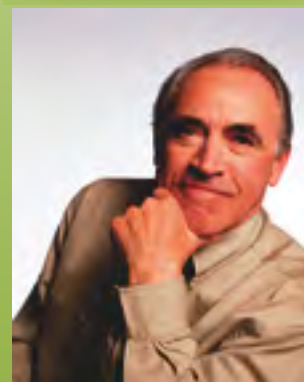
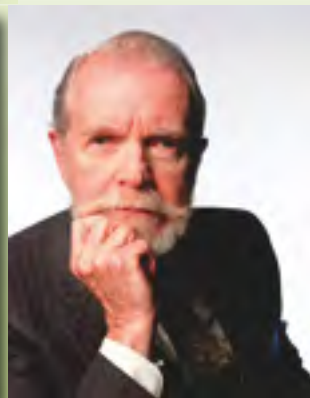


Senior Step


A Guide for Adapting to Limb Loss



A Publication of the National Limb Loss Information Center

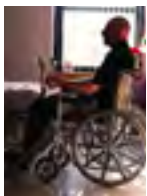









Senior **Step** Table of Contents

	6..... Coping With Aging and Amputation: How Changing the Way You Think Could Change Your Health
	10..... One Step at a Time: Recovering From Limb Loss (handout)
	13 Getting By With a Little Help From Our Friends: Resources for Recovery (handout)
	14 Dealing With Grief and Depression
	17 Coping With Amputation: Is It Grief or Depression? (handout)
	18 Pain Management and the Amputee
	23 What You Need to Know About Pain Medications (handout)
	24 Alternative Pain Management Therapies (handout)
	25 Pain Resources
	26 What Happened to Your Leg, Grandma?
	29 When a Grandparent Loses a Limb: Helping Children Cope (handout)
	31 You and Your Prosthetist: Making the Relationship Count
	34 To Wear or Not to Wear . . . A Lower-Limb Prosthesis
	38 Older Adults Can Thrive as Prosthesis Users
	41 Young at Heart (handout)
	42 Tips for Skin and Socket Care
	45 Avoiding Injury: Safety Tips for Seniors With Amputations

Senior Step

Table of Contents

	48 Before You Fall: Tips for Preventing Falls in the Home (handout)
	49 Assistive Devices: Restoring the Comforts of Home (handout)
	51 Choosing an Assisted Care Facility
	54 Weigh to Go: Weight Control for Amputees
	57 Weighing Your Options for Weight Loss (handout)
	58 Keep Moving: Exercises for People With Lower-Extremity Amputations (handout)
	61 Keep Moving: Advanced Exercises for People With Lower-Extremity Amputations
	64 Questions About Blood Pressure (handout)
	65 Vascular Disease (handout)
	67 Saving Your Other Limb
	69 Who Cares for Caregivers?
	71 Other Caregiver Resources
	72 Resources for Seniors With Limb Differences and Their Caregivers (handout)
	76 Caregiving Tips: Journaling
	77 The Special Needs of Geriatric Patients in O&P
	82 The Team Approach to Amputee Rehabilitation
	86 Annotated Bibliography



Welcome to *Senior Step* . . .

Famed bandleader Les Brown once said, "You are never too old to set another goal or to dream a new dream." But is aging well with limb loss an impossible dream? We think not. ACA's goal with the publication of *Senior Step* is to provide a resource guide to support and educate older amputees, their caregivers, and their service providers.

Aging baby boomers, diabetes, obesity, and a sedentary lifestyle are all contributing factors to an increase in amputations. We know, however, that education and a commitment to lifestyle changes can prevent or improve the conditions that place older Americans at risk for amputation. If you have already suffered an amputation, education and a similar commitment to change can become your foundation for an enhanced quality of life.

Whether you are aging with limb loss or are a new amputee, a caregiver, or a service provider, we hope you find something within these pages to inform, inspire, or motivate you. Articles designated as handouts in the Table of Contents may be copied in multiples and distributed without permission from the ACA.

As always, we welcome your feedback. Let us know what you think about *Senior Step* and what you think ACA's next steps should be.

With warmest regards,

Patricia J. Isenberg, MS, CMT
ACA Chief Operating Officer
Manager of Training & Outreach

The Amputee Coalition of America and the National Limb Loss Information Center do not endorse any specific technology, company or device. Consumers are urged to consult with their healthcare providers before making any decisions involving their care.

Senior **Step**

Published by

Amputee Coalition of America

900 E. Hill Ave., Ste. 285

Knoxville, TN 37915-2568

865/524-8772

1-888/AMP-KNOW (267-5669)

FAX & TTY: 865/525-7917

E-mail: editor@amputee-coalition.org

Web site: www.amputee-coalition.org

ACA Mission

To reach out to people with limb loss and to empower them through education, support and advocacy.

President & CEO

Paddy Rossbach, RN

Editor

Nancy M. Carroll

Senior Editor

Rick Bowers

Associate Editor

Bill Dupes

Graphic Design

Patrick Alley

ACA Medical Director

Douglas G. Smith, MD

ACA General Counsel

Douglas McCormack, Esq.

ACA Board of Directors

Executive Board:

Chairman

David McGill

Vice-Chair

Maynard Carkhuff

Secretary

Kathleen K. Spozio

Treasurer

Charlie Steele

Directors:

Jeff Cain, MD

Eve Rachel Markewich, Esq.

Patrick Chelf

Richard N. Myers, Jr

Marshall J. Cohen, Esq.

Marianne Rankin

Hon. John J. Farley, III

Sarah Reinertsen

Ralph Fowler

Acknowledgments

Senior Step was a dream project that began more than two years ago. Early on, Kevin Carroll, Karen Alberts, and Ross Taubman helped define the project. Susan Tipton conducted the consumer and professional needs assessment survey. Katherine Sluder and Lynn Luna conducted extensive research for background information and to identify appropriate resources. Guidance (and deadlines) from Rick Bowers and Nancy Carroll were instrumental at every stage of development. Paddy Rossbach, Leslie Duncan, Vicki Foster, and Penny Bever provided ongoing encouragement (and occasional nudges). Pat Alley exceeded all expectations with his design work. Applause and kudos for each of you!



Coping With Aging and Amputation: *How Changing the Way You Think Could Change Your Health*

by Omal Bani Saberi, LCSW, CCHT

*“To grow old is to pass from passion
to compassion.”*

- Albert Camus

We all get older. Unfortunately, many of us have to deal with amputation at the same time. Though we don't have much control over aging, we do have some power over the way we see ourselves.

As you age, you may face:

- Feelings of dependency
- Depression
- Helplessness

- Loss of control of your body and life
- Financial problems
- Reduced social life
- Physical illness, pain and other medical or health problems.

All of these problems will likely be intensified when an amputation occurs. Change is hard after all. You have lived decades with the way your body has looked, and you have used your limbs to do things without much thought. Now what you have taken for granted - the way you look, the way you move - has to be looked at in a different way, and you have to readjust to the world.

So What Do You Do?

First, you deal with the feelings of your loss. A part of your body is gone, and you have to deal with your anger, sadness, helplessness, loss of control, etc. Since amputation is a grief process, this may take some time. The good news is that as time passes, the feelings of loss, although still there, will be less intense.

You can learn to cope with life differently by changing the way you think. Mind and body affect each other greatly. If you think less of yourself or are mad at your body, you are likely to sleep less, eat more/less, and not let other people near you. Can you imagine how much just these three things can affect

- Your thinking
- Your concentration
- Your focus
- How you get support
- How quickly your body heals?

Imagine yourself as a camera, the photographer, the lens, the film. You can choose which picture to take, what to focus on, and which lens you will use to view your limb loss and your life.

Perhaps you will choose the close-up lens and focus on how your limb loss looks — the scars, the flabby skin, the way clothes don't fit like they did before. Perhaps you will get stuck there. What can you do? You can choose to look at these realities up close for a while and then in time choose to place them in the background and focus instead on other things about your body and your life. Your essential tools are patience and a willingness to reframe the camera lens.

This doesn't mean that you have to deny your feelings; it just means that you will need to look at your life and your limb loss in a different way. Are you willing to do this? Are you willing to see that in a very real way in your everyday life, you can learn new ways of doing and being? You aren't as helpless as you believe.



You have lost a limb, but you have not lost yourself or your ability to voice what you are thinking and feeling.

Watch Out!

Always remember that what you think determines what you do in life. Some thoughts might, however, be deceiving you about your physical, mental and emotional self.

Physical

Your thoughts may say, “Now that I am an amputee, I look different. Losing a limb means that I am a different person and that all I was in the past has disappeared.”

Is this really true? Of course, you look different now and there are changes and adjustments that you will have to make as an amputee. But are you really all that different? Before your amputation, was your physical appearance the only feature that mattered? No. Certainly you are far more than your physical appearance. You have skills, talents, and characteristics like compassion, integrity, love, understanding, etc. Are these parts of you less important than your limb loss? Certainly not!

How else can you tell your mind to stop telling you lies about your body? Decide to change unhealthy habits. Make lifestyle changes, and take more control of your life. Often we indulge in unhealthy habits because we are unhappy, nervous or depressed. Get some professional help if you need it.

Attitudinal

“A study that has been ongoing for 50 years has found that a flexible personality is one key to aging well,” notes Dr. Peter Lichtenberg. Limb loss, of course, is a new experience but, just as with aging, it is likely that the more flexible and open-minded you are, the more quickly your body will heal and the better your life will be.

You may think, “I’m too old now to learn to live with limb loss. I don’t think I can cope. It’s just too hard to live without all of my body parts. My friends won’t know how to deal with me. They



may, in fact, not even want to be around me anymore. Who cares anyway? Who knows how many years I have to live?"

So how should you respond to such harsh and negative thoughts? First, be honest and admit that coping with aging and limb loss is difficult, but do not get stuck. Think back about how you've coped with other losses in your life.

Your belief that your friends may not be able to deal with your amputation is almost certainly not true. People who know and love you may be waiting for you to tell them how involved they can be in your life. They too are undergoing a loss and may not know how to "be there" for you. In fact, they may be waiting for a signal from you to let them know what to do. The friends who leave probably do so because of their own fears. Don't take this personally! Some people may just be unable to cope with these circumstances at this time.

If your mind is telling you that nobody cares and that you may not live much longer anyway, you may be stuck in depression. *(See the articles that follow on depression.)* You may need professional help. As far as not knowing how many more years you have to live, that's true for all of us. How we live the rest of our lives is what's really important. Quality matters.

Change your attitude. If you have a sense of helplessness or dependency, raise your voice and assert yourself with confidence. Take an active role with your medical team and the other professionals in your life. Communicate the pain or discomfort you may have. The old belief that medical professionals were gods is not true. They are human beings who need your input to help you. If you are on medication, speak up if you think that you are taking too little or too much.

Emotional

You may think, “I will never get over this loss. I won’t be attractive to anyone anymore. I won’t be able to have an intimate or sexual relationship. I can’t have anyone be that close to me.”

Those of you who have been in a long-term relationship before

your amputation may close yourself off from your mate. At first, this can be understandable (due to pain and discomfort.) After a while, keeping your mate away keeps you from having to deal with the emotional side of your disability. Unconsciously, if you allow your mate to be sexual, you will have to admit that your beliefs about being attractive or sexual may not be true. The way to overcome these feelings is to communicate

honestly what you are afraid of and then slowly have your mate touch your body, even where your limb used to be. Of course, the mechanics of sex or lovemaking may have to change (slightly), but don’t be afraid of this. Allow your mate to touch you. She or he may not feel as negatively about your body as you do. This technique will often help you become more intimate and more sexual with your mate again.

If you are single, it might be a challenge to meet interesting people. It is for most of us, especially as we age and experience limb loss. Don’t write yourself off, however. Losing a limb is not a turnoff to everyone. Be vulnerable, take risks and feel confident about yourself. After all, your life up to now has taught you many things. Remember, how *you* think and feel about *you* largely



determines how other people will treat you. If you are not open and ready, those who want to treat you well cannot get close enough to do so.

Other Ways to Help Yourself

Don’t isolate yourself. This can shorten your life span. People who are lonely often suffer from more health problems. If you are nearing retirement age or are already retired, it may be a great time to revive an old hobby or interest or to learn something new. You might also like to volunteer in your community. When people are active and “giving back,” they usually feel more fulfilled and less lonely. They are also more likely to feel better about their lives in general.

Focusing on the Right Things

As you experience aging and limb loss, you have power and control over what you choose to focus on. You can have images of self-respect, dignity and compassion and fill your surroundings with people who care about you, or you can get stuck negatively focusing on how your body looks and allowing this small part of you to define your whole life. What images will you choose to focus on?

My wish for you is that you will choose the lens that will show all of who you are and will not limit you to your age and your limb loss. ❖



One Step at a Time: *Recovering From Limb Loss*

by Patricia Isenberg, MS

Recovery may be defined as a return to a normal condition.

Individuals Recover Differently

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 will, from time to time, 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.

What Is Recovery

Livneh and Antonak in *Psychosocial Adaptation to Chronic Illness and Disability* (1997) list six signs of recovery:

- A sense of balance in emotions and relationships
- Awareness of abilities and limitations
- Positive self-concept and a sense of accomplishment
- Ability to get around in the environment
- Participation in social, vocational and/or recreational activities
- Setting priorities.

Recovery is a tall order for anyone, with or without limb loss!

Whatever recovery means to you:

- Take time to learn what makes everyone's recovery different.
- Determine your personal goals.
- Ask for help when you need it.

There are many issues that affect recovery from amputation. These can be divided into four categories:

1. Issues related to the amputation

- Whether the amputation was sudden or due to a chronic, debilitating illness
- The level of the amputation
- Whether the amputation surgery was successful in stabilizing the condition that caused it
- How the day-to-day ability to function will be affected

2. Individual characteristics

- Age or health status. Obviously, the older you are, the greater the chance that you have other conditions (known as comorbid conditions) that could impact your recovery.
- Current stage of life
- Financial status
- Ethnic background

3. Personality traits

- Coping strategies used before the surgery
- Sense of control over the situation
- Attitudes toward health and sickness
- Self-concept and body image
- Experience coping with other similar losses

4. Characteristics of the physical and social environment

- Availability of a support system, such as family, friends or a support group
- Availability of appropriate medical care
- Accessibility of services in the community
- Living arrangements
- How other people view limb loss

The Recovery Process		
The Amputee Coalition of America uses six phases to describe the recovery process of amputation.		
PHASE	CHARACTERISTIC	DESCRIPTION
Enduring	Surviving amputation surgery and the pain that follows	Hanging on; focusing on present to get through the pain; blocking out distress about 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 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

The Recovery Process

Recovery from amputation is an ongoing process.

It is clear that:

- Not everyone has the same response to amputation.
- The highest level of recovery is not achieved by everyone.
- Recovery does not happen in a particular order. Individuals may experience phases one after another and then regress to an earlier phase. A person might skip one or more phases, or one phase could overlap with another.
- Each phase of recovery requires different coping patterns.

Resources for Recovery

A variety of resources exist to help you successfully recover from amputation.

- Peer visitation
- Amputee support groups
- Online support groups
- Amputee Coalition of America Web site (www.amputee-coalition.org)
- Individual or group counseling with a social worker or psychologist
- Vocational Rehabilitation
- Supportive family and friends

Still not sure how to get the help you need? Call the Amputee Coalition of America at 888/267-5669 and speak with an information specialist. ♦



Getting By With a Little Help From Our Friends: *Resources for Recovery*

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

Why Peer Support?

Sharing experiences with another amputee teaches 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 assistance
- How to deal with changes in family relationships
- How others cope with amputation.

Peer support is an important part of successful rehabilitation.

ACA Resources to Support Your Recovery

• **Peer Visitation**

A peer visitor is a trained volunteer who:

- Is a good role model
- Offers emotional support in person, by phone or by e-mail
- Gives you information about resources that are available
- Listens and understands

Call 888/267-5669; the ACA will find a peer visitor for you.

• **Online Support Group**

The online support group is for people who do not have a local group or those who cannot attend a local meeting. Call 888/267-5669 to join ACA's online support group.

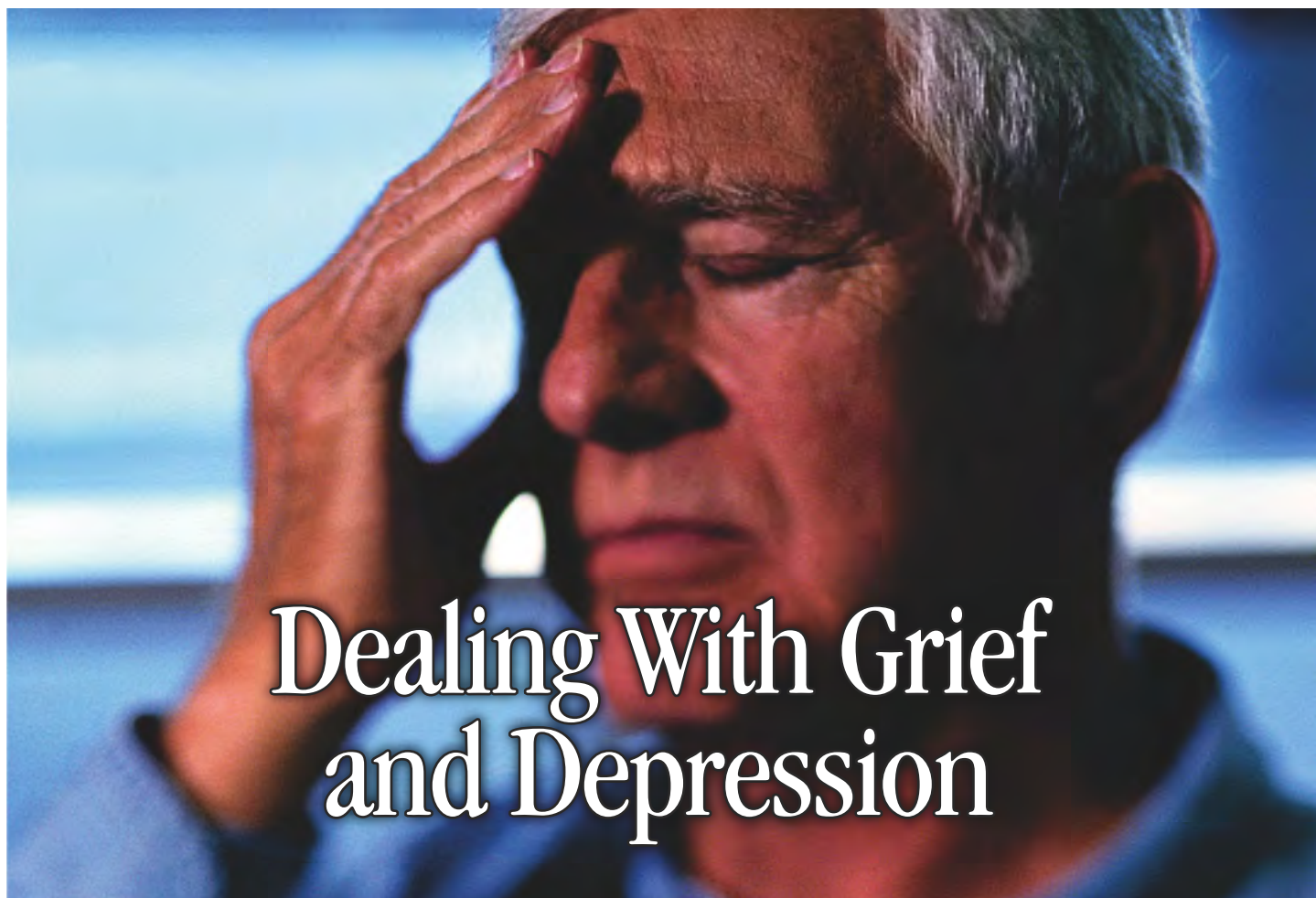
• **Local Support Groups**

You can get more information or find an amputee support group by visiting ACA's Web site: www.amputee-coalition.org or by calling ACA at 888/267-5669.

• **Information Center**

Trained information specialists, librarians and professional advisors are available to answer your questions or find the resources you need. Call ACA at 888/267-5669 to speak with an information specialist.





Dealing With Grief and Depression

by Omal Bani Saberi, LCSW, CCHT

When a part of our body is lost, we experience a grieving process that is not easy. Emotional recovery, like physical recovery, is based on your own timetable and other factors. These include: age, gender, circumstances of your limb loss (accident, disease, birth), how you coped with problems in your life before your limb loss, support or lack of support from family or friends, cultural values and norms, and socioeconomic factors.

The new amputee may experience feelings of depression that are difficult to ward off. What are these feelings, and how can you work through them?

Signs & Symptoms of Depression

- Loss of appetite, changes in eating patterns
- Lack of energy
- Sleeplessness or sleeping more than usual
- Poor concentration
- Loss of interest in enjoyable activities

- Loss of interest in sex
- Social withdrawal
- Feelings of hopelessness, worthlessness, or inappropriate guilt
- Emotions that are flat — expressed robotically — rather than with feeling

Surviving Depression

Following are some suggestions for overcoming your depression, physically, emotionally, mentally and spiritually.

Physically

1. **Get your rest.** Be sure to get out of bed, get dressed, and, if possible, go out of the house.
2. **Make sure you eat well** — not too many sweets. Foods with sugar will give you quick bursts of energy then quickly let you down, taking you deeper into depression.

3. Get involved in physical and recreational activities that do not cause you pain. Exercise and gentle movement help decrease depression.

4. Practice deep breathing. This helps to relax muscles, decrease pain, and relax and focus the mind.

5. Decrease alcoholic beverage intake. Alcohol is a depressant. Eliminate other drugs that you use to self-medicate. If using prescription drugs, make sure you take them when prescribed.

6. Emphasize your best features; don't focus on the loss. For example, if you have beautiful skin or eyes, a bright smile, a terrific figure or a great personality, this is the time to value your assets.

Emotionally

1. You are not alone.

2. You are not to blame. It is important that you feel the anger, because if you don't, it will lead to depression.

3. Write letters and don't mail them. Journal your feelings.

4. Increase contact with supportive family and friends.

5. Assert yourself and communicate clearly. Tell those around you what you need and don't need. For example, you

may need to expend less energy this year; conserve your energy. Go to a movie or rent a video, especially if the weather is harsh.

6. Tell your loved ones you are experiencing grief and talk honestly about your loss together. This gives your loved ones the chance to express their feelings, since they too have to adjust to your loss.



7. Remember, people want to help but often don't know what to do to support you. So ask, ask, ask! You can still remain independent. Allow others to give to you, so you can replenish your energy.

8. Explore meditation, guided imagery and hypnotherapy.

9. Contact a support group. Contact the ACA office toll-free at 888/267-5669 for help in locating a support group or joining ACA's online support group.

10. Laughter is a healer of depression, so add humor.

11. Get professional help if the depression becomes overwhelming and no small changes are

occurring. Everyone needs help at some point in his or her life. You are worth it. If finances are a problem, call your local mental health office or the ACA at 888/267-5669 for information on financial resources.

12. Most importantly, know that these feelings will lessen over time; however, for now, get support!

Mentally

1. **Commit yourself to work with the medical staff, even when you don't want to.**
2. **Do not make big decisions such as beginning or ending a relationship, or buying or selling a house or car, when you are depressed.**
3. **Go to a mental health professional for evaluation and medication if necessary.**
4. **Seek alternative medicine, massage, acupressure, acupuncture and hypnotherapy for pain management, phantom pain, sleeplessness, anxiety and depression.**
5. **Replace negative self-talk about your body and life with positive messages.**

Spiritually

1. **Forgive yourself; don't judge.** Dr. Harold H. Bloomfield, co-author of *How to Heal Depression*, states, "The primary reason to forgive is for your peace of mind



and the quality of all your future relationships. That's what we do when we forgive — let go of the imaginary (but painful) control of the way we think things could be, and we untie ourselves from the burden of judging the way they are."

2. Learn to think of yourself in a different way.

- Keep your dreams and create a new definition of success.
- Accept support from loved ones while remaining independent.
- Make new traditions and memories, creating hope for the present and future. Make goals and objectives for the future and start small.
- If your religion or spirituality is important to you, become more involved with it.

Summary

Amputation is an enormous loss and learning to adjust is a process that takes time — so be gentle with yourself. Try not to isolate yourself or withdraw from people; use your experiences to build new memories and start new traditions to reach your goals. Sure, there will be adjustments along the road to success — but it is still your path. Who you are has not changed. Always remember, you are much more than your physical experience. ❖

Resources

National Mental Health Association
2001 N. Beauregard Street, 12th Floor
Alexandria, VA 22311
800/969-6642
www.nmha.org

Directory of community mental health services
www.nmha.org/affiliates/directory/index.cfm

Coping With Limb Loss

Ellen Winchell, PhD
Available through ACA (888/267-5669)

Coping With Amputation:

Dr. Alan Wolfelt in *Death and Grief: A Guide for Clergy* shares the following information to help you decide if you are experiencing normal grief or clinical depression.

Is It Grief or Depression?

Normal Grief	Clinical Depression
You are able to respond to comfort and support	You cannot accept comfort or support
You are often openly angry	You are irritable and may complain but do not directly express anger
You can relate your depressed feelings to your experience of loss	You do not relate experiences to a particular life event
You can still experience moments of enjoyment in life	You have a sense of doom that overshadows your days
You may have physical complaints that come and go	You have physical complaints most or all of the time
You might express guilt over some aspect of the amputation	You feel guilty about most things much of the time
These feelings sometimes affect your self-esteem	Your self-esteem is low most of the time



If you think you are depressed, see your physician or a mental health professional immediately.

To find a mental health professional in your area, contact the following:

National Mental Health Association

www.nmha.org
800/969-6642
TTY Line: 800/433-5959

National Institute of Mental Health

www.nimh.nih.gov
866/615-6464
TTY Line: 301/443-8431

Pain Management and the Amputee

by Partners Against Pain® and the
National Limb Loss Information Center, 2003

This article provides important — and practical — information you can use to get the help you need to manage your pain. In many instances, pain will decrease over time. In some cases, however, it may be necessary to take more aggressive steps to control it. The information contained in this article is provided to give you information to cover a variety of situations.

One of the most important things to remember is that pain can be caused by an ill-fitting prosthesis; therefore, maintaining a good fit at all times is imperative. Many of the tips provided here are questions for you to ask yourself. The answers will give you more information about your condition and the treatment needed to manage your pain. **Remember:** You have a right to ask questions and to understand your options.

Long after surgical wounds have healed, most amputees still experience pain in their amputated limb and in the part that is now missing. Pain that feels like it comes from a missing limb, finger or toe is called “phantom pain.” Sensations in the missing limb aren’t always painful, however. It is common for an amputee to still feel his or her missing limb. Sensations such as movement, touch, pressure, itching, posture, and heat and cold can still sometimes be felt although the body part is no longer present.

Despite the labels, phantom pain and phantom sensation are very real to the amputees who experience them. They are physical, not psychological. There is still much to be learned about phantom pain; at present there is only speculation and theory. Dr. Douglas Smith, MD, ACA medical director, has written several articles about pain for

the ACA, including a series titled *The Phantom Menace*. The series can be found in the ACA online library catalog or can be requested by contacting the ACA.

Why Is Managing Pain Important?

“Pain is a thief. Pain robs the person in pain of the chance to enjoy being alive. . . .” Unrelieved pain can completely change your quality of life. It can make it hard to sleep, to work, to socialize, and to perform daily activities. Relationships with friends and relatives may become strained. Ongoing pain can leave you with no appetite, which can lead to weakness. Pain that is not treated can also cause depression and feelings of hopelessness. Many people think that pain is an unavoidable part of limb loss, and your condition may indeed cause pain. Pain can and should be treated, however, and there are many options available today for managing it effectively.



You Are the Expert

The most important part of good pain control is the role you play. Remember that nobody understands your pain the way you do. Only you know how much pain you feel and where it hurts. But you may have to help your doctors, nurses, friends and family understand your pain. And, you or a caregiver may have to ask for the help you need. Learning to communicate with your doctors, nurses, friends and family will help you become an active participant in your care.

Remember:

- You are not a “bad” patient if you tell your doctor you have pain, nor are you bothering him or her. Doctors want to make you feel as comfortable as possible and improve the

quality of your life. They cannot do this unless you share your experience of pain with them.

- Coping with unrelieved pain can be exhausting and can keep you from enjoying friends, relatives, and other activities. You are not being weak when you ask for pain relief; in fact, you are being strong.
- Most side-effects from pain medicine can be managed as long as you tell your doctor about them.
- If you feel your pain is not being adequately relieved, tell your doctor right away. Your doctor will reassess your pain carefully and might prescribe a different medication, adjust the dosage, use a combination of drugs to relieve your pain, or refer you to a pain specialist.
- Pain does not necessarily mean your condition is getting worse.
- Some cultures, and even some families, have very individual beliefs about pain and its meaning. When you have severe pain, it may be useful to look more closely at your beliefs.

The Two Types of Pain

There are two types of pain: acute and persistent. What makes them different is how long they last. Acute pain tends to be severe and lasts a relatively short time. It is a signal that the body is being injured, and most of the time the pain goes away when the injury heals. Pain after surgery or after breaking a bone are examples of acute pain. If you are going to have any kind of procedure related to your condition, make sure to ask your doctor ahead of time:

- How much pain to expect
- How long the pain may last
- Most importantly, how the pain will be managed before, during and afterward.

Persistent pain can last for long periods of time, even years. It can range from mild to severe. Doctors disagree on when to say that pain is no longer acute and has become persistent, but, generally, if the pain is still present three to six months after it began, it is considered persistent.

Phantom Pain and Residual Limb Pain

As previously stated, most amputees experience residual limb pain and/or “phantom pain.”

Residual limb pain is believed to come from injuries to nerves at the site of the amputation. At the ends of these injured nerve



fibers, neuromas are formed. These bundles of nerve fibers may send out pain impulses in a random fashion or they may give off pain signals when they are trapped by other tissue, such as muscle.

In contrast, phantom pain is thought to originate in the brain itself. When the part of the brain

that controlled the limb before it was amputated no longer has a function, other areas of the brain fill in.

Getting the Most From a Doctor's Appointment

Feeling nervous or anxious before going to the doctor is very common. This can make it hard to remember what happened during the visit. Even though you think you are listening carefully, you may not hear everything the doctor says. Remember that you are an active participant in your care. Do whatever you need to do to understand. Following are some suggestions to help you prepare for a trip to the doctor:

- Write out your questions ahead of time and bring them with you.
- Bring someone along to help listen and take notes. Speak openly and honestly with the doctor or nurse.
- Let him or her know how much information you want.
- Work toward trust and respect.
- Report what is really going on and don't leave anything out! Don't leave until all of your questions have been answered.
- Remember that there is no such thing as a silly or dumb question!
- Ask for explanations of words or concepts you don't understand.
- Keep asking questions until what you want to know is clear.

- Repeat back to the doctor what you think you have heard.
- Make sure you've had time to share all of the information you wish to share.
- Do not let anyone make you feel rushed. It's your appointment!
- Insist on privacy. Important discussions should take place in a private place, not in the hallway or at a reception desk.
- Be willing to reschedule another visit if more time is needed. The management of chronic pain is often time consuming, and a treatment plan evolves over time.

How to Talk With Your Doctor About Pain

You should talk openly about your pain with your doctor and any other professionals treating you for pain. Your doctor needs to know what kind of pain you are feeling and how bad it is so that he or she can prescribe the most effective treatment program for you.

Some people find it difficult to talk about their pain at all. Some have trouble finding the right words to communicate how the pain feels. Many people don't know what to tell the doctor or what questions to ask about their pain. While your doctor may ask you some of the following four questions, reading them here and thinking about how you would answer them will help when you get to your appointment.

1. Where is the pain? Your pain may be in more than one place. List all of the painful areas. You may even want to draw a simple picture of your body and mark or color the areas where you feel your pain.

2. What does the pain feel like? Is it aching? Throbbing? Burning? Sharp? Dull? The following list includes some of the words frequently used to describe pain. If you don't find a word here that describes what you feel, use the most descriptive words you can find.

Aching	Sharp	Dull
Burning	Crushing	Pins and needles
Sore	Stabbing	Prickling
Pounding	Throbbing	Shooting
Crampy	Knot-like	Deep
On-the-surface	Stretching	Pressing
Tight	Pinching	Tender
Electric	Pulsing	Gnawing

Be sure to tell your doctor or nurse if you use words other than “pain” to describe this unpleasant sensation. For example, some people describe it as discomfort or as being uncomfortable or say simply that they “hurt.” Just be aware that those words alone may not communicate all of the information you want your doctor to have.

3. How much pain are you feeling? Descriptive words tell the doctor what the pain feels like, but the doctor also needs to know how much pain you are feeling. There is no blood test, visual test or foolproof way to measure pain. The doctor will rely on you to tell him or her how much you hurt. He or she may be able to help you, though, by asking you to use a pain rating scale to “measure” your pain.

A numbered pain rating scale asks you to rate your pain by picking the number from 0 (no pain) to 10 (worst pain imaginable) that best indicates how bad the pain feels to you (*see Figure 1*). The doctor will write down the number in your chart and compare it to the number you select next time. This way, you will both be able to see how your pain level is changing.

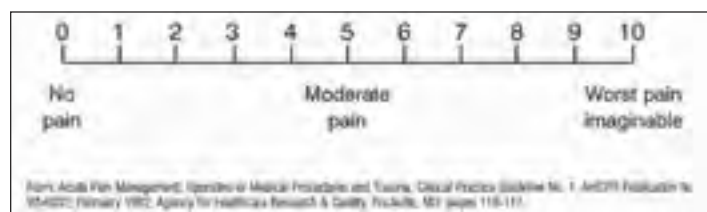


Figure 1

A “faces” pain rating scale is helpful for people who have trouble speaking or understanding how to respond to the 0 to 10 scale (*see Figure 2*). There are several different scales that use a series of faces with expressions from smiling (0 = “no hurt”) to tearful (10 = “hurts worst”). It is important to stay to the scale. Exaggeration of your pain on the scales will make it extraordinarily difficult to judge the success or effects of treatments.



Figure 2

At each appointment, your doctor should ask you to rate your pain using the same kind of scale each time. He or she should then record your pain level.

The most important part of having your pain rated using a scale is your honesty. You shouldn't "play it down" and say your pain is a Level 3 when it is a Level 7. If you do, you may not get the treatment you need.

4. What makes your pain better or worse? You may have found ways to make your pain feel better like using heat or cold or sitting or lying in certain positions. Keep track of what does and doesn't work for yourself, for your doctor, and for caregivers who want to help you.

A pain diary is another tool to help you keep track over several days of changes in your pain, what makes it better or worse, the medication you've used, and how your treatments are working. Use the same scale to rate your pain each time. Taking the diary to your doctor's appointments will provide a good deal of information that may help him or her evaluate your pain treatment plan. No matter what causes the pain or makes it feel better, keeping a careful record is a helpful way to communicate with your doctor. These diaries aren't meant for everyone, however. If you find that keeping a diary makes you concentrate more on the pain, you might want to try another option.

How to Find a Pain Management Specialist

Each person's pain should be addressed individually; therefore, ACA highly recommends that you consult with a qualified pain management physician near you who offers a comprehensive pain management program.

Although the best place to start is with your family physician or surgeon, he or she may not be able to help with chronic pain. If not, ask him or her to check with the anesthesia department at your local hospital or medical center. Many anesthesiologists today become trained in the field of pain management. Frequently, they will direct a staff of other physicians, nurses, therapists, and medical professionals who together offer a variety



of treatments. These comprehensive or multidisciplinary types of practices are the best way to deal with the complex pain issues of amputees.

Not all pain management specialists are anesthesiologists. Neurologists, internists, and rehabilitation physicians may also have completed advanced training in this field. The key is to find someone with the proper training — one who has access to and is willing to involve all of the professionals who may be needed to treat your particular problem.

Some pain centers offer only one type of treatment, such as acupuncture or manipulations, and treat only a special

type of complaint, such as headaches or back pain. Remember that it may be difficult to find someone with extensive pain management experience so it is important that you:

- Ask questions.
- Check staff credentials and training, as well as their experience in handling phantom pain.
- Be sure you understand what medicines you might be given, what to expect, and their side-effects.
- Inquire about alternative treatments and how they might be appropriate.
- Always ask about fees and insurance reimbursement.

Treating Pain After Amputation

Post-amputation pain is complicated and can be difficult to treat. A number of therapies may be appropriate, including the following:

- Proper prosthetic fit
- Physical therapy, exercises, TENS (Transcutaneous Electrical Nerve Stimulation) units, and related treatments
- Relaxation and stress-management techniques
- Biofeedback, cognitive and behavioral therapy
- Nonsteroidal anti-inflammatory drugs (NSAIDs)
- Additional medicines, including antidepressants and neuroleptic agents
- Oral opioid analgesics
- Muscle relaxers.



From this list, you can see that the professionals involved could be your prosthetist, physical therapist, psychologist, psychiatrist, family doctor, anesthesiologist, physiatrist, internist, orthopedist and neurosurgeon, as well as technicians and other professionals. Ask them to explain the various interventions that are available to you.

If you do experience pain or discomfort, tell your doctor, nurse, prosthetist, physical therapist or other caregiver right away so your doctor can take steps to relieve your pain.

What to Do If Your Pain Is Not Being Managed

If you've done all of your homework, asked all of your questions, shared your own information honestly, and your pain is still not being adequately managed:

- First, speak to your healthcare professional or a case manager to express your concerns.
- Always bring your diary, if you decide to create one, to visits with your doctor to show the impact that pain is having on your quality of life.
- Ask what other options are available to you.

If you still feel you are not receiving adequate care, ask your doctor to refer you to a pain specialist. These doctors have received specialized training in managing pain from many different types of illness.

Remember: You Are Not Alone

The Amputee Coalition of America (ACA) is a national, nonprofit amputee consumer educational organization representing people who have experienced amputation or are born with limb differences. The ACA includes individual amputees, education and support groups for amputees, professionals, family members and friends of amputees, limb loss-related agencies, and organizations. The organization has regional representatives located across the United States who are experienced support group leaders and can offer referrals to the amputee support groups nearest you. It has also established and

maintains a database of trained and experienced amputee peers who are willing to communicate by phone, fax, e-mail, postal service, or, when possible, in person. Amputees are matched as nearly as possible with referrals to fellow amputees who have experienced similar limb loss and are of comparable age.

There are many resources in your community that can provide guidance and support. Your hospital social worker and nurse educator are both valuable sources of information and are willing to listen if you need to talk.

In addition to the ACA, there are other organizations that can be helpful. Many of these organizations have local chapters you can contact to help you and your loved ones learn to effectively manage pain and live your life to its fullest.

The American Pain Foundation Pain Care Bill of Rights

As a person with pain, you have:

- The right to have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists, and other healthcare professionals
- The right to have your pain thoroughly assessed and promptly treated
- The right to be informed by your doctor about what may be causing your pain, possible treatments, and the benefits, risks and costs of each
- The right to participate actively in decisions about how to manage your pain
- The right to have your pain reassessed regularly and your treatment adjusted if your pain has not been eased
- The right to be referred to a pain specialist if your pain persists
- The right to get clear and prompt answers to your questions, to take time to make decisions, and to refuse a particular type of treatment if you choose.

Although not always required by law, these are rights you should expect and, if necessary, demand for your pain care. ❖

This article is published as a public service by Partners Against Pain®, One Stamford Forum, Stamford, CT. It was made possible through an educational grant from Purdue Pharma L.P. A7158 6/03.

What You Need to Know About Pain Medications

Your physician should determine the best approach for managing your pain based on its cause. He or she may consider prescribing medication in either of the following cases:

- There is no way to treat the cause of the pain.
- It will take time for the treatment to take effect.

Questions to Ask Your Doctor or Pharmacist

- How much medicine should I take?
- How often should I take it?
- If my pain is not relieved, can I take more? If the dose should be increased, by how much?
- Should I call you before increasing the dose?
- What if I forget to take the medicine or take it too late?
- Should I take my medicine with food?
- How much liquid should I drink with the medicine?
- How long does it take the medicine to start working (called “onset of action”)?
- Is it safe to drink alcoholic beverages, drive, or operate machinery after I have taken pain medicine?
- What other medicines can I take with this pain medicine?
- What side-effects from the medicine are possible, and how can I prevent them?

Types of Pain Medicine

For mild pain, your doctor may recommend acetaminophen and other nonsteroidal anti-inflammatory (NSAIDs) medications, including aspirin and ibuprofen.

- Most of these medications are available without a doctor’s prescription.



- NSAIDs used alone have a limit to their pain-relieving effect — so taking a higher dose may not be recommended.
- Even though aspirin is an excellent pain reliever, it too has its limitations.
- Although these medications are available without a prescription, your medical team will still need to monitor you.

For moderate to severe pain, your doctor may prescribe opioid pain medication, which requires a prescription.

- Opioids can be taken by mouth (pill or liquid), as a suppository, by injection, or through a patch on the body.
- Unlike NSAIDs, most opioid pain relievers don’t have a limit on their ability to relieve pain. Usually, the higher the dose, the greater the pain relief.
- Your doctor will be careful, of course, to ensure your dose is appropriate to manage your level of pain.

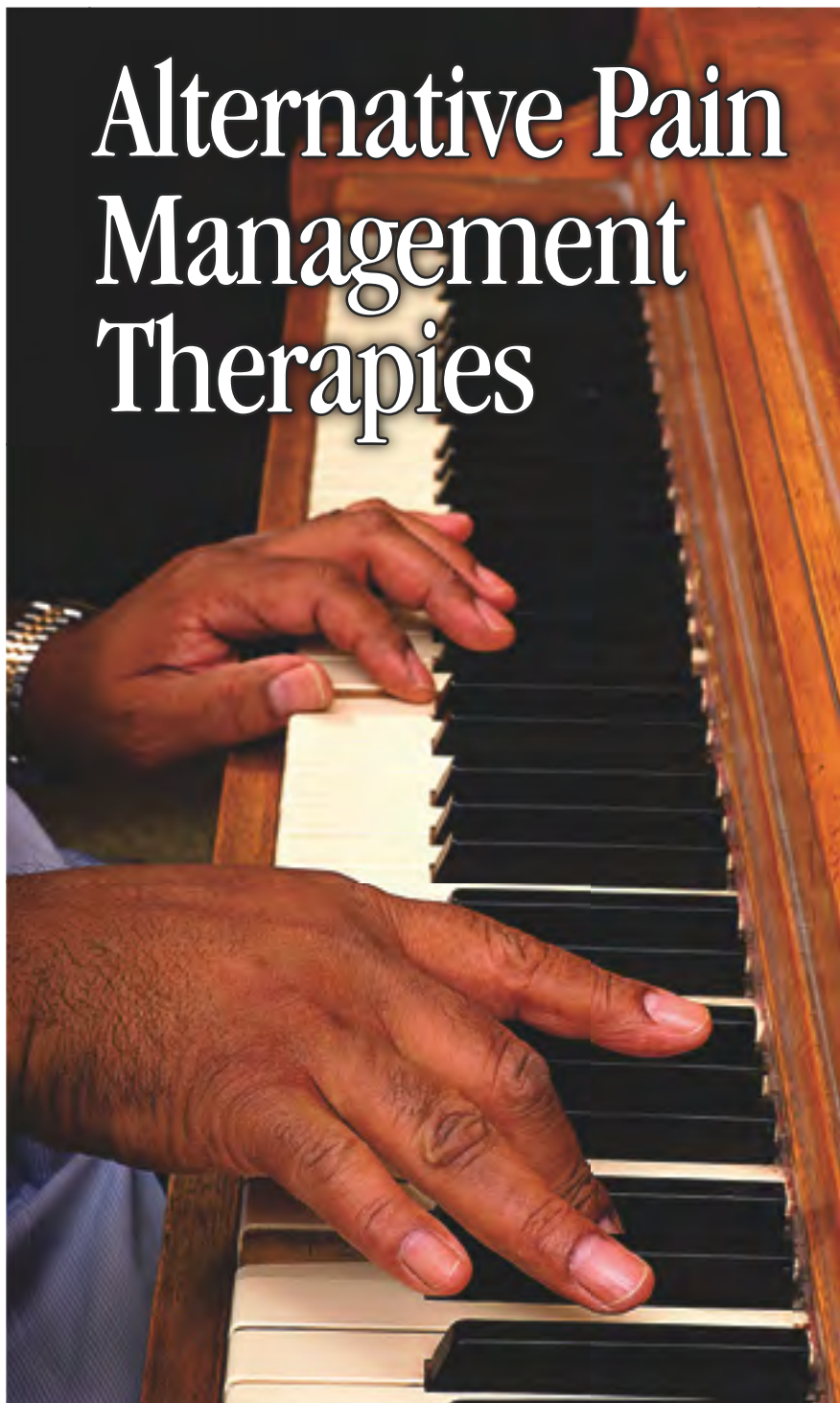
As with any treatment for pain, if these medications aren’t helping you, your healthcare team will try an alternative. Sometimes your doctor may prescribe nonopioids along with opioids to treat specific types of pain (for example, prescribing NSAIDs along with opioids to treat bone pain). ❖

Some nondrug therapies are helpful in relieving pain. The alternative therapies described below may be used alone or in combination with traditional pain medication. If you are interested, it is important to discuss these with your physician to determine which might be appropriate for you.

Common Alternative Pain Management Therapies

- **Applying a heating pad or cold cloth to specific muscle areas** can provide relief from pain. Heat can relax the muscles while cold refreshes the area.
- **Deep muscle relaxation** works by allowing the amputee to release tension immediately. Learning relaxation skills will take time, however.
- **Therapeutic touch** concentrates on the body's energy field. Some believe that massaging the energy field that surrounds the body can correct imbalances that lead to pain or discomfort.
- **Distraction therapy** is used to turn a person's attention away from a painful activity to make him or her more comfortable.
- **Massage therapy** can work by massaging the external, outer mechanisms of pain to reach the root cause.
- **Music therapy** uses music to restore, maintain, and improve physical health and well-being.
- **Acupuncture** is the Chinese practice of puncturing the body at specific points with very fine needles to cure disease or relieve pain.
- **Deep breathing** helps with the ability to cope, to control stress, and to relax the patient.
- **Hypnotherapy** involves relaxation and concentration. During hypnosis, the patient focuses on things he or she wants to experience instead of pain.
- **Biofeedback** uses special machines to learn how to relax specific muscles in the body to reduce tension.

Alternative Pain Management Therapies



- **Guided imagery** focuses and directs the imagination. It teaches people to use their imagination to cope with or distract themselves from the pain.
- **Transcutaneous Electrical Nerve Stimulation (TENS)** provides relief of pain by applying electrical stimulation to the skin. ❖

Pain Resources

If you need additional help with your pain, you may:

- Request a referral from your family physician to a local pain clinic or the anesthesia department at a local hospital.
- Call your county society of anesthesiologists and ask for a list of pain management specialists in your area.

The following resources may also be helpful:

- **American Academy of Pain Management**

Telephone: 209/533-9744

E-mail: aapm@aapainmanage.org

Web site: www.aapainmanage.org

- **American Pain Foundation**

Telephone: 888/615-7246

E-mail: info@painfoundation.org

Web site: www.painfoundation.org

- **American Pain Society**

Telephone: 844/375-4715

E-mail: info@ampainsoc.org

Web site: www.ampainsoc.org

- **American Society of Anesthesiologists**

Telephone: 847/825-5586

E-mail: mail@asahq.org

Web site: www.asahq.org

- **Amputee Coalition of America (ACA)**

900 East Hill Ave., Suite 285

Knoxville, TN 37915

Telephone: 888/AMP-KNOW (267-5669)

E-mail: acainfo@amputee-coalition.org

Web site: www.amputee-coalition.org

- **International Association for the Study of Pain**

Telephone: 206/547-6409

E-mail: iaspdesk@juno.com

Web site: www.iasp-pain.org

- **Mayday Pain Project**

E-mail: mail@painandhealth.org

Web site: www.painandhealth.org

- **The National Foundation for the Treatment of Pain**

Telephone: 731/862-9332

E-mail: jfshmd@houston.rr.com

Web site: www.paincare.org

- **National Institutes of Health**

Telephone: 301/496-4000

E-mail: niinfo@od.nih.gov

Web site: www.nih.gov

- **National Library of Medicine**

Telephone: 888/346-3656

E-mail: custserv@nlm.nih.gov

Web site: www.nlm.nih.gov

- **Pain Net**

Telephone: 614/481-5960

E-mail: info@painnet.com

Web site: www.painnet.com

- **Pain and Policy Studies Group**

Telephone: 608/263-7662

E-mail: ppsg@med.wisc.edu

Web site: www.medsch.wisc.edu/painpolicy

- **World Wide Congress of Pain**

Telephone: 800/328-2308

E-mail: editor@pain.com

Web site: www.pain.com



“What Happened to Your Leg, Grandma?”

by Christina DiMartino

June DiMenna suffered with diabetes for years. After exhausting every treatment available, she had to have her left foot amputated. The procedure took place a week after she turned 67.

“I quickly realized that there are many details to think about when one has a limb amputated,” she says. “The list stacks up over time - especially for people like me who have always been independent. But there was one thing that I didn’t anticipate, or even think about, that turned out to be a critical detail - how my grandchildren would understand and accept what had happened to me.”

DiMenna lives near her three daughters and four grandchildren who range in age from 3 to 10.

“It isn’t unusual for me to see all of my grandchildren several times a week,” DiMenna says. “We have always spent ample and valuable time together. The thought that they wouldn’t understand or that they might try to reject my affection was devastating.”

Melinda Hinkle, who suffered a left below-knee amputation in an auto accident 20 years ago, has similar concerns. Hinkle’s son, daughter-in-law and two grandchildren - ages 2 and 4 - live on the opposite side of the country from her. Between visits back and forth, she only sees the children about four times each year.

“They are growing up, and I know the time will come when they will begin to realize that their grandmother is different. I don’t know how to explain my amputation to them. I’m afraid it will frighten them, or they will think the same thing will happen to them. It’s time for me to have a plan so I know how to answer the questions they will have. I want them to feel free to discuss my amputation with me any time they want.”

“Honesty is the best policy” when explaining an amputation to grandchildren. Stephen T. Wegener, PhD, is an associate professor, vice-chairman and chief of rehabilitation psychology at Johns Hopkins University School of Medicine, Physical Medicine and Rehabilitation Division. He focuses on providing psychological services to people with chronic illness or traumatic injuries, including those with amputations. He says that children generally ask questions at an age when they can handle the answers.

“Children are very observant,” Dr. Wegener says. “The answer to ‘When should you explain your amputation to your grandchild?’ is ‘When they begin asking.’”

Two issues are relevant to communicating the details of an amputation to a child, Dr. Wegener says. “One is the age of the child, and the other is how the child interacts with the amputation - and this can be quite different depending on the circumstances. If the child has grown up familiar with your amputation, he or she may react differently than if you have an amputation procedure during the child’s youth. In the latter case, the child will of course realize that something has happened to make the grandparent different.”

Dr. Wegener says that this does not mean that the child will automatically be traumatized. Instead, he

suggests some general guidelines to help the child gain acceptance and understanding.

“A child’s response to the amputation event will mirror that of the person with the amputation,” he says. “Children will always respond to an adult’s emotional tone. First, give a response that is age-appropriate. Younger children require less specific details. Older children may require a more complex response to be satisfied with the answers you provide. It is best to anticipate the child’s questions. Depending on the child’s personality, you might consider opening the conversation yourself. Say to the child, ‘Let me tell you what happened to me’ or ‘I had to have my leg removed so I could be healthy again,’ for example.

“Having a good understanding of how the child will react is a good idea. Does he or she worry easily? The amputation may have been performed to improve your health, but it might

make the child fearful that his or her leg will also be amputated or cause other fearful and worrisome thoughts.”

Children can say (and think) the strangest things, but they aren’t strange at all to them. For instance, Dr. Wegener says he has never heard of a child asking where the leg went after the doctor took it off - but it might be a good idea to be prepared for the question. He says most children accept the explanation that the doctor disposed of the amputated limb somehow. But if a child does ask, merely tell him or her that the doctor took care of it and that you aren’t worried about where it is.

“When the conversation does begin with your grandchildren about your amputation, it is a good opportunity to discuss the differences between all the people in the world,” Dr. Wegener says. “Take advantage of



the time to talk about diversity and acceptance, and explain how this is just one of the many ways that people can be different.”

Children, Dr. Wegener suggests, are most concerned about their own security. If you have always spent valuable time with the child, he or she may worry that your amputation will change your relationship.

“The child may ask, ‘Does this mean that I can’t come to your house anymore, Grandpa?’” he says. “It is very important to communicate that things are going to be okay and that you will still spend valuable time with the child. Discuss these issues with the child’s parents and work together to ensure that you will continue to spend time with the child.

“You may also have to explain to the child why you can’t do some of the things you did together in the past. Perhaps you took regular walks after school. You could play board or video games, engage in arts and crafts projects or spend more time reading together, for example.”

There is also the issue of the hospital and rehabilitation center, when and if they apply. If a child is fearful of hospitals, it is best to not force him to go there.

“Don’t force the child to confront the limb loss either,” Dr. Wegener says. “Children will find their own time to deal with it. I have never seen a case where a child is traumatized or has serious anxiety or depression in such a situation, but if it happens,

the parents should confer with a medical professional. It is best to not assume that there will be a problem, however. The majority of children find their own way - and time - and they deal with such things with surprising resilience.”



Teens who are sensitive to peer pressure may have a different type of difficulty dealing with a grandparent’s amputation, Dr. Wegener says. “Adolescents may feel somewhat embarrassed, and may even try to avoid the grandparent,” he says. “It is best for the person with the amputation to engage in a conversation directly with the child - rather than allowing a parent to do it. Limb loss can also be an opportunity for teens to learn about change. As a grandparent, you can be a mentor for such a learning experience.”

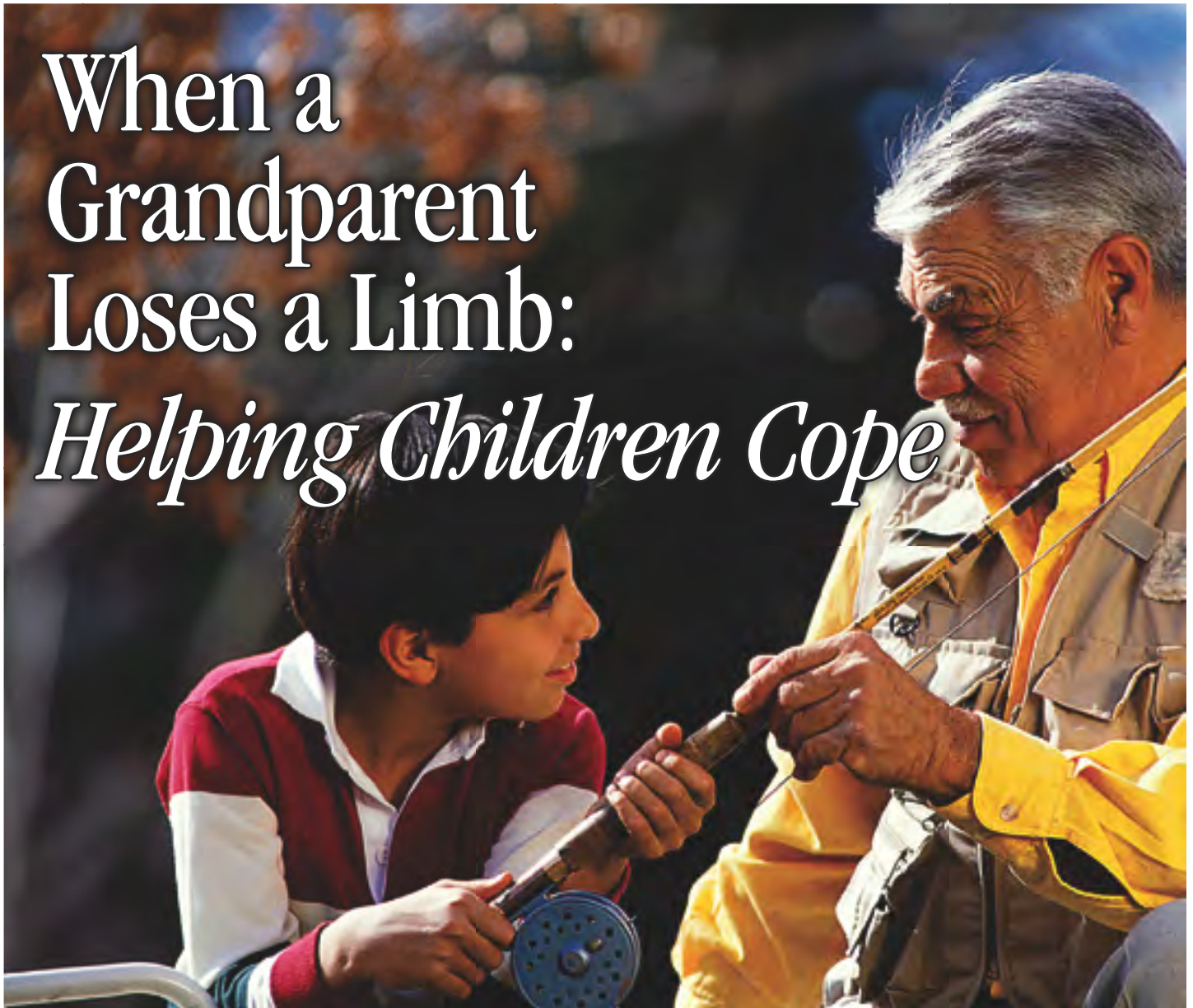
There is a caveat to explaining an amputation to a grandchild who doesn’t ask about it, however. Dr. Wegener says that some children are timid and shy and may need some prompting or intervention to get them engaged in a conversation.

“A parent may ask a child with this type of personality, ‘How do you think your grandfather is doing? Are you worried about him?’” Dr. Wegener

says. “Once the child acknowledges the amputation, then you can begin offering explanations.”

The most important thing to remember is that children bounce back quickly. Once they have an understanding of why the amputation was necessary and how it will change the circumstances of their lives, they will likely move on and accept the “new normal.” ♦

When a Grandparent Loses a Limb: *Helping Children Cope*



by Patricia Isenberg, MS

Questions that children may ask include:

- **Where is your arm/leg? What happened to it?**

Did it break off? Be prepared to assist the child with an answer that is appropriate for his or her age. Avoid giving children too much information, such as details about a complicated disease process or the amputation surgery.

- **Does it hurt?** Pain is scary to children; the longer the pain endures, the more frightened the child will be. Talk about different types of pain in terms the child can understand. (Remember the time you burned your finger? Or the time you fell off your bike?) Remind the child that

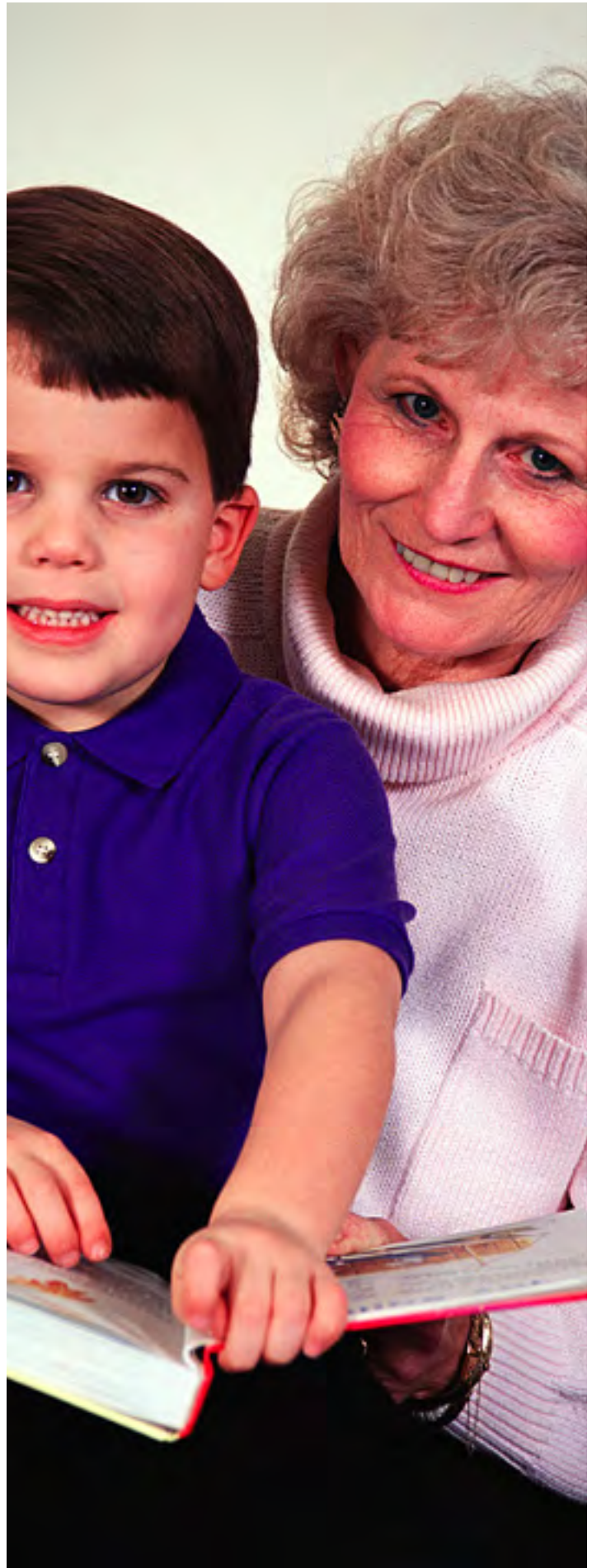
sometimes pain is short-lived; at other times, pain lasts for days; but, eventually, the pain gets better.

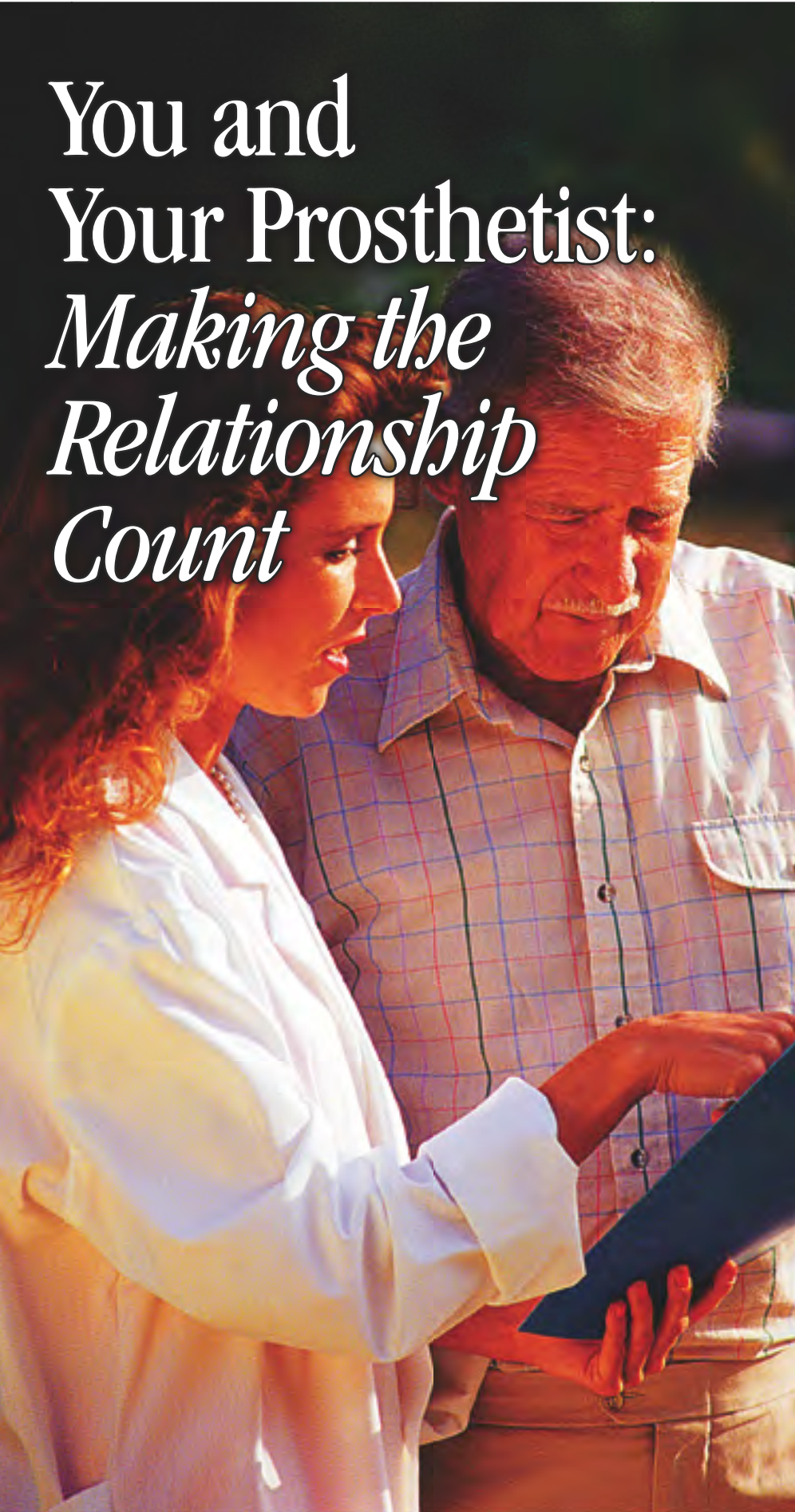
- **Can this happen to me?** Alleviate fears by giving information that kids can understand. A child who heard that someone was asleep when his leg was removed developed a fear of bedtime. Remember that your explanations need to be planned to avoid creating additional fears or anxiety.

- **Is this my fault?** Younger children are egocentric; when things happen, they feel responsible. Make certain that children know they did not do anything to make this happen.

Things to Remember

- **Avoid adverse reactions.** Avoid the potential situation of the child crying or screaming in response to seeing your residual limb for the first time by preparing the child in advance. Show pictures of other people with limb loss (available from your prosthetist or therapist or *inMotion* magazine) to desensitize the child. Explain that even though you look different, you are still normal.
- **Encourage open discussion.** Ask the child to talk about his or her feelings and concerns. If he or she is uncomfortable, suggest writing or even drawing to express his or her feelings.
- **Limb loss is not a punishment.** Grandma did not lose her leg because she is a bad person. Depending upon the child's age, however, you may want to discuss lifestyle changes that might have prevented the amputation.
- **The child will not “catch” this.** Hugging and touching are still safe and very important parts of healing for the entire family.
- **Everything's different, but nothing has changed.** Focus on the familiar, but prepare gently for the differences. For example, Grandpa or Grandma may not be able to walk the dog for a few weeks (or months). However, you are still the child's grandparent regardless of the limb difference. Talk about what is important: You can still read a bedtime story or brush hair.
- **Call upon the child's natural desire to help.** Tell your grandchild that he or she can be Granny's legs until you learn to use the new ones.
- **Explain the new words.** Make a game out of spelling or pronouncing the words that have become a new part of your vocabulary, such as prosthesis, socket, residual limb, and prosthetist.
- **Children are curious.** Remove the mystery from the prosthesis by asking the prosthetist to spend time with the child, explaining the materials and components used. The child should be encouraged to manipulate the components. ❖





You and Your Prosthetist: *Making the Relationship Count*

by Becky Bruce

The best prosthetist for you is a person you trust, who is experienced and ethical and who has credentials that make you feel secure. This qualified professional will provide you with a prosthesis geared to your lifestyle for safe, dependable use and comfortable fit. A successful relationship with your prosthetist, however, requires open and honest communication and the patience, persistence, and willingness to work on problems until they are resolved.

What Should I Know before I Choose a Prosthetist?

First, it is a good idea to identify your needs. Discuss your options with your physician, therapist or other specialists. Decide what is most important to you, such as your vocation, leisure activities, hobbies, recreational interests, etc.

- **Gather information** on what is available and appropriate for your level of functioning and type of amputation.
- **Make a list of your goals** based on your lifestyle and needs.
- **Consider other medical problems that might affect performance, circulation or healing.** Make sure these are being monitored and considered as part of your plan.

How Do I Locate Services?

A list of practitioners is available from the Amputee Coalition of America (ACA), your rehabilitation team, a local amputee support group (if one is available), or your peer visitor.

How Should I Choose?

The relationship you develop with your prosthetist is very important. It is important to choose a prosthetic office that is convenient. Often, there will be multiple visits during the manufacturing process and later for routine adjustments and maintenance. Your initial impressions and instincts about whether you can work successfully with a prosthetist are important. This long-term relationship requires open, honest communication and a willingness to solve problems together. There are many factors to consider:

- How do staff talk to patients?
 - Are staff members helpful with phone calls, appointments, billing and customer service?
- How convenient is the facility?
 - Are there accessible restrooms and parking?
 - How is the general atmosphere regarding cleanliness and comfort?
- Are educational materials and patient resources visible and available.

- Did the prosthetist offer you information to read explaining options?
- Is there an interest in all aspects of your adjustment or just delivering a device?

What Should I Ask the Prosthetist?

It is important that the first meeting with the prosthetist be informative. You should note whether he or she showed interest in your concerns. Does he or she listen and try to address your concerns honestly? You must ask every question that comes to mind and express every concern or fear. If you are not treated as part of the team now, don't expect your needs to be addressed later.

Questions To Ask the Prosthetist

- What are your credentials and training?
- What is your experience fitting people with my particular type of limb loss?
- Do you have other patients with an amputation like mine that I could meet or talk to about their experience?
- Are videos available for me to view other amputees with the same type of prosthesis?
- What about prosthetic repairs and follow-up service?



Do Your Homework

- Receive a list of prosthetists in your area from the ACA.
- Visit and interview several local practitioners and facilities.
- Check references.
- Ask questions of other amputees.

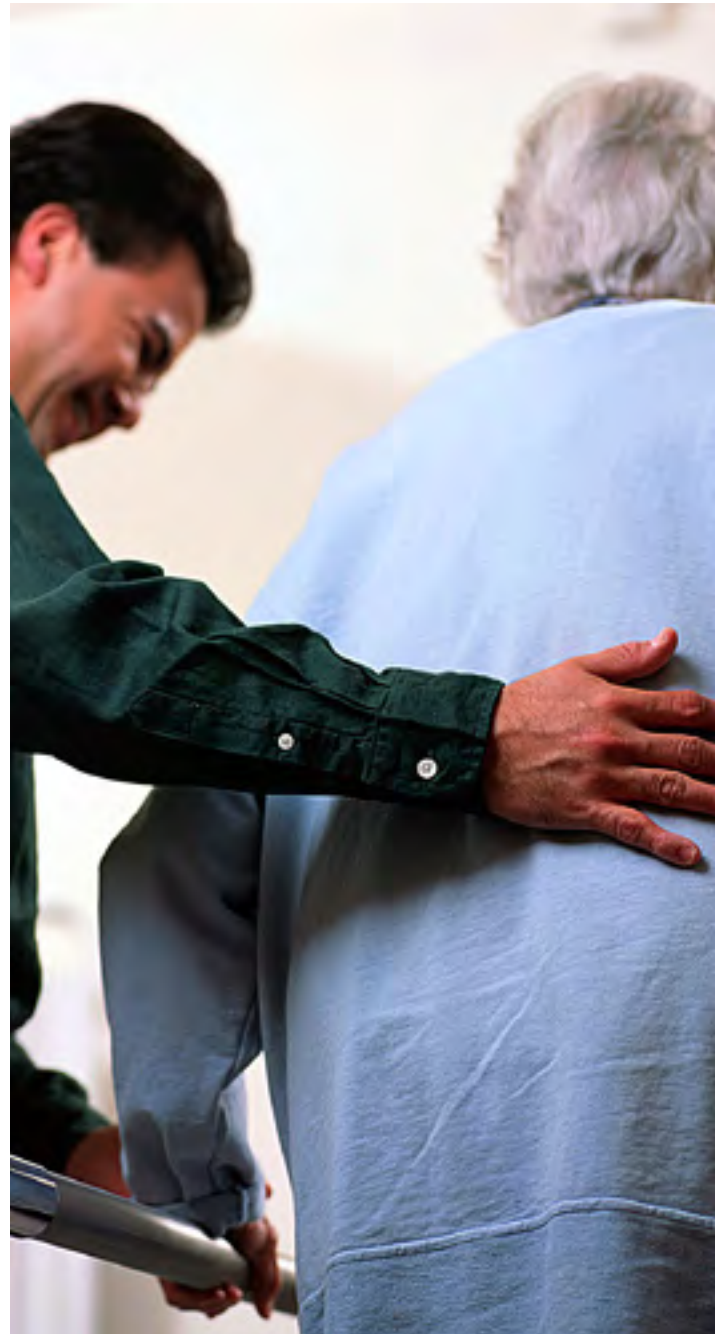
Questions To Ask Yourself

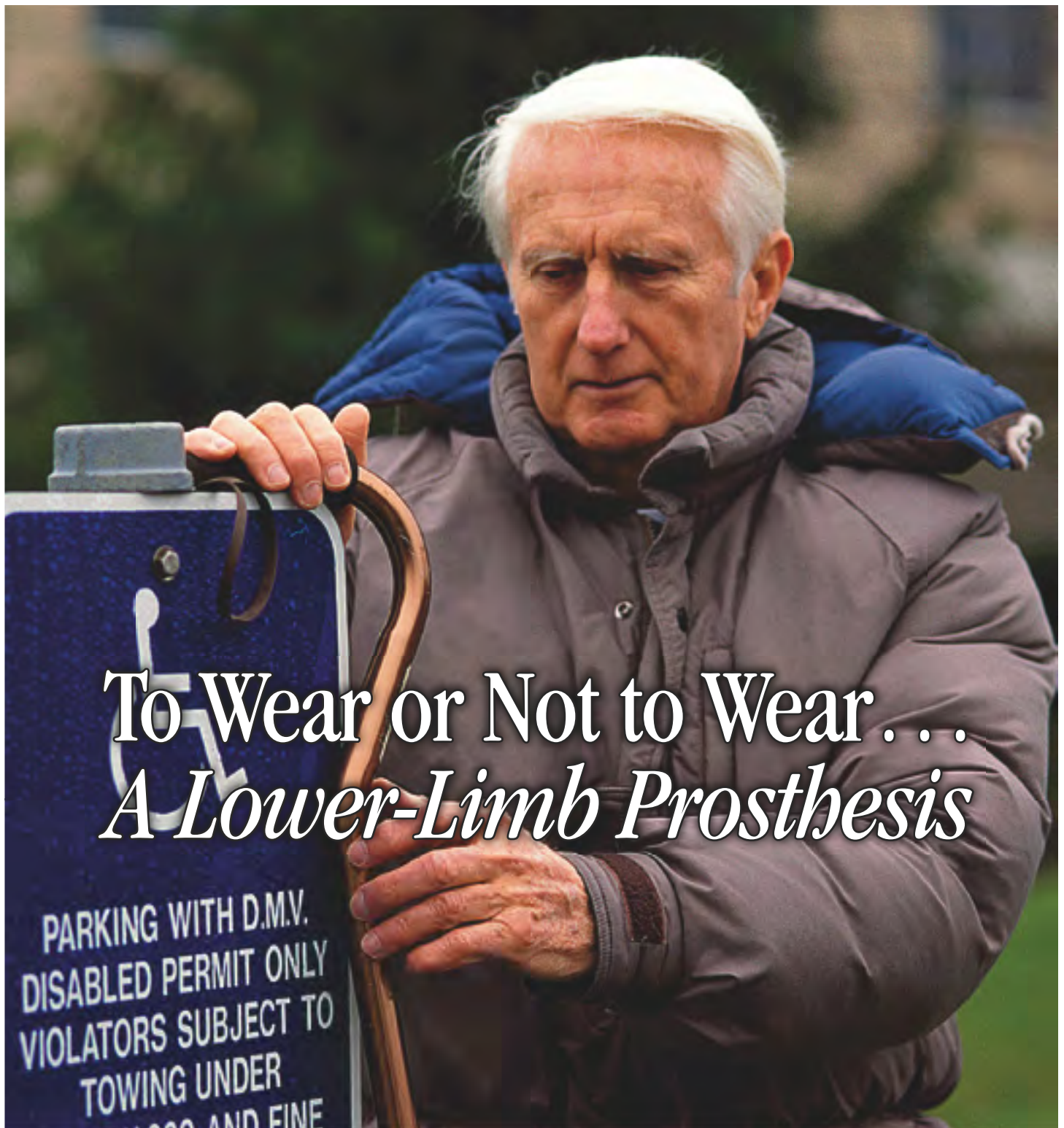
- Was the prosthetist reliable?
- Did he or she provide the services and care promised?
- Did he or she communicate with other team members (your physician, therapist, etc.)?
- Has training or therapy been offered to assist you in making the most of your new limb?
- Did the prosthetist or therapist work with you until you were satisfied with the level of comfort and function?
 - If you had a problem, were you able to discuss it openly and did you feel that your practitioner really “listened”?
 - What steps were taken toward a satisfactory resolution?
- Does the quality of the prosthesis or components used meet your expectations?
 - Were prosthetic components and options discussed with you and explained to your satisfaction?
- Are you able to function adequately in your daily activities?
- Were billing and charges in line with what you were promised?
- Did your insurance coverage get handled satisfactorily?
- Would you recommend this practitioner or facility to another patient?
 - If not, why?
 - Did you discuss this with the practitioner?

Final Note:

A prosthesis will not totally replace every quality and function of the limb you lost. If anyone tells you it will, or if you expect it to, then you may be very disappointed! What you need to seek is a knowledgeable, competent practitioner who is sensitive to your needs, lifestyle and priorities. Together you can work as a team to find the correct balance of function, appearance and comfort required. Together you will meet challenges as you become more active and demanding in your use of the device. In the end, you will grow and solve problems together by applying new information and technology as it is available.

Be realistic about your expectations. Also, be patient with yourself and your team. Progress will be measured inch by inch and you must learn to walk before you can run. There are no miracles - only people who persist in seeking and working toward a goal. ❖





To Wear or Not to Wear... *A Lower-Limb Prosthesis*

by Paddy Rossbach, RN

Whether you choose to or are able to wear a prosthesis after amputation will depend on many things. Most amputations in seniors are the result of circulation problems from diabetes or peripheral vascular disease (PVD). Poor circulation affects all parts of

the body, not just the legs. So, you may also be dealing with other problems. These might include heart or kidney disease, memory loss, loss of feeling in your hands and remaining foot, and poor circulation in your remaining foot.

You may not have been active for some time. You may have been hospitalized for surgeries to save as much of your leg as possible. You may be weak, exhausted, and even depressed. But don't lose hope! With good care from your entire healthcare team, the support of friends and family, and a "can do" attitude on your part, it is possible to walk again.

Some of you may **choose** not to wear a prosthesis. You may find it easier or feel safer using a wheelchair, crutches or a walker. Or, due to health problems, you may not have the stamina required for physical therapy and using a prosthesis. This is fine as long as you remain as active as possible (*see the exercise articles in this issue*).

Most people who wear a prosthesis also occasionally use a wheelchair and/or crutches, canes or walkers. These devices help them maintain their independence when:

- Their prosthesis is being repaired.
- They are awaiting a new prosthesis.
- They are recuperating from skin breakdown.
- They are fatigued from using their prosthesis.
- They are experiencing balance or coordination problems.
- Safety is a concern.

What Do You Need to Walk Again?

First, you need a team made up of a surgeon, nurses, therapists, social workers and a prosthetist (a person who makes and fits artificial limbs). This team will work together to plan the best surgery, rehabilitation, and prosthetic care for you.

The main ingredients for success are:

- Surgery that leaves a well-healed, well-shaped, well-padded limb that is the best length for the type of prosthesis you will use
- An appropriate amount of physical therapy that
 - Keeps your joints flexible
 - Strengthens your remaining limb
 - Teaches you how to carry out activities of daily living
 - Trains you in using your prosthesis
- A certified prosthetist
 - Who is experienced in working with older amputees
 - Who can fit you with a lightweight limb

– Who offers components (feet, knees, etc.) that will help you walk safely and, most importantly, COMFORTABLY!

- A healthful diet to give you the strength to work hard
- Appropriate care of any other health problems you may have
- Pain control.

If any of these ingredients are missing, however, you might not be a good candidate for a prosthesis. A residual limb that is not



well-healed, well-shaped, and well-padded may not be able to bear weight into your prosthesis or may cause you pain when you wear it. Without appropriate physical therapy, your limb may be inflexible and/or too weak to wear a prosthesis or you may not know the proper way to walk with it. Unless you have a prosthetist who is well-trained in fitting older patients with appropriate lightweight components, the prosthesis may merely become a burden for you. Since wearing a prosthesis requires more energy from a person, being in good health is essential. Eating a proper diet and taking care of your other health problems will help ensure that you can manage the additional stress that wearing a prosthesis puts on your body and heart. Finally, if the prosthesis is painful, you will not wear it. It will merely sit in your closet.

Tips For Before Your Surgery

If you know you are going to have an amputation and have time

- Find the right prosthetist – with the help of a family member, if possible – before you have the surgery (*see the article You and Your Prosthetist: Making the Relationship Count*).
- Choose a prosthetist you can get to easily, whom you feel comfortable talking to, and who is knowledgeable and explains things in terms you can understand.
- Check his or her qualifications and ask to speak to some of his or her other patients to see how they are getting along.
- Ask him or her to call your surgeon to discuss your care after the surgery.

Tips For After Your Surgery

When you are discharged from the hospital, it is important that

- You know how to take care of the remaining part of your limb.
- You know how to check your incision.
- You know how to keep the swelling down.
- You make arrangements to continue with physical therapy.
- You make follow-up appointments with your surgeon so that once you are healed you will be in good shape to start being fitted for your new prosthesis!

Making a Prosthesis

Making a prosthesis takes time and skill. There are many ways to do it. Following are some general things you should know.

During your first visit with your prosthetist, he or she will probably

- Take a full history of your health including medications and any other treatments you are having, such as dialysis
- Examine and measure your residual limb so that he or she can make an exact mold of it (The process of measuring the residual limb and making a mold of it may be done mainly by computer or by plaster-casting techniques)
- Discuss with you what activities you hope to do



- Suggest different feet, knees, and how the prosthesis is going to be held on, etc.
- Discuss your insurance coverage and what out-of-pocket expenses you may be expected to pay.

At the next visit, your prosthetist will probably have a “diagnostic socket” ready for you to try on. This is a clear plastic container close to the exact shape of the outer contour of your residual limb. The prosthetist can see if it fits your residual limb perfectly or needs any changes made to it before he or she makes your permanent socket.

At the next visit

- Your prosthesis will probably be ready. (The socket will be made of a different material than the diagnostic socket, and the parts you have chosen will be attached to it.)
- Your prosthetist will help you put the prosthesis on. You will stand up in parallel bars to line up all of the parts to make it comfortable. This “alignment” will be changed often at the beginning as your body starts standing up straighter, etc. These changes are perfectly normal.
- Your prosthetist will teach you
 - How to put the prosthesis on and take it off
 - How to check if it is on correctly
 - How to add extra socks or take some off if your residual limb shrinks or swells. (He or she should explain that as you use your prosthesis more, the swelling will go out of your limb.)
- He or she will either start teaching you to walk using parallel bars or refer you to a physical therapist. (You will walk for short periods at first and check your limb often for pressure.)
- He or she will tell you when to come back for another appointment.

Things to Remember

In the beginning, a lot of changes will occur. Your limb will change shape, so your socket must be changed by your prosthetist. This is very important. If the socket does not fit well, you will not be able to walk properly and could get a blister or sore spot. At first, you will need to visit the prosthetist often. As things settle down, the visits will get less and less.

Examine your limb every time you take off the prosthesis. Use a mirror if necessary and massage the limb to get the circulation going. Wash the limb with a mild soap and pat it dry every day. Don't use anything that includes alcohol because it will dry the skin, which may then crack and become infected. Also, wash any socks, silicone liners, and the inside of your socket with mild soap and water (or as the manufacturer advises) and rinse them every day. A buildup of sweat and dirt will cause infections.

Although it is more difficult to walk with an above-knee prosthesis, with the right care it is possible for older amputees. Always use a walker or cane if you feel unsure of yourself.

Remember, eat right, stay active, make sure your prosthesis is fitting correctly, visit your prosthetist regularly, and look after the rest of your health needs. Life is definitely different, but it can still be enjoyable and fulfilling. ❖



Older Adults Can Thrive as Prosthesis Users

by Kevin Carroll, MS, CP, FAAOP

Have you heard the one about the 95-year-old lady who wears a prosthetic leg? She can walk, drive a car, and leads a totally independent lifestyle. So, why does her son keeps pressuring her to move into a nursing home? He's getting lonely living there by himself!

It might sound like a joke, but it's a true story. And just one example of how older prosthesis users can do much more than survive — they can thrive. Clearly, those who are thriving have a number of important qualities in common.

Look Beyond Age

The saying, "Age is a state of mind," is important to people who lose a limb. They must try not to focus on age as the only measure of their ability to recover. Age provides a way to count years, but it doesn't measure a person's heart, mind or motivation. Some people in their 80s adapt to a prosthesis better than others

who are 30 years younger. The difference is one of expectation. People who expect to do well are generally people who have a strong sense of purpose in their life — something beyond themselves that they feel is important.

I met a 97-year-old lady in Ohio who is responsible for three great-grandchildren, ages 9, 10 and 11. She gets them off to school every day, has dinner for them every evening, and also looks after her 80-year-old son. Her expectation is that she is going to live to be 115, and she probably will.

What do you expect for yourself? To be able to garden, to care for your family, to be independent? Do your rehabilitation team and family also expect a good outcome? Whether expectations are positive or negative, people tend to live up to them. Amputees and clinicians must look past stereotypes related to aging. You must expect that a positive outcome is possible whether you are 70, 80

or even 90 years old. The simple fact is that Americans — including prosthesis users — are living longer, healthier lives than ever before.

Often when people begin wearing a prosthesis, their families and friends rally around them in a show of support. This plays an important part in the recovery process. It is also important for new amputees to assert their independence. Well-meaning loved ones can actually “kill with kindness” by doing too much for the new prosthesis user.

One thing I’ve observed is families who want to get older adults a powered wheelchair to help them out. A wheelchair can be depressing to new amputees. Using a wheelchair can discourage them from making the effort to walk and try other basic activities. I encourage people who are beginning the rehabilitation process in a wheelchair to make getting out of the chair and up on their feet their No. 1 goal. And if they have to use a wheelchair they shouldn’t use one that’s electrically powered. The upper-body movement that’s required to move a manual wheelchair is actually great exercise.

Understanding Functional Levels

Every consumer needs to understand how decisions are made regarding the type of components they can have on their limb. Medicare has established guidelines that assign each person what’s known as a “functional level.”

- Functional level 0 is assigned to a person with no ability or potential to move about or transfer.
- Functional level 1 is assigned to a person with the ability or potential to transfer or move about on level surfaces at a fixed pace.
- Functional level 2 means the person has the ability or potential to move about and can cross low-level barriers like curbs.
- Functional level 3 is assigned to a person with the ability or potential to walk at variable speeds.
- Functional level 4 is reserved for exceptionally active individuals such as athletes and children.

A person’s functional level is determined by the rehabilitation team, which includes the physician, prosthetist and therapists. Older adults are typically assigned a functional level of 1 or 2. As the functional level increases, so does the variety and sophistication of the prosthetic components that are available.

Over the years, I have seen many older adults become motivated to work harder on their rehabilitation when they understand how functional levels work. Let’s use prosthetic feet as an example.

- Individuals at functional level 1 can have the most basic, single-axis foot that is made.
- At functional level 2, they can have a multi-axial foot and ankle.
- At functional level 3, they can select from a range of lightweight, dynamic feet.

All prosthesis users should know their current functional level and ask their prosthetist what they can do to reach the next level. Older adults who start out at a functional level 1 may be able to work their way up to a functional level of 2 or 3. The higher functional level will give them the opportunity to acquire advanced, lightweight components that can help increase their mobility.

Get Physical

Physical therapy is hard work that is well worth the effort. I recommend that older adults have physical therapy both before and after they get their prosthesis and schedule a return visit to their therapist each year. Therapy loosens up the residual limb





and increases muscle tone and coordination. People who only go once or twice and then stop

are missing out on the real benefits of physical therapy. It is important to find a physical therapist who has experience with prosthesis users.

I encourage new prosthesis users to attend up to 10 sessions of occupational therapy to

- Become familiar with putting their prosthesis on
- Learn to bath and dress themselves
- Practice other specific skills.

An occupational therapist can also visit the home and help modify the living environment.

Keep Things Light

Many important considerations go into the design of a prosthesis for an older adult. One of the most critical is its weight.

- Older adults usually have less strength and stamina and will function much better with a lighter limb.
- Legs that are too heavy cause users to feel a dragging sensation in every step, and, although they may get used to it, the weight is burdensome and tiring.
- The weight can discourage them from being active or from doing even simple things like going to the grocery store or to church.
- Some people may stop wearing their prosthesis altogether if it feels too heavy and uncomfortable.
- A heavy prosthesis also pulls on the skin of the residual limb. This is a special concern for older adults since the elasticity of their skin has decreased, making it more fragile and susceptible to breakdown.

Each component of the older adult's prosthesis needs to be as lightweight as possible. Ask about the materials in the component and how they affect the weight. For example, carbon composites, titanium and aluminum are much lighter materials than wood and stainless steel.

Although there are many new and exciting knees, pylons,

feet and ankles available, some of these components may increase the weight of the prosthesis. Therefore, consumers should carefully consider the benefits of the more specialized components they are interested in versus the weight they are adding. An adjustable foot that lets you wear different heel heights may sound great, but how often will you need that feature? If it's once or twice a year, is it worth carrying around a heavier foot the rest of the time?

People With Diabetes Be Aware

Older adults with diabetes have to be especially careful about the fit of their prosthesis.

- People with diabetes often have a loss of sensation in their residual limb due to nerve damage or neuropathy. They may not know if their prosthesis is causing sore spots or pressure damage because they are unable to feel it.
- It is important for people with diabetes to examine the skin of their residual limb every day for potential signs of trouble. If they can't see the bottom of their residual limb, they should use a mirror or ask someone to help them.
- People with diabetes must be diligent in their efforts to protect and monitor their residual limb as well as their remaining sound foot.

Putting the Pieces Together

Older adults who are successful prosthesis users have several important qualities in common.

- They are able to look beyond age and expect to have a full and active life.
- In many cases, older adults with a good understanding of functional levels are able to push themselves to a higher level of rehabilitation. This increases their choices of prosthetic components.
- Physical and occupational therapy are a key part of their recovery process.
- These prosthesis users understand why it's important to have a lightweight prosthesis.
- They strive to be smart consumers in regard to prosthetic components and new technology.
- Finally, because many older adult prosthesis users also have diabetes, they dedicate themselves to carefully monitoring their residual limb and sound foot for any early signs of trouble.

With a positive outlook and a willingness to work at their recovery, older adult prosthesis users can truly thrive! ♦

Young at Heart

by Kevin Carroll, MS, CP, FAAOP

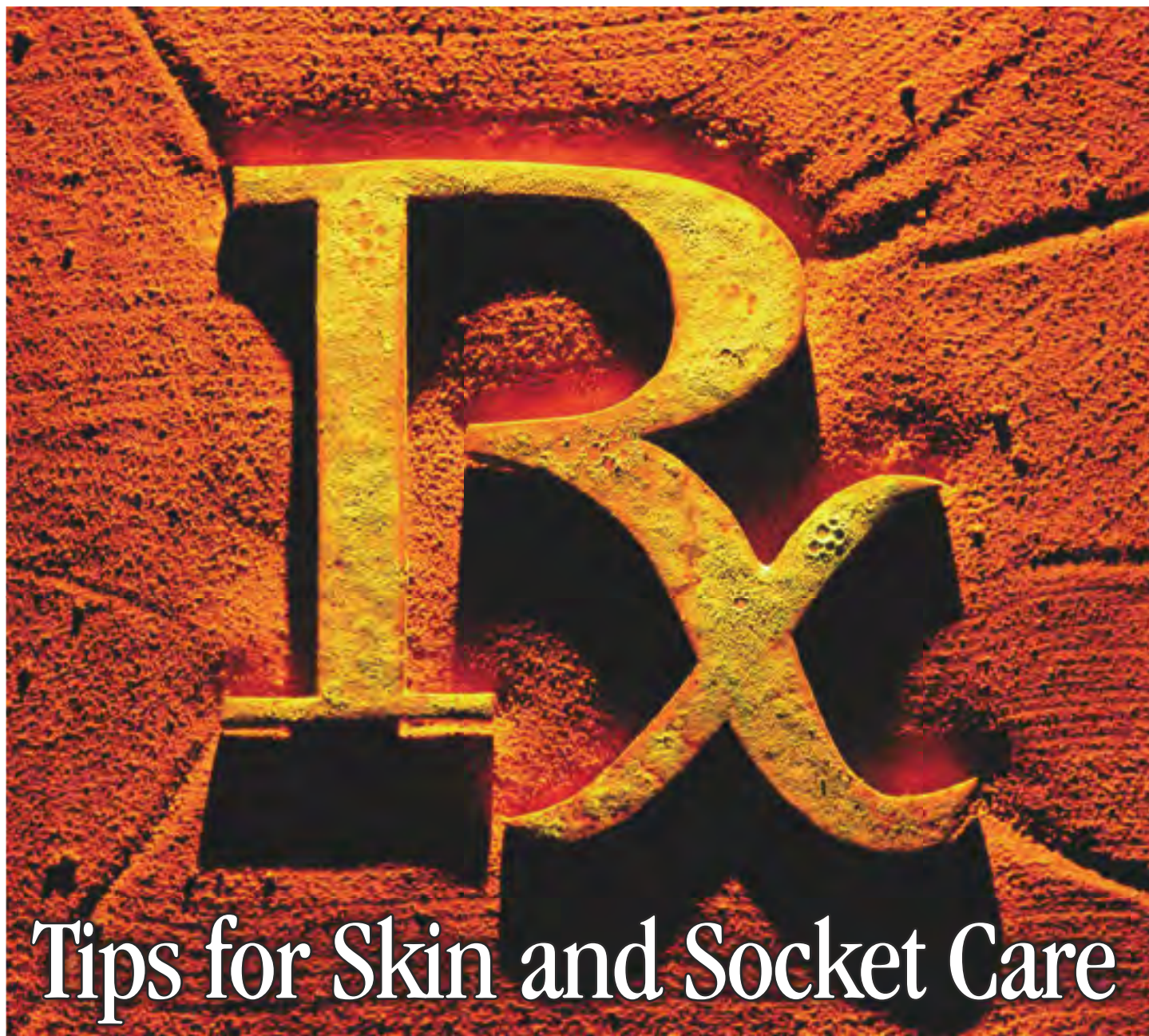
A while back, I visited with a prosthetic patient who was 95 years old. She was not preoccupied with her age or her health, but she was interested in getting a lightweight leg so she could be more active.

Her main expectation was that her prosthesis would last at least five years before it needed to be replaced. After all, she had a lot to do and she didn't want to be slowed down by any mechanical problems with her artificial limb. This one lady - who's planning on getting her next prosthesis around age 100 - symbolizes the positive mindset of a productive older adult.

She has a sense of purpose in her life and goals that motivate her to stay active and mobile. It may be gardening or spending time with friends, but, whatever the case, being interested in life is critical to your success as an older prosthesis user.

So is playing a proactive role in your prosthetic care. When this woman had her prosthetic evaluation with me, she took the lead, telling me what she wanted from her prosthesis and what her expectations were. At 95, she wasn't about to settle for a dormant life, wearing a heavy leg, or not being heard by her prosthetist.

Many older adults struggle with their ability to hear, which means they might have to ask their care providers to speak slowly and loudly. Like this lady, if you insist on being heard, you are much more likely to get what you want, need and deserve to have. Her approach to life offers many lessons for both prosthesis users and clinicians. ♦



Tips for Skin and Socket Care

**Note: Always consult your physician or prosthetist if sores or blisters erupt, which can lead to ulcers and serious infections.*

by Paddy Rossbach, RN

For your prosthesis to work at maximum efficiency, your socket needs to fit your residual limb intimately. This is called a “total contact” socket, and fabricating this socket requires the skills of a prosthetist. Though sockets are usually made of flexible materials, often they are limited in their ability to flex and change shape while maintaining support. However, if you have a major change in the shape

of your residual limb, the socket also has to have one to avoid the complications of friction and pressure that can cause sores, blisters and even serious ulcers and infections.

Comfort in a prosthetic socket depends on:

- Maintaining a good fit
- Correct alignment
- Skin care.

Fit and alignment are the responsibility of your prosthetist; however, he or she cannot help you unless you tell him or her when something is wrong. The first rule, therefore, is “Communication.”

Skin care is the responsibility of the individual. There are a few basic rules, the first of which is cleanliness. Remember that your residual limb is encased in a completely - or partially - airtight socket, which does not breathe or allow sweat to evaporate. Sweat is acidic and salty and, when allowed to dry, forms tiny crystals (like sandpaper) on your skin. If this sweat is left on the skin and socket, bacteria can grow, and if the skin is broken, infections may occur, which can become severe if left untreated.

To avoid skin problems, follow these steps:

- Every day, or more often if necessary, wash your residual limb and everything in contact with your skin with a mild or antibacterial soap and rinse well. This includes socks, nylon sheaths, silicone suction sockets, gel inserts and flexible or hard sockets. Note the manufacturer's instructions for cleaning and follow closely.
- Do not shave your residual limb. Shaving can cause ingrown hairs and often leads to infected hair follicles.
- Only use softening creams when your skin is at risk of cracking or peeling.
- Do not use alcohol-based products on your residual limb; they dry out the skin, can cause cracking or peeling, and create a potential site for infection.
- If you must cover an abrasion, use the thinnest dressing possible. If the abrasion was caused by pressure, adding a bulky dressing will increase the pressure.
- Do not add soft materials such as wool to "pad" a sore spot. This will only add more pressure.
- Be aware of how your socket fits. Adjust sock ply if appropriate. If you cannot maintain a good fit, visit your prosthetist.
- Try to maintain the same body weight. A gain or loss of five pounds should be manageable; more than that will probably require an adjustment to your prosthesis.

If a problem does occur, it usually falls into one of the following categories:

- Rash
- Blister
- Ulcer
- Infection, local or disseminated
- Verrucous (wartlike) hyperplasia.

First, visit your prosthetist. The problem can usually be solved with an adjustment to your prosthesis. If you have an ulcer or infection — or if you have diabetes or circulatory disease and have anything more than a mild rash — consult your physician immediately. The following treatments are short-term. Problems that persist require help from both your physician and prosthetist.

Rashes

A rash can be caused by either an allergic reaction, often to your own sweat, or a fungus, similar to athlete's foot. Rashes occur more frequently in people who perspire heavily and use heavy suction liners.

To avoid rashes:

- Wash and rinse your limb and liner every day.
- Lightly dust your residual limb with a medicated talc powder such as Gold Bond at night, and, if this is not contraindicated by the manufacturer, before donning your liner. (Ammens is preferred by some because it does not contain talc.) Suction will not be affected as long as the dusting is light.

Or

- Use a light film of diaper rash cream such as Balmex at night and under the liner if not contraindicated by the manufacturer.

To treat rashes:

- Use an antihistamine lotion, such as Benadryl, which will usually take care of the rash if it is an allergic reaction.
- If you do not catch the rash quickly enough, you may have to resort to an over-the-counter-strength cortisone cream.
- Use a commercially available athlete's foot treatment such as Tinactin.

Remember, if the rash does not respond within 24 hours, seek medical help. Sometimes, it is necessary to wear a thin sheath under the liner during treatment to allow for a little air flow.

Blisters

A blister can be caused by abnormal pressure or by shearing of the skin against “tacky” silicone or plastic.

To avoid blisters:

- Maintain a good fit; if necessary, add or remove a sock during the day.
- You might also want to use a commercially available “paint-on” film dressing, such as MedLogic’s LiquiShield, which is designed to help prevent skin breakdown.

To treat blisters: *(Note: Individuals with diabetes or circulatory disease should see their physician)*

- A surface blister should be left intact if possible. If it opens, keep it clean and covered with a thin layer of antibiotic ointment.
- A line of itchy blisters sometimes appears around the edge of, or inside of, silicone liners, especially in hot weather. A little mineral or baby oil around and under the edge of the liner prevents this. Treat the blisters as above.
- Blisters that occur with above-knee sockets can sometimes be covered with thin, transparent dressings such as LiquiShield.

Ulcers and local and disseminated infections should all be treated by your physician; however, the fit of your prosthesis should also be checked. If the cause of the pressure is removed, the problem will often be resolved without the need for aggressive measures.

Verrucous Hyperplasia

This is an itchy, red, raised, circular area on the distal end of a residual limb caused by suction being applied to the end of the limb. This condition frequently occurs when the socket is too tight and the limb does not make total contact with the bottom of the socket.

To prevent verrucous hyperplasia:

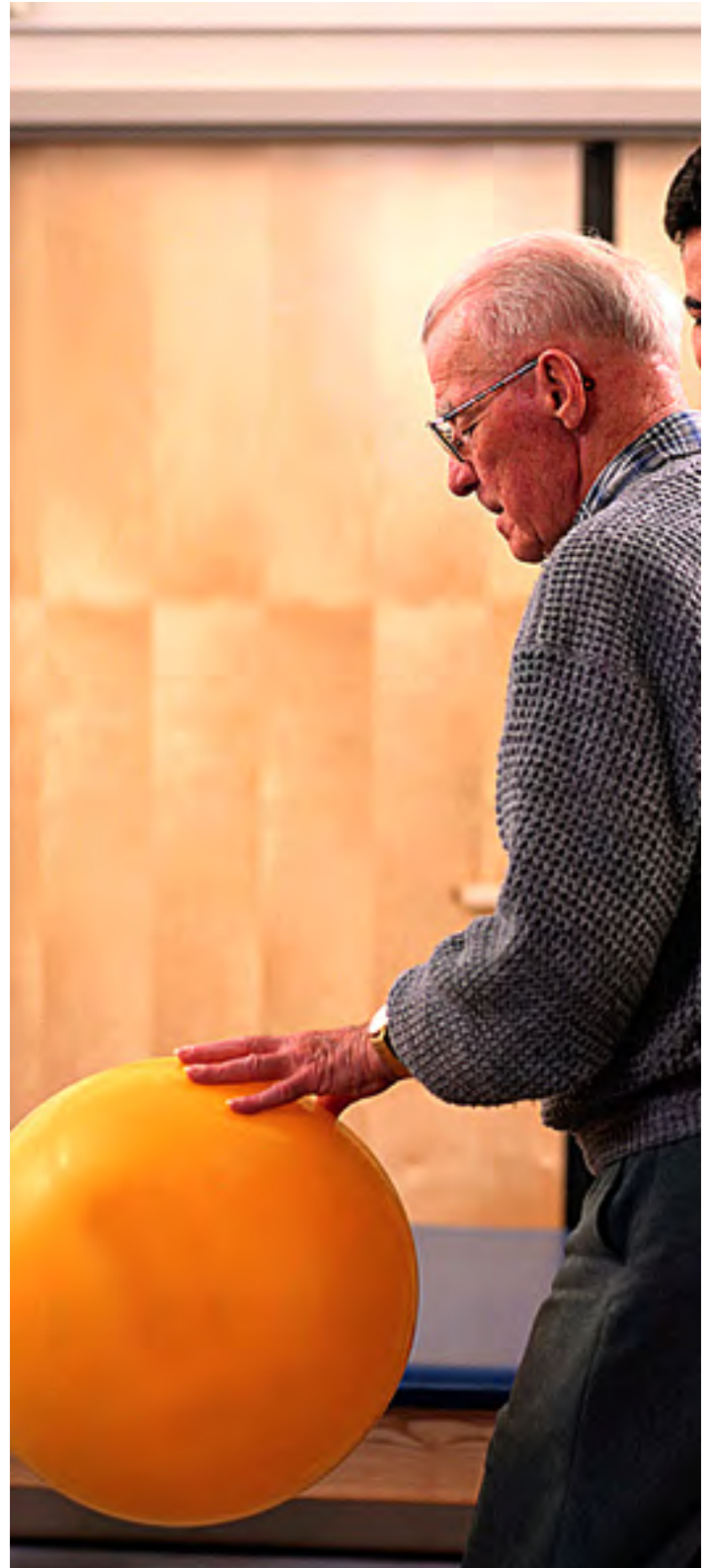
- Maintain a good “total contact” socket fit.

To treat verrucous hyperplasia:

- Remove the cause.

Excessive Sweating

Excessive sweating can be reduced by using a strong antiperspirant gel on the residual limb. Apply every night until sweating is reduced, then as often as necessary to control sweating. Do not use this if there are any breaks in skin integrity. A stronger preparation, Dri-sol, is available by prescription. ❖





Avoiding Injury: *Safety Tips for Seniors With Amputations*

As you age, simply being an amputee may increase your risk for various types of injuries. You are more likely to fall and hurt yourself. You also may not be able to stay fit because of a more sedentary lifestyle. Other injuries may occur because:

- Your prosthesis fits poorly
- Your prosthesis does not provide proper shock absorption
- Your prosthesis prevents you from achieving a proper gait.

The injuries that can occur include:

- Broken bones
- Undue stress on the heart
- Back and hip problems
- Skin breakdown

- Additional stress on the sound limb, which might lead to ulcers, infection and, in extreme cases, the amputation of your sound limb.

Broken Bones

Our bones generally decrease in density, mass and strength as we age, especially beyond age 50. They become thinner, more brittle, more porous and easier to break. This disorder is known as osteoporosis.

Amputees who use lower-extremity prostheses need to be especially careful to protect your bones because of the importance of your residual limb for support.

Participating in activities that put weight on your bones is one of the most important ways to keep your bones strong. Unfortunately, it may be difficult to bear weight on your residual limb. This may become even more difficult as you lose more and more bone density. To prevent this problem, it is important to become active again as soon as possible after your amputation. Then you must stay active. Activities that are especially good for strengthening your bones include aerobics, walking, running, weight-lifting, skating, dancing, basketball and tennis.

Many amputees participate in able-bodied exercise and sports programs, and there are many programs that are for amputees only. (For information on such programs, please contact the ACA.)

Before beginning any new exercise program, it's a good idea to talk with a doctor. If desired, a physical therapist (PT) who has experience with amputees can help you design an exercise program that fits your needs.

Exercise will also help protect your bones by developing the muscles around them. Even if you can't participate in a full exercise program, it's a good idea to contract and release the muscles of your residual limb a few minutes every day to develop them.

Including foods that are rich in calcium like milk, yogurt, dark green vegetables, and fish in your diet is also important for your bones. A physician can tell you how much calcium you need on a daily basis and prescribe calcium, vitamin D, estrogen or fluoride supplements.

Undue Stress on the Heart

Because amputees who use a prosthesis generally use more energy to walk than able-bodied people do, good overall physical health is essential.

For some older amputees, the problem is even more severe, explains Terrence P. Sheehan, MD, a physiatrist and the medical director of Kessler-Adventist Rehabilitation Hospital. "For many



amputees, loss of a limb is part of a larger problem with the blood vessels, including the blood vessels to the other major structures such as the heart. If the heart is not functioning well, all efforts will take more energy and the stress of ambulating with a limb deficiency can exacerbate the heart problems."

The primary care physician, the cardiologist, the physiatrist and the PT can help with these issues. A thorough assessment followed by proper medication and physical training can help the amputee develop the stamina needed to handle the added strain of walking with a prosthesis. Eating a heart-healthy diet is also important.

Back and Hip Problems

Back and hip problems caused by the stress and strain of walking with an improper gait, using prostheses, or using crutches are sometimes a major problem for amputees.

"Lower-extremity amputation causes a change in the center of gravity, disrupting the biomechanical symmetry of the back and hips," explains Dr. Sheehan. "The joints of the lower back and sound limb are stressed and muscles are used abnormally. This often leads to chronic pain, a propensity to repeated acute spasm and strain, and acute inflammatory processes such as bursitis."

Although some of the back problems you have might not be caused by your gait or prosthesis, it is important that PTs and prosthetists know about them. They may be able to deal with the problems through proper prosthetic fit, more appropriate components, or gait training. In addition, you should learn about good body mechanics to avoid as many problems as possible. A physiatrist and a chiropractor can help.

"Many patients don't understand why their backs hurt," explains Bill Sheppard, DC, a chiropractor and below-knee amputee. X-rays sometimes show misalignment of their back, he explains, and usually one side is rather high or rather low because of the improper fit of the prosthesis.

Skin Breakdown

As you age, your skin is likely to become thinner, more fragile, and less elastic. This can be especially dangerous for your residual limb, which is often in contact with your prosthesis and is pulled, stretched and rubbed by the socket. Friction, heat, pressure, shear and moisture within the socket combine to bring about damage to the skin. As with shoes, a properly fitting prosthesis is essential to preventing this painful problem.

Swelling, weight fluctuations and muscle changes caused by atrophy, disease, and loss of soft tissue can all affect the size of your limb and the fit of your prosthesis. The volume of your limb can even change throughout the day as you walk around. Although they will not solve the problem completely, a proper diet, regular exercise, and the maintenance of muscle tone and weight can help minimize these fluctuations. In addition, gel-type liners, which are more cushioning than socks, may help.

Skin damage can also result from the use of certain detergents to clean the residual limb and the use of some topical medications inside the socket.

Ultimately, attention to hygiene and skin care is essential for protecting your skin from damage. “There are a few basic rules for skin care, the first of which is cleanliness,” says Paddy Rossbach, RN and ACA president and CEO. “If you wear a prosthesis, your residual limb is encased in a completely or partially airtight socket that does not breathe or allow sweat to evaporate. Sweat is acidic and salty, and when it is allowed to dry, it forms tiny crystals (like sandpaper) on your skin. If this sweat is left on the skin and socket, bacteria can grow. If the skin is broken, infections may occur and can become severe if left untreated.”

She warns: “Always consult your physician or prosthetist if sores or blisters erupt because they could lead to ulcers and serious infections. If you have diabetes or circulatory disease and have anything more than a mild rash, consult your physician immediately.”

Although cleanliness is essential, the details of how it is achieved may vary depending on your specific condition and the type of prosthesis you use. *(For more detailed information on basic skin care, see the article [Tips for Skin and Socket Care](#) in this publication).*

One thing is essential: You should pay attention to any pain in your residual limb, and if any kind of problem is detected, do not ignore it.


Injury to the Sound Limb

Many senior amputees have lost a limb as a result of diabetes, vascular problems, or the lack of sensation in their limb (neuropathy). It may be that the sound limb, or remaining limb, is affected by the same problem that caused the amputation.

When you wear a prosthesis on your residual limb, however, your sound limb may receive additional stress during walking. Diabetic amputees with neuropathy often avoid putting full weight on their prosthesis and instead put more weight on their sound limb. They may try to get off the prosthesis as quickly as possible and will therefore swing the sound limb faster. As a result, their sound limb hits the ground harder, which may cause damage to the heel. In addition, they may hold their weight on the front of their sound foot longer as they walk because they are hesitant to put weight on their prosthesis. This additional time on the front of their foot may then cause calluses on that area, which can lead to foot ulcers and, ultimately, amputation. To avoid such problems, amputees should wear appropriate shoes that fit correctly, inspect their sound foot daily, and report changes to their physician.

According to statistics, about half of diabetic amputees will develop infections in their sound foot and possible amputation within two years of their first amputation. With proper caution, this might be prevented. ❖

Note: This article is partly based on [Prosthetics and Aging: Mobility for the Long Run](#), by Kevin Carroll, MS, CP, FAAOP (First Step—2001) and [Keeping the Sound Limb Sound: Foot Issues for Amputees With Diabetes](#), by Robert Gailey, PhD, PT (inMotion, March/April 2003).



Your home may be your haven, your castle, and your favorite place in the world. It can also be safe for you after your amputation, if you look around and follow these tips to keep from falling:

- Remove throw rugs and secure large area rugs with carpet tape or tacks.
- Rearrange furniture to allow enough room to navigate.
- Position heavy furniture so that there is something to grab if you begin to fall.
- Leave a light on at night.
- Wipe spills immediately.
- Reduce clutter.
- If thresholds cause problems, have them lowered or removed.
- Move any furniture that has sharp edges away from main pathways.
- Use a shower chair with arms.
- Have handrails and grab bars installed in bathrooms.
- Use nonskid strips or mats for inclines, stairs, tubs and showers.
- Adjust doors with automatic closures so that they do not bump you from behind.
- Move telephone and extension cords from the traffic areas.

Other things you can do to prevent falls include:

- Exercise regularly to increase your strength and improve your balance.
- Review your medications with your doctor or pharmacist; some medications can make you dizzy or sleepy or affect your balance.
- Have your vision checked every year.
- Rise slowly after sitting or lying down.

Before You Fall: *Tips for Preventing Falls in the Home*



Assistive Devices: *Restoring the Comforts of Home*

The place where people are meant to feel the most comfortable – the home – may quickly become a painful reminder of a life left behind after losing a limb. Tasks that once seemed simple may become difficult and energy-consuming. At times like these, it helps to remember that assistive devices for the home are plentiful and continue to be improved, revised or invented.

The following manufacturers and distributors offer assistive devices for the older amputee. Some of them have toll-free numbers or offer convenient shopping and ordering online. Many will send you a catalog or offer a printable online catalog so that you can compare products. As always, check with your physician to determine which products might work best for you. Then, check prices, warranties, repair services, and which are covered by Medicare, Medicaid, or your private insurance.

Accessible Environments, Inc.

800/776-1461

www.accessibleenvironments.net

Products: safety devices (grab bars, risers), mobility aids (canes, scooters, wheelchairs), lifts, and eating, bathing, and dressing aids

Advanced Peripheral Technologies

708/301-4508

www.advancedperipheral.com

Products: power supplies, computer mouse emulators

AssisTECH

716/789-4197

www.assisttech.com

Products: adaptive computer keyboards

Bruno

800/882-8183

www.bruno.com

Products: power chairs, scooters, vehicle lifts, stair lifts

Hunter Digital

310/476-1874

www.nohandsmouse.com

Products: foot-controlled computer mouse

Invacare Corporation

800/333-6900

www.invacare.com

Products: scooters, lifts, wheelchairs, walkers, seating accessories

Keen Mobility

503/285-9090

www.keenmobility.com

Products: cushions, crutches, canes and accessories

Maddak, Inc.

973/628-7600

<http://service.maddak.com/index.asp>

Products: safety devices (grab bars, risers), mobility aids (canes, scooters, wheelchairs), lifts, and eating, bathing and dressing aids

Mobility, Inc.

858/456-8121

www.mobilityinc.net

Products: durable medical equipment (toilet lifts, shower chairs)

Orthotic Mobility Systems, Inc.

888/OMS-4046

www.orthoticmobility.com

Products: crutches and canes

Otto Bock

800/328-4058

www.ottobockus.com

Products: wheelchair accessories, cushions, bath safety devices

Pathlighter

877/728-4544

www.pathlighter.com

Products: lighted cane

Pride Mobility

800/800-8585

www.pridemobility.com

Products: power wheelchairs, power scooters, lift chairs

Roll-A-Bout Corporation

888/736-6151

www.roll-a-bout.com

Products: rolling walker with platform for supporting the limb

Rolli-Moden

800/707-2395

www.rolli-moden.com

Products: clothing and accessories for wheelchair users

Sammons Preston Rolyan

800/323-5547

www.sammonspreston.com

Products: household helpers, kitchen and dressing aids, exercise products and personal care items

ScootAround

888/441-7575

www.scootaround.com

Products: rental power chairs and scooters for those who travel

Sunrise Medical

303/218-5544

www.sunrisemedical.com

Products: wheelchairs, lifts, cushions, walkers, and kitchen, eating and dressing aids

Thomas Fetterman, Inc.

888/582-6900

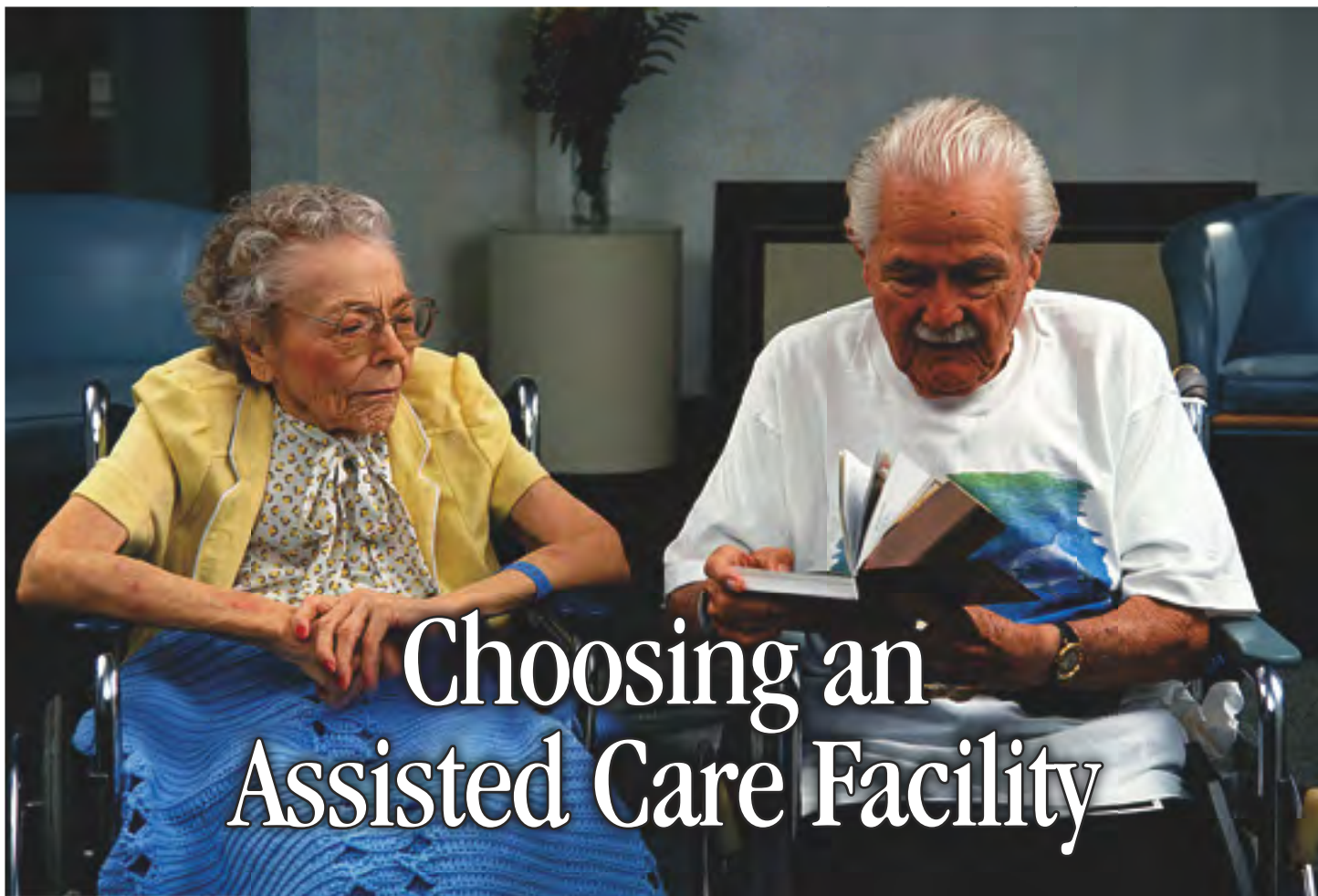
www.fetterman-crutches.com

Products: crutches and crutch tips

Westons

www.westons.com

Products: safety devices, mobility aids, lifts, back supports, and eating, bathing and dressing aids



by Christina DiMartino

The Assisted Living Federation of America (ALFA), headquartered in Fairfax, Virginia, reports that there are about 6.5 million older people in assisted living communities. This number is expected to double by 2020.

Assisted living is less costly than both nursing homes and home healthcare. The average rate for assisted living in a private room is about two-thirds that of a room in a nursing home.

ALFA defines assisted living as a housing and healthcare alternative

- Combining independence with personal care
- Offering a warm, dignified community setting
- Having available a special combination of housing, personal supportive services and healthcare designed to meet residents' daily needs.

Other alternatives listed by AFLA include:

- **Independent Living:** A residential living setting that may or may not provide hospitality or supportive services. In this setting, the senior adult leads an independent lifestyle that requires minimal or no extra assistance. The government offers such subsidized housing for seniors who qualify. Independent living also includes rental-assisted or market-rate apartments or cottages where residents usually have complete choice in whether to participate in a facility's services or programs.
- **Congregate Housing:** Similar to independent living, this type of rental housing usually provides convenience or supportive services like meals, housekeeping and transportation.
- **Continuing Care Retirement Communities:** Referred to as CCRCs, these communities offer several levels of assistance, including independent living, assisted living

and nursing home care. They differ from other types of care facilities in that they usually provide a written agreement or long-term contract between the resident and the community.

- **Nursing Home:** These facilities provide 24-hour skilled care for the more acute patients. Patients generally rely on assistance for any needed living activities, including bathing, dressing and toileting.

Another option is for the senior to reside in his or her own home, with on-site nursing or attendant care as needed. This can be as little as brief visits a few times a week to 24-hour, 7-day-a-week care. The cost of this option is a problem for many people.

For Extra-Special Needs

People with amputations have legitimate additional concerns about how their special needs will be met. Adequate care facilities are designed with mobility needs in mind. Their staff members are highly trained in how to care for residents with all types of physical restrictions.

Sunrise Senior Living, Inc., is one of the nation's largest providers of senior living. Sherill Garvey is the senior vice president of

Resident Care and Services at Sunrise. She says that encouraging independence is of primary importance, regardless of the mobility restriction.

"This is accomplished through the design of the housing facility, employee training and proactive care," Garvey says. "It is of equal importance for team members to understand the special needs of those without arms or legs and help these people preserve their dignity."

The Search for a Home

Garvey says the search for an assisted living community can be a pleasant task. You will, however, need some background information and should not be afraid to ask questions.

Garvey stresses the importance of not waiting until an emergency forces you to find a new home in an assisted care facility.

- Begin your search years before you need it.
- It is best not to feel pressured or rushed into making this important decision in a stressful situation.
- But if you have not handled this part of your care in advance, it should be attended to at the first sign of a potential need.



Garvey suggests:

- Discuss your needs with your doctor.
- Ask your medical professional to suggest facilities where he or she has patients.
- Talk with your friends about their experiences.
- Attend open houses, happy hours and special events at communities that interest you.
- Tour the facility, confer with the administration, and learn the answers to your questions.
- During both scheduled and unannounced visits, ask the tough questions about how the community can meet your particular needs.
- If the answers are satisfactory, ask them if they are willing to put them in writing as a part of your contract.

If you have the time and a desire to give of yourself, volunteer your time in a senior community before you have the need for one of your own. Doing so will provide you with a sense of fulfillment and will bring much pleasure to others. At the same time, it will give you insight into what to expect when it is time for you to move into a facility.

Garvey also offers the following tips and things to consider before making a decision about a facility:

- Use your senses. When touring the community, do you gain a sense of warmth and comfort? What do you see, smell, hear and feel?
- Is the community clean and tidy? Are areas free of debris, providing a sense of organization?
- Are residents engaged in meaningful activities? Do they appear happy and content?
- Do all areas of the facility smell fresh?
- Taste the food. Look over a few menus from previous days. Choices and variety make dining a pleasurable experience.
- Are you permitted to view all areas of the facility, other than those that protect residents' privacy?
- Are the sounds pleasant and calming? Does music follow you from one area to another?
- Is the facility a place where you could comfortably live? Would you want to have friends and family visit you there?

"The best assisted living providers anticipate physical needs when designing communities," Garvey says. "The Administration on

Aging found that over 70 percent of people age 80 and over have at least one disability."

Look for these features when evaluating a facility:

- Well-designed common areas and suites that accommodate ease and safety in movement
- Wide doorways, ramps, elevators and carpeting that enable easy mobility
- Bathroom features that include easy-in/out showers, shower seats and handrails
- Easy access to outdoor areas, such as a terraces or courtyards, and freedom of use for residents to enjoy fresh air and sunlight.

The level and range of activities and programs in the facilities you evaluate should welcome residents of all abilities. They should include activities inside the home and outside in the neighborhood. Garvey says to look for the following:

- Transportation to and from events.
- Daily activities and programs that are centered on residents' interests, not what is convenient for staff.
- A facility where residents look interested and engaged in their activities.
- Activities that celebrate the uniqueness of each resident and offer diverse and educational opportunities for everyone
- Quality and variety in programming that keeps residents active and busy — a key to staying youthful.

"The facility is your home," Garvey adds. "Friends and family should be welcomed in the community any time you choose."

A reputable assisted living community will also offer personal care services, such as medication management. It will provide assistance when needed with bathing and dressing, in addition to providing living quarters and meals. However, Garvey says the best facilities go beyond these basic needs.

Before making a final decision on a community, ask yourself one final question: Does the community offer the environment, services and care necessary for me to live a quality life? If the answer is yes, move forward knowing that this new home will be a great place to enjoy your life. ❖



Weigh to Go: *Weight Control for Amputees*

Weight control means maintaining weight at a healthy level and is important for amputees:

- To reduce the energy used when wearing a prosthesis

- To maintain proper fit of the socket
- To reduce or prevent secondary conditions, such as back pain
- To control diseases, such as diabetes and high blood pressure.

The Weight-control Information Network (WIN) is a national information service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institutes of Health (NIH). WIN was established in 1994 to provide information on obesity, weight control and nutrition. WIN produces and collects materials and disseminates them to consumers and healthcare professionals. According to the WIN, you should ask your healthcare provider what a healthy weight is for you. If you begin to lose or gain weight and do not know why, your healthcare provider should be able to tell you if this change is healthy or not.

Health Risks of Being Underweight

- Poor memory
- Decreased immunity

- Osteoporosis (bone loss)
- Decreased muscle strength
- Hypothermia (lowered body temperature).

Health Risks of Being Overweight:

- Type 2 diabetes
- High blood pressure
- High blood cholesterol
- Heart disease and stroke
- Some types of cancer
- Sleep apnea (breathing stops for short periods during sleep)
- Osteoarthritis (wearing away of the joints)
- Gallbladder diseases.

Eating Tips for Older Adults From WIN

- Eat breakfast every day.
- Select high-fiber foods like whole grain breads and cereals, beans, vegetables and fruits. These can lower your risk for chronic diseases like heart disease and diabetes.
- Choose lean meat, poultry and seafood with the skin removed. As your body ages, you need fewer calories, especially if you are not very active.
- Have three servings of low-fat milk, yogurt, cheese a day.
- Keep nutrient-rich snacks on hand. These include dried apricots, whole-wheat crackers, peanut butter, low-fat

cheese, and low-sodium soup.

- Drink plenty of water.

Evaluating Weight-Loss Programs

Experts agree that the best way to reach a healthy weight is to follow a sensible eating plan and engage in regular physical activity. Weight-loss programs should encourage healthful behaviors that help you lose weight and that you can maintain over time. WIN emphasizes that safe and effective weight-loss programs should include:

- Healthful eating plans that reduce calories but do not rule out specific foods or food groups
- Regular physical activity and/or exercise instruction
- Tips on healthful behavior changes that also consider your cultural needs
- Slow and steady weight loss of about $\frac{3}{4}$ of a pound to 2 pounds per week and not more than 3 pounds per week (weight loss may be faster at the start of a program)
- A plan to keep the weight off after you have lost it.

Portion Control

According to the experts at WIN, you do not need to measure and count everything you eat for the rest of your life — just long enough to recognize standard serving sizes. Try these other ideas to help you control portions at home:

- Take a standard serving out of the package and eat it off of a plate instead of eating straight out of a large box or bag.
- Avoid eating in front of the TV or while busy with other activities. Pay attention to what you are eating and fully enjoy the smell and taste of your foods.
- Eat slowly so your brain can get the message that your stomach is full.
- Take seconds of vegetables or salads instead of higher-fat, higher-calorie parts of a meal such as meats or desserts.
- When cooking in large batches, freeze food that you will not serve right away. This way, you won't be tempted to finish eating the whole batch before the food goes bad. And you'll have ready-made food for another day. Freeze in meal-sized containers.
- Try to eat three sensible meals at regular times throughout the day. Skipping meals may lead you to eat larger portions of high-calorie, high-fat foods at your next meal or snack.
- Eat breakfast every day.

- Keep snacking to a minimum. Eating many snacks throughout the day may lead to weight gain.
- When you do have a treat like chips, cookies, or ice cream, eat only one serving, eat it slowly, and enjoy it!

For additional information, go to www.niddk.nih.gov/health/nutrition.htm

Overcoming the Myth

One of the most popular myths about weight loss is that everyone who loses weight will eventually gain it back. The National Weight Control Registry (NWCR) is a research study founded in 1993, which has surveyed more than 3,000 individuals who have lost significant amounts of weight and kept the weight off for long periods of time.



Research conducted by the NWCR has shown that successful weight loss and weight maintenance is indeed possible. It is related to the following points:

- Successful weight control is a long-term process. It requires commitment, patience, and the practice of healthful eating.
- Weight control is about more than healthful eating. It also must include a change in shopping habits, cooking and dining out, and attitudes about food.
- Walking was cited as the most frequent physical activity.
- About 50 percent of participants lost weight on their own without any type of formal program.
- About 42 percent of participants reported that losing the weight was harder than maintaining the loss.
- No matter which program or diet was used to lose weight, weight control consisted of eating low-fat foods and engaging in regular physical activity.
- Over time, it takes less effort to maintain weight loss.
- People who lose weight successfully do not allow themselves to go hungry.
- People are more inclined to eat if they are thirsty because they confuse thirst for hunger.

The NWCR has published a number of articles describing

- The eating and exercise habits of successful weight losers
- The behavioral strategies they use to maintain their weight
- The effect of successful weight loss maintenance on other areas of their lives. ♦

For additional information, visit the NWCR Web site at www.nwcr.ws



Weighing Your Options for Weight Loss

According to the Partnership for Healthy Weight Management (PHWM), more than half of all Americans are overweight or obese. If you are in this group, what you weigh is the result of several factors:

- How much and what kinds of food you eat
- Whether your lifestyle includes regular physical activity
- Whether you use food to respond to stress and other situations in your life
- Your physiologic and genetic makeup
- Your age and health status.

Successful weight loss and weight management should address all of these factors. And that's the reason to ignore products and programs that promise quick and easy results or that promise permanent results without permanent changes in your lifestyle.

The PHWM has developed voluntary guidelines for providers of weight loss products or services. Participating programs will answer important questions about how their product or service works, how much it costs, how well it works and any risks involved in the program. To obtain a copy of the guidelines or to reprint a form you can use when evaluating weight loss programs, visit the PHWM's Web site at www.consumer.gov/weightloss/setgoals.htm or call toll-free 888/878-3256 for a copy of the brochure.

Compare weight loss programs and products by asking the following questions from PHWM:

1. What's involved in following the program?

Get details about the number of calories and types of foods you will eat. For diets under 1,500 calories, be sure to check with your healthcare provider. Find out about exercise requirements.



2. What are the staff qualifications? What kind of support will you receive and how often?

3. What are the risks or side-effects? If prescription or over-the-counter medications are involved, check with your physician first. Report any side-effects immediately.

4. What are all the costs?

Get an itemized list of prices

for membership, visits, food, testing or supplements.

5. How can you improve your chances for keeping the weight off?

6. How successful are other people who follow this program? Ask about percentage of completion, average weight loss, and how long they have kept the weight off. ♦

Information Resources

American Dietetic Association

800/877-1600

www.eatright.org/Public/index.cfm

Nutrition fact sheets

American Obesity Association

800/98-OBESE

www.obesity.org

Fact sheets and statistics

National Institute of Diabetes and Digestive and Kidney Diseases

www.niddk.nih.gov

Fact sheets, including easy-to-read materials

Shape Up America!

www.shapeup.org

Educational and fitness information, online support

Tufts University Nutrition Navigator

www.navigator.tufts.edu

Online review of nutrition information; site for seniors

Keep Moving:

Exercises for People With Lower-Extremity Amputations

by Melissa Wolff-Burke, EdD, PT, ATC, and Elizabeth Cole, PT

Getting back to your previous activities may be your objective following amputation. Even if you decide not to use a prosthesis (or are unable to use one), the following exercises are designed to help you reach your goals. Many of these activities can be done with or without a prosthesis while lying on a firm surface, sitting in a straight back chair or on the edge of your bed, or standing at a counter. Very little equipment is needed to keep you and your residual limb in good working order. Exercises are an essential part of maintaining your health and function, and getting back to your hobbies and activities is possible in the near future, if you keep moving!

As always, please be sure to check with your physician or physical therapist before beginning any exercises. Your fitness level, your general health, and the condition of your residual limb will all play a role in how rigorously you can exercise. A qualified health professional can teach you how to stay within your target heart range.

Range of motion

Following your amputation, you will need to decrease the amount of time your leg is bent. Because you will initially spend more time sitting, the remaining joints of your leg, and even your back, will spend more time bent or flexed. Too much of this can cause problems for your muscles and joints because they get used to being in a shortened position and you may develop a contracture. A contracture is when your joints cannot go through the full range of motion. This can cause problems whether you are ready for a prosthesis or not. Often a contracture can be avoided by simply paying attention to the following simple exercises.

- Perform flexibility/range of motion slowly, holding each position for 30 seconds.

- Do not bounce.
- Count aloud slowly (try counting in another language) or use a timer.
- Stretching is a mild sensation of tension - not painful agony. Use your good judgment to find the right amount of stretch.
- Be sure to stretch your knee and hip many times every day.
- Do not hold your breath.

Knee flexibility exercises and positions

To keep the motion in your knee, let your



Picture 1

knee rest on a cushioned board or on the leg rest of your wheelchair in its fully extended position. If you don't have a wheelchair leg rest, position your leg on a couch or chair. See if you can devise other ways throughout the day to avoid sitting in the same position. Perhaps you have a cane or stick handy and can do the rotation stretch shown in Picture 2. Lying on your stomach is a great way to stretch out many joints. See Picture 1.



Picture 2

Hip and back flexibility exercises and positions

By resting flat on your stomach or on your elbows, as shown in the picture, you can maintain or improve the flexibility (extension) of your knees, hips and lower back. It is recommended that

you lie on your stomach twice a day for 10-20 minutes. If your breathing is impeded or it's uncomfortable for you, use pillows under your chest for support or ask the advice of a physical therapist.

Strength

Now that you are on the way to being more flexible, let's look at some ways to make you stronger. You will need to rely on your nonamputated limb heavily now. Therefore, strengthening exercises will involve both your amputated limb and your nonamputated limb. The exercises shown below can be performed with either leg.

- If you are adding weights as shown in Picture 3, the nonamputated leg may be able to manage heavier weights.
- You can begin with no weights on your limb and try to move it in all directions as many times as possible. As you add weights, keep the repetitions to a maximum 25 and then move on to a heavier weight or a more challenging exercise (Picture 4).
- Don't forget your stomach muscles and your arms as you will need a lot of help from them to get moving (Picture 5 and Picture 6).
- Try playing "tug of war" with an elastic band tied to a sturdy object or held by your foot or a friend (Picture 7). Pull the band in all directions. Begin in a sitting position, and then try it kneeling and standing.



Picture 3

you can work on balance and agility skills.

Balance

Whether you are sitting up, lying down, standing or walking, your balance will be different following



Picture 4

Strengthening does not need to be done every day. It is best if you do it every other day and alternate it with a different activity. On your days off from strengthening,

your amputation. You will need to re-train your brain, and that takes practice. Many people with amputations have risen in the night, tried to take a step and found themselves on the floor. Their brain forgot to remind them that the limb was no longer there, and the balance center did not figure it out soon enough.

- Help your brain by practicing very simple activities such as sitting and reaching for objects (Picture 8), kneeling (Picture 9) and standing on one leg.
- Stand up and turn from side to side, with or without a prosthesis. Hold on to a counter and reach forward, sideways, and back to exercise the balance center in your brain. (Picture 10, Picture 11)

If you are going to use a prosthesis, you will need to work on basic balance activities before you become an accomplished walker. Being able to balance on your prosthetic leg with full weight is necessary for a smooth walk. With every step, there is a moment when you have only one leg on the ground. That leg, whether prosthetic or natural, will have to be able to hold all your weight. Practice accepting weight on your prosthesis by leaning over the prosthetic leg (Picture 12). Then



Picture 5



Picture 6



Picture 7



Picture 8



Picture 9

kick a ball to someone using your nonprosthetic leg to do the kicking (Picture 13). Hold



Picture 10

on to a rail and lift your non-prosthetic leg up to the step and then bring it back to the floor (Pictures 14 & 15). If both of your legs have been amputated, step up with either leg.

Agility

In addition to good balance, you will want to practice your agility. Agility is what lets you move confidently from place to place and gets you out of the way of a fast-moving object.



Picture 12



Picture 11



Picture 13

- Sit or stand and play catch (Picture 16). Begin by having your partner throw the ball directly to you, then make this more challenging by having the ball tossed out to the side. This should be done in a place where you cannot fall into anything that can injure you.
- Sit in a chair and throw or kick a ball against a wall.
- Dancing with or without a partner is a great way to work on your balance and agility. Even if you just stand in one spot and rock back and forth, you are working on your strength, balance, agility and togetherness! (Picture 17)



Picture 14



Picture 15

Conclusion

Range of motion, strength, balance and agility all play a part in your plans to get back to what you like to do. By following these exercises or those prescribed by your health professional, you will reap the rewards when you are ready to get moving! ♦



Picture 16

A special "thank you" to the members of the Winchester Amputee Support group for being models and reviewers of this article.



Picture 17



Keep Moving: *Advanced Exercises for People With Lower- Extremity Amputations*

by Melissa Wolff-Burke, EdD, PT, ATC, and Elizabeth Cole, PT

The previous article discussed exercises to help you maintain the range of motion (ROM) in your limbs and back and help you get moving again after an amputation. Many of those activities can be made more challenging by adding weight, not using any object for support, standing instead of sitting, or even standing on one leg. If you have already mastered those activities, you can keep moving by trying the following advanced exercises.

As always, please be sure to check with your physician or physical therapist before beginning any exercises. Your fitness level, your general health, and the condition of your residual limb will all play a role in how rigorously you can exercise. A qualified health professional can teach you how to stay within your target heart range.

Strength Exercises

Strength is needed in each leg, your arms and your trunk (stomach and back). In addition to your legs, your stomach and back muscles play a crucial role in standing and moving. If your trunk is not strong, it will not be able to hold up to the demands you make on it all day every day.



Seated push up

Place a stable chair against a wall to prevent it from tipping over. While sitting in the chair, place your hands on the armrests. Push down into the armrests to raise your hips one to two inches off of the seat and then rest. To make this more difficult, lift one leg.

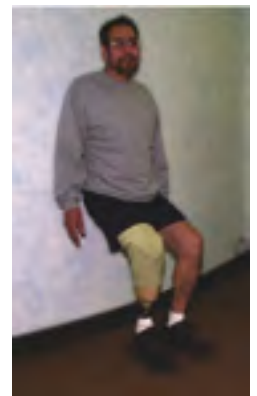
Partial squats

Hold onto a sturdy piece of furniture or the kitchen sink. Place even weight onto both legs, and simply squat as if you are sitting on a very tall stool. You're not working toward a full squat. Do this 10 times. Exercising the muscles of your thighs will make it easier to sit and rise from a chair.



Wall squat (More advanced)

Stand with your back against the wall beside a sturdy piece of furniture in case additional support is needed. Slowly slide your body down the wall until your knees are slightly bent. To make this exercise more difficult, slide a little lower down the wall or do this on one leg. You can stand on your intact leg or your prosthetic leg. Hold this position for five to 30 seconds. Be sure to breathe the entire time you perform this exercise. Holding your breath is bad for your heart and your hemorrhoids! If your amputation is above the knee, you will need to do this exercise on your intact leg only since most prosthetic knees will not support your weight if there is too much bend in the knee.



Pelvic tilt

While on your back, with or without your prosthesis, bend both hips and knees to 90 degrees. Place your hands on your thighs just above your knees, and flatten the small of your back

by pressing down with your stomach muscles. Do not allow your thighs to move. Hold this position for two to three seconds while breathing normally. This exercise strengthens the abdominal muscle (stomach).

You can make this exercise more difficult by lifting your head.



Balance Exercises

One of the most difficult rehabilitation activities is retraining you and your brain to accept weight into the socket of your prosthesis. To use your prosthesis and its foot and knee components to their fullest advantage, however, you must put all of your weight into the socket and use all of your leg muscles to control it. Though it will be difficult to learn to use your remaining leg muscles to balance on each leg while standing and walking, it will pay off in a smoother, less tiring gait.

Even weight bearing

While standing in line, shaving, or brushing your teeth, think about how much weight you have on each leg. Do you stand with most of your weight on your unaffected leg? Many people with an amputation shift all of their weight onto the unaffected leg and use the prosthesis only as a perch. Stand with your weight evenly on both legs while performing one typical daily task, such as talking on the telephone. By increasing your awareness and changing this one simple habit, you can improve your balance on a daily basis.

All fours

While on your hands and knees, begin by raising one arm in front of you. Put your arm down. Now try to raise a leg behind you. When you can do this with ease, raise your opposite arm and leg together, hold them for two to three seconds while breathing, and relax. Then switch sides. Keep your eyes down so that you don't strain your neck, and keep your back flat.



Kick ball

Practice this fun exercise with a friend. While you are up against a wall or using a chair, alternate kicking a ball with one leg and then the other. Quickly changing the leg that you kick with will help improve your balance and coordination.

Hip lift

If you don't use a prosthesis, or when you are not wearing one, be aware of how you hold your hip. If



you tend to slouch, tighten the muscles of your standing leg to even out your hips.

Uneven surfaces

A good way to work on your balance is to make the surface on which you are standing uneven. Place a pillow or cushion on a carpet and stand on it. You might want to rest your hands on a table top. For safety, be sure the pillow is on carpet and not a slick surface. Sway back and forth slightly or reach for something on the counter. You will need to tighten the muscles of your residual limb inside the prosthetic socket.



Agility Exercises

Once you have mastered balance activities, you will find that you are moving more easily. It is also likely that you will be doing more, and you may find that you occasionally need to move faster, slower, backwards or sideways. By practicing the following exercises and varying the speed and step length, you will improve your agility and accomplish tasks with more confidence.

Braiding

Using the back of your couch for balance assistance, take a few steps to one side crossing your prosthetic leg in front of and then behind your unaffected leg. Stand as straight as you can and try to use your hands for balance only. If your amputation is above the knee, be sure to take small steps ensuring that you don't put too much weight on the toe of your prosthesis, which could cause the knee to bend.



Circle

Walk around a chair in each direction.

Ball toss

Do this exercise with a friend. If you are using a prosthesis and really want to challenge your balance, stand up to catch the ball. If you are not using a prosthesis or are just beginning this exercise, sit while you catch the ball. This exercise requires strength, coordination, balance and agility, and it's fun!



Endurance Exercises

You have already been improving your endurance by working on your range of motion, strength, balance and agility. Every time you do an extra repetition, use a heavier weight, or spend more time exercising, you are improving your endurance. To focus more on endurance, you simply need to work a little harder and a little longer at the things you have already been doing. You might also add an aerobic activity. If you have access to a stationary bike, a treadmill, a rower or a pool, you can use it to improve your endurance. And, of course, there is always just plain walking. It is a good idea to seek the assistance of a health professional to determine your current level of fitness and your target heart rate (THR). You don't want to stress your heart too much or too little. Once you learn your THR and how to take your pulse, you will be able to do effective endurance activities with confidence.

Stationary bike

If you have a stationary bike, get on it! Stop using it as a clothes rack. You can ride a bike with one leg. It would, however, help to have a strap to hold your foot in place. If you cannot get on your bike, how about placing it on a table top, sitting behind the table, and moving the pedals with your hands?

Conclusion

If you are interested in doing more exercise or have specific concerns, a physical therapist who has experience working with people with amputations can help you. If, on the other hand, your needs are more general and you would like to exercise at home, several books and videos can be purchased through the ACA to help you.

If you can set a goal, break it down into small bits, and make exercise a part of your daily plan, you will find that it becomes a good habit. Set aside some time each day to work on one of these activities, get a friend to join you, play some music and have some fun. Applaud your efforts, great and small, and you will keep moving. ❖



Questions About Blood Pressure

What Is Blood Pressure?

Blood pressure is given as two numbers that measure the force of blood against the walls of your arteries. The top number (systolic) is the pressure of blood while your heart is beating. The bottom number (diastolic) is the pressure while your heart is at rest. A blood pressure of 120/80 is read as “120 over 80.”

What Is High Blood Pressure?

Anything above 120/80 is considered high blood pressure or hypertension. High blood pressure usually has no warning signs so it is important to have your blood pressure checked regularly.

Why Is It a problem?

It is estimated that one in four adults in the U.S. has high blood pressure. As many as one-third of these many not even realize they have it. High blood pressure can lead to heart disease, kidney disease, stroke, and impaired vision.

How Can I Prevent or Control It?

- Have your blood pressure checked regularly.
- Maintain a healthy weight.
- Follow a healthful diet rich in fruits, vegetables, and low-fat dairy products.
- Exercise regularly.
- Quit smoking.
- Limit caffeine and alcohol.
- Take medications as directed by your physician.
- Control your stress.

Where Can I Learn More?

Visit the National Heart, Lung, and Blood Institute at www.nhlbi.nih.gov or the American Heart Association at www.americanheart.org ❖

Vascular Disease



What disease affects more than 12 million people in the U.S.? Peripheral arterial disease (PAD) is a form of atherosclerosis, or narrowing of the arteries. This disease is sometimes referred to as hardening of the arteries. PAD causes fatty substances to build up inside the artery walls over time. The buildup creates a blockage that limits blood flow and can cause blood clots.

Diabetes is a major cause of PAD. People with diabetes cannot properly use the sugar they ingest. This sugar builds up and causes changes in their blood vessels that lead to circulation problems. PAD is an important risk factor for foot ulcers that can lead to amputation in people with diabetes

What Are the Risk Factors?

- People with diabetes are more likely to have PAD.
- People who smoke are more likely to have PAD.
- People with PAD are five times more likely to have an amputation.
- The risk of limb loss due to PAD increases with age. People 65 or older are 2 to 3 times more likely to undergo amputation of a limb.
- Men with PAD are twice as likely to undergo an amputation as women with PAD.
- African Americans, Native Americans, and

Hispanic Americans are at increased risk of amputation since they have a higher risk for diabetes and cardiovascular disease.

What Are the Symptoms of PAD?

- Painful leg cramps when walking that stop when resting
- Numbness, weakness, or heaviness in the legs
- Burning or aching pain in the feet or toes while resting, particularly at night
- Color changes in the skin
- Toe and foot sores that do not heal
- Many people have no symptoms with PAD.

How Can PAD, Diabetes or Further Limb Loss Be Prevented?

To prevent or control PAD, contact the American Heart Association at www.americanheart.org.

To prevent or control diabetes, contact the American Diabetes Association (ADA) at www.diabetes.org.

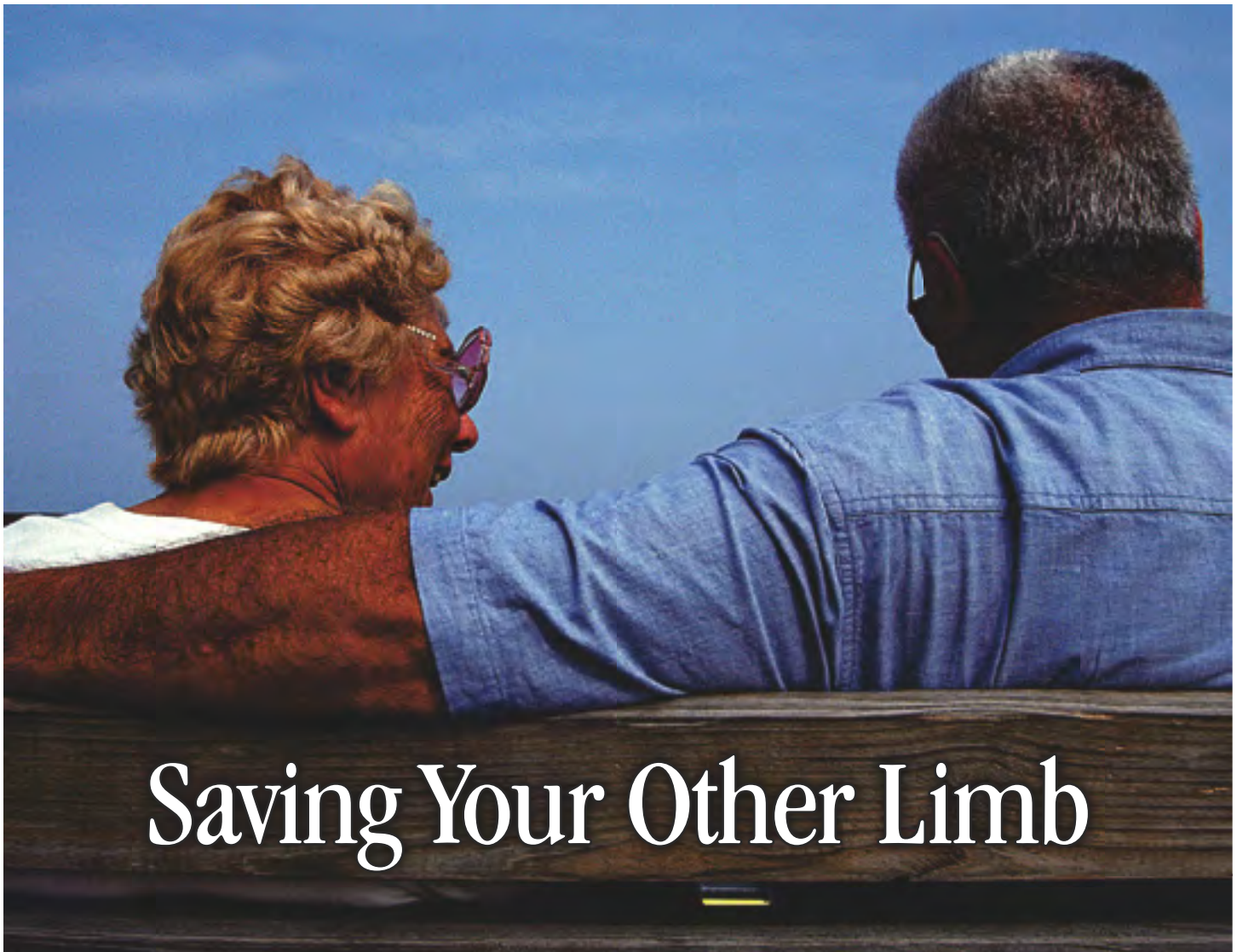
To prevent further limb loss, it is important to:

- Stop smoking.
- Exercise regularly.
- Eat a healthful diet based on the Diabetes Food Pyramid (see www.diabetes.org/nutrition-and-recipes/nutrition/foodpyramid.jsp or contact the ADA).
- Get regular checkups.
- Follow your physician's orders.
- Work with your healthcare team to manage your PAD.

This information was adapted from:

- A 2002 fact sheet developed by ACA's National Limb Loss Information Center in partnership with the American Heart Association and the American Diabetes Association
- Information from the Vascular Disease Foundation.





Saving Your Other Limb

Adapted from an article by John H. Bowker, MD

This information provides a blueprint for saving your other leg. You can stop the vicious cycle of events leading to amputation. The first step is to realize that no one should care more about your leg than you.

You are a person living with an amputated leg. Chances are good that your other leg is still intact. And you have no desire to lose it. If you are in good health, a nonsmoker and your amputation was the result of an accident, your chances of losing the other leg are quite small. If the amputation was related to poor circulation and/or diabetes, the other leg remains at high risk for loss. Despite the gloomy statistics there are things you can do to avoid this.

Most lower-limb amputations in people middle aged or older are related to one or both of the following:

- Poor circulation in the feet and legs due to blood vessel (artery) disease
- Loss of protective sensation to the feet (sensory neuropathy) related to diabetes.

Ways to protect your foot or leg are related to what caused your amputation. If you do not have diabetes, but lost your foot because of poor circulation, you should have normal sensation.

- This is a big plus because you feel any injury to your foot and seek prompt medical attention.
- You should quit smoking or using any other form of tobacco. You should severely restrict all caffeine-

containing products. Nicotine and caffeine cause reduction of blood flow in the small arteries of the feet.

- Any injury to a foot with poor circulation will either be slow to heal or fail to heal at all.

Loss of Feeling

The chief problem for a person with diabetes is the loss of protective sensation in the foot. Protective sensation helps by:

- Allowing you to recognize a possible injury, such as when you pull your foot back if you feel something sharp
- Preventing more serious injuries
- Alerting you to an injury that needs immediate care.

Basic Things You Can Do to Make Up for a Lack of Protective Sensation:

- **Never walk barefoot.** Carpet and bare floors may conceal hazards like needles or bits of glass. These items can cause injuries that go unnoticed until an abscess forms.
- **Examine your foot every day for injury or redness.** If your eyesight has been affected by diabetes, have a family member or friend do this for you.
- **See a certified pedorthist to obtain properly fitted in-depth shoes with multidensity inserts (orthoses).**
These should be custom-molded if you have any prominent foot bones or a history of foot ulcers.
- **Shake out your shoes each day before putting them on to dislodge any objects,** such as pebbles, before they cause an ulcer.
- **Wear water shoes that have thick rubber soles and stretch mesh uppers when you swim** to avoid burns from hot pavement or sand, cuts from shells or glass, or abrasions from the rough cement bottoms of swimming pools.
- **Prevent calluses and corns, which often lead to foot ulcers, by using properly fitted shoes and inserts.** If they do occur, do not treat them with over-the-counter callus/corn removers. These preparations dissolve the callus then destroy the numbed skin. Instead, get a referral from your physician to a health professional for callus/corn removal and nail care.

Foot Ulcers

Foot ulcer treatment in the person with diabetes must be prompt and effective to avoid an infection that might lead to limb loss.

- The ulcer should be evaluated for severity.
- Arterial circulation to the foot should be checked to see if it is adequate for healing. If not, a vascular surgeon should be consulted.
- Pressure on the ulcerated part of the foot should be eliminated or minimized. That means no unprotected walking on that foot. There are special shoes available that remove pressure from the forefoot or the heel, depending on the location of the ulcer.
- Tobacco use should be stopped totally and permanently.
- Caffeine should be eliminated until healing is complete - then resumed in small amounts, if desired.

Foot Abscess

A foot abscess in someone with diabetes is an emergency. An abscess requires prompt, wide surgical drainage to save as much of the foot as possible. Unfortunately, many people with diabetes, because they have lost sensation, deny that there is a problem and fail to seek help for minor infections. The minor infection may then develop until it becomes impossible to save the foot.

Reducing Blood Sugar Levels

People with diabetes can reduce the chance of a second amputation by keeping their blood sugar levels under tight control. Constant high blood sugar levels lead directly to blindness, kidney failure and loss of foot sensation ending in amputation. High sugar levels also interfere with white blood cell functions, impairing the body's ability to ward off infection. You should know that the Diabetes Control and Complications Trial, sponsored by the American Diabetes Association, demonstrated that these complications can be either prevented or stopped in their progression by good control of blood sugar levels. ❖



Who Cares for Caregivers?

by Nancy Carroll

In 1993, Suzanne Mintz founded the National Family Caregivers Association (NFCA). NFCA is a nonprofit membership organization dedicated to improving the quality of life for family caregivers.

Positive Communication

How do you tell your loved one how you feel without being hurtful? Suzanne suggests choosing your words carefully so you can get the anger out without verbally attacking the person. Here are some examples of things you might say if you are angry:

- I'm not angry at you, I'm angry at the disease (or accident) that took your leg.
- I am so frustrated and tired and angry that I don't have enough time for myself.
- I want the amputation to go away and I know it won't.

- I know it's affecting you and it's affecting me, too.
- I feel so upset and lonely.

Identify sources of your frustration other than the person by saying such things as:

- I'm frustrated because the home care person didn't show up.
- I'm frustrated because someone parked in the handicapped parking spot at the grocery store.
- I'm frustrated because it takes an hour to help you get dressed in the morning. It's not your fault.

Getting Help

How do you make time for a break? Perhaps you have family members nearby, yet most of the burden falls on you. How do you get your family to share in the responsibilities of caregiving?

Suzanne suggests holding a family meeting. “The idea of the family meeting is to get everything out on the table, to understand where each person is coming from, and to underscore the fact that the primary caregiver cannot continue to do everything alone, that they sometimes need help from the rest of the family,” Suzanne says.

It is important to have someone outside the family, such as a therapist, a social worker or a minister, attend the meeting. The outside person’s role is to help the family find ways to meet the needs of the caregiver. Everyone should have an opportunity to talk about what is going on and express their thoughts and feelings. Hopefully, a family meeting will lead to:

- A better understanding of what the caregiver is going through
- An understanding of the importance of helping the caregiver
- Offers of financial assistance
- Help in finding assistive products and services
- Offers to provide a break for the caregiver.

Combating Isolation

Reaching out to others can be difficult, especially when you’ve been isolated for a while. It requires a firm resolve that you’re going to find people you can rely on, whether they are phone pals, friends, neighbors, or people at church. “It’s really important to maintain some kind of network



because not only can friends keep you from being isolated, they can also be there for you when you need support and help,” Suzanne says.

The Four Rules of Self-Advocacy for Caregivers

1. Take charge of your life.
2. Love, honor and value yourself.
3. Seek and, at times, demand help.
4. Stand up and be counted.

Support for Caregivers

Caregiver support groups offer important benefits.

- Caregivers make friends with people who are in similar situations.
- Caregivers can learn how others cope.
- Caregivers have an opportunity to vent their feelings with others who understand what they are going through.
- Caregivers have time away from caregiving.

People may say they are interested in caregiver support groups, but statistics show that not many people use them, Suzanne notes. If support groups are so helpful, why don’t more people attend?

- Some people are reluctant to share their feelings.
- Some people can’t find a convenient time or place for support group meetings.
- Some people have problems with transportation.
- Others prefer different types of interaction such as e-mail or “chat rooms” on the Internet.

Membership in the NFCA is another solution. The organization has over 20,000 members. Membership for family caregivers is free. You will receive information about practical aspects of caregiving as well as emotional ones, all written from a caregiver’s perspective. ❖

For more information on NFCA membership, call 800/896-3650, write NFCA, 10400 Connecticut Avenue, Kensington, MD 20895, send e-mail to info@nfcacares.org or visit the NFCA Web site at www.nfcacares.org

Other Caregiver Resources

Easter Seal Society

230 West Monroe Street, Suite 1800

Chicago, IL 60606

Telephone: 800/221-6827

E-mail: info@easter-seals.org

Web site: www.easter-seals.org

Offers respite services (varies from location to location), gives referrals to over 400 locations nationwide, supports direct rehabilitation services to disabled people, and provides family support groups.

Friends Health Connection

P.O. Box 114

New Brunswick, NJ 08903

Telephone: 800/483-7436

E-mail: info@friendshealthconnection.org

Web site: www.48friend.org

Matches people with health problems with others in similar situations, brings together family, friends, and caregivers of people with health problems with others in similar situations via the Family Network, and publishes a newsletter.

FamilyCareAmerica

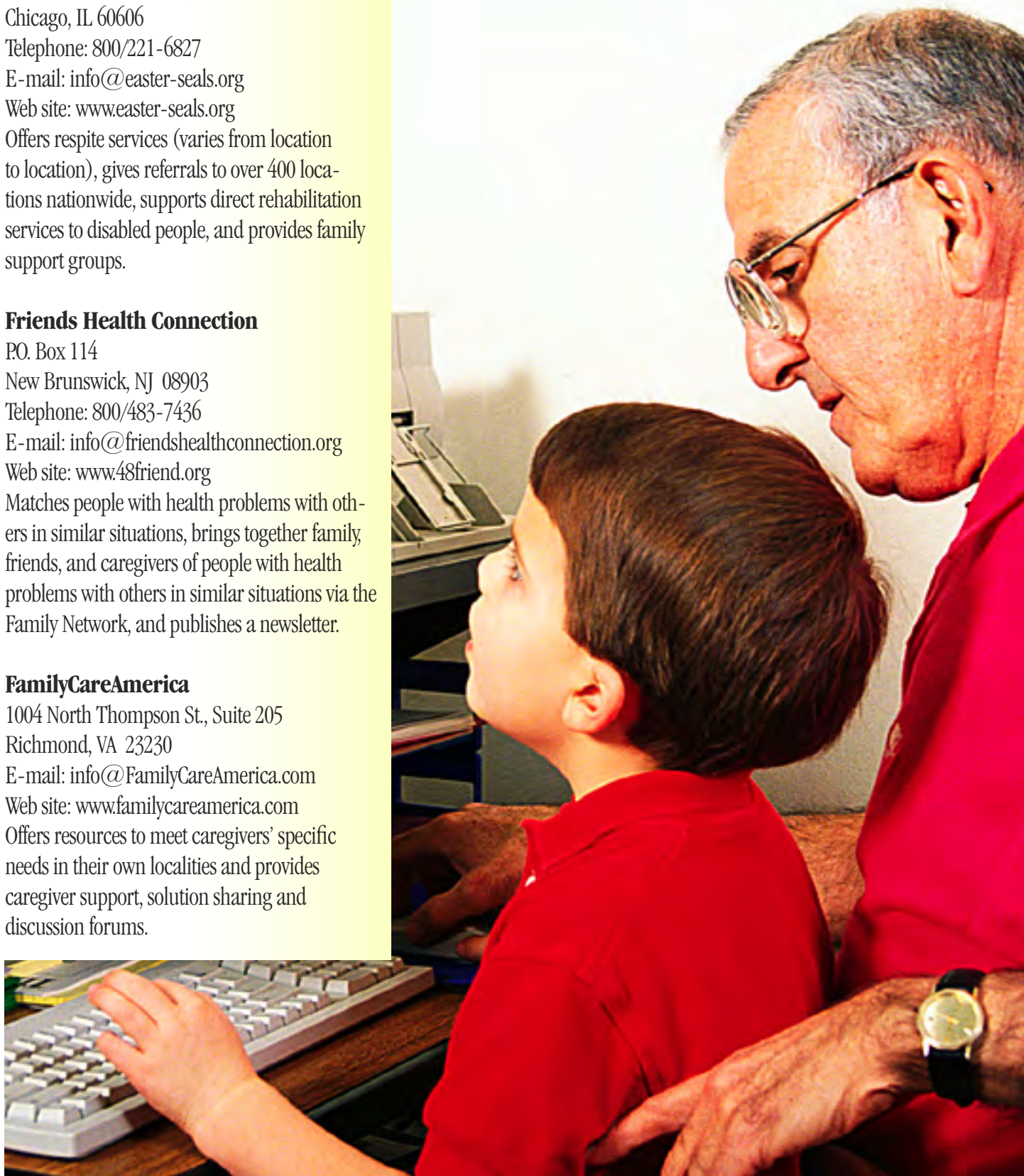
1004 North Thompson St., Suite 205

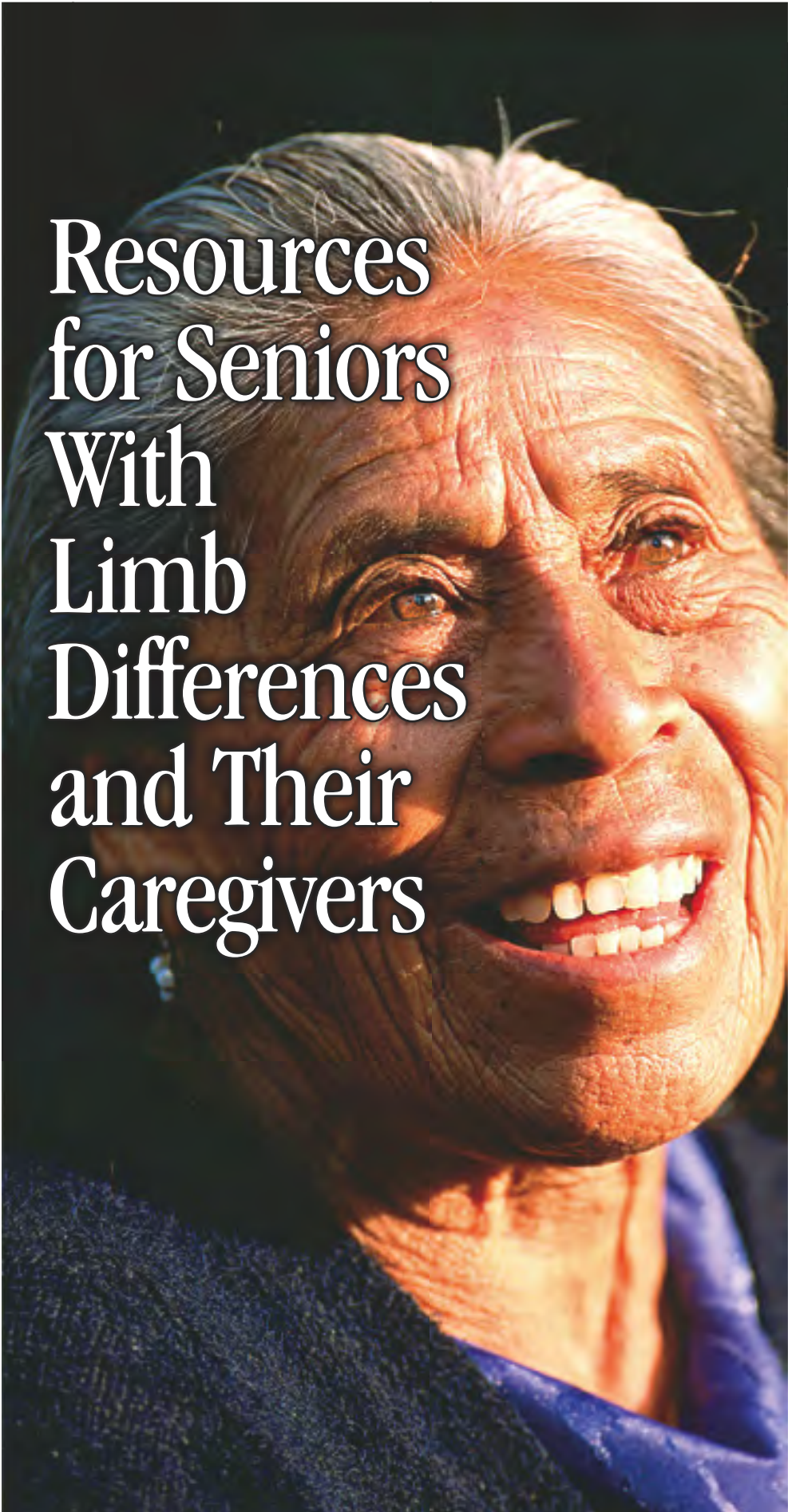
Richmond, VA 23230

E-mail: info@FamilyCareAmerica.com

Web site: www.familycareamerica.com

Offers resources to meet caregivers' specific needs in their own localities and provides caregiver support, solution sharing and discussion forums.





Resources for Seniors With Limb Differences and Their Caregivers

by Rick Bowers

Your mother is 97. She's a bilateral leg amputee, her diabetes is out of control, and she's fighting colon cancer to stay alive. Sometimes, she is so heavily medicated that she doesn't even know where she is or who she is. You've struggled for months to care for her at home, and it's taking an emotional and physical toll on you. Even worse, you realize that your mother is not getting the care she needs and that it is endangering her health.

What do you do? More than likely, you'll put her in some type of facility like a nursing home where you hope she will get the care she needs. You'll then feel guilty that you didn't do more, but, in this case, it was probably the right decision. However, in many cases, it is not.

"No matter how old they get, most people would prefer to continue living in their own home rather than in an institution," says caregiving consultant Connie Siskowski, RN, MPA. Unfortunately, older individuals often find it difficult to perform many of the daily tasks they must do to live a normal life. And these difficulties may be even greater if they are missing an arm, a leg or several limbs.

In fact, many older amputees might also have one or more secondary physical conditions, such as diabetes or peripheral vascular disease, back problems, bone density and muscle loss, problems caused by the overuse of one limb, osteoporosis, skin problems, added stress on the heart, or added risk

of cardiovascular problems due to inactivity. Additionally, there are often mental health concerns.

It might be a terrible error, however, to put them in a nursing home or assisted-living environment when all they might need is just a little help — something as basic as having someone check in on them, cook their meals, give them their medication, tidy their home or deliver their groceries.

Historically, much of this type of caregiving assistance has been done by family members. Unfortunately, in the modern world, not everyone has family members who live nearby or who have the time to devote to taking care of them every day. In addition, Medicare cuts and managed care limits for home care and home healthcare services may make the situation seem even bleaker.

Because of all the possibilities for assistance, before considering an expensive nursing home or even expensive in-home medical care, the extent of the individual's difficulties should be determined. Often, less expensive companion care, automated assistance, or housing modifications can solve the problem. Such solutions might include:

- A personal help button that can be used to summon emergency assistance
- Adding safety bars in the bathroom
- Moving the individual to a one-level home
- Volunteer companions
- Inexpensive housekeeping services
- Canine companions
- A computerized medication reminder system
- Lifts that help people out of beds and chairs.

Caregiver Resources

The following is a list of resources that might help older amputees and their caregivers start searching for the many types of assistance that are available.

Area Agencies on Aging (AAA)

Telephone: 800/677-1116 or check in the local telephone directory's Yellow Pages under "Senior Citizens Services and Organizations."

E-mail: AoAInfo@aoa.gov

Web site: www.aoa.dhhs.gov/eldfam/how_to_find/agencies/agencies.asp

These agencies provide information about groups that provide home-delivered meals, transportation, home health services, employment services, adult day care, and other services.

Assistive Technology Act Projects Technical Assistance Project

1700 North Moore St., Suite 1540

Arlington, VA 22209

Telephone: 703/524-6686 (ask to speak to a Technical Assistance Project staff member)

E-mail: resnaTA@resna.org

Web site: www.resna.org/taproject/at/statecontacts.html

These projects, which exist in every state, commonwealth and territory of the United States, work to reduce or eliminate barriers that impede access to and funding for assistive technology devices and services for individuals with disabilities of all ages.

Beep 'N Tell Medication Reminder

This special pill bottle has an alarm that beeps loudly when it's time for patients to take their medication. It also allows patients or caregivers to record reminders.

e-pill, LLC

70 Walnut Street

Wellesley, MA 02481

Telephone: 800/549-0095

E-mail: info@epill.com

Web site: www.epill.com

"Benefits Check Up"

This free and simple online service allows seniors to search more than 1,150 federal and state programs and find those they might be eligible for.

Web site: www.benefitscheckup.org

Canine Companions for Independence (CCI)

Nonprofit organization that provides free assistance dogs for eligible people with disabilities. There is a \$100 Team Training registration fee, which is reimbursed in supplies.

P.O. Box 446

Santa Rosa, CA 95402

Telephone: 800/572-2275

E-mail: info@caninecompanions.org

Web site: www.caninecompanions.org

Caregiver Background Screening Service

Offers tips for hiring in-home assistants for seniors.

Web site: www.govstate.mo.us/old/background/seniorasst.htm

Caregiver.com Weekly Newsletter

Free newsletter.

Telephone: 800/829-2734

Web site: www.caregiver.com

The Caregivers Marketplace

This is a group-purchasing plan that offers savings to family caregivers on a variety of selected products and services that they are likely to purchase regularly.

P.O. Box 1631

Charleston, RI 02813

Telephone: 866/327-8340

E-mail: ContactUs@caregiversmarketplace.com

Web site: www.caregiversmarketplace.com

Children of Aging Parents (CAPS)

A caregiver's organization that offers information, education, support groups and referrals to children who are taking care of their parents.

P.O. Box 7250

Penndel, PA 19047

Telephone: 800/227-7294

Web site: www.caps4caregivers.org

Department of Social Services

Every state and many local governments have a Department of Social Services (sometimes called Department of Health & Social Services or Department of Health & Human Services). The department offers information, referrals and assistance for the elderly and helps them identify community resources that can help with their care, including transportation and nutrition services. It also assesses medical and supportive needs and coordinates a variety of services.



Telephone: Check in the local telephone directory's Blue Pages or in its Government & Municipal Guide.
Web site: www.aphsa.org/links/statemap.asp

DisabilityInfo.gov

This government Web site is a one-stop source of information for people with disabilities and their families and contains information on such issues as housing, health-care, technology, education and employment.

Web site: www.DisabilityInfo.gov

The Eldercare Locator

This toll-free directory assistance helps individuals locate aging services nationwide.

Telephone: 800/677-1116

E-mail: eldercare_locator@aoa.gov

Web site: www.eldercare.gov

Family Caregiver Alliance

Nonprofit support organization for caregivers.

690 Market St., Suite 600

San Francisco, CA 94104

Telephone: 800/445-8106

E-mail: info@caregiver.org

Web site: www.caregiver.org

FirstGov for Seniors

This Web site allows seniors to find lots of health information and services at one location 24 hours a day, 7 days a week. Users will be able to access all of the government sites that provide services for senior citizens, and they will be able to do a lot of their tasks (like changing their address) online, rather than going to an agency.

Web site: www.seniors.gov

National Alliance for Caregiving

Alliance of companies and organizations that are concerned with family caregiving.

4720 Montgomery Lane, 5th Floor

Bethesda, MD 20814

E-mail: info@caregiving.org

Web site: www.caregiving.org

National Association for Home Care (NAHC)

The NAHC works to ensure that elderly, chronically ill or disabled people can obtain healthcare and services in their homes so that institutionalization is a last resort. The association provides information on what types of home care services are available, how to find them, how to assess them and how to pay for them.

228 7th St., SE

Washington, DC 20003

Telephone: 202/547-7424

Web site: www.nahc.org/Consumer/coninfo.html

National Family Caregivers Association (NFCA)

Organization for family caregivers that offers free memberships, a toll-free advisory service, a pharmacy discount program, advocacy and information.

10400 Connecticut Avenue

Kensington, MD 20895

Telephone: 800/896-3650

E-mail: info@nfcacares.org

Web site: www.nfcacares.org

National Family Caregiver Support Program

Program that provides information to caregivers about available services, assistance in gaining access to supportive services, individual counseling, support groups, caregiver training, respite care, and supplemental services to complement the care provided by caregivers.

Telephone: 202/619-0724

E-mail: AoAInfo@aoa.gov

Web site: www.aoa.gov/prof/aoaprof/caregiver/careprof/state_by_state/state_contact.asp

Personal (or Medical) Emergency Response Systems

A Personal Emergency Response System (PERS) is an electronic device that can be worn on the wrist or as a pendant. In an

emergency, pushing a button on the device will send a signal to an emergency response service center that monitors the device, which will contact you or notify the appropriate emergency personnel (medical, fire or police). In addition, many PERS services will also remind subscribers when to take medications, when they have doctor appointments, etc. Following are several providers of PERS services.

Care24 Incorporated

Telephone: 800/538-9968

Web site: www.care24.com

LifeFone

Telephone: 800/882-2280

Web site: www.lifefone.com

Lifeline Personal Response and Support Services

Telephone: 800/380-3111

Web site: www.lifelinesys.com

Personal Safety Corporation

Telephone: 866/723-2527

Web site: www.padalarm.com

Response Link

Telephone: 800/894-1428

Web site: www.responselink.com

SeniorNet

This nonprofit organization offers seniors education about and access to computer technology and the Web.

Web site: www.seniornet.org

Visiting Nurse Associations of America (VNAA)

These community-based, nonprofit organizations provide a range of home care services.

Telephone: Check in the local telephone directory's Yellow Pages under "Health Agencies" or "Nurses."

E-mail: vnaa@vnaa.org

Web site: www.vnaa.org

Well Spouse Foundation

A support organization for partners of those with disabilities.

Telephone: 800/838-0879

E-mail: info@wellspouse.org

Web site: www.wellspouse.org



Caregiver Tips: *Journaling*

by Patricia Isenberg, MS

Never kept a journal before? You might want to start because journaling:

- Gives you a private place to record your thoughts and feelings
- Can be used as a tool for problem-solving
- Provides a place to “practice” things you want or need to say
- Might become a way for you to explore other issues in your life besides caregiving.

Make the journaling process your own. You don’t need to write in complete sentences. Use single words, rhyming words, or make up your own words. Or maybe you don’t even want to write at all. Feeling pressure? Draw a picture of a monster that represents the stress you feel. Borrow your child’s crayons to add color and emotion.

How Do You Begin?

- Select a notebook and determine when and where you want to do your journaling. Try to establish a routine.
- For your first entry, finish this sentence, “I hope this journal will help me to . . .”
- As you journal, think about who or what should be the focus of that journaling experience. On Monday, you may focus on, “Why am I so angry today?” By Friday, you may want to write a letter to your spouse, rehearsing some things you really want to say to her or him.

How Do You Keep Going?

Professional writers sometimes encounter what they term “writer’s block,” an inability to put words on paper. When that happens:

- Find a quote from someone else, write it in your journal, and describe your feelings about that quote. There are many quotation books and Internet sites for finding quotes on almost any subject you can think of.
- Play some music and allow it to guide your writing.
- Besides dealing with issues in your life, journaling can and should also include the joys. Stuck for a topic? List the top 10 things you love about your life, your job, or where you live. ♦

The Special Needs of Geriatric Patients in O&P

Practitioners address the challenges and rewards of treating the geriatric patient

by Rachel Kelley

The geriatric patient presents the O&P practitioner with a comprehensive and sometimes complex set of issues. In addition to multiple and often chronic medical conditions, such as obesity, diabetes and the additional trauma of losing a limb, the older patient can be confronted with the loss of independence due to cognitive decline and other physical disabilities. This overwhelming sense of loss can trigger depression and loneliness. Working with elderly patients also can be a rewarding and joyous experience. They bring with them a unique wisdom that can only belong to a person who has lived many years. Through interviews with practitioners who work extensively with geriatric patients, this article addresses the special needs, challenges and rewards of working with the elderly in O&P.

Special Needs and Challenges

Geriatric patients provide unique challenges for orthotists and prosthetists. The older patient often comes to the practitioner with multiple medical problems that must be considered when being fitted for a prosthesis or orthosis.

John Schulte, CPO, FAAOP, mid-Atlantic clinical vice president for Hanger Prosthetics & Orthotics in Annapolis, Md., said the problems can range from cerebral vascular accidents to arthritis, as well as obesity and diabetes.



“They also have visual and hearing impairments that can make it difficult for them to don and doff devices and understand instructions,” he said.

Oftentimes, the older patient has pulmonary disorders, such as emphysema, that limit their ability to walk long or even short distances. This can hinder the rehabilitation process. They usually have loss of skin turgor and are

not able to take the pressures imposed by a socket or orthotic device such as an ankle foot orthosis (AFO).

“Moreover, because of diabetes and vascular insufficiency, they oftentimes have insensate feet,” said Schulte. “They can



have a foreign body in their shoe that may lead to open sores and possibly infections. So custom shoes and orthotics are essential.”

Additionally, obesity and a sedentary lifestyle can cause pressure areas, said Schulte.

“Just the redundant tissue in the posterior aspect of a transtibial prosthesis can compromise circulation, leading to pressure areas and sores,” Schulte said. “It is a compounding type of issue.”

Sally Lamb, CP, of Coastal Orthotics and Prosthetics in Newport Beach, Calif., sees many patients, particularly elderly women, who have osteoporosis with compression fractures.

“We fit them with corsets and occasionally a C.A.S.H. or Jewett orthosis,” she said. “Sometimes we will use custom body jackets depending on the severity of the fractures.”

Lamb also sees many older people who have flat foot deformities, which often lead to valgus knee problems and premature wearing of both hip and knee joints. She will use a high-back arch support to manage this disorder.

“It is more aggressive in cupping the calcaneus and providing medial lateral stability,” she said.

She may also incorporate custom molded articulated ankle AFOs. This allows free motion at the ankle yet provides superior medial lateral support to control ankle and foot motion. Occasionally, a Richie brace may be used for this diagnosis.

The most difficult disorder to brace is thoracic kyphosis, frequently seen in



Kevin Carroll, MS, CP, FAAOP, national vice president of prosthetics for Hanger Prosthetics & Orthotics, frequently educates his patients regarding conditions related to foot problems. Oftentimes, he said, patients will come into his office who have peripheral neuropathy and not even realize there is a problem. They may have visited their physician and the physician didn’t take the time to remove the prosthesis and examine the residual limb.

“I see this all the time,” said Carroll. “An older patient will tell me everything is fine, yet when they take off the prosthesis, they have a big sore. They cannot see it due to poor vision, or they are unable to feel the ulcer because of the neuropathy.”



osteoporotic women in their 70s and 80s, said Lamb.

“We often use a soft thoracic lumbosacral orthosis (TLSO) for that, but it is hard to reverse this diagnosis when someone has weak abdominal and upper thoracic muscles.”

Lamb added that she is constantly addressing peripheral neuropathy problems through education on proper footwear and visual inspections.

Kevin Carroll, MS, CP, FAAOP, national vice president of prosthetics for Hanger Prosthetics & Orthotics, frequently

Choosing the Appropriate Device

There are specific criteria when considering which type of device — whether orthotic or prosthetic — when working with the elderly.

Loren Rojek, CPO, president of Fountain Valley Orthotics and Prosthetics in Fountain Valley, Calif., said that for the prosthetic patient, good hand strength and dexterity is important.

“If they don’t have those, we become limited on what types of suspension we can use,” he said. “We tell them their first prostheses is their interim prostheses. The residual limb does atrophy due to nonuse. After the other conditions such as diabetes have been addressed, they become better physically and are able to do more activities. We look at what their potential is and use the appropriate components.”

Initially, said Rojek, function is important to the patient. They want to walk. After they have the prostheses for a while, they start focusing on cosmesis.



Activity levels are another factor.

“If a patient is highly active, we wouldn’t want to cut them short and give them improper componentry,” he said. “If they are lower activity, we want to go with certain guidelines that have been set down and give them the most appropriate components without charging Medicare or their insurance company additional fees for something that will not be used.”

From an orthotic perspective, Rojek again looks at hand dexterity and strength.

“If they have a stroke and they are paralyzed on one side, we want to make sure the straps are conveniently located toward the middle of the body where they put the buckle or loop in. Otherwise, they will have a hard time stretching from one side to the other.”

Rojek added that many times older patients will want to use their existing shoes, and that can be a challenge when getting an AFO. They don’t want anyone to see they are handicapped.

“Sometimes they think having an orthosis will make them look handicapped even though they may be dragging their foot without it.” To make the device appear less conspicuous, Rojek will look at the outerwear, e.g., skirts and pants, and if, for example, an AFO is prescribed, the color of the device may be changed to match the clothing.

Raymond Francis, CP, chief prosthetist for Ohio Willow Wood in Mount Sterling, Ohio, uses lightweight components for the geriatric patient.

“They are usually weaker than the nongeriatric,” said Francis. “Their lack of strength becomes an issue, so a prosthesis needs to be as light as possible.”

At the same time, Francis said, function or strength cannot be sacrificed in attempts to make the device lighter. He recognizes that fit is an important factor of lightness.

“By that I mean if the socket fits really well, it feels like it is a part of the body. This transfers into less weight being perceived by the patient as well as energy expenditure required by the patient.”

Psychological Issues

Because older patients have often experienced illness, death of loved ones, impaired function and loss of independence, the elderly are at a high risk for depression. The cumulative effect of these negative experiences can be overwhelming. Complicating a diagnosis of depression in the elderly person may be Alzheimer’s disease or other dementias, medications or sleep disorders.

“Dementia will sometimes mask depression in the older patient,” said Schulte. “Many times, because they are in a

rehabilitation facility or staying with loved ones, a diagnosis of depression is not made and they don't get the necessary treatment."

Carroll believes there is a stigma about depression among the older population. They feel ashamed and embarrassed to admit there may be something wrong.

"You have to be discreet and cautious about how you introduce the idea of seeing a counselor," said Carroll. "The best setting is to introduce the counselor at the rehabilitation facility where everyone else is seeing a counselor too."

It may get to a point where the older patient feels suicidal. Carroll believes it is important for the clinician to identify whether this may be true.

"Oftentimes, practitioners are not trained in how to deal with suicidal patients," he said. "Thoughts of suicide are frequently hidden. The clinician needs to be educated on how to approach this issue."

For a variety of reasons such as loneliness and loss of independence, the older patient can experience anxiety and fear. There is a scenario that often takes place with the geriatric patient, said Francis. The children of these patients frequently have moved away. The parent has lost a limb, which brings back the children temporarily.

"They fuss over the parent, which the geriatric patient enjoys. The parent misses not having their family around. It doesn't take the geriatric patient long to figure out that the quicker they get well, the quicker their children will return to their own home."



When Not to Fit a Prosthesis

There are circumstances when it is not in the patient's best interest to fit a prosthesis. According to Schulte, the patient must be able to understand the prosthesis itself.

"Our goal is to get everyone up and back into society," he said. "If the person is not cognizant enough to understand how to use the device, or has a hearing impairment that prevents him or her from hearing the click of the lock in a pin suspension system, we can actually cause them to break a hip."

Moreover, if the elderly patient lives alone and does not have good home care, they are left alone trying to cope with the situation. They may get exhausted in attempts to put the device on by themselves.

"The only time we feel it is not appropriate to fit a prostheses is when a patient cannot safely get out of a chair and do a pivot transfer," said Francis. "If a patient can't do that by himself or herself, than we raise an eyebrow as to whether he or she is a prosthetic candidate."

Basically, if a patient has the ability to get out of bed and transfer, they more than likely will be fitted with a prostheses.

Education and Rehabilitation

Education and follow up are crucial components of treatment. Schulte believes all clinicians are educators whether they are teaching someone how to tie their shoes using a special Velcro lace or donning and doffing a prostheses.

"A lot of times practitioners need to realize that the geriatric patient may not be comprehending what they are trying to communicate," said Schulte.

Schulte and his staff will have the patients watch videos or send them home with written information.

“Everytime we have a follow-up visit, we review and make sure they understand how everything works,” he said. Additionally, the diabetic patient who is obese, for example, may not be able to see their feet.

“So we teach them how to look at the underside of their feet with a mirror, make sure that they understand the importance of keeping their feet dry and to check their shoes everyday for foreign objects, especially if they have children in the house. They can end up with little matchbox toys, jacks or marbles in their shoe and not realize it.”

Carroll emphasized the importance of a team approach in the rehabilitation process. Everybody must be on the same page, he said. Everyone, including the physical therapist, prosthetist and physician, must collaborate and include the patient and family in the plan of care.

Francis said he and his staff like to see the elderly patient for follow-up visits in the early stages because their progress is somewhat slower than the younger patient. Often, transportation is an issue.

“Many do not drive or don’t want to drive, especially if they have a limb loss. They are afraid, so they have to depend on someone to bring them,” said Francis.

Schulte said dealing with rehabilitation in the geriatric population is a world all its own. The physical therapist and occupational therapist must focus on getting them up and moving.



This will help to prevent pulmonary edema and pneumonia.

“It must be a team effort,” he said.

Challenges and Rewards

It can be challenging to work with the geriatric population, but it can also be rewarding. The older person tends to have more medical issues and their cognitive impairments can make it difficult for them to comprehend and follow through with instructions.

“Their inability to understand can pose difficulties,” said Schulte.

However, Schulte enjoys seeing older patients increase their level of activity after being fitted with a device.

“Whether it is an AFO to control the damage done from a stroke, a hip abduction orthosis that keeps them from getting the chronic pain from a dislocation or just a prosthesis that enables them to get up and about, this part of my work is extremely satisfying.”

Carroll said it is a challenge to make certain that their skin can hold up to the use of a prosthesis.



“You can’t always gain their trust,” she said. “They gather an initial opinion when they first meet you. You have to win them over with your knowledge, information and presentation.”

Francis finds that older people generally appreciate the things that are done for them, whereas young people seem to expect it.

“I call it old-fashioned respect,” he said. “I get great joy from knowing that I have helped them.”

Francis also realizes that some of his older patients have gotten to the point where they do not understand simple instructions.

“You know they are going to go home with this prosthesis and some of the instructions that appear simple will become mentally taxing for them. They just don’t remember what you have told them. It is disheartening,” said Francis.

Optimizing Chances for Success

Lamb believes that giving the older patient the time they need, being patient and listening are crucial components of successful treatment outcomes.

“Quite often with our clients, they have been to a physician and they are not sure why they are seeing us. They may not even understand what their diagnosis is, so we explain that to them in detail.”

Often times, they will have expectations that are not realistic or they may be pessimistic about the outcome, said Lamb.

“First we have to explain things properly so they are understood,” she said. “When we repeat ourselves, we are not always listening to what we are saying as a practitioner, so it is important that we listen to ourselves and pay attention to how it could be misunderstood. We do a lot of reinforcement.”

Schulte emphasized that the older person must have the cognitive ability to understand what is happening.

“They must be able to check the device for wear and a positive fit. They also need to have some kind of support system or advocate, either from a loved one or a rehabilitation center

“Gel liners have made a huge difference, as well as the use of modern components,” he said.

Carroll enjoys talking with elderly patients. Their stories, he said, can keep you going forever.

“We can learn a lot by listening to them,” he said.

Lamb also enjoys listening to her elderly patients.

“I like to chat with them. I see the young person underneath the 85-year-old patient.”

Lamb said she can also lose patience with some of her older patients. Sometimes they do not listen or will not trust the practitioner.

— anybody who can give us feedback. We put our phone number on the device. That way, whomever is taking care of that patient can call us with any questions.”

Success, according to Francis, depends on the particular patient’s motivation. If cognitive and medical issues are minimal, they will rehabilitate quickly.

“Usually if there is a dedicated spouse, this will occur. If there isn’t, it will take longer.”

Advice to New Practitioners

Rojek does his best to really listen to the patient. If they don’t want something the first time he sees them, he does not force it on them.

“They will never be happy with the device if we do that,” he said. “They need to make the decision.”

Schultz believes treating the geriatric patient, in many ways, is not unlike treating a child.

“The child believes you and trusts you. That is the same with the geriatric patient. They are often frustrated with their disabilities. Do not write them off. There is a lot of experience and willingness to talk in the geriatric patient. He or she is a young person in an old body. Try not to walk past them when they are sitting in the hallway in a nursing home. Take a minute and talk to them. It can make a huge difference in their life.”

Future of Geriatric Care

According to the World Health Organization, there were 600 million people age 60 and older in 2000. By 2025, this number will increase to 1.2 billion. By 2050, 2 billion people will be age 60 or older. Today, about two-thirds of all older people are living in the developing world; by 2025, it will be 75 percent. It is apparent that people are living longer.

In 1900, life expectancy at birth was about 49 years. In 1997, life expectancy at birth was 70 years for women and 74 years for men. Currently, people who survive to age 65 can expect to live an average of 18 more years. As people age, chronic diseases contribute to declines in functioning and the increased need for prosthetic and orthotic care.



“The patients we see are getting older and limbs are being amputated later,” said Carroll. “There is going to be a huge growth in older adults using prosthetic systems.”

Schulte thinks the need for geriatric specialists will increase.

“There will be a unique need within the O&P field for these specialists,” said Schulte. “They will deal with the many specific issues associated with geriatric care such as lighter components and complex medical problems affecting O&P treatment and follow up of this population.” ♦

For more information:

- <http://www.worldhealth.net/resources/WorldAgingReport.pdf>
- *Fifty Facts from the World Health Report 1998.* Available at <http://www.who.int/whr2001/2001/archives/1998/factse.htm>
- Federal Interagency Forum on Aging-Related Statistics. *Older Americans 2000: Key Indicators of Well-Being.* Available at www.agingstats.gov/chartbook2000

Copyright 2004, SLACK Incorporated. Revised 24 February 2004. Reprinted by permission.



The Team Approach to Amputee Rehabilitation

by Rick Bowers

In recent years, there have been dramatic changes — both positive and negative — in the medical world. One change, however, seems to be causing great and unnecessary harm to many amputees, according to some prominent members of the prosthetic and physical therapy communities.

Many amputees aren't getting the kind of healthcare services they need and deserve, says Bella J. May, EdD, PT, FAPTA, an acclaimed educator, researcher, author and physical therapist (PT).

Kevin Carroll, CP, the vice-president of prosthetics for Hanger Orthopedic Group, explains the problem. "Traditionally, after amputation, a patient would be referred to a rehab hospital or

an amputee clinic where the doctor in charge would bring together a team consisting of a prosthetist, a physical therapist, an occupational therapist, and maybe a case manager and a psychologist. The doctor would keep everything together and make sure that the physical therapist and occupational therapist would be involved, and generally you'd have a good outcome."

That's changed as physicians have become less and less involved, explains Robert Bedotto, CPO, PT. "I think doctors are kind of 'washing their hands' of patients because the hospitals just want to get rid of them. I mean, an amputee gets two days, if they get that, in the hospital. The physical therapist can't even come in and do proper wrapping of the residual limb. I see patients many times who are ready for a temporary prosthesis, but nobody's ever taught them how to wrap, nobody's done preprosthetic work. It's kind of like we've

slipped back wards. When I was a PT and starting out, we used to keep amputees in the rehab center for six months or more. Now, they're lucky if they get six sessions."

As a result of this lack of coordination by physicians and the rush to discharge patients from the hospital, patients' access to the care they need at the appropriate time has become fragmented, and there is little unified effort to ensure that all of a patient's rehabilitation needs are met. A revived "team approach" among healthcare providers is, thus, needed to ensure that patients have access to a total rehabilitation experience.

A Lack of Knowledge

"An older individual who has diabetes is more likely to come to amputation after long-term attempts to save the limb, and, if an amputation is done, it is usually done by a vascular surgeon or a general surgeon who is educated in amputation surgery but not in amputation rehabilitation," May explains. "That individual is less likely to be referred to a rehabilitation center and more likely to fall through the cracks. They'll be sent home, the physician may well not involve physical therapy early, they'll sit at home until the residual limb is totally healed, and then at that point, which could be four or five months down the road, the surgeon may say, 'Oh, well, he'd better go see a prosthetist.'"

At that point, the patient may already have severe problems as a result of not seeing a physical therapist and being inactive for so long. He or she may end up with contractures, weakness, edema and other problems. In addition, he or she will not have been properly prepared for using a prosthesis, which might require the strengthening of certain muscles.

To avoid these problems, "both the prosthetist and the PT would like for the patient to get involved in the system before surgery or immediately after surgery," says May.

Building Team Relationships

Educating surgeons on the importance of pre-amputation and immediate post-amputation involvement of physical therapists and prosthetists is perhaps the best method of ensuring that both are involved in the rehabilitation process early. When



Photo courtesy of Hanger Orthopedic Group

Kevin Carroll, MS, CP, FAAOP, with Lillie Mae Lambert and Jonas Dennis, who was born in 1899.

doctors understand the importance of the team approach to amputee rehabilitation, May says, most are willing to refer the patient to an amputee clinic or other members of the health-care team in a timely manner and follow up with the patient to ensure that he or she is following the prescribed program. "Most of them want what's best for their patients," she says. "Many are just not aware of what's available."

Relationships also need to be nurtured between prosthetists and PTs to ensure that patients reach their highest level of independence, May says. "We need to learn how best to work together, how to develop strong communications, and to truly understand each other's profession."

May's goal is to educate prosthetists on the role and education level of the physical therapist, which prosthetists are often unaware of. This is important because the amputating surgeon will at some point need to send the patient to a prosthetist, and if the team approach is not developed at the physician level, the prosthetist can refer the patient to the physical therapist, although it will at that time already be quite late in the rehabilitation process.

However, although the prosthetist can refer patients for physical therapy, most insurance companies still ultimately require a physician to sign off on the therapy.

Bedotto argues that although some prosthetists might balk at this added expectation of them to make the referral to a PT, they should look at it differently. "If I make a prosthesis, I care about anything that's going to contribute to the success of it, including physical therapy. It's just a professional thing."

May says it has to be a two-way street. "To work effectively with the prosthetist, I need to reach out to the prosthetist and not only educate him or her about what I do, but learn the problems and issues that he or she faces from his or her point of view."

Carroll feels the same way and says that he's always found physical therapists to be complementary to his work. "I have much more successful outcomes when I work with physical therapists than when I don't."

He paints a picture of the give and take required in this relationship. "The therapist will explain to me that something could be changed with the prosthesis. I will talk about the logics of the dynamics of the prosthesis, and they'll talk about physiological aspects of the person that they're trying to treat, such as muscle imbalances. Both should, therefore, be very knowledgeable of one another's field."

Carroll points out another important way that prosthetists can



help patients get the full benefit of therapy. Amputees, he says, go to physical therapy because they want to learn how to walk, but the PTs start working their upper-body muscles and other muscles and there doesn't seem to be an emphasis on walking. Amputees often don't understand that they have to learn balance and other aspects of walking before they can walk properly, and sometimes they

stop going to physical therapy because they consider it too much useless work. Carroll explains, however, that physical therapy is very important, and the patients who build a relationship with a physical therapist and continue to go back for therapy do a lot better with their prosthesis. The prosthetists' part, he says, is, therefore, to continually encourage patients to go to physical therapy and occupational therapy and to make them understand their importance.

Sometimes, he says, amputees don't know that they have a problem with their walking, etc., until a couple of years down the road when they get back problems and body pains because they are walking so poorly. To avoid such problems, Carroll recommends that his patients see a physical therapist every year for an evaluation. "The ones who continue to do that are the best walkers, and the ones who don't follow through are the ones who lose out over the years and start declining."

Carroll also stresses the involvement of the occupational therapist (OT). "I think it's important for occupational therapy to be involved, especially in the beginning to teach the person how to put the prosthesis on, how to take it off, how to dress themselves, how to take care of their personal hygiene, and all that stuff that they have to do at home. Bringing that whole team together goes back to the doctor, who should continually follow up with that particular patient."

The physician, the prosthetist, the physical therapist, the occupational therapist and the patient should all walk hand in hand together, he says.

Leading the Team

Perhaps one of the most critical aspects of developing this inclusive team approach to amputee rehabilitation is the patient.

“The patient should lead the rehabilitation team,” says May. She argues that all the other members should be equals with different roles. “We each have our special ties and our areas of expertise, and we each need to contribute those things that we can contribute best. I am the expert in physical therapy; therefore, I know what physical therapy can and cannot offer. The prosthetist similarly is the expert in prosthetics and prosthetic components and is, therefore, the best person to select the most optimum prosthetic components.” He or she also knows funding sources, she says, and which components would work best for someone who is elderly and/or overweight, etc.

Consumers need to recognize that they have a very important voice, she says. “They have the right to demand the appropriate level of rehabilitation, but I think too often, neither the patient nor the family, either because of timidity or lack of knowledge, will speak up for themselves.”

This is a common problem and is to be expected. After all, most patients have never had an amputation before. They know little or nothing about what they need. In fact, Bedotto, says, they often don’t even ask about warranties, what happens if their prosthesis breaks, or how long it’s going to last. “Unfortunately, a lot of patients feel like second-class citizens and don’t understand that they can change anything. Sadly enough, what they often say is, ‘Well, I have to go wherever my insurance tells me. I may not get the best care, but I can’t afford it.’” He says patients have to take responsibility for their care, speak up to doctors, and say, “This is what I want.”

It’s important to give patients choices, Bedotto says, if they are to be the real leaders of the team. “Getting a prosthesis is a pretty major thing in their life. It’s a pretty major expense for the insurance company, and if there’s a co-pay, it can be a major expense for the patients. And yet, they just go to whomever.”



He finds it surprising that consumers know how to pick other types of vendors, but they don’t know how to pick a physician or healthcare provider. “They look at it like it’s not their money, but somebody’s paying a very good premium today for very little care. If they want to hire a plumber or electrician, they’re going to find out what they need done and what it’s going to cost. They’re going to get at least three estimates. They have to ask the same types of questions about their healthcare.”

If doctors want to do what’s best for their patients, Bedotto says, they should have their patients visit two or three prosthetists and see who they think they can work with. The same is true for physical and occupational therapists.

In the end, it’s really about education, and that’s why unbiased organizations like the ACA are so important to helping amputees become the leaders of their healthcare team, Bedotto says. “Patients are being blitzed with information, but they’re being blitzed by manufacturers who want to sell their products. Unfortunately, this type of education can’t come from manufacturers. It has to come from an unbiased source. It’s education and magazines like the ACA’s *inMotion* and *First Step*, physical therapy magazines, O&P magazines and physicians’ magazines that can help.”

Discovering What Healthcare Is Really About

“Healthcare is about caring,” Bedotto says. “Most people go into this profession because they care and they want to make a difference.” The purpose should be service, caring and giving patients the best care possible, not just getting the patient out of the system as quickly and as cheaply as possible.

The key element in healthcare, he says, should be hope. Bringing some of that hope back is what the “team approach” is all about. It’s about making sure that all aspects of the patient’s problems are dealt with by the right professional at the right time. It’s about total rehabilitation. ❖

Annotated Bibliography

Caregivers

Books

American Medical Association Guide to Home Caregiving. New York: J. Wiley & Sons, 2001.

Covers topics such as giving medications, providing a healthful diet, symptoms to monitor, wound care, incontinence, risks of immobility, dealing with specific illnesses, paying for home healthcare, providing long-term care, and care for the caregiver. Includes a resource list.

Berman, Claire. **Caring for Yourself While Caring for Your Aging Parents: How to Help, How to Survive.** 2nd edition. New York, NY: Henry Holt, 2001.

This guide focuses on the importance of caregivers taking care of themselves as well as their parents.

Caregiving Sourcebook. Detroit, MI: Omnigraphics, 2001.

This compendium of information from various government agencies and organizations provides an overall look at caregiving in America, including caregiving responsibilities and concerns, caregiving for specific conditions and diseases, care environments, legal and financial information, and insurance information. Includes a directory of additional resources.

Carr, Sasha, and Sandra Choron. **Caregiver's Essential Handbook: More Than 1,200 Tips to Help You Care for and Comfort the Seniors in Your Life.**

Chicago, IL: Contemporary Books, 2003.

Offers tips on such issues as finances, home safety, health and travel.

DeGraff, Alfred H. **Caregivers and Personal Assistants: How to Find, Hire and Manage the People Who Help You (or Your Loved One!).** 3rd edition. Fort Collins, CO: Saratoga Access, 2002.

Offers specific strategies for recruiting, hiring and managing paid help providers. Includes information for help recipients, seniors, family caregivers, paid aides, agency staff, and counselors.



Meyer, Maria M., with Paula Derr. **The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers.**

2nd edition. Portland, OR: CareTrust Publications LLC, 2002.

A basic, easy-to-understand guide to home healthcare. Part 1 focuses on preparing to become a caregiver and includes information on such issues as making the home safe and comfortable, financial and legal decisions that may arise, and communication with doctors, nurses, and other health professionals. Part 2 provides information on day-to-day issues such as activities of daily living, avoiding caregiver burnout, diet and nutrition, hospice care, and body mechanics for positioning, moving and transfers. Part 3 is a collection of resources.

Periodicals

Caregiving Newsletter. Park Ridge, IL: Tad Publishing Co.

A monthly newsletter that has information on such topics as the emotional issues of caregiving, hiring home health help, purchasing home medical equipment supplies, and avoiding caregiver burnout. For more information, visit www.caregiving.com or call 773/334-5794.

Today's Caregiver. Hollywood, FL: Caregiver Media Group.

A national magazine dedicated to caregivers. For more information, visit www.caregiver.com or call 800/829-2734.



Web Resources

Caregiving.com

www.caregiving.com

This site, which is produced by the Center for Family Caregivers, offers online support groups, weekly tips, and informative resource materials.

Eldercare Locator

www.eldercare.gov

Produced by the U.S. Administration on Aging, this locator service helps identify local services for seniors and their caregivers. Searchable by state and zip code, results generally include a local Information and Referral agency, the Area Agency on Aging, and the State Unit on Aging. These agencies can provide further information about local services available.

ElderWeb

www.elderweb.com

This site provides information on long-term care to professionals and family members. Links are provided to medical, housing, legal, and financial information.

Family Caregiver Alliance

www.caregiver.org

A nonprofit organization, the Family Caregiver Alliance provides support to caregivers.

MedlinePlus: Caregivers

www.nlm.nih.gov/medlineplus/caregivers.html

MedlinePlus, a service of the U.S. National Library of Medicine and the National Institutes of Health, has compiled links to information for caregivers. Subject headings include General/Overviews, Coping, Specific Conditions, Dictionaries, Directories, Law and Policy, Statistics, and Seniors.

National Alliance for Caregiving

www.caregiving.org

This nonprofit alliance of organizations provides support for caregivers and the professionals that assist them.

National Family Caregivers Association

www.nfcacares.org

This grassroots organization works to educate, support and empower caregivers. Its Web site offers an array of statistical and educational materials.

Resource Directory for Older People

www.nia.nih.gov/resource

A collaborative effort of the National Institute on Aging and the Administration on Aging, this directory is a database of national and state-level agencies, resource centers, professional societies, private groups, and volunteer programs for older adults and geriatric professionals.

Diabetes and Vascular Disease

Books

Ahroni, Jessie H. **101 Foot Care Tips for People with Diabetes.** Alexandria, VA: American Diabetes Association, 2000.

Foot problems that can lead to an amputation are a common occurrence in people with diabetes. This book offers advice on how to minimize the risk of such problems through proper foot care, exercise and good footwear.

American Diabetes Association Complete Guide to Diabetes. 3rd edition. Alexandria, VA: American Diabetes Association, 2002.

This guide provides a comprehensive overview of major issues related to diabetes, including types of diabetes, management of diabetes, healthcare, insulin, eating, fitness, complications, emotional issues, diabetes in the workplace, and new medications and therapies.

Milchovich, Sue K., and Barbara Dunn-Long. **Diabetes Mellitus: A Practical Handbook.** 8th edition. Boulder, CO: Bull Publishing Company, 2003.

Provides information on all aspects of diabetes, including diet, exercise, insulin and complications.

Rapaport, Wendy Satin. **When Diabetes Hits Home: The Whole Family's Guide to Emotional Health.** Alexandria, VA: American Diabetes Association, 1998.

This book looks at how a diagnosis of diabetes for one family member affects the emotional health of the whole family. Different chapters are written for parents, siblings, couples, and even grandparents, teachers, friends and baby sitters.

Senneff, John A. **Numb Toes and Aching Soles: Coping with Peripheral Neuropathy.** San Antonio, TX: Medpress, 1999.

A guide to the types of peripheral neuropathy, its causes, symptoms, tests for it, conventional and alternative treatments, and ways of coping day-to-day.



Take Charge of Your Diabetes. 3rd edition. Atlanta, GA: U.S. Dept. of Health and Human Services; Centers for Disease Control and Prevention, 2003.

Primarily written for those with adult-onset diabetes, this book describes health problems often encountered by people with diabetes and offers tips for alleviating them.

The Uncomplicated Guide to Diabetes Complications. 2nd edition. Alexandria, VA: American Diabetes Association, 2002.

This guide includes a large listing of diabetes complications and ways to prevent and treat them. Complications covered include eye disease and blindness, skin and dental problems, feet and amputations, stroke, gastrointestinal problems, heart disease, sexual concerns, kidney disease, neuropathy, and psychosocial complications. Chapters are devoted to peripheral vascular disease, neuropathy, and peripheral neuropathy.



Touchette, Nancy. ***The Diabetes Problem Solver: Quick Answers to Your Questions About Treatment & Self-Care.*** Alexandria, VA: American Diabetes Association, 1999.

This book looks at diabetes and health problems related to diabetes, along with symptoms, treatments and prevention.

University of Mexico Diabetes Care Team. ***101 Tips for Staying Healthy with Diabetes (& Avoiding Complications).*** 2nd edition. Alexandria, VA: American Diabetes Association, 1999.

Offers tips, techniques, and strategies for preventing and treating complications related to diabetes.

Periodicals

Diabetes Forecast. Alexandria, VA: American Diabetes Association.

This monthly publication offers up-to-date information on diabetes research and treatment, as well as tips for coping daily with diabetes. Also covers diet, exercise, support and care. Available with a membership to the American Diabetes Association. For more information, visit

www.diabetes.org/diabetes-forecast.jsp?WTLPromo=HOME_forecast&vms=130499984328 or call 1-800/806-7801.

Diabetes Interview. Fairfax, CA: King's Publishing, Inc. This monthly resource for people with diabetes offers articles on healthful living, as well as coverage of new products, research, and treatment options. For more information, visit www.diabetesworld.com or call 1-800/488-8468.

Diabetes Self-Management. New York, NY: R.A. Rapaport Publishing, Inc.

A bimonthly publication that contains instructive how-to articles for people with diabetes on such topics as diet, exercise, treatment and emotional issues. For more information, visit www.diabetesselfmanagement.com or call 1-800/234-0923.

Web Resources

American Association of Diabetes Educators

www.diabeteseducator.org

Offers general diabetes information, as well as a searchable database that can be used to find a diabetes educator.

American Diabetes Association

www.diabetes.org

National nonprofit organization whose stated mission is “to prevent and cure diabetes and to improve the lives of all people affected by diabetes.” Includes a link to diabetes statistics for seniors.

American Heart Association

www.americanheart.org

A national association with the mission to reduce disability and death from cardiovascular diseases and stroke.

CDC Diabetes Public Health Resource

www.cdc.gov/diabetes

Produced by the Centers for Disease Control and Prevention, this site has links to frequently asked questions about diabetes, statistical information, and other informational documents.

Joslin Diabetes Center

www.joslin.org

A nonprofit organization affiliated with Harvard Medical School, the Joslin Diabetes Center is a diabetes research, treatment and education institution. This site provides information for beginners, general overviews, and information about management and research.

Legs For Life

www.legsforlife.org/main.shtml

A national screening program for peripheral vascular disease.



MedlinePlus: Diabetes

www.nlm.nih.gov/medlineplus/diabetes.html

MedlinePlus, a service of the U.S. National Library of Medicine and the National Institutes of Health, has compiled links to information on diabetes. Subject headings include General/Overviews, Alternative Therapy, Anatomy/Physiology, Clinical Trials, Coping, Diagnosis/Symptoms, Disease Management, Prevention/Screening, Research, Specific Conditions, Treatment, Genetics, Statistics and Seniors.

National Diabetes Information Clearinghouse

www.diabetes.niddk.nih.gov

A service of the National Institute of Diabetes and Digestive and Kidney Diseases, this clearinghouse provides general information on diabetes, treatments, complications and clinical trials. It will also take inquiries about diabetes-related issues via phone, e-mail, fax and mail.

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

www.niddk.nih.gov

The NIDDK, part of the National Institutes of Health, conducts and supports research on diabetes and other diseases. This site provides health information, news, and information on clinical trials.

Vascular Disease Foundation

www.vdf.org

A nonprofit agency, the VDF works to increase awareness about the prevention, diagnosis and management of vascular disease.

Vascular Web

www.vascularweb.org

Provides information on vascular disease and vascular conditions, along with a find-a-physician search capability.

General Health

Books

Kandel, Joseph, and Christine Adamec. *The Encyclopedia of Senior Health and Well-Being*. New York: Facts on File, Inc., 2003.

This is a general reference source that covers medical and life issues of the senior population.

The Johns Hopkins Medical Guide to Health After 50: The Latest Recommendations from the Hopkins Specialists. New York: Rebus, Inc., 2002.

This guide to health concerns of people over 50 provides information on warning signs, diagnostic steps, and treatment options for major medical problems that are likely to affect the aging population.

Periodicals

AARP The Magazine. Washington, DC: AARP.

This bimonthly magazine comes with a membership to AARP. One section of the magazine is devoted to health. For more information, visit www.aarpmagazine.org or call 1-888/687-2277.

The Johns Hopkins Medical Letter: Health After

50. Palm Coast, FL: Medletter Associates, Inc.

A monthly newsletter focused on people over 50 that provides the latest news and developments in modern healthcare. For more information, visit www.hopkinsafter50.com/html/bs/bsHA50.php or call 386/447-6313.

Web Resources

AARP

www.aarp.org

AARP provides a wealth of information specifically for seniors on a variety of topics, including health and wellness. Free access is available to the Ageline Database, which has summaries of books, journal and magazine articles, research reports, and videos on topics about seniors and aging.

familydoctor.org: Seniors

www.familydoctor.org/seniors.xml

This site is provided by the American Academy of Family Physicians and has articles on common conditions in older adults, active living, mental health, staying healthy, managing your medical care, and end-of-life care.

FirstGov for Seniors

www.seniors.gov

This government site, maintained by the Social Security Administration, has information for seniors on a variety of topics including health and general services.

Healthy Aging: Health Information for Older Adults

www.cdc.gov/aging/health_issues.htm

A site from the CDC that has general health information and statistics pertinent to older adults.

healthfinder: justforyou – Seniors

www.healthfinder.gov/justforyou/justforyou.asp?KeywordID=172&branch=1

Developed by the U.S. Department of Health and Human Services together with other federal agencies, healthfinder is a source for finding government and nonprofit health and human service information.

MayoClinic.com: Senior Health Center

www.mayohealth.org/home?id=4.1.3



This site provides articles on staying healthy and happy as you age, specific information on various diseases and conditions, and a drug search tool to find out more about particular medications.

MedlinePlus: Seniors' Health Topics/Issues

www.nlm.nih.gov/medlineplus/seniorshealth.html

www.nlm.nih.gov/medlineplus/seniorshealthissues.html

MedlinePlus, a service of the U.S. National Library of Medicine and the National Institutes of Health, has compiled links to health information for seniors.

NIHSeniorHealth.gov

www.nihseniorhealth.gov

This is a web site for older adults developed by the National Institute on Aging and the National Library of Medicine. It addresses several health topics with general background information, open-captioned videos, quizzes and frequently asked questions (FAQs).



Seniors' Health

www.health.nih.gov/search.asp?category_id=27

Senior health topics from the National Institutes of Health.

U.S. Administration on Aging (AoA)

www.aoa.dhhs.gov

The AoA, part of the U.S. Department of Health and Human Services, offers an overview of topics, programs and services related to aging. A special section of the site is designated for elders and families.

Limb Loss

Books

A Survivor's Guide For The Recent Amputee. Winter Park, FL: United Amputee Services Association, Inc., 2002.

This book provides the amputee with pertinent information regarding amputation, caring for the residual limb, prostheses, returning to daily activities, and a variety of other topics. It also offers encouragement from others who have traveled the same road.

Wallace, Carol S. ***Challenged by Amputation: Embracing a New Life.*** Carmichael, CA: Inclusion Concepts, 1995.

This book can help patients during the amputation process. It not only dedicates chapters to important issues that come up after the actual surgery, it prepares the patient for an amputation ahead of time.

Wallace, Carol S. ***Selecting and Working with a Prosthetist.*** Fair Oaks, CA : Wallace & Associates, 2002.

This book guides people through the process of getting and using a prosthetic limb.

Wallace, Carol S. ***What to Expect Before and After.*** Fair Oaks, CA : Wallace & Associates, 2002.

This book provides basic information about what to expect before, during, and after amputation surgery. It describes some of the challenges amputees face and the resources that are available to help.

Winchell, Ellen. ***Coping With Limb Loss.*** Garden City Park, NY: Avery Publishing Group, 1995.

This is a book for anyone who has undergone an amputation. It gives practical advice on how to deal with emotions, doctors and other issues following an amputation. It also provides a list of resources and contacts.



Periodicals

inMotion magazine. Knoxville, TN: Amputee Coalition of America.

An award-winning bimonthly magazine that addresses the needs and concerns of amputees and those who care for and about them. Call 1-888/267-5669 for more information.

Web Resources

Amputee Coalition of America (ACA)

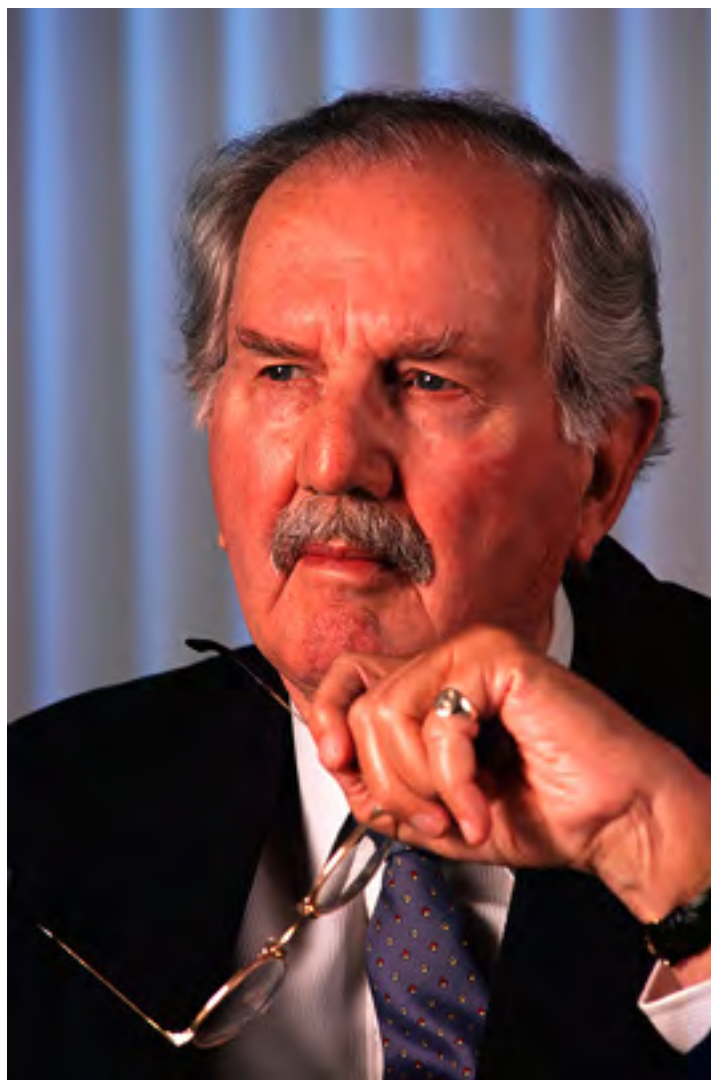
www.amputee-coalition.org

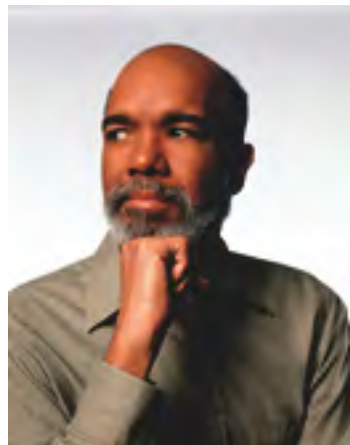
The ACA is a national, nonprofit amputee consumer educational organization representing people who have experienced amputation or are born with limb differences. The ACA operates the National Limb Loss Information Center (NLLIC), which provides comprehensive resources for people with limb loss, as well as their families, friends, and the healthcare professionals involved in their lives.

surviving limb loss

www.survivinglimbloss.org

This is the online version of a series of pamphlets developed by the Landmine Survivors Network to educate amputees and their families on all aspects of amputation. The series includes information on amputation surgery, rehabilitation, emotional issues, getting back to work, and information for families.





900 E. Hill Ave., Ste. 285
Knoxville, TN 37915-2568
Toll-free: 888/267-5669
www.amputee-coalition.org