines
- Community mental health centers
- Mental health professionals
- Primary care physicians

You may have heard that people who talk about killing themselves won't try to do it. That's not true! Many of them do try—and succeed.

you're feeling that no one understands what you're going through, group therapy involving other people with SCI may be helpful.

Important:

For the best total care, keep your primary care physician informed about other health-care professionals that you see. That includes mental health professionals. And make sure your primary care physician knows about any medications you're taking to help your depression.

What Is Psychotherapy

This approach is often called “talk therapy.” Sometimes just talking about whatever is disturbing you can help. Many types of professionals are trained to listen and guide you in sorting out your problems. These include psychologists, social workers, psychiatrists, psychiatric nurse practitioners, family therapists, and *pastoral counselors*. How they work with you depends on your needs. They may see you alone, with your spouse or other family members, or in a group of people facing similar issues. There are several forms of psychotherapy. No matter what form you and your therapist choose, it's essential for you to trust and be open with the person you're working with.



What Is Psychopharmacology

Your primary care physician may suggest *antidepressant* medication to improve your mood and outlook on life. This is called “psychopharmacology.” Only a medical doctor—someone with an MD degree, not a PhD—can prescribe medications. Your primary care physician may prescribe a medication or may refer you to a specialist for a prescription. In either case, the doctor will work with you to find an antidepressant that helps.

It’s important to understand several things about antidepressants:

- Different types of antidepressants work differently in the body. Not every medicine works for every person. You may need to try more than one before you find one that works well for you.
- Antidepressants often need time before they take full effect. This may be as long as 4 to 6 weeks. People sometimes stop taking a medication before it has a chance to help because they don’t think the medication is working.
- Antidepressant doses often need to be adjusted over time. You may require blood tests or other tests regularly. These tests help your doctor check medication levels for safety and effectiveness.
- Some antidepressants have common side effects. You may not be one of the people who has those side effects. But if you are, tell your doctor promptly. There are usually easy ways to manage side effects. Or your doctor may decide that it’s better for you to try another medication.
- Some antidepressants may react with other medications you are taking. Be sure to tell your doctor about all medications

Alcohol and Drugs: What You Need to Know

Alcohol can cause depression or make it worse. So can sedatives, drugs that aid sleep, and narcotics or street drugs.

Some people turn to alcohol or drugs to feel better when they’re depressed. This is called *self-medication*. It can lead to dependence or addiction. And like depression, it can ruin lives. If you’re feel-

ing down about something specific or about life in general, talk to someone: a close friend who can be objective, your primary care physician, a member of the clergy, a counselor or therapist. It’s easier and safer than taking drugs or alcohol to solve the problem.

you are taking, including over-the-counter medications and herbal remedies.

Important:

If you want to stop taking or change your medication, talk with the doctor who prescribed it first. No matter what, don't just stop taking an antidepressant! That can cause medical problems. To protect your health, you may need to reduce the dose bit by bit before you stop completely.

Your doctor will discuss medication options with you. Ask your doctor the following questions to make sure you understand everything you need to know about your new medicine:

1. What medication do you recommend?
2. Why do you suggest it for me?
3. When should I expect to notice that it's working?
4. What are the possible side effects?
5. What signs of those side effects should I watch for?
6. What should I do if I have any of those signs?

Are Side Effects a Problem

Several types of medications are used to treat depression. People with SCI are at special risk for some side effects including weight gain or weight loss, urine retention, and constipation.



Alcohol and drugs can make it hard for a doctor to find out whether you have depression and if so, how best to treat it. If you use alcohol or drugs, tell your primary care physician and/or mental health profes-

sional. That information will help them know how best to help you.



Side effects can be managed safely. You can help by making sure your doctor knows about them. Before you take any medication for depression, suggest that the doctor refer to ***Depression Following Spinal Cord Injury: A Clinical Practice Guideline for Primary Care Physicians***, available free from PVA (www.pva.org or (888) 860-7244).

Important:

A serious side effect is *autonomic dysreflexia*. It is a medical emergency. Everyone who has SCI needs to know the warning signs of autonomic dysreflexia and what to do about them. For a free copy of ***Autonomic Dysreflexia: What You Should Know***, visit the PVA website at www.pva.org.

What Are Alternative Medications

Alternative medications are drugs that aren't regulated by the U.S. Food and Drug Administration. That means they haven't undergone testing to make sure they're safe and effective.

St. John's wort is just one of several alternative medications that's claimed to be helpful for depression. Because these products are unregulated, the public doesn't have information about proper doses and side effects.

Before you try an alternative medication, for depression or any other condition, talk with your primary care physician. If you're already taking any of these products, make sure all your doctors know.

Will My Insurance Cover Treatment

Medical insurance companies differ a lot in their coverage of treatment for depression. Some companies cover only visits to mental health professionals in their official "network." (You can get a list of providers in the network from your insurance company.) Some limit the number of visits they will cover. Even Medicaid and Medicare rules differ by state. That's why it's a good idea to find out about your insurance company's rules before you begin seeing a mental health professional regularly.

Sometimes insurance companies pay for treatment outside their network. Your primary care physician, rehab center staff, or family members can be advocates with your insurance com-

pany. They may be able to get approval for you to see a mental health professional outside the network who has expertise in treating people with SCI. It's worth a try. (Be sure to get pre-approval in writing.)

Important:

If you need help for depression, you can get it—even if you don't have insurance or your insurance doesn't cover the treatment suggested by your primary care physician or mental health provider. Contact your local community mental health center.

Get Involved

Do you live alone? Have you lost touch with friends and family? Have you stopped working? Have you stopped participating in sports, hobbies, or social outings? If the answer to any of these questions is yes, you're putting your health at risk. Loneliness and isolation are common signs of depression. They're also possible causes of depression.

What can you do? You don't need to rush out and get married or find a roommate. But you should think of ways to have rewarding contact with other people. You can do that through work, neighborhood groups, sports, and other recreational and social activities. Whether they're able-bodied or in a wheelchair, people who are doing something worthwhile are less likely to feel depressed and more likely to be satisfied with their lives.

Volunteering is another option. By volunteering your time and talents, you can make a difference in your community and meet people who share your interests. Churches, hospitals, veterans groups, civic clubs, and other nonprofit organizations often look for volunteers. It doesn't matter what you choose. What matters is that you're connecting with people and being productive.

You're Not Alone

Spinal cord injury is traumatic. It's not unusual for people to have strong feelings after a life-changing event like SCI. Grief, anger, frustration, depression, even despair—these are all natural reactions. **It's important to remember—you're not alone.**

There are groups around the country that can put you in touch with other people who have SCI. A good place to start is your rehab center. Many rehab centers offer SCI support groups or may be able to direct you to support groups or organizations in your local community. Swapping stories and trading tips is a great way to make friends and see things in a new light.

Sometimes solving other problems in your life relating to your disability can ease depression. Appendix A on page 16 lists sources of information and aid for people with SCI.

Another great resource is the Internet. Whatever you're interested in, the Internet can connect you with all kinds of people who share the same hobbies and interests. If you want to learn more about the Internet and e-mail, call or visit your local library. Computer access and assistance are available for people with disabilities at public libraries.

Help Is Available

It's OK to ask for help with depression. In fact, it's the smart thing to do. **Depression is a medical condition, and it can be treated.** When you have other medical problems, you call a doctor. Accepting help for depression is no different from seeing an optometrist for your eyes or a dentist for your teeth—or rehab center staff for the physical adjustment to SCI. Getting help is part of taking charge of your life.

Help IS available. No matter how small your community, some people and agencies are available to help you with issues related to SCI and depression.

When you find a treatment that works well for you, you'll feel the difference. It's unmistakable. Favorite things will give you pleasure again. The world will seem like a friendlier place. And people around you will notice the change. In obvious and subtle ways, the quality of your life will improve.

Important:

It may be hard to believe now, but when you feel better, your life will be better. So if you think you may be depressed, get help! You have nothing to lose, and everything to gain.

Glossary

alternative medications—Products that are not regulated by the U.S. Food and Drug Administration and are used without prescriptions to treat some medical conditions. These products have not undergone the thorough testing for safety and effectiveness required for regulated medications. Consumers may not have information about proper doses and side effects.

antidepressant—A medication prescribed to improve a person's mood and outlook on life.

autonomic dysreflexia—An abnormal and dangerous response to pain or other stimuli below the spinal cord injury, usually (but not always) one at or above the 6th thoracic vertebra (T6). The body, unable to react normally to the stimulus, responds with increasing blood pressure, which can reach dangerously high levels, causing stroke or even death.

bipolar disorder—A type of depression characterized by wide mood swings from elevated or agitated to deeply depressed with feelings of worthlessness (formerly called manic depression).

depression—A condition in which a person feels sad, hopeless, or powerless. It can be brief or long term, and can range from a mild sense of feeling blue to more severe forms in which it disrupts a person's life.

family therapist—A mental health professional trained to help with family problems.

health-care professional—An individual who provides medical care, including doctors, physicians assistants, nurses, nursing assistants, therapists, and social workers.

insomnia—Trouble falling asleep and/or staying asleep.

manic depression—See bipolar disorder

mental health professionals—Specialists trained to help with mental health problems. They include medical doctors, such as psychiatrists, and other medical professionals, such as psychologists, social workers, and psychiatric nurse practitioners.

pastoral counselor—A minister, priest, rabbi, or other religious affiliated person with training and experience in mental health counseling.

primary care physician—A licensed medical doctor, usually a family physician or internist, who provides and coordinates care for patients' medical needs, including referral to specialists.

psychiatric nurse practitioner—A registered nurse with advanced practice training in evaluating and treating mental and emotional disorders.

psychiatrist—A licensed medical doctor who is trained to deal with mental illness.

psychologist—A person who is trained to evaluate and provide therapy for mental, emotional, and behavioral conditions.

psychopharmacology—The use of medications to treat mental and emotional conditions.

psychotherapy—The treatment of mental and emotional conditions using talk therapy and counseling.

self-medication—Use of alcohol, drugs, or alternative medications to try to make bad or unpleasant feelings go away.

social worker—A social services professional usually with graduate training and certified as a licensed clinical social worker.

APPENDIX A

Resources for People with SCI

*Housing**

Assisted living; personal care homes; return to own home; independent living centers; state veterans homes; nursing home placement; housing authority for subsidized housing and rental aid programs; local realtor; U.S. Department of Housing and Urban Development

*Transportation**

Local public transit authority; area agency on aging; state division of rehabilitation services; Medicaid taxi services; VA**;; independent living centers; places of worship (churches, synagogues, mosques); rental van services

*Personal care assistance**

Home health agencies; independent living centers; family members; training of people who can hire and manage their own employees; Medicaid waiver programs; state funding options; VA

*Home access**

Independent living centers; civic groups; houses of worship; state department rehabilitation services; VA; workers' compensation

*Jobs, vocational help**

State employment agency; independent living centers; state division of rehabilitation services; VA

*Leisure, sports, and recreation**

Independent living centers; PVA**;; National Spinal Cord Injury Association; houses of worship; YMCA/YWCA; local fitness centers; county parks and

recreation service; Chamber of Commerce; state sports associations; senior citizen centers

*Peer support**

Independent living centers; local rehabilitation hospitals; PVA; National Spinal Cord Injury Association; local SCI or PVA chapters; disability-specific support groups

*Family support**

Independent living centers; local rehabilitation hospitals; mental health center or professional; local SCI or PVA chapters; disability-specific support groups

*Finances**

Supplement Security Income (SSI); Social Security Disability Income (SSDI); VA for veterans who served in wartime or are connected to a branch of military service; workers' compensation; food stamps; Aid to Families with Dependent Children (AFDC); state department of rehabilitation services

*Adaptive equipment**

VA; independent living centers; PVA; National Spinal Cord Injury Association; Medicare; private insurance

*Caregiver burnout**

VA for respite for veterans; respite care through local hospitals and nursing homes; homemaker services through VA or state funding; local support groups; mental health center or professional

*Look in your local phone book to find federal, state, county, and local government agencies. For information on local resources, call the National SCI Hotline at (800) 526-3456; the National Council on Independent Living at (703) 525-3406; or check the Internet <http://www.spinalcord.uab.edu>.

**VA = Department of Veterans Affairs; PVA = Paralyzed Veterans of America. References to VA are appropriate for veterans only.

Medical History

Complete the following. Share this information with your family and caregivers, as well as your health-care professionals.

Name: _____

Date of birth: ____/____/____ Sex: M or F

Date of spinal cord injury: ____/____/____

Level of injury: Complete _____ Incomplete _____

Primary health-care professional: _____

Phone number: _____

Allergies, including medications: _____

MEDICATIONS

List medications taken regularly (prescription and over-the-counter):

- | | |
|----------|----------|
| 1. _____ | 4. _____ |
| 2. _____ | 5. _____ |
| 3. _____ | 6. _____ |

List medications taken as needed (prescription and over-the-counter):

- | | |
|----------|----------|
| 1. _____ | 4. _____ |
| 2. _____ | 5. _____ |
| 3. _____ | 6. _____ |

Have you ever taken a medication for depression? Yes No

If yes, what drug? _____ When? _____

EMERGENCY INFORMATION

In case of emergency, call: _____

Relationship: _____ Phone number: () _____

INSURANCE INFORMATION

Name of insurance company: _____

Identification number: _____

Group number: _____ Phone number: () _____

Douglas



My husband, Douglas, received a T5 spinal cord injury in Vietnam. I met him while he was in rehab at the VA SCI center where I was a nurse. When faced with serious problems, he always looked for solutions. Instead of, "Why did this happen to me?" he would ask, "What can I do about this?"

After Douglas was released from the hospital and got a job, we were married. Things went great for several years. Then we hit a bad patch. He became increasingly irritable and moody. Activities that he used to enjoy, like our mixed-doubles bowling league, became "too much trouble."

He started to drink heavily several nights a week. He'd rather stay home and drink by himself than go out with friends. He had frequent bowel accidents and stopped being careful about hygiene and skin care. This put him at serious risk for pressure ulcers.

We talked about it when we were both calm and he agreed he needed help.

One day when he was in a calm mood, I sat down with him and told him he needed to see a doctor about the changes in his personality. At first he denied any change. But when I mentioned specific behavior changes—quitting bowling, not doing his skin care—he said I might have a point. He agreed to schedule an appointment at the local VA SCI center.

Douglas came out of that appointment with some changes to his bowel routine and a prescription for antidepressant medication. The bowel problems cleared up. He regained his interest in life. Within a few weeks, it felt like I had my husband back again.

Acknowledgments

The Consortium for Spinal Cord Medicine Clinical Practice Guidelines is composed of 18 organizations interested in the care and treatment of people with spinal cord injury. The Consortium Steering Committee established a guideline development panel to make recommendations on the management and rehabilitation of individuals dealing with depression following an SCI. The recommendations within this consumer guide are based on scientific research compiled from 1966 to 1998 and used in the Consortium's clinical practice guideline (CPG) *Depression Following Spinal Cord Injury: A Clinical Practice Guideline for Primary Care Physicians*. The Paralyzed Veterans of America provided financial support and administrative resources for all aspects of guideline and consumer guide development.

The consumer guide panel was chaired by Jason Mask, LCSW, and consisted of five members with experience in the management and treatment of depression in individuals with SCI. Meeting life's demands in spite of a spinal cord injury requires much adaptation. For many with SCI, depression is a major life-limiting problem. Creation of a consumer guide that addresses the problems required a diverse, experienced, and sensitive panel. The Consortium would like to thank all members of the consumer guide panel for providing the essential ingredients of knowledge, experience, empathy, and practicality.

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In the end, those who are continually living with and learning about their injury are the best evaluators of a teaching tool such as this consumer guide. The Consortium would like to thank the consumer focus group for their critical review of and comments on the manuscript. Chaired by PVA's Fred Cowell, the focus group included Frank Anderson, Buckeye PVA; Harlon Cauthron, Arizona PVA; Donald H. Gerdson, Iowa PVA; Ronald T. Hoskins, Delaware-Maryland PVA; Don Hyslop, California PVA; Bruce Kent, Bayou Gulf States PVA; Del McNeal, Florida Gulf Coast PVA; and Ken Weas, Central Florida PVA. Their varied life experiences with SCI provided wise perspectives that refined and improved this consumer guide.

Finally, it is essential to recognize the investigators who are studying the effects of depression and SCI. Research is the source of solutions; there is still much to be done in the future.

The Consortium will continue to develop clinical practice guidelines and consumer guides on topics in spinal cord injury care. Look for consumer guides on other topics relating to spinal cord injury. All professional guidelines and consumer guides developed by the Consortium can be found by visiting the PVA website at www.pva.org.

consortium for
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MEDICINE**
CLINICAL PRACTICE GUIDELINES



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