

## DEALING WITH YOUR EMOTIONS



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# Emotional Recovery

## *The Long and Winding Road*

by Patricia Isenberg, MS

**Recovery.** Return to a normal condition.

Have you ever wondered why some people seem to bounce back from the tragedies in their lives, while others find themselves trapped in a cycle of despair, anger or depression?



Most of us compare ourselves to those around us. It is natural, then, for people with limb loss to compare their recovery process to the experiences of other amputees.

People respond differently to the loss of a limb, however, and many issues affect their recovery. The following factors largely account for the individual nature of recovery:

- **Issues associated with the amputation:** Was it due to trauma or disease? What is the level of amputation? How successful was the surgery? What are the chances for returning to what is a “normal” life for you?
- **Individual characteristics:** What is your age or health status? How will this affect you financially?
- **Personality traits:** How have you coped with problems before? What is your attitude about your health? Do you feel a sense of control in spite of the loss?
- **Physical and social environment:** Do you have a support system? Are the services you need appropriate and accessible? What are your living arrangements and how will they accommodate your limb loss?

Recovery is an ongoing process, much like a long and winding road. Though several phases typically occur on the road to recovery (see table on page 25), when they will occur for a particular person and in which order is not predictable.

One person may experience the phases one after another and then regress to an earlier phase. Someone else might skip one or more phases or find that one phase overlaps with another. Each phase of recovery has special challenges and requires different coping strategies. Unfortunately, some people never completely recover.

Sometimes the road to recovery is bumpy, and a range of emotional issues might arise. The following information describes some of them. We hope that by reading these brief descriptions, you will be able to recognize problems early and seek appropriate help, when necessary. For additional information, call the Amputee Coalition of America (888/AMP-KNOW) or see the resources listed at the end of this article.

Anxiety disorders are the most common emotional disorders, affecting more than 25 million Americans. These disorders are different from normal feelings of nervousness or uncertainty that we all have. Untreated anxiety disorders cause you to avoid people, places or situations that trigger or worsen your symptoms. People with anxiety disorders may also suffer from depression or abuse alcohol or drugs to try to cover up or avoid the symptoms. (See pages 26-30 for more information about depression and drug

abuse.) Although treatment takes time, most anxiety disorders respond well to psychotherapy and/or medication.

**Generalized Anxiety Disorder (GAD).** GAD is characterized by chronic worry and irritability that seem to have no cause. The worry is more intense than the current situation warrants. Restlessness, trouble falling asleep or staying asleep, and muscle tension are other symptoms. GAD can occur during any phase of recovery from limb loss. Seek support or professional advice if the symptoms are incapacitating or last six months.

**Panic Disorder.** People with panic disorder experience an overwhelming terror that occurs suddenly and without warning. Symptoms include rapid heartbeat, shortness of breath, fear, and a sense of losing control or “going crazy.” Panic attacks might even occur during sleep. Since the attacks cannot be predicted, people may constantly worry about having another one. Panic disorder is often related to traumatic amputations, such as accidents or military injuries, and could begin during any phase of recovery. Seek professional help if you have four or more attacks within a month or have persistent fear that lasts longer than one month following a panic attack.

## Phases of Recovery

The Amputee Coalition of America uses these six phases to describe the recovery process following the loss of a limb.

PHASE	CHARACTERISTICS	THOUGHTS & FEELINGS IN THIS PHASE
Enduring	Surviving amputation surgery and the pain that follows	Hanging on; focusing on present to get through the pain; blocking out distress about the future – it is a conscious choice not to deal with the full meaning of the loss; self-protection
Suffering	Questioning: Why me? How will I ...?	Intense feelings about the loss: fear, denial, anger, depression; vulnerable and confused; return to enduring stage; emotional anguish about the loss of self adds to the pain
Reckoning	Becoming aware of the new reality	Coming to terms with the extent of the loss; accepting what is left after the loss; implications of the loss for future – how will roles change; ongoing process; minimizing one's own losses in comparison to others' losses
Reconciling	Putting the loss in perspective	Regaining control; increased awareness of one's strengths and uniqueness; more assertive; taking control of one's life; self-management of illness and recovery; changed body image; need for intimacy
Normalizing	Reordering priorities	Bringing balance to one's life; establishing and maintaining new routines; once again, doing the things that matter; allowing priorities other than the loss to dominate; advocating for self
Thriving	Living life to the fullest	Being more than before; trusting self and others; confidence; being a role model to others; this level of recovery is not attained by everyone

**Phobias.** These are irrational fears that lead you to avoid situations that trigger anxiety. The symptoms are similar to those experienced during a panic attack and may occur particularly following a traumatic event. If you experience fear that seems unreasonable or excessive and that interferes with your activities or relationships, seek professional advice.

**Post-Traumatic Stress Disorder (PTSD).** PTSD can occur in anyone who experiences a traumatic event, especially if that event was life-threatening. The symptoms can range from reliving the event (flashbacks) such as a military injury to an overall numbness. Other symptoms include anxiety, exaggerated or inappropriate startle reactions, nightmares, and an inability to sleep. These symptoms may be seen as a common response immediately

following the trauma but should be evaluated for ASD (*see following description*). PTSD requires professional assistance.

**Acute Stress Disorder (ASD).** ASD occurs in the first month following a traumatic event. The symptoms that define ASD overlap with those for PTSD, although there are a greater number of dissociative symptoms for ASD, such as not knowing where you are, forgetting important parts of the traumatic event, or feeling as if you are outside of your body. ASD is found following car accidents and in victims of violence. ASD is a strong predictor for PTSD, meaning that people who experience ASD are more likely to develop PTSD later on. If ASD symptoms continue for more than one month past the traumatic event, an assessment for PTSD is appropriate.

### Resources

**American Psychiatric Association**  
[www.healthyminds.org](http://www.healthyminds.org)

**American Psychological Association**  
[www.apa.org](http://www.apa.org)

**American Trauma Society**  
[www.amtrauma.org](http://www.amtrauma.org)

**Anxiety Disorders Association of America**  
[www.adaa.org](http://www.adaa.org)

**Mental Help Net**  
[www.mentalhelp.net](http://www.mentalhelp.net)

**National Center for Post-Traumatic Stress Disorder**  
[www.ncptsd.va.gov](http://www.ncptsd.va.gov)

**National Institute of Mental Health**  
[www.nimh.nih.gov](http://www.nimh.nih.gov)

**National Mental Health Association**  
[www.nmha.org](http://www.nmha.org)

# The Dual Danger of Diabetes and Depression

by Bill Dupes

Life is full of emotional ups and downs; we all have our share of good days and bad. But when the “down” times keep going or interfere with your ability to function, you may be suffering from a common, but serious, illness: depression. Depression affects your mood, mind, behavior, relationships, and even your body.



## The Elusive Symptoms of Depression

Depression's symptoms are sometimes mistaken for conditions that are associated with other illnesses. Depression symptoms include:

- Persistent sad mood
- Loss of interest in activities that were once enjoyed
- Drastic change in appetite or weight
- Difficulty sleeping or oversleeping
- Restlessness
- Loss of energy
- Feelings of worthlessness or guilt
- Difficulty thinking or concentrating
- Recurrent thoughts of death or suicide.

## A Vicious Circle

Research shows that depression is closely linked with trauma such as limb loss and with serious illnesses such as diabetes. Depression can strike anyone, but the risk is doubled for people with diabetes and two to four times higher for amputees.

Even otherwise healthy people with depression are at greater risk for deteriorating health or developing an illness. Part of the reason may be that some of the factors that increase the risk of diabetes also cause or increase the risk of depression. Some of these risk factors include being overweight, doing little or no physical activity and failing to receive healthcare. Depression leads to poorer physical and mental functioning, so a person is less likely to follow a prescribed diet or medication plan. The worse a person's health becomes, the deeper the depression grows. And so it goes.

Research has shown that about 19 million

people in the United States experience depression each year. So why is it that nearly two-thirds never get the help they need, even though counseling and medication could improve their mental health? A recent study published in the Centers for Disease Control and Prevention's *Morbidity and Mortality Weekly Report* serves to explain this phenomenon and demonstrate that depression and diabetes are even more closely linked than previously thought.

## A Wake-Up Call for the City That Never Sleeps

More than half a million New Yorkers have been diagnosed with diabetes, and an estimated 300,000 New Yorkers experience serious psychological distress (SPD), including depression. New Yorkers with diabetes are twice as likely to experience depression, anxiety, schizophrenia and other psychological disorders than those without diabetes, according to a study conducted by the New York City Department of Health and Mental Hygiene. The survey of nearly 10,000 adults also found that people with comorbid (two coexisting medical conditions) diabetes and depression are more likely than those with only diabetes to experience poor physical and mental health, live in poverty, and lack access to proper healthcare and social support.

Among New Yorkers with both diabetes and depression:

- 49 percent were divorced, separated or widowed compared with 25 percent of people with diabetes only.
- 70 percent had incomes under \$25,000 compared with 43 percent of people with



diabetes only.

- 11 percent had private insurance compared with 41 percent with diabetes only.
- 42 percent cited cost as reason for not getting a prescription filled or not seeing a doctor compared with only 16 percent of people with diabetes only.
- 26 percent used emergency rooms as their usual source of healthcare — that's more than twice that of people with diabetes only (10 percent).

In addition, New Yorkers with both conditions were:

- Nearly twice as likely to report fair or poor health (78 percent compared with 40 percent in the diabetes-only group)
- Nearly three times more likely to report that poor health limited their activities (64 percent compared with 22 percent in the diabetes-only group)
- Seven times more likely to report limited daily activities due to poor mental health (63 percent compared with 9 percent in the diabetes-only group).

### Depression: An Equal Opportunity Disorder

Nationally, depression occurs more often in females than in males. This holds true across racial/ethnic groups but appears more often among African Americans and Hispanic Americans. Other factors associated with depression include poor education; being separated, divorced, widowed or never married; and unemployment.

While both men and women can develop the standard symptoms of depression, they often have different ways of coping. Conditioned to be the “strong, silent type,” men may say they’re tired, grouchy or bored rather than admit their true feelings.

Instead of asking for help, men may turn to alcohol or drugs or become frustrated, discouraged and angry. Some throw themselves into their work to hide their depression from themselves and



others; some may respond to depression by engaging in reckless behavior.

Women often express depression by becoming withdrawn and gaining or losing weight. Although women are equally as reluctant as men to seek professional help, they are far more likely to rely on less formal resources, such as prayer or a support system of family or friends.

But depression isn't just for grown-ups; even infants are vulnerable. Studies indicate that stress has been associated with the development of allergies and the triggering of Type 1 diabetes or the autoimmune process behind it. Infants and young children are typically in close proximity to their caregivers and are very sensitive to their environment and the mood of their parents. Psychological stress in the family (marital problems, irregular sleeping patterns, illness, low socioeconomic status, etc.) can be passed on to a child, creating stress levels severe enough to trigger or promote the autoimmune progression.

### Finding Your Way Back

Fortunately, depression can be controlled if diagnosed and properly treated. The first step should be a thorough examination to rule out any physical illnesses that may cause depressive symptoms. Since some drugs cause the same symptoms as depression, you should tell your doctor about any medications you are using. If a physical cause isn't found, your doctor will refer you to a mental health

professional for evaluation.

The most common treatments for depression are antidepressant medication, psychotherapy or a combination of both. Deciding which method is right for you will depend on the nature of the depression. Medication can relieve physical symptoms quickly, while psychotherapy can provide the opportunity to learn more effective ways of handling problems.

There are other things you can do to help yourself get better. Some people find participating in support groups very helpful. It may also help to spend some time with other people and to try activities that make you feel better, such as mild exercise or yoga. Just don't expect too much from yourself right away. Feeling better takes time.

If you don't know where to go for help, ask your doctor or health clinic for assistance. You can also check the Yellow Pages under “mental health,” “health,” “social services,” “crisis intervention services,” “hotlines,” “hospitals” or “physicians.” Or you can contact the National Hopeline Network at 800/784-2433 or on the Web at [www.hopeline.com](http://www.hopeline.com) to locate a crisis center. The emergency room doctor at a hospital may also be able to provide temporary help for an emotional problem and tell you where to get more help.

*For more information, see page 25 or go to the resources section on pages 125-128 and look under Diabetes.*

# Hooked! The Danger of Prescription-Drug Abuse

by Saul Morris, PhD

It starts from the very moment of amputation when most patients are given a PCA (patient-controlled analgesia) pump so that when they wake up from the deep sleep of anesthesia they can control their own level of pain.

What am I talking about? The possibility of becoming a prescription-drug abuser or addict.

## What Is Drug Abuse and Addiction?

Drug abuse refers to using a drug for purposes for which it was not intended or in excessive quantities.

Drug addiction is a state of physical or psychological dependence on a drug and is characterized by compulsive, at times uncontrollable, drug craving, seeking, and use that persist even in the face of extremely negative consequences. Physical addiction is characterized by needing more and more of the drug to achieve the same effect (tolerance) and withdrawal symptoms that disappear when further medication is taken.

All sorts of drugs can be abused, including illegal drugs (such as heroin or cannabis), prescription medicines (such as tranquilizers or painkillers), and other medicines that can be purchased off of the supermarket shelf (such as cough mixtures or herbal remedies).

## The Risk for Amputees

It is estimated that 4.7 million adults abuse prescription drugs each year, many of whom become addicted. Though amputees are not necessarily the greatest abusers, the amount of prescription drugs given to new amputees to control their preoperative and postoperative pain greatly increases their chances of becoming abusers or addicts. And we haven't even counted all of the other medications they might already be taking. As an amputee, you will probably be taking many different drugs, not just for pain but also for sleep, nervousness, depression, etc. That's a lot of drugs, and it is very easy to fall into the trap of abuse and addiction.

## Dealing With Pain

For amputees who suffer from chronic nonmalignant pain, opioid drugs are commonly prescribed because of their analgesic, or pain-relieving, properties.

Among the compounds that fall within the opioid class – sometimes referred to as narcotics – are morphine, codeine, and related medications. Morphine is often used before or after surgery to alleviate severe pain. Codeine is used for milder pain. Other opioids prescribed to alleviate pain include oxycodone (OxyContin is an oral, controlled-release form of the drug), propoxyphene (Darvon), hydrocodone (Vicodin), hydromorphone (Dilaudid), and meperidine (Demerol), which is used less often because of side-effects.

Contrary to common fears, numerous studies have shown that addiction is extremely rare in pain patients taking opioid drugs, even those with a history of drug abuse or addiction. Patients with chronic nonmalignant pain will develop a physical dependence on opioid drugs, but this is not the same thing as addiction, which is an aberrant psychological state.

Unrelieved pain has many negative health consequences, including:

- Increased stress, metabolic rate, blood clotting and water retention
- Delayed healing
- Hormonal imbalances
- Impaired immune system and gastrointestinal functioning
- Decreased mobility
- Problems with appetite and sleep
- Needless suffering.

Chronic nonmalignant pain also causes many emotional/psychological problems, including low self-esteem, powerlessness, hopelessness and depression.

Because pain control is so important in helping people avoid these negative consequences, it is important that patients not be overly fearful of becoming addicted as long as they take their medications as prescribed.

The medical community once wrongly believed that giving pain-control medication to patients



would automatically lead to addiction. As a result, many patients suffered unnecessarily. Fortunately, it is now understood that if such patients take their medication as prescribed, the possibility of becoming addicted is almost nonexistent. Note the words “as prescribed.”

If you follow your healthcare providers' instructions, you should have no problems or worries. If you do not, watch out!

I am trained in both medicine and psychology, and I myself came very close to becoming addicted to pain medication after my own amputation surgery!

### What Causes Drug Abuse and Addiction?

This depends on the nature of the drug, the person taking the drug, and the circumstances under which it is taken. Some medications – for example, certain sleeping pills or painkillers – are physically addictive. They have a specific effect on the body that leads to tolerance and withdrawal symptoms. Others may lead to a psychological addiction if people have a craving for the effect that the drug causes.

There has been some speculation that some people may be more prone to drug abuse and addiction than others. Research is being done to learn whether there may even be genes that predispose certain people to addiction. Social circumstances are also important factors in drug abuse. Peer pressure, emotional distress, and low self-esteem can all lead individuals to abuse drugs. Ease of access to drugs is another important influence.

People abuse drugs for a reason. Understanding a person's motivation helps explain why he or she is abusing drugs.

### Prescription-Drug Abuse

Though prescription medications, such as pain relievers, tranquilizers, stimulants and sedatives, are very useful treatment tools, sometimes people do not take them as directed, and, as a result, they may become addicted. Pain relievers, for example, make surgery possible and enable many individuals with chronic pain to lead productive lives. While most people who take

these medications use them responsibly, the inappropriate or nonmedical use of them is a serious public health concern.

Patients, healthcare professionals, and pharmacists all have roles in preventing the misuse of and addiction to prescription medications. When a doctor prescribes a pain relief medication, central nervous system (CNS) depressant or stimulant, the patient should follow the directions for use carefully, learn what effects the medication could have, and determine any potential interactions with other medications. The patient should read all of the information provided by the pharmacist. Physicians and other healthcare providers should screen for any type of substance abuse during routine history-taking, with questions about which prescription drugs and over-the-counter medicines the patient is taking and why. Providers should note any rapid increases in the amount of a medication needed or frequent requests for refills before the quantity prescribed should have been used; these may be indicators of abuse.

### Commonly Abused Prescription Medications

While many prescription medications can be abused or misused, opioids, CNS depressants and stimulants are the most commonly abused.

Opioids can effectively change the way a person experiences pain. In addition, they can affect regions of the brain that determine what we perceive as pleasure, resulting in the initial euphoria that many opioids produce. They can also produce drowsiness, cause constipation, and, depending upon the amount taken, depress breathing. Taking a large single dose could even cause severe respiratory depression or death.

Opioids may interact with other medications and are only safe to use with other medications under a physician's supervision. Typically, they should not be used with substances like alcohol, antihistamines, barbiturates or benzodiazepines. Since these substances slow breathing, their combined effects could lead to



life-threatening respiratory depression.

Long-term use can also lead to physical dependence. The body adapts to the presence of the substance, and withdrawal symptoms occur if use is reduced abruptly. This can also include tolerance, which means that higher doses must be taken to obtain the same initial effects. Note that physical dependence is not the same as addiction; physical dependence can occur even with appropriate long-term use of opioid and other medications.

Individuals taking prescribed opioid medications should not only be given these medications under appropriate medical supervision but should also be medically supervised when stopping their use in order to reduce or avoid withdrawal symptoms. Symptoms of withdrawal can include restlessness, muscle and bone pain, insomnia, diarrhea, vomiting, cold flashes with goose bumps (“cold turkey”), and involuntary leg movements.

### Warning Signs of Drug Abuse or Addiction

Many signs indicate that an individual might have a drug or alcohol addiction. The following drug addiction signs are cues to look for in yourself or others. Be aware that possessing several of these signs does not always mean that a drug addiction is present. If one is suspected, however, be supportive of the individual on his or her road to recovery.

## Drug Addiction Signs

- Increase or decrease in appetite, changes in eating habits, unexplained weight loss or gain
- Smell of substance on breath, body or clothes
- Extreme hyperactivity; excessive talkativeness
- Change in activities; loss of interest in things that were important before
- Changes in habits at home; loss of interest in family and family activities
- Difficulty in paying attention; forgetfulness
- Lack of motivation, energy, self-esteem, or discipline; bored, “I don’t care” attitude
- Defensiveness, temper tantrums, resentful behavior (everything’s a hassle)
- Unexplained moodiness, irritability or nervousness; violent temper or bizarre behavior
- Unexplained silliness or giddiness
- Paranoia, suspiciousness
- Excessive need for privacy; keeps door locked or closed, won’t let people in
- Secretive or suspicious behavior
- Car accidents, “fender benders,” household accidents
- Change in personal grooming habits
- Doctor shopping – several appointments with different doctors to stock up on medication

## Do I Have a Problem?

You have a problem if you keep craving and using a drug even if it’s causing trouble for you. The trouble may be with your health, with money, with work or school, or with your relationships with family or friends who may be aware you’re having a problem before you realize it because they see changes in your behavior.

## What Other Problems Might I Experience?

When you abuse any medication, you risk doing irreparable damage to yourself, your family, and your relationship to them. If you abuse certain medications, for example, they will alter your ability to balance properly, and you could fall and hurt yourself.



Some could also cause you to miss physical therapy and/or doctor appointments, thereby hindering your healing process.

Unfortunately, even if you take some of these medications as your healthcare provider instructs, you may still experience some of these problems and unwanted reactions. If this happens, contact your healthcare provider at once so that he or she can change your medication or the dosage.

## Can Addiction Be Treated?

Yes, but addiction is a chronic, relapsing disease. It may take a number of attempts before you can remain free of drugs or alcohol. If you have any kind of drug problem, please take your first step toward healing today.

## Why Should I Quit?

Breaking your addiction is the only way to stop the problems drugs are causing in your life. It may not be easy to quit, but your efforts will be rewarded by better health, better relationships with the people in your life, and a sense of accomplishment that only living drug-free can give you. As you think about quitting, you may want to make a list of your reasons for wanting to quit.

## How Do I Stop?

The first step is realizing that you control your own behavior. You can’t control how the people around you act, but you can control how you react. It’s the only real control you have in your life. So use it. The following are the first steps to breaking your addiction:

- 1. Commit to quitting.** Once you decide to quit, make plans to really do it.
- 2. Get help from your doctor.** He or

she can be your biggest ally, even if you’re trying to quit a drug he or she prescribed. Your doctor may be able to prescribe medicine that makes you less likely to crave the addictive drug. Talking with your doctor or a counselor about your problems can be helpful too.

**3. Get support.** Contact one of the local organizations that provide assistance for substance abuse or addiction. Look up their contact information in the Yellow Pages or call your local health department for a list. For referrals to treatment programs, you may also call 800/662-HELP or visit the Substance Abuse & Mental Health Services Administration online at <http://findtreatment.samhsa.gov>.

These groups want you to succeed and will give you the tools and support you need to quit using these drugs and move on with your life. Ask your family and friends for support too.

**Note:** This article is intended for educational purposes only. For specific advice about appropriate drugs for your condition, potential side-effects/interactions, or drug abuse and addiction, you should contact a doctor and/or a mental health professional.

## Sources

**National Institute on Drug Abuse**  
[www.nida.nih.gov](http://www.nida.nih.gov)

**Schaffer Library of Drug Policy**  
[www.druglibrary.org/schaffer/asap/factsheet.html](http://www.druglibrary.org/schaffer/asap/factsheet.html)

## About the Author



*Saul Morris, PhD, is a below-knee amputee and veteran naval commander, who is educated in both psychology and medicine. He is the founder and director of M-STAR (Michigan Society To Advance Rehabilitation), an organization that provides amputee peer counseling to new amputees.*

# Not Just Surviving, But Thriving

by Rick Bowers

Since she first realized that she might need to have her left leg amputated, four things have helped Iris Navarro continue to thrive: her faith, a special book, a great sense of humor, and a new computerized prosthetic leg.

When Navarro fell from a ladder several years ago and crushed some bones in her leg, the doctors first tried to save it. Unfortunately, the leg never healed. Ultimately, her doctor told her that she should have the leg amputated and asked her if she wanted to think about it.

"No, I've thought about it enough," she replied, giving permission to amputate. She had already mentally prepared herself by talking to prosthetists and amputees and by reading *You're Not Alone*, a book about remarkable amputees.

"That book was wonderful!" she says. "At first, I couldn't read it. I would cry every time I would open it. And then one day, I just said, 'I've got to read this book.' I read every story, and it was so inspiring to see how others had endured limb loss and accepted it."

In addition to hearing others' inspirational stories, she considers the ability to laugh to be essential to the healing process. "People go with the flow," she explains. "If I had come home depressed after losing my leg, people would have followed my lead. But when I came back upbeat, people said I was an inspiration."

Along those lines, Navarro has found several ways to have fun with her prosthesis. She has her prosthetic socket painted in bright colors with images of fish, starfish and sea horses, and she uses it as a conversation piece.

Her prosthesis also has a nifty attachment called a push-button rotator, which allows her to rotate her leg at the knee and turn it upside down. Though the device is meant to help her with daily activities like getting dressed and getting in and out of her car, she also uses it for comic relief.

If she notices a child staring at her prosthesis, she'll call the child over to her. "When they come over, I ask them if they stepped in chewing gum, how would they get it off the bottom of their foot.

Then I say, 'Let me show you how I'd get it off mine.' Then I rotate my leg at the knee until it's completely upside down and the bottom of my shoe is facing the ceiling, and it just flips them out," she says, laughing.

Her amputation hasn't stopped Navarro from laughing or slowed her down. Now in her late 60s and retired, she goes everywhere. Her flashy 1970s-era yellow convertible Pontiac and a new beach buggy help her get around on and off the road with ease, and her new computerized prosthetic leg, which was largely paid for by insurance and Medicare, helps her get around on foot. In the future, she wants to visit soldiers who have lost their limbs.

Navarro has learned to thrive as an amputee, and she's more than willing to teach others her simple secret of success. It's all about painting your world in beautiful colors, laughing at yourself, comparing yourself to those less fortunate, and serving others. It's about seeing the world as a place of hope – a place of bright beginnings.

*For more information about push-button rotators, please visit [www.amputee-coalition.org/first\\_step/firststepv2\\_s1a04.html](http://www.amputee-coalition.org/first_step/firststepv2_s1a04.html)*

*To learn more about thriving as an older amputee, order a copy of Senior Step: A Guide for Adapting to Limb Loss, which is published by the ACA. Individual copies are \$15, including shipping and handling. To order, call the ACA toll-free at 888/267-5669.*



Navarro demonstrates her favorite trick



Navarro and Lance Armstrong at the Tour de Georgia

# When You Are Down and Troubled ... Finding Emotional Support

by Patricia Isenberg, MS

Reaching out is the first step in emotional recovery from limb loss. But how do you find the help that is best-suited to your needs?

This article will talk about the advantages of peer support and professional support, as well as how to evaluate the support that you receive.

## Peer Support

Peer support gives you an opportunity to discuss your feelings with someone who truly understands. The benefits of peer support include lowering stress, raising self-esteem, and finding new ways of coping.

Peer support, from a trained volunteer, can be an important component in your recovery since sharing experiences with another amputee can teach you:

- That others have similar feelings of loss and grief
- What it's like to perform daily activities without a limb
- How a prosthesis is used
- Where to find information and assistance
- How to deal with changes in family relationships
- How others cope with amputation.

The support resources available from the ACA's National Peer Network and National Limb Loss Information Center include:

- **Peer visitation.** *"There's nothing like talking to another amputee." "I wish someone had told me about peer visitation."* An ACA-certified peer visitor is a volunteer trained to be a good role model; to offer emotional support in person, by phone or by

e-mail; and to give you information about resources that are available. ACA peer visitors do not give advice or promote any products or services.

- **Online support group.** *"I live in a rural area and would have no support without friends I made in the online support group."* The ACA professionally moderated online support group is for people who do not have a local group or those who cannot attend a local meeting. The group meets twice monthly to share experiences and information.
- **Local support groups.** *"My support group is like my extended family."* Amputee support groups are a great source of emotional support and education. Many also offer social and recreational opportunities. You may contact the ACA for a list of support groups and their locations and contact information. (See pages 34-35.)
- **Information center.** *"I received a large packet of information that covered all the questions I had."* Trained information specialists, librarians, and professional advisors are available to answer your questions or find the additional resources you need to facilitate your recovery. (See pages 21-22.)

## Choosing a Psychotherapist or Counselor

Sometimes outside help from a trained, licensed professional is needed in order to work through problems. Through



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therapy, millions of Americans of all ages learn to live healthier, more productive lives. Counseling works by helping you look at your behaviors, feelings and thoughts and learn more effective ways to deal with difficult situations. Counseling, whether in individual, group or family sessions, is most effective when you and the therapist are able to communicate openly. Research has demonstrated that emotional, cognitive and physical health are closely linked and that therapy can improve a person's overall health status. The American Psychological Association recommends that you consider professional help if:

- You feel an overwhelming sense of helplessness and sadness.
- Your problems do not seem to get better, even with help from family, friends or peers.
- You find it difficult to carry out everyday activities (you are unable to concentrate on work, for example).
- You worry excessively, expect the worst, or are constantly on edge.
- Your actions are harmful to yourself or to others (you are drinking too much alcohol, abusing drugs, or becoming overly argumentative and aggressive, for example).
- You think about harming yourself or someone else.

### What Type of Therapist Do You Need?

There are many types of licensed mental health professionals, with different educational backgrounds, training, licenses, philosophies and techniques.

- **Psychiatrists** are medical doctors and can prescribe medication. Some psychiatrists also provide psychotherapy but may refer to and work in conjunction with other psychotherapists.
- **Psychologists** usually have a Doctorate in Psychology and have completed a supervised internship.
- **Counselors** usually have a Master's Degree in Counseling and have completed a supervised internship.
- **Clinical Social Workers** typically have a Master's Degree in Social Work and have completed a supervised internship.
- Other types of licensed professionals include **Marriage and Family Counselors** and **Chemical Dependency Counselors**.

### Questions to Ask

In most communities, you have a choice of mental health providers. Ask for references from your physician, friends, and the local mental health association. Then, make appointments to "interview" and select the person who seems to be the best fit for you. Ask the therapist:

- What are your credentials? May I see them?
- How long have you been in practice?
- What experience do you have working with people with limb loss?
- What are the clinical skills you might use in working with me?
- How do you view my role in the process?
- What are the charges? Do you accept my insurance?

As you are interviewing, observe the therapist and ask yourself:

- Does this person seem genuine, respectful, responsive and caring?
- Does the therapist see me as the expert in my life?
- Do I feel this person will help me solve my problems?

- How comfortable do I feel talking to this therapist?
- Did he or she answer my questions?

### How Will You Know That Counseling Is Working?

First, remind yourself that it takes time to build a trusting relationship with a therapist and to begin to see (and feel) results. But it is important to evaluate how things are going. Honest answers to the following questions will help. If your answers are positive, you are probably on the right track. If you do not feel good about some or all of the answers, discuss them with your therapist, family or healthcare provider.

- Am I beginning to understand my problems?
- Do I feel less anxious or worried?
- Is it easier for me to make decisions?
- Do I feel OK with the progress I am making?
- Am I able to discuss my feelings and what I need to work on next?

### Resources

(See Resources on page 25.)

## GUIDELINES FOR EVALUATING A THERAPIST/COUNSELOR

Adapted from the Boston Association to Stop Treatment Abuse

	Appropriate	Inappropriate (Seek help somewhere else)	Unethical (Seek help elsewhere and report this behavior)
<b>Qualifications, Professionalism</b>	<ul style="list-style-type: none"> <li>• Policies regarding fees and appointments are clear</li> <li>• Information about training and experience are available</li> <li>• Therapist is concerned about your needs</li> <li>• Therapist maintains confidentiality</li> </ul>	<ul style="list-style-type: none"> <li>• Unprofessional behavior or comments (being friendly is OK, becoming your friend is not)</li> <li>• Places too much attention on therapist's feelings or problems</li> </ul>	<ul style="list-style-type: none"> <li>• Avoids or refuses to give information about credentials/licensing</li> <li>• Uses alcohol or illegal drugs during sessions</li> <li>• Suggests or indulges in an intimate relationship with you</li> </ul>
<b>Knowledge, Skills</b>	<ul style="list-style-type: none"> <li>• Helps you learn how to deal with your life your way</li> <li>• Promotes positive change</li> <li>• Supports and encourages your self-confidence and ability to make your own decisions</li> </ul>	<ul style="list-style-type: none"> <li>• If therapist insists on drugs as the only treatment possibility and you are not comfortable with this</li> <li>• If you feel that you are giving in to the therapist, rather than finding your own way</li> </ul>	<ul style="list-style-type: none"> <li>• Makes degrading, humiliating, intimidating, or shaming comments to you or about you</li> <li>• Pressures you personally, emotionally or socially in a way that feels uncomfortable</li> </ul>
<b>Use of Feelings</b>	<ul style="list-style-type: none"> <li>• Treats you with respect, care and dignity</li> <li>• Willingly and professionally discusses your feelings</li> <li>• Demonstrates how feelings can be safely discussed and understood rather than acted upon</li> </ul>	<ul style="list-style-type: none"> <li>• If therapist suggests any mutual activity that makes you uncomfortable</li> <li>• If you enjoy the therapist's attention, but feel it's not right</li> </ul>	<ul style="list-style-type: none"> <li>• Makes inappropriate comments</li> <li>• Touches you in any way that makes you feel uncomfortable</li> <li>• Has sexual contact with you, in or out of the office, with or without your consent</li> </ul>

# Sharing the Knowledge

by Rick Bowers

In 2002, Sherri Samuels had her right leg amputated above the knee following a terrible car accident. As devastating as the surgery was, what made it worse was not having another amputee to turn to for information and emotional support.

"No one could tell me how my life would change," she says.

Finally, just before the surgery, two people paid her a visit – a family friend who is a bilateral below-knee amputee and her soon-to-be prosthetist who is also a below-knee amputee.

"When Skip, the prosthetist, came to see me, the world changed," Sherri says. "He hopped into the room and tossed his prosthesis at me with a great attitude. He also rode his motorcycle over later on after I left the hospital. It was just enlightening." It was only then that she began to find the ability to imagine a bright future for herself.



*Sherri and William Samuels*

## The ACA?

Unfortunately, Sherri didn't find out about the Amputee Coalition of America (ACA) until she came home from the hospital. "Nobody in the hospital or rehab knew about the ACA," she laments.

She finally discovered the ACA through her prosthetist. "He had the ACA's magazines, *inMotion* and *First Step*, on the tables in his office," Sherri explains. "Once I found out about it though, the ACA was very helpful."

## The Support Group

The entire incident had a profound impact on Sherri and her husband, William. In fact, Sherri had decided while she was still in the hospital to start a support group for amputees.

"I decided that no one should have to deal with limb loss alone and struggle to find information and resources like I had," Sherri says. "I had already done the research so I would be happy to share it."

So when she got out of the hospital, she and

William started planting the seeds for the support group Sherri had decided to call Out On A Limb – Memphis Area Limb Loss Support.

"We worked very hard," Sherri says. "We contacted every prosthetist, orthopedist and rehab facility we could find. We then sent out press releases to every radio station, television station and newspaper. We called every local hospital and a host of social support agencies. We followed up every phone conversation with a mailing of fliers and contact information."

Over time, people eventually began to hear about them, William says, "and they also began to realize that we were not out to sell them anything, which was important."

William, a social worker at Jewish Family Service, a United Way-affiliated social service agency, had important and useful experience working with support groups. In addition, Jewish Family Service was willing to sponsor the group.

Twelve people, including amputees, family members and professionals, came to the group's



*Bob Silver and William Samuels at the Memphis Amputee Support Library*

first meeting, which is about what they expected. "Our second meeting had almost 20," Sherri says.

The couple became even more dedicated to making the group a success once they realized that there were no other amputee support groups in or near the sprawling city of Memphis, Tennessee, where they live. And they were charged up even more when they attended the ACA's 2004 Annual Educational Conference & Exposition, where they met other support group leaders and attended some ACA meetings and workshops.

### Taking Advantage of the ACA

Since the couple found out about the ACA, it has become an important part of what they do. The ACA sent them a support group manual and other documentation that they needed to get started, and the ACA's library staff advised them on establishing the Memphis Amputee Support Library, the area's only public access library devoted to limb loss.

"Don't try to 'reinvent the wheel,'" Sherri says, advising others to also take advantage of existing resources. "We sometimes called the ACA two to five times a day and thought, 'They're going to be sick of us,' but they never made us feel we were bothering them," William says.

When the two did their first peer visit since Sherri became an ACA-certified peer visitor and William received a certificate showing that he took the training, they immediately had *inMotion* and *First Step* sent to the new amputee.

"*inMotion* is critical," Sherri explains. "It's a very professional-looking publication that shows active and interesting people doing all kinds of things, and it really makes a difference to amputees to see what's out there. A nice-looking magazine makes things seem normal. If you've got a magazine on something about you, you feel like it's okay."

### Establishing Contacts

ACA publications have also helped the couple establish relationships with

medical professionals. "Having these publications adds legitimacy to an independent support group," Sherri says. Because the couple believe that it's best to meet contacts in person when possible, having attractive literature to take along is important.

Although it takes time to meet a lot of people in person, they advise those starting support groups to do it because a lot of people are skeptical if they've never heard of you. If you can't meet them in person, the couple advise, it's important to call the facility and get the name of the person to e-mail or fax information to so that it doesn't just go to a random person and get lost. The social work or physical therapy department is a good place to get the name of a particular contact person, they say.

"If you've got the time, it's better to take one place each week, make an appointment, and go down and meet with them," William stresses. "Let them see you, take copies of *inMotion* along, and don't take a lot of their time."

They agree that prosthetists' offices and then social work and physical therapy departments are probably the best sources for meeting amputees. They say it's usually a waste of time to try to go through administrators at large hospitals, unless the hospital is in a small town. "The administrators are just too busy," William says.

### Giving Others "Ownership" of the Group

Although Sherri and William have invested a lot of themselves in starting the group, they don't feel the need to control everything.

"Don't make your group a 'sole proprietorship,'" Sherri advises. "Share the responsibility, and give other people 'ownership' in it. One person can't do it all, and these people have skills and ideas that they can bring to the group to help it grow beyond what you can do alone."

The two are more concerned about

fulfilling their mission of support for amputees than being in charge. They believe that knowledge is power, and they are willing to share everything they've learned over the years about limb loss and building a support group.

"The opportunity to share all of the interesting and useful things that I've learned and to share all of the people that I've met has been a real blessing," Sherri says. "Connecting with people – sharing knowledge. That's what truly matters."

*Anyone developing or enhancing an existing amputee support group is encouraged to call Sherri and William at 901/767-8511 or to e-mail them at MemphisLimbLoss@aol.com. You can also become a part of their online support list serve at <http://groups.yahoo.com/group/MemphisLimbLoss/>.*

### Reaching Out to Others

In response to the devastation left by hurricanes Katrina and Rita, Out On A Limb provided support and information to local relief organizations, medical providers, displaced amputees, people with medical conditions that might require amputation, and their families. Among other things, members of the group visited emergency shelters, clinics, and local hospitals to distribute information (including ACA's *inMotion* and *First Step* publications) and provided trained amputee peer visitors.

"We explained to the Red Cross how critical it is that sick amputees facing surgery receive peer visitations and how vital a role the Amputee Coalition of America can have in helping amputees and families reestablish themselves after their trauma," says a representative of the support group.

# Going Public: Overcoming the Emotional Barriers That Keep You Inside

by Warren Sumners, MA

# W

Why is it so difficult for many amputees to go out in public?

Why was it so difficult for me to go out when I first became an amputee?



*Warren Sumners talks to his grandson Mitchell about their day out at Disney World.*



No doubt, there are physical barriers, but the most difficult barriers for many of us are the ones in our minds. We can find ways to deal with the physical barriers if we can get a handle on the emotional ones.

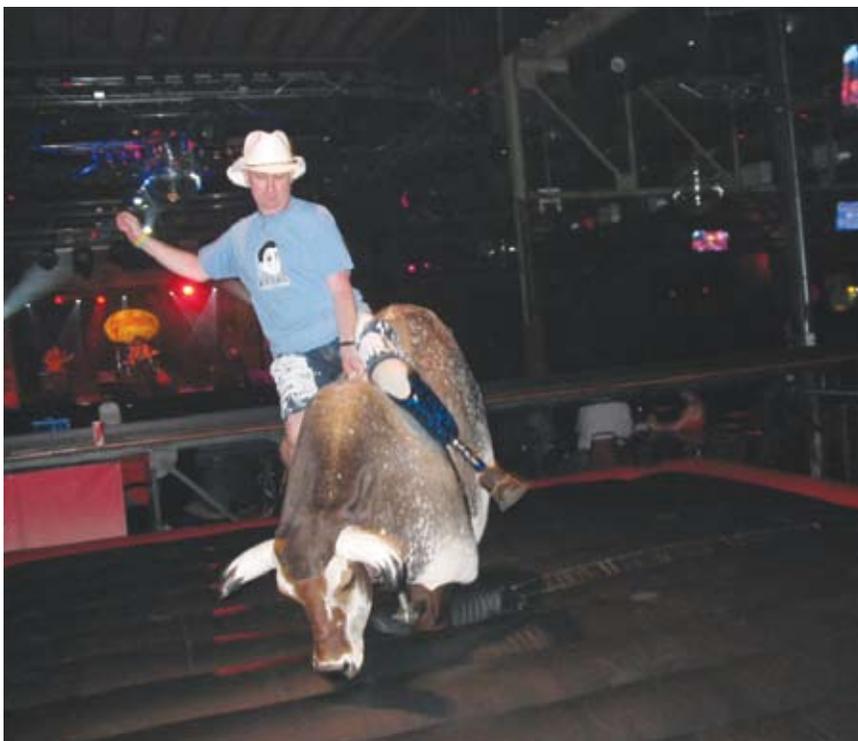
We know that we should leave the house, and we want to, but we don't know how we will be able to get along in the world as amputees. And it's easy to see why this "new world" is so scary. As new amputees, we must deal with the trauma of our amputation, its impact on our job or career, its impact on our finances, the stress of daily living, depression and anxiety, concerns about sexual relations, our changed relationships with family and

friends, our new self-image, and on and on. And even if we've been amputees for a while, these problems can periodically return to haunt us.

Still, getting out of the house can help us in many ways. It can improve our attitude, give us the opportunity to exercise, help us stay busy, give us the opportunity to be around others, help eliminate boredom from our life, help us get back to work, and help us build our support system. Usually, the busier we are, the better off we are physically and emotionally.

## **The Risks of Going Out**

Certainly, when we first go out of our house after



our amputation, we are at risk for physical problems like falling, getting injured, difficulty finding a restroom, and even being stranded with no one to help us. Perhaps even worse, we are at risk for being rejected, being thought of as a “freak,” being ridiculed, being stared at, being laughed at, being pitied, having to answer uncomfortable questions, and being dependent on others. Even after a few trips out of the safety of our house, we may still be uncomfortable and filled with self-doubt in public. It will be even worse if we have had a bad experience the first time we ventured out.

I have several close friends with Parkinson’s disease and multiple sclerosis, and they tell me that they have the same types of fears. Even worse, people may think that they are drunk because of their loss of motor coordination and the “shakes” they experience. Yet, these friends still strongly agree that getting out and participating in life is essential to their long-term health.

### Facing the Facts and Our Excuses

We must face the fact that we are going to be amputees for the rest of our life. Our

lost limbs won’t grow back! So unless we plan to stay home forever, we’re going to have to go out sooner or later.

We must also face the fact that we will always be physically different from others and then decide how we’re going to handle that. Sure, we are missing a part of our body, but the core of our being was not in that limb. We were not our leg, arm, foot or hand before becoming an amputee so why should we be defined in that way now?

We can define ourselves rather than letting others do so. We can decide if we are “handicapped,” “inconvenienced,” “disabled,” “a person with a disability,” or “a differently abled person.” It’s our choice. And it could affect the rest of our life since others tend to see us as we see ourselves.

Certainly, it takes hard work to have a positive attitude. We all have feelings of frustration, pain, depression, concerns about looking different, feelings of dependence, and the feeling that we are a burden to those around us. We can’t let those be the focus in our life, however.

We must also face our announced reasons, or excuses, for not going out today: “My stump hurts. It’s too hot or cold. I

don’t feel well. I’m tired. My hair is a mess. I’m waiting for a phone call. I need to polish and wax my wheelchair or prosthetic leg. I want to go alone. I don’t want to go alone.” Or whatever other excuse we can think of. Though there are times when our reasons are quite legitimate, we need to make sure that we aren’t just making excuses. Excuses are unacceptable when they prevent us from living the life we deserve.

The longer and more often we stay away from the public, the harder it gets to go out. Prepare yourself mentally, and expect the best. A friend used to say, “Don’t horriblize.” Don’t dwell on the negative things that might happen if you go outside. Not going outside also has a high price.

### Small Victories

My life as an amputee has been a series of small victories. Like washing dishes, cooking a complete meal, traveling out of town on a business trip, taking my grandkids to Disney World. Learn to celebrate every victory! Going out of the house is a major victory that will have a long-term impact on your life and those around you.

My first trips from the house were just for short walks in the neighborhood. I felt like everyone was staring at me because I looked so different. I thought I was a freak! Actually, everyone just smiled and waved or stopped to talk and ask how I was doing. It was actually fun.

Next, I went to the grocery store with my wife. Many adults would not look at me and seemed embarrassed. Children were much more honest and stared at my empty sleeve. This upset some parents, but I just smiled at the kids, showed them my empty sleeve, and told them that I had lost my arm in an accident. Most would smile back and say, “OK.”

After that, I moved on to going to restaurants, to church, and to see friends. I also joined a Toastmasters club. The amputation did not hold me back or define me as a person.

I discovered that many people fear what they don't understand. They haven't been around amputees so they don't know how to act. We need to make the effort to help them understand and put them at ease.

What did you know about amputees before your amputation? Your family, friends and neighbors are your support system, but even they usually don't know what to say or do. Don't expect them to understand what you are going through without your help. Two-way communication is critical.

And one more thing: Don't take your problems out on them when they make simple mistakes. They did not cause your amputation nor are they bad people because they have all of their limbs.

### “Horriblizing”

When you think of venturing out into the world, do you feel queasy thinking about all of the things that might go wrong? “I might get attacked because criminals might see my amputation as a weakness. I might get stranded and be unable to walk to get help.” These are certainly things that could happen, but the solution may be preparation rather than withdrawal from the world. Some companies, for example, will give you a free cell phone that only calls 911 in an emergency.

Although you might fear being attacked by a stranger, you will more likely be subjected to all kinds of acts of courtesy and kindness from them. There are many nice people out there. They open doors, offer to carry packages, or just want to help in any way they can. One amputee told me she was surprised to have a perfect stranger pull her out of a snow bank. Another said that she was offended at first when people wanted to help her, but she finally understood that they were just trying to be courteous.

Accept these kindnesses with grace, a thank you, and a smile. Note: I know that they are making that extra effort because of my amputation, but they just want to



be nice, and it makes them feel good. This is not pity. Remember, you are a person of worth.

### Meeting Others

Support groups can be a wonderful addition to your life and a good reason to go out. At support group meetings, you will find people you can share your experiences and concerns with. You will likely develop special bonds with some of them. In addition, you will get the opportunity to enjoy special speakers and “amputee humor” that can only come from other amputees.

Don't expect a “pity party.” Most of these amputees don't have time for that in their lives.

I was not eager to attend my first meeting of Amputees Together in Tampa, Florida, because I felt that I didn't need support. Wrong! It was a great experience. Now, my wife and I look forward to each meeting. In that room, my wife and other nonamputees are the ones who are different.

If you can find a support group in your area, give it a chance. If not, contact the Amputee Coalition of America (ACA) to help you find or start one.

Otherwise, consider joining us in the ACA Online Support Group once a month.

We discuss all kinds of topics: going out in bad weather, driving a car, pain management, being a burden to those around us, and so forth. And there's also amputee humor, of course.

If you're not ready to go out yet, participating in the ACA Online Support Group is a great way to start meeting people again and preparing to “go public.” Lean on us a little. It doesn't mean that you are weak; it shows that you are smart.

Every day and every week, we should be adding good things to our life. Going out should be one of the things we are thinking about. Do it now. You can't do it any younger.

*For more information about the ACA Online Support Group or to join, call 888/267-5669, or visit the ACA Web site at [www.amputee-coalition.org](http://www.amputee-coalition.org)*

### About the Author



*Warren Sumners has a Master's Degree in Counseling, is a right shoulder amputee, and is the volunteer national facilitator for the ACA Online Support Group.*

# Altered States

## *Our Body Image, Relationships and Sexuality*

by Sandra Houston, PhD

**B**ody image (the attitudes we have about our body) and self-perception (our thoughts, feelings and reactions to our selves) are issues that everyone deals with.

Early in life, we are taught to be aware of our body shape, size and physical attributes. Our body image changes as we go through life, interacting with others in various situations, both good and bad. The Hollywood ideal is impossible for most of us to achieve, yet our self-perceptions are shaped and driven by the media and lead us to want to be thinner, prettier and healthier. The further we see ourselves from these artificial standards of beauty, the more likely our body image will suffer.

Obviously, after the loss of a limb, we become even further removed from these ideals. We are forced to deal psychologically with changes in function, sensation and body image. But the more you focus your energy on what's missing – not just the limb but also the things you could do before – the more likely you will become depressed and angry. In fact, many studies have found that the more negative amputees feel about their body image, the less satisfied they are with their life. It doesn't have to be that way for you, however. Psychological studies have also found that the majority of amputees are well-adjusted and have full and rewarding lifestyles.

The way to learn to live with these altered perceptions is by recognizing that you're still basically the same person inside that you were before the amputation. Successful adjustment is achieved by focusing on overcoming obstacles, learning to do the things you enjoyed before (which may require some creative adjustment), and seeing yourself as a whole person who just happens to have a missing body part. Don't limit yourself with the label of "disabled." The focus should no longer be on what's gone, but on the future.

If you have a prosthesis and are learning to use it, your body image will probably begin to change to incorporate the artificial limb. You'll know this is



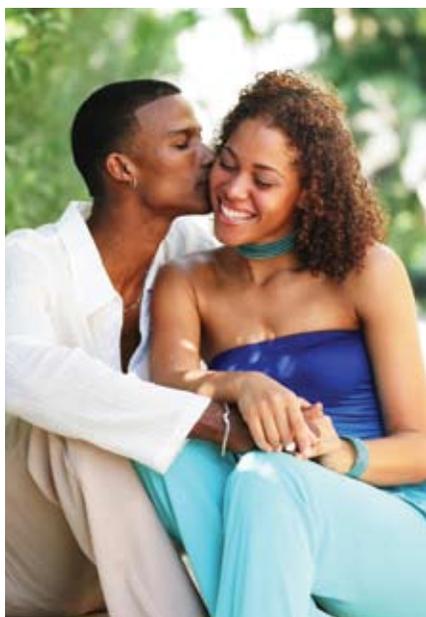
starting to happen when you begin to feel naked without it.

### **Relationships**

Relationships with others come in many forms. There are those people we are intimate with, nodding acquaintances, and those in between. Regardless of the degree of closeness, the connections we have to others have a profound impact on our quality of life. People who feel lonely and isolated are far more likely to experience depression and even physical disease than those who have a sense of connection and community. When we have no one else to communicate with, we are left to focus solely on ourselves. With nothing else to distract us, we tend to dwell on our problems and pain.

Some amputees may view their body change as a mark of shame. Afraid of rejection, they may view themselves as less desirable and then





project these feelings onto their friends, relatives, and even strangers. By doing this, they shut themselves off from friends and potential relationships to avoid the anticipated pain of rejection. Because social support and intimacy are so important to our physical and mental health, however, it is imperative that the new amputee recover from such a poor self-image. Fortunately, recent studies of people's social reactions to amputees indicate that a social stigma no longer exists, particularly when the amputee initiates the interaction. This is further evidenced by the marriage of former Beatle Paul McCartney to Heather Mills, an amputee.

Love and intimacy are what make us feel whole. Relationships are one of the most powerful factors in our emotional and physical well-being. But to feel connected to others doesn't mean you have to surround yourself with a crowd. Your need for connection can be met through those with whom you already share love and affection. It can also be fulfilled by getting involved in new activities with others. In this regard, joining an amputee support group can be beneficial in many ways. When you meet with other amputees who are living full and satisfying lives, you're more likely to believe you can do the same.

Healthy relationships are based on a mutual give and take of friendship, trust and respect. You may have lost some of your independence after the amputation so some of these relationships may need a discussion of how to adjust the balance of give and take. An amputee's spouse or parent may often feel overwhelmed by the new responsibilities he or she has to face. Communication is the key here. Discuss everything, "no holds barred." The more you can openly and honestly discuss your anger, fear and frustrations, the healthier and stronger the relationship will become.

## Sexuality

Many people believe that if you don't have sexual intercourse, you're not a sexual person. The truth is that we're all sexual beings. Sexual interaction is, however, the physical expression of our feelings and emotions in a loving relationship. Unfortunately, sexuality (which embraces the whole self) is often used synonymously with sex (generally meaning sexual intercourse).

Touching, affection and emotion are often overlooked aspects of sexual activity, even though touching and being touched are basic human needs. In fact, studies show that babies who don't receive the comfort of a loving touch develop later than those who do.

Unfortunately, some amputees say that limb loss limits their sexuality. This is often associated with a negative self-image. Because society's view of sexuality is based on youth and physical attractiveness, you may feel that you are less sexually attractive after your amputation and avoid this part of life.

Sexual intimacy places you in a vulnerable position with your partner and puts you at risk for rejection. It is crucial, therefore, that you and your partner discuss your fears and anxieties about your body and how it might now look and function somewhat differently. Without open communication, there is a lot of room for misunderstanding and

hurt feelings.

Our sensuality and sexuality always begin with us, and we sometimes create our own barriers to expressing these components. One of these barriers is concentrating too much on the performance and not enough on the sensations. To fully experience the sensations of touch, you must let go of all thoughts and expectations and focus on the sensations of pleasure available at that moment. As your awareness of the sexual sensations improves, both your self-image and level of sexuality will improve.

Sex is a give and take proposition. We alternate between focusing on our partner's pleasure and our own. There are many ways to share pleasure so give yourself permission to expand your definition of sexual expression. What may have once been a comfortable position for you may, since your amputation, be uncomfortable or even painful. In addition, you may experience balance problems. Sometimes, something as simple as positioning with pillows can help with your stability. Sex is the fun part of a relationship so experiment, explore, and enjoy discovering what works best for you and your partner now. Amputees all over the world have returned to loving, sexual relationships after their amputation. You can too.

## About the Author



*Sandra Houston, PhD, is a clinical psychologist and retired professor of psychology from the University of Central Florida. She had a private practice*

*for 30 years, specializing in marriage and sex therapy. She has been a hip-disarticulation amputee since 1982. With over 50 professional publications and presentations, she continues lecturing and writing in the field of rehabilitation psychology.*

# Swept Off Your Feet

by John P. Foppe

Being born without arms, I often wondered if I would ever find someone to love me. I certainly experienced my share of dating failures and rejections. Despite each slight, however, I tried to maintain a positive attitude.



I rationalized that I had a good life. I pretended to be content. I admitted that dating was a struggle, but I kept trying. Though I might have looked OK on the outside, inwardly, I experienced moments of deep frustration, resignation, self-pity, anger and impatience. As I watched my friends and younger brothers marry, I felt like the hunchback, Quasimodo; I felt weak, ugly and powerless as the world of love left me behind. One August day, three years

ago, however, my Esmeralda walked in and turned my life upside down.

I was the guest speaker for a local organization's fundraiser, and several of my family members attended. My brother Jim's fiancée, Emma, invited her girlfriend and roommate, Christine, along to hear me. While people mingled during the cocktail hour, I sat off to the side with a pen and paper in my toes, putting the final touches on my speech.

My brother Ron sat down beside me, gently poked me, and whispered, "Check out the good-looking girl who just walked in with Jim and Emma." I looked up from my notes and spotted a tall blonde in a sleek ruby-red summer dress. Meg Ryan just walked in the door, I thought. Her wavy gold hair glided across her sun-drenched cheeks as she gracefully turned to shake someone's hand. In a smoked-filled room of gray suits and dull dresses, she radiated a confident, sexy aura of femininity.

"I bet Paul flirts with her," Ron quipped under his breath.

Obviously, she was closer in age to me than she was to my younger brother Paul. I was miffed that Ron didn't see me as a contender for her attention. But, thankfully, Ron's comment irked me into action. Otherwise, I would have hesitated, allowing her beauty to intimidate me, fearing she wouldn't be attracted to a guy without arms.

"Not if I get there first!" I said.

Defiantly, I sprang up and walked across the room to meet her. I remember the gleam in her piercing blue-green eyes as I introduced myself. She told me that she had heard about me through her job and that she had always wanted to hear me speak. Flattered, I thanked her for coming.

Though I have been speaking to groups for 15 years, the speech I gave that night was like no other I have delivered before or since. I was nervous but not for all of the usual reasons a speaker gets nervous. I could see Christine clearly from the podium, and I wanted her to enjoy what I said and to respect me for saying it. As I spoke, all of the other audience members faded.

"You're a funny speaker," Christine said afterward. I asked her if she wanted to go out for a drink. We all went to a nearby lounge, and I, of course, sat next to Christine. We talked effortlessly.

Christine was different, comfortable to be with. I felt no need to impress her. I didn't feel guarded. The cynicism and



fear that usually clouded my head and hardened my heart were gone.

When it came time to say goodbye, Christine invited me to a pool party she was hosting the following weekend in St. Louis, where she lived. Though I was delighted, I felt uneasy about going to a party where I wouldn't know anyone. Then I remembered that Emma and Jim would be there, which was reassuring.

Jim and I went to the party together. I met Christine's entire family, and we visited over a meal of hot dogs and hamburgers, which I ate with my feet. What were they thinking?

I debated internally whether or not to go for a swim. I knew that once I took off my shirt and exposed my stubs, Christine's nieces and nephew would ask all sort of questions. But, this was a pool party. Christine said she loved the water. It would have been easier to have muscular arms under my shirt, but long before that day, I had come to terms with the fact that my disability would never change. I had been down the self-pity road before, and it was a dead end! I needed to take the higher road, to show her confidence. And kids' questions were a good way to

break the ice. So, I sat on a lounge chair, pulled off my shirt with my toes, and jumped into the pool. As I suspected, the kids asked their questions. I answered matter-of-factly.

Before I left, I asked Christine if she would like to go out to dinner Saturday night. "Yes," she said, without hesitation. As my one-hour drive home from St. Louis sped by, her "yes" played over and over in my mind. Happiness spread down to my toes.

As the new week began, I couldn't stop thinking about her. I counted the days until Saturday. With only two days remaining, on Thursday afternoon, I had to go back to St. Louis for an appointment. I realized that I would finish my meeting about the time that Christine got off work. I am driving all the way over to St. Louis, and I will be close to where she lives, I thought. I'd really like to see her.

Often, when two people first begin to date, an invisible "person" visits them in the form of a voice in their minds, speaking to their insecurities and past hurts. Sometimes it starts to strategize and calculate the next move for them. "Is this the right time to call?" it asks. "Maybe it's

too soon.” Sometimes, the voice simply prevents them from enjoying the moment, asking sabotaging questions like “What is she thinking?” and “Does he like me?”

By Thursday, the insecure voice in my head was running amuck, asking all sorts of questions. I called Jim and explained my concerns. “Everything is already set up for our date on Saturday,” I said. “I don’t want to come on too strong. Maybe I should leave well enough alone?”

When I finally finished, there was a long silence on the phone. Finally, Jim spoke in his monotone voice. “You’re plotting, but not about how to see Christine,” he said. “You’re wondering how to protect yourself from getting hurt.” The voice of truth!

How many times had I been hurt before? In high school, some girls slighted me in favor of hooking up with my athletic buddies. In college, my Spring Formal date cancelled at the last minute with some lame excuse. In my early 20s, a young lady stood me up and left me standing in a restaurant parking lot for over an hour. And, there was the woman who fell asleep on my couch while I cooked her dinner. And now, could I trust Christine?

Through the line, Jim’s voice brought my thoughts back. “Get out of your head and into your heart,” he said. “Be authentic; tell her that you want to see her.”

Jim helped me to see that I had developed a deep wound of rejection. Over time, a scab of fear had grown over the injury, and now it was exuding frustration and resignation. Just removing my shirt at a pool and pretending to be confident was not going to do it. Healing meant stripping myself of something else, of my deeply-held belief that no woman could love *me* – a man without arms. I had to be truly open to the possibility that Christine might like me.

I took a deep breath and called Christine. I simply told her that I would be in the neighborhood and that I’d like to see her. I proposed that we get a cup of coffee. She agreed.

We met at Borders and talked about the happenings of our week. A couple of hours flew by.

On Saturday night, Christine answered the door wearing a stunning short black dress. Her gold hair was drawn up into big, alluring curls. We went to Bar Italia, a sophisticated restaurant in St. Louis’ cosmopolitan Central West End district. On the wrought-iron-fenced terrace, we dined over a delectable meal of veal and red wine. We talked about our families, friends and religion. We laughed about past dating misadventures. There was never an awkward silence. That night, the hesitant, insecure voice in my head kept silent.

Depending on the formality of a restaurant, I sometimes take off the sock covering my left foot when I eat. I hold the utensil in my toes. So after dinner, I reclined in my chair resting my bare foot on my knee under the table. While I was

sharing a story, I felt the warm, tender touch of Christine’s hand holding my foot. The gleam in her eye was stronger than ever. No woman had ever expressed such intimate affection to me before. I instantly knew I could trust her.

I was swept off my feet! Several weeks later, after 54 days of dating, we were engaged.

In the end, Christine says it best: “You can’t control who you fall in love with.”

#### About the Author

*Professional speaker John Foppe's mission is to redefine human ability. He is a disability coach and the author of What's Your Excuse? Making the Most of What You Have, which has been translated into Spanish and is available via his Web site ([www.johnfoppe.com](http://www.johnfoppe.com)). You can contact Foppe by e-mail at [seminars@johnfoppe.com](mailto:seminars@johnfoppe.com)*

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# When to Help Your Child and When to Let Go

by Rick Bowers

If you have a child with a limb difference, one of the questions you must ask yourself is, “How much should I help my child?”



Different parents answer in different ways. Some cater to their child's every need and protect him or her from the outside world in every way. Others step back and let their child learn to do things for himself or herself.

Many people with limb differences go on to live happy and successful lives. They become doctors, prosthetists, truck drivers, lawyers, judges, athletes, police officers, firefighters, nurses, soldiers – you name it. And seemingly without exception, the ones who learn to do things for themselves are the most successful.

## Life-Changing Moments

Many of them, like John Foppe, who was born without arms, can point to the time in their life when their parents “saw the light.”

When Foppe was a child, he was dependent on others until he was in the fifth grade. That's when his mother, Carole, decided to get her son over his dependence on others. She told his brothers not to help him anymore. They weren't to help him dress, get items from the cupboard, or do anything else.

Foppe recalls lying on the floor sweating, crying and struggling to put his pants on alone without arms. He calls it the turning point in his life. By the time he reached high school, he was amazingly adept at using his feet for hands.

Now in his 30s, Foppe has a Master's Degree in Social Work and is an author and motivational speaker. He drives, paints watercolors, types, cooks, and even eats bratwurst and big, greasy cheeseburgers – all with his toes.

Foppe attributes much of his current success to his family's tough love. "At first, I hated it," he says. "I didn't understand how they could be so mean." But now, he says, "I'm eternally grateful."

### Exceeding Expectations

Expect as much from a child with an amputation as you would from any other child, advises Mary Williams Clark, MD. "Give them chores to do," she says. "Work hard if you have to with their teachers so that they're not given high grades 'because he tries so hard' or regarded as 'the poor thing – it's hard for her.' People who do that do them no real favor."

Children with limb differences seem to do better when parents only give assistance when necessary and don't put limitations on them. When parents expect great things from them and let them learn to do things for themselves, they are often surprised at how much their children can do.



Liz Uchytel, "she was always doing things for herself. I worried that she would not be able to crawl because you need two hands and I was sure she was going to fall on her face. But, she taught herself how to crawl." Uchytel also surprised her mother when she became a baton twirler at age 6 and when she later learned how to type with speed and accuracy.

the elbow, supports such a view. "Within reason and with appropriate accommodation, being treated like other children is probably best for amputee children," he says.

Still, there are many ways parents can effectively help their children, Baird explains. "Just like with other children," he says, "parents can help by showing as much love as they can,

*"I am one of five girls. My parents claim that the reason that I turned out 'so good' was that they never had the time, or the energy for that matter, to treat me any differently than the other girls." – Theresa Uchytel, Miss Iowa 2000*

### Becoming Miss Iowa

Theresa Uchytel (pronounced you-ka-til), who was born without a left hand, is a perfect example.

"As Theresa grew," says her mother,



It was probably even a greater surprise when Uchytel grew up to become Miss Iowa in the 2000 Miss America Pageant, a world champion baton twirler, and a program manager at Gateway Computers.

"I am one of five girls," she explains. "My parents claim that the reason that I turned out 'so good' was that they never had the time, or energy for that matter, to treat me any differently than the other girls."

### Helping Children Help Themselves

Pryor Baird, an MD in Psychiatry who was born without a left arm below

by helping the child find and develop areas of interest and strength, and by helping the child adapt to 'a world of nonamputees.'"

He explains how his father helped him help himself rather than do everything for him. "When I was 6," he explains, "my dad, who was an engineer, did not cut my fingernails but instead designed a one-handed nail-clipping device for me. Later, when I was a medical student at the University of Virginia, my dad designed a device that allowed me to 'percuss' (tap on) a patient's abdomen or thorax – a task that normally requires two hands."

Rudy Garcia-Tolson (Photo courtesy of Challenged Athletes Foundation)



### What About Sports?

Parents might be tempted to think, "Well, yes, my child can study just like anyone else and excel in school, but he or she can't do "rough stuff" like sports.

Consider Rudy Garcia-Tolson.

Garcia-Tolson was born with several rare congenital birth defects. When he was 5, the doctors gave him and his parents a choice: Keep his legs and stay in a wheelchair or walk with the help of prostheses. He chose to not only walk, but to swim and run as well. Soon after recovering from bilateral knee disarticulations, he began swimming,

### Let Them Reach for Anything

Paddy Rossbach, president and CEO of the ACA, notes that parents are pleasantly surprised when their children or teens with limb differences return from events they have attended alone, such as the ACA's youth events, because, almost without exception, they notice a big change in their children; they have matured, become more independent, and suddenly realize that not only are they not alone, but they are capable of and able to do much more than they thought. Because of this, Rossbach encourages parents to

the same way you would treat your other children. Parents who try to do everything for their children are sending the message that they are not able to do things for themselves."

She offers the example of one of the ski camps she ran. "It included four 6-year-olds away for five days for the first time without their parents," she says. "Not only did they all learn to ski, but they learned to put on their own prostheses! They returned home full of things they could do."

It is also very important, she says, for parents of children with limb differences to learn from other parents who have faced the same situation. Support groups, she notes, are excellent for people to meet and discuss issues of common interest in a relaxed atmosphere. Hearing how other parents have learned to cope and let their children "fly" will enable them to open the door to a brighter future of independence for their child. (See

*"Within reason and with appropriate accommodation, being treated like other children is probably best for amputee children." – Pryor Baird, MD in Psychiatry*

earning 43 ribbons and 14 medals in two years. When he decided to take up running, he entered competition with athletes of all abilities with the use of prosthetic feet. At the age of 10, he was the youngest bilateral amputee to complete a triathlon.

In 2003, he was selected as one of *People* magazine's 20 teens who will change the world. Now just 17, he's competed in several triathlons. He's carried the torch for the 2002 Olympic Winter Games. And he's broken numerous records on the track and in the water, including the world record for the men's 200-meter Individual Medley swimming event at the 2004 Athens Paralympic Games where he also won a gold medal.

encourage their children to reach for anything even if it seems impossible. "They will never know unless they try," she says.

"People with disabilities need to be stronger and more confident than those without if they are to compete with their able-bodied peers," Rossbach says. "This is why I stress the importance of 'letting go' of one's child with a disability as quickly as possible. By letting go, I mean let them be independent, deal with situations and do things for themselves. This will give them a sense of achievement, boost their self-confidence, and prepare them for some of the situations they will inevitably face in life. Probably the best advice is to treat this child

pages 32-35, or contact ACA for a list of support groups or camps in your area.)

Jim Abbott, a famous one-handed major-league baseball pitcher, once said that he will always be thankful that his parents never allowed him to use his lack of a hand as an excuse. Yours will probably be thankful too.



Courtesy of Jim Abbott ([www.jimabbott.info](http://www.jimabbott.info))