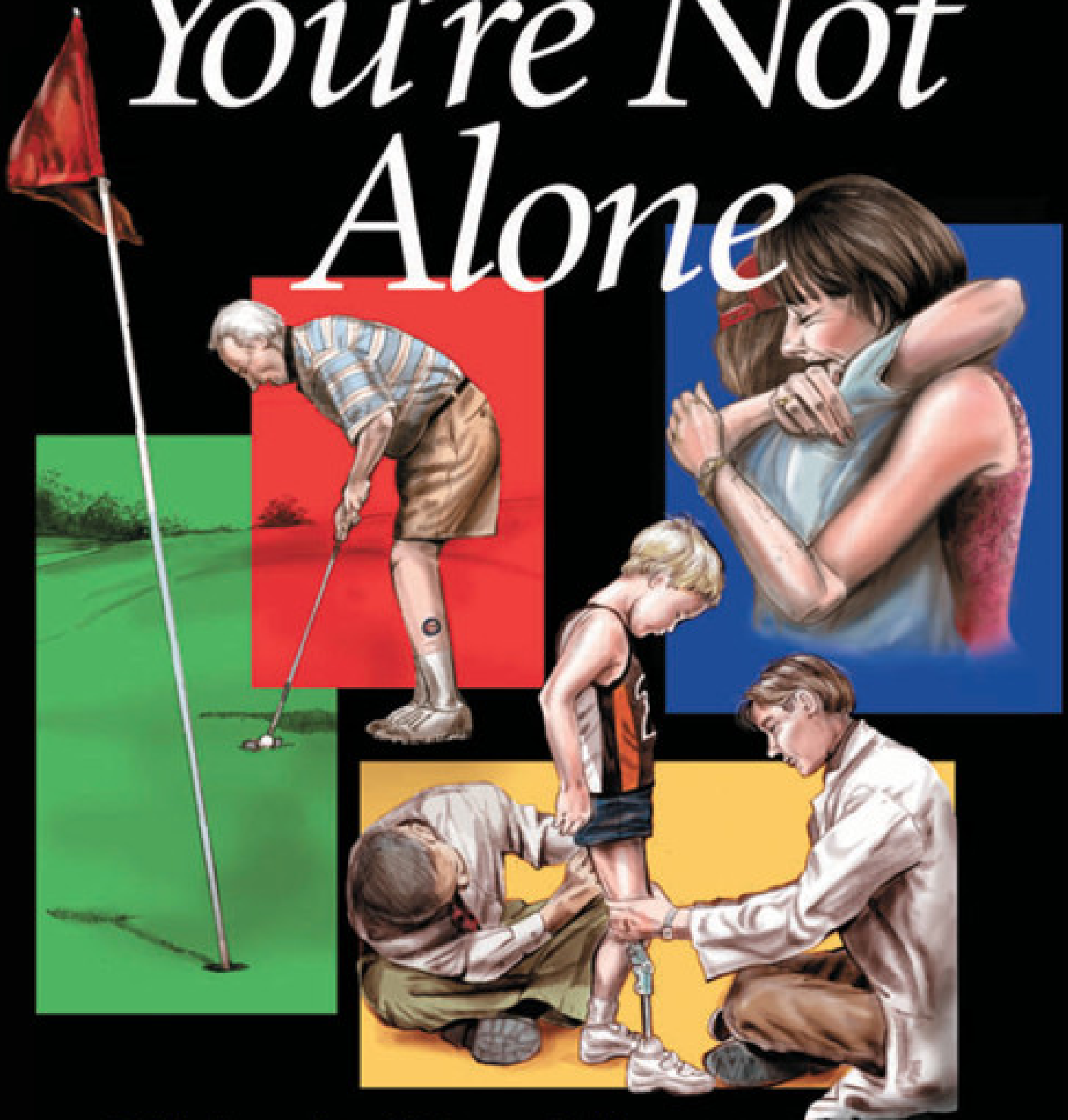


# You're Not Alone



*With the stories of 38 remarkable amputees  
who conquered the challenges of a lifetime*

---

John Sabolich, CPO  
Scott Sabolich, CP

# You're Not Alone



*With the stories of 38 remarkable amputees  
who conquered the challenges of a lifetime*

John Sabolich, CPO  
Scott Sabolich, CP

*One second I was standing; the next I was on the ground. I'll never forget the crunching sound of the wheels as they ran over me. I knew exactly what had happened. Both my legs had been cut off. I raised my head and saw one of my legs a few feet away in the middle of the track . . . I thought I was going to die . . . As I lay in the hospital, I wanted to kill myself. If there had been any way – a pair of scissors or a gun – I would have done it . . . But I talked with Roger Charter, another amputee. I saw a videotape of him running. “My God, look at that guy. He’s lost both legs above-the-knees, and he’s not walking – he’s running.” I saw Roger and other amputees who had faced the same kind of catastrophe, and I knew I wasn’t alone. I knew if they could make it, so could I . . . And now I’m just living for the day when that phone will ring, and it’s going to be someone calling me like I called Roger. It’s going to give me the opportunity to tell that person what I went through, and I’ll be able to help someone like other people helped me.*

*Brent Polanchek*

Library of Congress  
Catalog Card Number 91 – 62609

Copyright 2005

Scott Sabolich all rights reserved

This book may not be reproduced in whole or in part  
without written permission from Scott Sabolich.

For copies of this book  
or a free video, please contact:

**Scott Sabolich Prosthetic&Research**

10201 N. Broadway Extension

Oklahoma City,OK 73114

405.841.6800

Toll free 1.877.226.5424

[www.scottsabolich.com](http://www.scottsabolich.com)

ISBN # 0-9637331-2-5



*You're  
Not  
Alone*

*With the stories of 38 people who  
conquered the challenges of a lifetime*

By John Sabolich, CPO

and Scott Sabolich, CP

Linda Adlof, Editor

Carol Sorrels, Managing Editor

Emily Remmert, Contributing Writer



*It's a family affair. Three generations of certified prosthetists –  
Scott Sabolich, CP; John Sabolich, CPO; and Lester Sabolich, CPO  
(left to right)*

# Foreword

This fourth edition of *You're Not Alone* comes after years of growth and changes in the field of prosthetics. As I follow in my grandfather's and father's footsteps providing prosthetic care, I have seen firsthand these amazing changes. However, despite the latest materials and componentry available, there is one fact that has and will always remain unchanged. The pain, sense of loss, frustration and fear that amputees feel when they lose a limb is extremely traumatic and very real.

Unfortunately, I have found there is still too little information available for amputees today. The first edition of this book, published in 1991, was my father's vision that became a reality. It has proven to be an excellent resource for amputees and their families and has helped thousands of people across the world. We hear from many amputees who say reading this book has made a significant difference in their healing process and offered invaluable information about prosthetic options. Because of the greatness of the original work, I didn't feel it was necessary to make many changes. We have updated the technology section to reflect the latest advances in the field of prosthetics and included several more personal insights from amputees. As you cope with your individual situation and search for answers, I hope this book will offer you much-needed encouragement and provide you with the knowledge you need to make decisions about your prosthetic care.



Scott Sabolich, CP





# Introduction

*This book is dedicated to the millions of amputees, young and old, who have faced losses of limbs and struggled to find new direction for their lives*

You're Not Alone is a compendium of prosthetic information accompanied by a collection of personal stories from 38 amputees. Those who share their stories are candid about the physical and emotional pain of amputation, grief over losing an armor leg, frustrations and triumphs with a prosthesis, as well as the courage it takes to put pity aside and go on with life. They share their experiences, successes, inner strengths, hopes and dreams...many times things most of us take for granted. We believe their compelling stories will inspire everyone – whether you're an amputee or not.

As a resource, this book is designed to provide basic information for amputees or those who may be facing an operation to remove a limb. Friends and families will find understanding in these pages, too.

People facing amputation of a limb are frantically searching for answers, trying to piece their lives together and finding little – if any – helpful information. Many find themselves literally in tears, crying out for someone to talk to . . . another amputee...someone who understands...or something they can read that will give them some answers. Our hope is this book will fill part of that void. Some people may not agree with opinions expressed in this book. That's all right. You're Not Alone is a collection of opinions. Many of the stories are by our patients; some are not. Not all of the feelings of individual amputees represent our personal opinions, nor would their suggestions necessarily be the advice we would offer. But each person was asked to share his or her personal experiences and we respect their efforts.

We've seen the frustration of many amputees whose prostheses were ill-fitting, causing pain and keeping them from leading full, active lives. We have also seen old wooden legs evolve into lightweight, flexible, high-tech, more usable limbs. We've been there to see the faces of young children light up when they were able to run for the first time. Over the years, amputees have shared the grief and bewilderment of waking in a hospital bed, missing a limb, not knowing what to do next or who to turn to. They have so many questions, and there's just too little information available. Amputation is not something you think about unless it happens to you, a

loved one or a friend. In the midst of such a life-changing trauma, it's hard to comprehend all that needs to be considered. We try to address those needs, and in a special section, we've attempted to answer the most commonly asked questions.

Every amputation is different, and not all the suggestions will apply to every amputee. We hope it will serve as a guideline for everything from what to do before the amputation if you have a pending operation...to what you may feel upon waking and how to deal with those emotions...to proper fitting of a prosthesis...to prospects for future improvement in artificial limbs...and finally, to finding a way to mainstream back into life.

Our goal in compiling *You're Not Alone* is to encourage amputees not to give up and to keep asking questions until they are satisfied with the answers. Seek out other amputees for advice. Find a support group. Many amputees have shared the discovery of spiritual journeys and have found that their unwavering faith in God has led them to a new, deeper understanding of life. We encourage you also to call upon that inner strength and never give up.

Once you have read the personal accounts in *You're Not Alone*, we think you'll agree these amputees have very human and encouraging stories to share. They are people who have confronted one of life's toughest challenges and have gone on. They told their stories for this book because when they faced their amputations, they longed for something to read...something to hang on to... something to tell them that they were not alone.



# Frankly Speaking

*PRACTICAL ADVICE FROM JOHN SABOLICH, CPO AND SCOTT  
SABOLICH, CP*

“I awoke in my hospital room. Still groggy, a flat sheet was all I saw – a flat sheet where my leg used to be. What was I going to do? How could I go on? It just wasn’t fair. Why me, oh God, why me?”

These thoughts from one amputee tell the story. It’s a story of pain, bewilderment and searching. It’s a story that countless amputees have shared. We’ve heard it over and over in our years as prosthetists.

Those first feelings after waking from an amputation can be overwhelming. Questions, shock, changing emotions, loneliness, pain from the surgery, as well as phantom pain from the loss of a limb – an amputee may experience them all. And there may be anger or even ambivalence about going on with life.

An amputation is a life-changing experience. Unlike other operations, it is very visible. That fact becomes a major roadblock for some people. We’re frequently asked why one amputee seems to do so well, while another does not. We believe the answer is acceptance. Perhaps you are familiar with the first part of the Serenity Prayer: “God grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference.” This prayer offers good advice for each of us – amputee or not. But it holds an especially important message for amputees.

We all struggle with acceptance. All of us face changes in our lives that we must learn to accept if we are to be emotionally healthy and lead fulfilling lives. In the case of a person who must confront the loss of a limb, acceptance is crucial. Sometimes it’s easier to place the blame or take out the hurt for a loss on other things or other people. It’s easier to focus on the external and try to avoid dealing with your own inner feelings. Acceptance of an amputation may be difficult because the loss of a limb is so final.

As with any loss, there is a grieving period when you may want – and need – to scream or cry. But once you get through the grieving, the choice is yours; you can accept the change or fight it. But fighting it only leads to frustration and bitterness – and it’s emotionally draining. For some, the road

to acceptance is a long, arduous one. Others, who choose to face the change and work to accept it, are better equipped to move on with life. They focus on the change as a challenge.

Don't misunderstand. It doesn't happen overnight, and it isn't easy. An amputee has to take it one day at a time, sometimes maybe five minutes at a time, step-by-step. But if you can maintain a positive attitude – and focus on the solution rather than the problem – life does get better. Everything in life can be looked at two ways – positively or negatively. A person who seems to have it “all” but has a negative attitude can still be a miserable person. Cultivating a positive attitude about what life has to offer will pay off in the long run. We will more fully discuss grieving and mainstreaming back into life later in this section. But as we begin to share the process of change an amputee faces, we want you to understand that accepting yourself as you are is the all-important first step. Whether or not you decide to wear a prosthesis, your first goal has to be to accept yourself as a whole being – just the way you are right now.

Perhaps fashion model Ivy Gunter sums it up best when she says: “Focus on what you have, not what you don't have.” Ivy was at the pinnacle of her New York modeling career when cancer forced amputation of her leg above the knee. Determined not to let the amputation put an end to her career, she was fitted with a highly cosmetic prosthesis and returned to modeling. It was after the amputation that she became a real model – a role model for other amputees. Her positive attitude has given inspiration to amputees around the world. She reaffirmed that there is life after amputation – there is hope. In fact, there can be an even more complete life as you refocus your perspective after a tragedy.



Ivy Gunter,  
above-the-knee amputee,  
International Models Hall of Fame  
model.





## TOUCHING PEOPLE OF ALL AGES

While more than 75 percent of all amputees are over age 50, sex, race or age make no difference when it comes to losing a limb. Generally, amputations result when there is:

An accident. The accident may actually sever the limb, or crush major arteries or bones, and may force later surgical removal of the limb.

A life-threatening disease. There are many patients with diabetes, vascular disease, circulatory problems or cancer. A patient may face the alternative of giving up an arm or leg – or losing his or her life. A parent may confront a heart-wrenching decision when asked for permission to remove the limb of a young son or daughter who might otherwise die.

A congenital anomaly. Some infants are born without arms or legs, or with partial limbs, because of birth defects. In some cases, amputation of a deformed limb may one day become necessary to properly fit the child with a prosthesis.

A painful or paralyzed limb. An amputation is sometimes done to remove a withered arm or leg. We know no one likes to talk about it, and the thought of amputating a limb is difficult. The very idea may sound ghoulish and make you uncomfortable. You may not want to think about it. In fact, if you are facing a life-threatening situation, exactly what shape your residual limb is going to be in after the amputation may be the last thing on your mind. But maybe you need to refocus on what life holds for you once you survive. With that in mind, it is important to realize the way your amputation is done will significantly impact the rest of your life.

## LIMBS FOR THE OLDER AMPUTEE

When a person gets into their sixties, and especially into their seventies or eighties, it is important for the prosthetist to take a different approach in fitting techniques that accommodate the changes of aging. Consideration must be given to sitting comfort as well as walking comfort.

It is vital for the older above-the-knee amputee to be able to put on the prosthesis easily. Older patients are sometimes told a suction limb is best. This is not necessarily true. Other methods of suspending the prosthesis can be used making it easier to slide on the socket. For example, a gel liner with a pin or lanyard helps protect the skin and hold the loose tissue. It also makes it easier to slide the socket on and allows the use of socks to accommodate volume changes in the limb.

The older amputee usually has more movable, loose tissue in the residual limb. Therefore, the flexible socket needs to have adequate bone and muscle contouring so it is stable and won't rotate on the patient's leg. Otherwise, the foot will point in and out while the person tries to walk which is both unsafe and uncomfortable.

The advanced plastics and modern materials now make it possible to reduce the weight of a prosthesis even more than before. Therefore it takes less energy to walk.

Many times older amputees with poor balance may benefit from the use of a prosthesis that will allow them to transfer from the wheelchair to the bed or in conjunction with physical therapy to help regain balance. With a contoured socket that fits accurately, gait training and physical therapy, they can do quite well to the surprise of many therapists and doctors.

Lack of circulation is a major reason for amputation in the older population; therefore, it is important the socket be shaped in a manner to aid circulation, not restrict it. This is another reason for vascular and muscle contouring which is not present in many socket designs. In fact, some sockets may restrict blood flow.

In choosing componentry, an older patient with poor balance needs to consider a stance control or more stable locking knee on above-the knee cases to help prevent falls. A light-weight foot that has good energy absorbing qualities should also be used. There are many component choices, but the knee and foot are the two most important.

It is important the older amputee receives adequate gait training by a qualified physical therapist. The therapist can aid the patient in deciding if a cane or walker is needed, or if they can eventually walk unassisted.

Above all, the amputee needs to be heard and listened to carefully throughout their entire prosthetic management program. Older amputees have more alternatives in prosthetic care today than ever before. Those who previously would have been confined to a bed or wheelchair might be able to walk again and enjoy more independence.

## WHEN YOU'RE FACING AMPUTATION

Historically, the medical community has viewed amputation as destructive. That view has a negative psychological impact on patient and surgeon. If you change your mind-set and look at it as reconstructive, then you can focus on what the residual limb will do for you after the surgery. In other words, think of the surgery as fashioning the end of your limb to make it more capable of bearing weight, whether it's an arm or a leg.

If it's a non-emergency and you have time before your operation, we strongly suggest you consult a prosthetist. Working as a team, the patient, surgeon and prosthetist can discuss surgical options and decide what will best complement your future prosthetic management program. The idea of contacting a prosthetist before surgery is a concept beginning to be embraced by physicians, allied health organizations and amputee support groups across the country. Amputees, who have gone through the heartaches and physical pains of amputations that make it difficult to wear artificial limbs, recognize the need to contact a prosthetist early in the process as they begin to reshape their lives. But don't be surprised if your surgeon questions the idea. One amputee recently went back for revision surgery. Her doctor wanted to know why she wanted him to consult her prosthetist. "Because he is going to have to work with what is left for the rest of my life," she explained to him.

Exactly how much of a limb should be removed has recently become an issue of controversy. Many people, well-meaning doctors included, think the less removed, the better. They feel the longer the limb, the better the leverage, which may sound like the most logical approach. In reality, this may not always be the best option when it comes to fitting an amputee with a comfortable, functional prosthesis. Some physicians tend to leave all possible length of a limb – even when the person has no feeling in the lower part of the limb or there will be a lot of severe scar tissue. Those types of amputations generally set up a series of future problems for the amputee who wants to wear a prosthesis and become independently mobile again.

There are many things to consider when deciding on the level of amputation. Where an amputation is done may affect your mobility as well as the cosmetic look of your artificial limb.

Let's take the case of a knee disarticulation or a very long above-the-knee

amputation. The surgeon amputates at the knee leaving a long residual limb. In the past, amputation through the knee has been considered best for leverage and weight-bearing, as well as for a simple, clean surgery. (The limb is disjunct instead of being cut through the bone and muscles.) But some knee-disarticulation amputees find the long residual limb to be both functionally and cosmetically undesirable. The extra length can create several problems. Bulky knee width and unequal joint centers can cause cosmetic problems in the artificial limb, and bony protrusions can cause chronic prosthetic fitting problems. Traditionally preserving as much limb length as possible resulted in a more comfortable fitting socket and allowed the patient greater control of the knee. But advancements in socket design and fit as well as new knee designs make it possible for an above-the-knee amputee to achieve the same comfort and control of the knee.

Additionally, the prosthetic knee component takes up considerable space, which adds to the overall length of the prosthesis. You end up with a very long thigh. To compensate, the calf portion of the prosthesis must be shorter so the overall leg length will match the sound leg. Consequently, when the amputee with a knee disarticulation sits, the knee projects too far out and the foot doesn't touch the floor. When the amputee walks, the swing of the knee looks uneven. And because the knee joint protrudes so far, it can be difficult to get the necessary leverage to get up out of a chair, especially for a person who has had both legs removed. You should understand that the extra length in a residual limb may actually prohibit use of the type of knee joint you may want. Again, this is because of the space required by the knee component.

Other disarticulations (ankle, elbow and wrist) and amputations which leave very long residual limbs sometimes cause similar problems. Patients often object to the width of the prosthetic socket required by these amputations. The prosthesis often looks bulky, and there is usually no way around that. We've seen many patients with tears in their eyes because of the bulk of the finished artificial limb. Most women and many men find these levels of amputation cosmetically displeasing. However, we have seen a few disarticulation amputations where the surgeon trimmed down the large part of the bone, shortening it slightly, and the finished prosthesis looked reasonably good. Still, these may never look as good cosmetically as shorter amputations.

We are not saying that all amputations that leave longer residual limbs aren't advantageous for some patients. In the case of a child, concerns about bone growth and spur formation may outweigh the negative aspects of a disarticulation. But we believe it is imperative, especially in non-emergency situations, that the implications of the various surgical options be discussed thoroughly with the patient.

Leaving a very long residual limb is not as necessary as it once was because of advanced socket techniques and high-tech prosthetic componentry. In fact, many ankle-level (Symes) or long, below-the-knee amputees may do better with a somewhat shorter limb that is protected by the softer, thicker calf muscles. And blood circulation is normally better above-the-ankle. Few Symes amputees run on their prostheses, but running is relatively common among those with shorter below-the-knee residual limbs. One reason may be that the longer limb does not leave room for the shock-absorbing foot and ankle componentry, so the amputee receives an uncomfortable jarring with each running step.

There are a number of other factors that should be discussed, including rounding of bony prominences, scar placement and vascular viability (blood circulation) at various levels of amputation.

If possible, it is important that the surgery does not leave you with a lot of limb in which there is no feeling. You need to have intact sensation in the residual limb.

Other special procedures such as myodesis (muscle-to-bone reattachment), myoplasty (tying muscle to muscle), syostosis (bone-bridging), and prosthetic joint space requirements should be considered. It is also important that the doctor pay particular attention to the nerve endings during the operation. You may want to check with your surgeon on how that will be done. One surgeon with whom we work says that any time a nerve is cut, a neuroma is going to form. But how the nerve is cut may make a difference in the amount of pain the neuroma causes later. Painful neuroma formation can be decreased if the surgeon gently pulls the nerves down, clips them cleanly and allows them to retract up into the soft tissue or muscle bed, according to the surgeon. This surgical procedure helps keep the neuroma away from the scar tissue that forms naturally inside the end of the residual limb.

And again, in some cases where a surgeon tries to save the length of the

limb at all costs, an amputee may be left with undesirable, non-sensitive scar tissue. Scar tissue may not only adversely affect how well you function on your prosthesis, but also is often a source of constant skin breakdown. This is especially true if the scar tissue is stuck to the underlying bone, preventing the tissue from moving freely over bony areas.

The bottom line is to find out as much as you can from your surgeon and prosthetist before the operation. The fewer surprises, the better. We have worked with many amputees who overcame pain from initial operations only to face revision surgeries because their limbs were not amputated at levels best for prosthetic use.

Communication among patient, doctor and prosthetist can make a difference – the difference between an amputee struggling through life on crutches, dealing with unnecessary pain, or getting on with life using a prosthesis. As an amputee, you need not feel powerless. Through research, you can gather the knowledge to participate in the decisions that will affect your life.

So, how do you choose a surgeon and a prosthetist? Chances are you have no idea where to start. The best answer: ask for recommendations. Ask family, friends and other amputees. Find out how many amputations your surgeon has done. The more experience, the better. Ask if you can talk to several of his or her amputee-patients. It's helpful to talk with an amputee who has the same type and level of amputation.

The same goes for a prosthetist. First, consult only with a certified prosthetic facility. The American Board of Certification in Prosthetics and Orthotics monitors the profession and regularly reviews facilities to make sure they meet minimum standards. The American Orthotic and Prosthetic Association in Alexandria, Virginia, provides a list of certified prosthetists and prosthetic facilities on their website: [www.oandp.com](http://www.oandp.com).

But beyond certification, experience counts. You need a prosthetist who is experienced in dealing with your particular level of amputation. One prosthetist may serve a lot of below-the-knee amputees but may not have a great deal of experience fitting an amputee with a hemi-pelvectomy or hip disarticulation. And there is a significant difference between fitting a long above-the-knee and a short above-the-knee amputee. When it comes to getting a proper fit, it can make a difference whether a prosthetist makes 10 legs or as many as 100 each year for your level of amputation. Some

prosthetists are more open to using new technology and advanced materials than others. Again, ask to talk to several of the prosthetist's patients, especially amputees whose amputation level is the same as yours will be, and those who are as active as you want to be. Most amputees are more than willing to share what they have learned.

When it comes to selecting a surgeon or prosthetist, ask questions until you get the answers. If your prosthetist or doctor seems annoyed with all your questions, find another who will listen to you. There are a growing number of amputee support groups that can provide valuable information and be an on-going source of encouragement as you begin life with an amputation. For a list of amputee support groups, you can contact Amputee Coalition of America, 888-267-5669, or [www.amputee-coalition.org](http://www.amputee-coalition.org).

For the most part, there isn't enough communication between physicians and prosthetists, who are both earnestly trying to serve amputees but face daily time constraints. Still, the amputee is best served when the physician and prosthetist take the time for consultation. A real effort to communicate can only benefit the amputee.



## **AFTER SURGERY . . . IS MY LEG STILL THERE?**

What can you expect after the amputation? Amputees often complain they weren't told before surgery what they'd feel after the amputation. You may awaken after the operation and think your arm or leg is still there . . . that the doctor didn't amputate. No, you're not imagining it. It's a phenomenon called phantom limb. It can be merely a sensation or it may be pain.

It's common, but some amputees hesitate to even mention the sensation or pain to anyone, because they rationalize that it just couldn't be . . . and maybe worse, someone might laugh at the very idea. But amputees as well as physicians have told us that phantom sensation and phantom pain are very real indeed.

Initially, the pain from surgery will be the most overwhelming. Doctors often prescribe heavy sedatives, like morphine, for the pain. There may be side effects when the pain medicine is tapered off, and you can discuss these with your doctor.

Phantom pain is generally worse immediately following the amputation. Depending on how you lost your limb, you may feel as though your arm or leg is being twisted or bent in an awkward position. Amputees who have been through extended pain or traumatic accidents seem to experience greater phantom pain, but it depends on the individual. For some, it feels as mild as a tingling sensation. Others describe it as a stabbing, burning pain that comes in intense waves. The good news is that it normally gets better with time. Still, many amputees will experience episodes of phantom pain, ranging from mild to severe, throughout their lives.

One problem is that people, including some well-meaning doctors and nurses, tell the patient to forget about the leg or arm that has been amputated. The reasoning is "it's not there anymore, so it can't hurt you anymore." This makes phantom pain more difficult and harder to accept. It isn't necessarily healthy for the amputee.

Let's take the case of a leg amputation. After the surgery, the brain doesn't know the leg is gone and continues to crave information from the floor. We ask amputees not to forget their leg or their foot... but rather to imagine feeling the foot hitting the floor and the toes bending, even though they are gone. Cerebral projection – visualizing the amputated limb as if it is still

there – is something we've been experimenting with. We've found that patients who visualize their amputated limbs intact are usually the ones with the best gaits. And visualization also seems to help them deal with phantom pain.

If phantom pain continues to be a problem, you may want to ask your physical therapist or physician for treatment suggestions. Talk to your physician about prescribing neurontin. Many amputees have been helped with this medication. Other amputees often have “home remedy” tips on how they handle pain, and pain management centers offer a variety of approaches to deal with phantom pain. Here are some ideas for pain reduction, but not all of them apply to a new amputee. You should check with your doctor before trying these, and remember, what works for one amputee may not ease the pain of another.

- Try some mild, total-body exercise to increase circulation and/or exercise the residual limb.
- Visualize the missing limb and mentally exercise it.
- As you physically move the limb on your sound side, mentally move the missing limb in the same fashion in unison.
- Using basic relaxation techniques, tighten and then slowly relax the muscles in your residual limb.
- Massage your residual limb with your hands or with a shower massage.
- Soak in a warm bath, hot tub or whirlpool – or try wrapping your residual limb in a warm towel or a heating pad. Warmth often increases circulation and reduces pain.
- Wear a shrinker sock or properly applied Ace bandage. If you have your prosthesis off, try putting it on and taking a short walk.
- If you are wearing your prosthesis, take it off for a few minutes. Then, put it back on. Sometimes the residual limb is being pinched, and changing the position of the prosthesis may relieve the pressure.
- If you have been sitting for a period of time, change positions or stand to increase blood flow to the residual limb.
- Keep a diary of the pain. Some people find a relationship between the pain and certain foods.

Some amputees also use self-hypnosis, chiropractic treatment or a Transcutaneous Electrical Nerve Stimulator (TENS) unit. If phantom pain persists, you may want to ask your doctor or prosthetist for more information about pain management clinics. Another area under investigation is Biomagnetic Technology where special concentric, alternating-poled magnets are incorporated into the prosthetic socket. There is some evidence that this special magnetic affect results in increased circulation for the patient and may have a positive effect in reducing phantom or neuroma pain. There are also special socks containing tiny flexible metal fibers that have been shown to create a shield from radio waves and other sources of electro-magnetic radiation. It is believed that severed nerves are more susceptible to being triggered by these energy waves from overhead power lines, fluorescent light-bulbs, radios, television antennae, etc.

In addition to pain, the personal realization that you are now an amputee may hit you following surgery. “No matter how prepared you are for the operation, you’re never prepared for waking to see a flat sheet where your leg used to be,” says one amputee. Pulling back the sheet that first time can be a real emotional trauma – one that those of us who aren’t amputees can’t really describe or understand. It helps if you have someone to talk to, whether it’s a family member, a doctor, nurse or friend. Other amputees can be especially helpful in understanding the feelings you are experiencing. Your doctor, prosthetist or local amputee support group can give you names of amputees to call.

Some amputees will awaken after surgery to find a rigid cast, or a cast with a pole, knee and/or foot attached to their residual limb. There are pros and cons to this immediate post-operative fitting, and you may want to discuss these with your doctor and prosthetist. Many doctors and prosthetists dislike this type of fitting because the limb cannot be viewed through the cast during the healing process. Most amputees will find only a soft dressing covered by an Ace bandage on the residual limb.

You may be surprised to discover your limb is very swollen, rather bulbous and quite a bit larger than your other arm or leg. The swelling will go down, and the residual limb will shrink significantly over the first three to four months after the amputation. The muscles tend to atrophy, because they are not being used and the fluid build-up slowly goes away. Eventually a

mature residual limb will usually be smaller than the other arm or leg.

However, if you are fitted with a bone and muscle contoured socket that allows for muscle growth (hypertrophy), your residual limb can build back some of the muscle it lost. Using those muscles appropriately can help improve your gait.

The average hospital stay for a new amputee is seven to 10 days if there are no other medical complications. You can expect your medical staff to have you up and out of bed as early as the first day after surgery. You should consider beginning physical therapy that will prepare you for wearing a prosthesis. Your physical therapist or nurse can show you how to properly wrap your residual limb in a figure-eight configuration with an Ace bandage. This is important to help keep the swelling down.

A physical therapist can play a significant role in your recovery. Good forward-thinking should be to include the therapist in the doctor-patient-prosthetist team, even before surgery. After surgery, a physical therapist can help prevent flexion contractures, a sometimes permanent shortening of the muscle or tendon that may cause deformity or stiffening of a joint in the residual limb. As an example, some amputees develop a “frozen” joint that prevents successful prosthetic use. Make sure your physical therapist checks for the onset of flexion contractures.

Under the supervision of a therapist, you can learn to desensitize your residual limb. Limb desensitization is very important, yet frequently overlooked. An amputee who can't stand to have the residual limb touched will not be able to tolerate a prosthetic fitting. Once you can massage the limb, it's important to work your way up to patting it, rubbing it with a towel and even lightly slapping it. This will prevent the development of adhesions, and you will feel less and less nerve irritation.

After hospitalization, you may be referred to a rehabilitation facility, depending on the severity of the amputation and other medical problems. However, most amputees will be allowed to go home.

## GETTING TO KNOW YOUR RESIDUAL LIMB AND TEMPORARY PROSTHESIS

You should get a temporary prosthesis as soon as your doctor says it is okay. Usually, an amputee can wear a temporary as soon as the stitches are removed – about two to six weeks after the amputation. In the meantime, you should be getting acquainted with your residual limb – massaging, desensitizing, exercising and working with it. You will hear the residual limb referred to as a “stump.” This is a blunt and sometimes shocking term that maybe offensive to some people, particularly new amputees. Although the word stump has been used historically, we prefer the term residual limb.

Learning to accept or bond with your residual limb is an important step for amputees. After a time, some amputees even choose to name their residual limbs – like “short arm” or “my little leg.” One fun-loving teenager Leslie Wilson draws a face on her short leg to make it a conversation piece when she is at the beach. Sometimes a spouse or companion affectionately nicknames the residual limb.

For some, it is all part of the healing process as you learn to accept your amputation. The journey to acceptance can be a spiritual healing, according to an amputee who lost her leg to cancer as a youth. She and other amputees say you have to first get over thinking that the residual limb is ugly. She admits that even after 20 years, there is an occasional twinge of sadness when she catches a glimpse of herself in a full-length mirror. She says you have to acknowledge the sadness and go on from there – you don't have to like what you see, but you do have to accept it and move on. Learning to look at, touch and massage the residual limb will help you accept the amputation. After all, it's part of your body. As far as you are concerned, it is your armor leg – not just a stump or residual limb.

You should continue wrapping the leg or arm with an Ace bandage each day. If you forget how, there are a number of amputee publications that will show you the proper wrapping method for each type of amputation. It is important not to wrap the residual limb too tightly above the end of the amputation, which will restrict circulation. The bandage should be removed and rewrapped several times each day, because it will become loose as the limb shrinks and fail to provide adequate support.

We do not recommend using the shrinker or reducer socks until after the

stitches are removed and the surgery is more healed. When donning a shrinker sock before the surgery has healed, it can hang on the bulbous end of the limb and pull on the incision. Once the incision has healed, a shrinker sock is more convenient and helps further reduce the residual limb for prosthetic use. Even after you get your temporary prosthesis, you should use a shrinker when not wearing your artificial limb to keep swelling to a minimum. Some amputees continue to wear them throughout life, finding the support from a shrinker particularly comfortable at night.

Getting your temporary prosthesis can be exciting and a little frightening. You will have lots of questions, and you shouldn't be embarrassed to ask your prosthetist about whatever concerns you. You may want to make a written list so you don't forget important questions. If you have talked with your prosthetist prior to surgery, you will already have a working relationship. If not, as you go for your first fitting, be sure to communicate your needs. A prosthetist is neither a mind-reader nor a magician – but can become an important part of your life. An amputee-prosthetist relationship differs from a patient-doctor relationship because of the amount of time you spend with the prosthetist. A good prosthetist will spend hours and days with you during the fitting process and for the rest of your life.

The fitting process will begin with the prosthetist taking an impression or cast, along with measurements of your residual limb, so a socket can be properly designed. Taking a cast involves wrapping a wet plaster of paris bandage around the residual limb. After the material hardens, it is removed and used to make your first socket.

Do not be shocked when your temporary isn't as lightweight and attractive like other prostheses you may have seen. Usually, a temporary is somewhat bulky and less cosmetic than a permanent or definitive prosthesis. Normally, there is no cosmetic covering, so you will see the socket attached to various componentry.

You may ask, "Why do I need a temporary...why not just get a definitive artificial arm or leg?" The reason: your residual limb will continue to shrink, requiring socket adjustments. A temporary saves time and money, and adjustments can be made that will provide a better-fitting definitive prosthesis. That's the primary purpose of a temporary prosthesis. If you've lost your leg, it lets you be up and mobile, learning to walk and balance while your residual limb continues to shrink. Bearing weight helps shrink

the residual limb faster. If you've lost an arm, it allows you to pick up objects and manipulate your world. Many people are anxious to get into definitive, more cosmetic prostheses quickly. Going to a definitive prosthesis too early is a mistake in many cases, because it doesn't allow adequate time to let the temporary do its work. We advise patients to wear a temporary for a minimum of three months. Many times the shrinkage will continue for six months to a year.

After you are fitted with a temporary, and as the limb shrinks, you will use prosthetic socks to take up the extra space in the socket. You will continue to add socks to help the socket fit properly. Sometimes the residual limb will shrink so much that another socket will be necessary. At that time, if the arm or leg has matured, you will be ready for the preparatory stage. It depends on the individual.

In addition to shrinking the residual limb, the temporary leg or arm toughens and desensitizes the limb to prepare you for wearing a definitive prosthesis. If you've lost a leg, it helps you regain balance and relearn how to walk. At this point in the prosthetic fitting process, it is important for the amputee to learn to tighten the muscles in the residual limb while walking with the temporary prosthesis. It is one of the most important things we ever discuss with an amputee who is relearning to walk. Mastering the muscle control may take a while, but the benefits include better stability, more comfort and less limp. If you have lost an arm, the temporary prosthesis increases range of motion and strengthens the muscles. Most importantly, however, it encourages you to keep using both hands – preventing you from becoming one-handed.

Your temporary may cause you some initial pain, but the pain should not be excruciating. Some patients are more sensitive and will experience more discomfort. In lower extremity cases, you should be up and walking a short distance in a day or two, if there are no additional medical problems. If you are in pain for a long period of time, there is a good chance something is wrong. You may need to see your doctor; – there may be a medical problem that has gone undetected. You may also need to talk to your prosthetist or maybe another prosthetist, if you don't get your problem solved.

Whether you've lost an arm or leg, if you don't already have a physical therapist, your prosthetist should be able to recommend one who has experience with amputees. We prefer patients to get as much physical

therapy as possible – at least several days a week at first. But each individual is different, and it often depends on the type of amputation. Some amputees need little physical therapy while others need a great deal. Occupational therapists are especially helpful in training upper extremity amputees to be more functional, with or without prostheses.

At this point, we would like to touch on the need for daily hygienic care of your prosthesis. Many amputees notice they seem to perspire more heavily after an amputation. Sometimes this scares them – they think there is something wrong – but you need not worry. One reason the perspiration may appear greater is that after an amputation, there is less body surface from which to perspire. You're not necessarily perspiring more, but it is now concentrated over a smaller area.

You will notice that your residual limb perspires a lot inside the socket – encasing skin in plastic causes heat retention and moisture build-up. Perspiration inside the socket can be both a source of odor and bacteria as well as the culprit behind skin problems. But there are a variety of products available to help manage this problem. Using an antiperspirant on the residual limb is one answer. There is also a special prescription antiperspirant called Dry-Sol. But if you use Dry-Sol, it should be applied at night and washed off in the morning before donning your prosthesis. You need to ask your prosthetist or doctor for additional information on the proper use of Dry-Sol. Some amputees say that powdering the residual limb with baking soda is one simple solution to the moisture problem. However, others don't like powder because it builds up in the socket making it more of a chore to clean. It's a personal preference. Regardless of your choice, your prosthesis is now a part of you and should be cleansed daily just as you care for the rest of your body.

The socket should be thoroughly cleaned every day with alcohol or anti-bacterial soap and water. Many amputees prefer to bathe and clean the socket at night, so both the skin and the socket are completely dry when donning the prosthesis the following morning.

Stump socks also need to be laundered regularly. Most amputees report hand washing and line drying is preferable to prevent sock shrinkage and a must if you use soft, woolen socks. Some amputees find they even need to change socks more than once a day because of perspiration. Each amputee develops a personal hygiene regimen that fits individual needs and



schedules. You can find more hygiene tips in many amputee publications or ask your prosthetist.

## **DRAMATIC CHANGES IN PROSTHETICS**

As you look forward to your definitive artificial limb, you should realize that the world of prosthetics has changed dramatically in recent years. Amputees are now able to do things that were only dreamed of prior to the 1990s. Lightweight and flexible materials, advanced socket designs, and high-tech, computerized componentry have expanded the possibilities for amputees. For those who have lost legs, there is hope for even very short above-the-knee, hemi-pelvectomy, and hip-disarticulation amputees who have been told they would never walk. They are discovering what it is to be independently mobile again. For those who have lost arms, myoelectric prostheses offer a functional and cosmetic replacement for hooks, previously the only choice for upper extremity amputees.

The technology is available, but the individual amputee possesses the key ingredient for prosthetic success. Attitude. You must have the desire, commitment and motivation to make your artificial limb work for you. What each individual amputee can do with a prosthesis depends largely on the person. Sure, the type of amputation and other physical problems are important, but to a great extent, what you will be able to do depends on you. Technology is only a secondary factor in the successful use of a prosthesis.

Many of the improvements in prosthetics can be attributed to the inner desires of amputees. It was 1982 when 3-year-old Sarah East – wanting so badly to run and keep up with her playmates –inspired the development of the Oklahoma City (OKC) Running Leg. After seeing a movie of above-the-knee amputee Terry Fox running with a hop-skip motion and knowing Sarah's desire, that night John Sabolich sketched the design for the running leg.

Initially he just took a piece of elastic cord, wrapped it around her leg, came up in front of her knee and behind her hip, and tied it around her waist. This was primitive, but after further research and development, the OKC Running Leg was completed. Sarah put it on and she took off running. To our knowledge, she was the first above-the-knee amputee to run step-over-step. Sarah's run was documented on videotape and later by CNN.

That development spurred us to further research until in 1988 Roger Charter became the first bilateral above-the-knee amputee to run step-over-step. It was a feat previously thought impossible, but he proved it could be

done.

However, not every amputee wants to run. For many, the goal is simply to walk comfortably. But thanks to advances in technology, now the option exists. It's like Roger says: "I may never run a marathon. But if it starts to rain, I can pick up my pace and jog to the car." With technology and determination, there is no longer a stereotype of what an amputee can or cannot do.

In fact, there is so much available to amputees today that it may be confusing. We cannot stress enough that the socket is the most important element – more important than a computerized knee, an electric hand or a cosmetic covering. If the socket doesn't fit accurately, the prosthesis is going to be painful to wear and you'll be tempted to put it in the closet. All the high-tech "bells and whistles" won't help if you don't have a socket that fits.

As you become a prosthetic consumer for the first time, we encourage you to have realistic expectations about the look, feel and function of your artificial limb. And remember, not every amputee is the same. No two amputations are exactly alike, so fitting requirements differ. People vary in physical strength, as well as in the time it takes to adapt to a prosthesis. Try not to be overly critical of yourself, but set realistic goals and expectations.

We should also add that the terms "permanent" or "definitive" prosthesis can be misleading. No artificial limb is going to last the rest of your life. Depending on how active you are, you can expect a prosthesis to last two to five years, depending on your activity level. With children, it may be even less. It is mechanical, and mechanical things eventually break down. Major fluctuations in weight or volume can also necessitate a new socket or other changes in the prosthesis.

For the purpose of this discussion, we will answer some questions about sockets and prosthetic fittings for the most common amputations. Again, please realize each case is individual, and each person will have special fitting needs.

## ABOVE-THE-KNEE

Sockets have come a long way from the early days of artificial limbs. John Sabolich began experimenting with different above the- knee socket designs in the mid-1970s. Back then, the quadrilateral socket, a square-looking, hard socket was the current above-the-knee socket design. The old plug socket was also still used sometimes. It was largely a pre-determined cylindrical shape into which you “plugged” your leg.

The quadrilateral was made of hard, heavy plastics or wood, designed very wide from side-to-side and narrow from front-to back.

The theory was that for weight-bearing purposes, the large bone you sit on had to be placed on a seat or shelf-like structure near the back of the socket. The socket squeezed the leg from front to back, helping force that bone back on the socket shelf. This left little room in the groin, and the bones in the crotch area tended to strike the top of the square socket, often causing pain.

There were other problems with the quadrilateral socket. It didn't encompass and contain the lower pelvic bones, so you had to sit up on a hard ridge, increasing instability. The socket usually gapped along the upper outside part of the leg as weight was applied, contributing to misalignment of the thighbone and leaving the amputee with a noticeable limp. After experimenting with a combination of the plug and quad sockets, a shape not as wide from side-to-side as the original quad socket evolved. Known as the quadraplug, it was an improvement, but it remained far from the sophisticated socket designs of today.

Yet another socket design that was very narrow from side-to side, called the narrow ML, became available in the early 1980s. With this socket, the sitting bone was still mainly on the shelf, but it was forced more to the inside rather than the back of the hard socket. Unfortunately, even at best, only the tip of the sitting bone was contained inside the socket. This concept of placing part of the sitting bone inside the socket originally came out of German socket design efforts in the early 1950s and was revised by American prosthetists. The shape of the socket remained rounded and very generic, with no distinct muscle, bone or vascular contouring.

After a great deal of study, John Sabolich developed a design known as CAT-CAM, which stands for Contoured Adducted Trochanteric-Controlled

Alignment Method. The aim was to capture as much of the pelvic bone as possible within the socket and help bring the thighbone into better alignment under the amputee. The original CAT-CAM was wider than the narrow ML at the top to lock against the pelvic bone, and then narrowed down from the middle to the end of the socket. The advantage of the pelvic containment was that it helped keep the thighbone from drifting out from under the amputee. In addition, it helped stabilize the residual limb within the socket by locking the bones along the top of the brim, reducing inadvertent movement between the socket and the residual limb. This socket was an improvement over the quadrilateral socket and the narrow ML.

CAT-CAM evolved into a flexible design, with bone and muscle contouring. Tom Guth, CPO, collaborated with John on the design and development of the flexible CAT-CAM socket in 1984. The soft socket allowed a more intimate fit – especially around the pelvic bone – which increased comfort and control. We taught the CAT-CAM concept at the University of California, Los Angeles, in 1985. But our research did not stop, and much of what was taught then is now obsolete. Unfortunately, some amputees are still being fitted with variations of the narrow ML socket when they ask for a CAT-CAM or a Sabolich Socket. But the sockets are not the same. The narrow ML design is not bone-and-muscle contoured, nor does it contain the pelvic bone in a significant way like later socket designs.

In recent years, further refinement of CAT-CAM led to SCATCAM and ultimately, the Sabolich Socket. The totally flexible socket has anatomically-designed channels and grooves for various muscle, bone, tendon, vascular and nerve areas. It also has built-in reliefs for concentrated pressure spots. Years of experience with hundreds of patients and extensive cadaver studies led to the logically applied, bio-mechanical principles incorporated in the Sabolich Socket. Because it is totally flexible around the top, a higher, more intimate fit is possible. This higher fit is very important for rotational stability and better side-to-side control. It also aids in command and alignment of the thighbone, preventing it from shifting as much as in other socket designs.

Most recently, we began using an ultra-flexible plastic in socket designs for most levels of amputation. The soft, pliable plastic is more flexible and comfortable than any material previously used. Additionally, gel liners are often used in socket designs, providing a “prosthetic fat pad” to help protect

the sensitive residual bone and limb tissue. The liner reduces high impact, friction, and rotational forces. They may also be used for suspension providing a much more secure lock to the socket.

# HIP-DISARTICULATION AND HEMI-PELVECTOMY

Advanced CAT-CAM technology, originally designed for above-the-knee amputees, spilled over into socket designs for hip-disarticulation and hemipelvectomy amputees. In the past, anyone with a leg removed at the hip or pelvis had a hard, bucket-style prosthesis. The latest breakthrough for high-level amputees is the S.M.A.R.T. Socket– Sabolich/Martin Abilities Restoring Technology

Socket. The socket wraps around the hip area and sitting bone in an anatomically-contoured way to contain and support the pelvic bone, rather than forcing the amputee to sit on a flat, hard surface. Patients report they no longer feel like they are “sloshing around in a bucket,” and there is more security and stability. A special silicone interfacing that cushions the bones has been developed, providing much greater comfort.

All of these technological advances have resulted in a new generation of prosthetics for those with very high-level amputations.

It makes walking a reality for many who would have given up in the past. Of course, in the case of a hemipelvectomy, even the pelvic bone for sitting is removed. The latest socket design provides the necessary containment in a flexible socket with a special silicone interfacing while still emphasizes anatomical contouring.

Both hip-disarticulation and hemipelvectomy amputees are totally dependent on a mechanical hip joint and the general mechanics of a prosthesis to walk since there is no residual limb to move the prosthesis or stabilize an artificial knee. Attached to the socket is a modified, energy-storing hip joint. The joint has a self-activating spring that triggers flexion of the hip and knee, allowing an amputee to walk with less energy. In the latest design, the hip joint has been recessed into the socket to keep it from striking the chair when the amputee sits.

## **BELOW-THE-KNEE**

A below-the-knee amputee usually has an easier time adapting to a prosthesis, because the knee joint remains intact making it easier to walk. But even below-the-knee prostheses have seen significant advancement in recent years. A below-the-knee prosthesis used to be made very tight from front-to-back. The person's weight was concentrated on selected areas of the leg, but we've found success relying on bone and muscle contouring in conjunction with total-surface-bearing fitting principles to distribute the weight properly. The latest below-the-knee socket does just that. The improved socket design is now being made even more comfortable with a silicone interfacing.

A below-the-knee socket may also use vacuum pressure to hold the prosthesis on. This method provides significantly greater control and comfort and may be used for those who are more active.

Earlier designs used belts and straps to hold the leg on, but the trend is toward a silicone suction cushion with a silicone suspension sleeve. The sleeve, which resembles an athletic knee support, holds the leg in place with tension and creates a slight suction effect that holds the leg on. It provides better support and stability, while allowing greater range of knee movement. One earlier design sometimes still in use is called supracondylar suspension. The socket comes up over the knee and clamps on above the joint. This design isn't used as often, because it limits knee flexion and the high trimline shows through trousers or pants.

For those active below-the knee amputees who experience some volume changes throughout the day, there is a system that creates a vacuum to suspend the socket securely. A special shock-absorbing pylon acts as a pump to draw out excess air between the liner and the socket. With each step, the pumping action has been shown to help increase normal circulation in the limb. When fitted correctly, we find this method of suspension to be ideal for those below-the-knee amputees with a mid to short limb.



## LEGS IN MOTION

We again want to emphasize that componentry is secondary. Some amputees get very excited about all the advanced hips, knees and feet. Sometimes an amputee goes looking for a mechanical miracle when the real problem is the socket. A socket has to fit accurately and be comfortable before man-made gadgetry is going to help.

Having said that, there are many components that will aid individual amputees with their special problems.

We want to touch on the main components so you have a starting place. But if there is something special you want to be able to do, like sit Indian-style on the floor or rotate the ankle for a golf swing, there is a component that will allow you to do that. However, these “extras” may add some weight to your prosthesis. If doing one particular thing is important to you, ask if there is a component that will help you do it. But realize there may be trade-offs like the additional weight and extra maintenance. A prosthetist will never be able to duplicate what God originally created, but technology is making more things possible.

When you start looking at the various components, you will find there are two major types: endoskeletal and exoskeletal. Endoskeletal means the components are inside, much like the human leg, with a cosmetic covering on the outside. The older, conventional legs were all exoskeletal – hollow inside, with the strength built into the outside wooden and plastic surface. Today, most legs are endoskeletal, but occasionally look exoskeletal because of a semi-soft covering. We’ll talk more about coverings in the section on cosmetics.

Hydraulics have played a large role in helping amputees walk more naturally. Hydraulic knees have been on the market for years, but they weren’t always popular. Their main drawbacks have always been weight and maintenance. A hydraulic cylinder is heavy, and when that heavy cylinder is put into a leg that is already heavy, the total weight becomes prohibitive. Now that the other parts of the leg – the pylon, socket and foot – are made with lightweight composites and plastics, an amputee can better tolerate the weight of a hydraulic knee. Improvements in hydraulics have also made the artificial knees more reliable.

A hydraulic knee offers cadence and gait control. When walking or

running, it makes the swing movement of the knee more fluid and natural-looking, provides more stability, and helps make walking easier. Hydraulics allow you to change your pace quickly.

Some hydraulics have a small imbedded computer. Amputees that use this type of knee often comment on how much easier it is to walk than with other hydraulic knees; they feel less tired by the end of the day. The computer provides an electronic braking aid and may give you time to catch yourself and prevent the fall. It's often a good option for patients that have the ability to walk at different speeds, but is not necessarily the best option for everyone. For some people, other knees may offer better stability depending on individual needs. Medicare and some insurance companies will cover at least a portion of the cost of this design.

There is a knee that can prevent falls – one which often is used with weaker or older patients. It is known as the weight-activated safety knee and provides an extra measure of safety by acting as a mechanical brake. A knee component commonly used is the manual locking knee, with a switch to lock and unlock the knee. It is especially good for the older person with poor balance or muscular weakness who doesn't want to take any chances with a knee that automatically flexes.

For those amputees with a very long residual limb or knee disarticulation level, a polycentric design knee will provide stability when the knee is in full extension. This knee is often used for more active people because it's easier to control. When the knee is bent however, there is little to prevent it from buckling if the wearer is applying weight at that moment.

There are a variety of other knees, but these three are the most common types. The future of lower extremity prosthetic design continues to include more and more advanced computer systems. Scott Sabolich Prosthetics and Research is currently developing a next generation ankle joint which uses an advanced microprocessor, sensor technology, and artificial intelligence to provide similar advantages to a computerized knee but in a greatly advanced nature.

As far as feet are concerned, the latest are flexible and energy storing. They offer extra cushioning and shock-absorption that make walking easier. Several feet on the market incorporate the multi-axis principle. They adjust better to uneven surfaces and are especially useful to for people who walk over rough terrain.

Another foot option is an adjustable heel-height foot. Women who have had amputations frequently ask: “Will I be able to wear high heels again?” Years ago the answer was “no,” but the latest designs in feet allow women to wear a variety of shoes, from flats to high heels. The choice is up to the individual, but you should remember that the lower the heel, the easier it is to walk with your prosthesis.

Again, these are just a few of the options in feet. We could write another book just listing all the available components. The components that we are not describing further reinforces the need for good communication with your prosthetist. During your evaluation, make sure you discuss your needs and options.

## THE SHAPE AND FORM OF THINGS

Shape and form of a leg is important to a lot of amputees. Some women want a leg to look good so they can recapture their feelings of femininity after an amputation. The size and shape of a leg is important to many men.

Some people may tell you, “Well, you’ve had a leg amputated, so you’ll just have to get used to the look of a prosthesis.” Frankly, even though our lab was able to create a leg for model Ivy Gunter that allowed her to return to her career, much research is still needed in the area of cosmetics. Sculpturing something that closely resembles a human limb is an art form. Further studies with various silicones that will improve shape, skin texture, and coloration are now becoming reality.

If cosmetic appeal is especially important to you, tell your prosthetist early in the fitting process. You need to start thinking about shape long before the covering goes on. Sometimes, you may have to choose between a small bulge in the shape and the perfect alignment of the prosthesis. It may mean a sacrifice in the way you walk if you want a more perfectly shaped leg. But it is a decision you have the right to make.

The highly-cosmetic coverings are soft, one-piece designs and can be damaged if you lead a very athletic lifestyle. That doesn’t mean you can’t go for a hike or bike ride, but if you want to run competitively or play regularly on a softball team, we recommend a hard or semi-soft, two-piece cover. It isn’t as cosmetic, but it is more durable. This cover has to be split at the knee for above-the-knee amputees, forming a two-piece covering. For that reason, it sometimes is mistaken for an exoskeletal leg even though all the components are inside the cosmetic shell. Also, the two-piece leg design tends to allow a smoother walk since there is no foam covering to interfere with knee action. Of course, many amputee athletes choose not to wear any cosmetic covering at all since it’s lighter and doesn’t inhibit knee movement. Tattoos can even be applied to your prosthesis. For men, simulated hair and veins can be added to the leg.

Many of the same cosmetic principles used for artificial legs apply for upper body prostheses as well. You will want to discuss these options with your prosthetist. It’s important to point out that even with as much as a prosthetist can do to improve the looks of an artificial limb, the prosthetic leg or arm still isn’t flesh and blood. If you have extremely high expectations

for the look of the armor leg, you may be disappointed. Computer-aided design may one day take the guesswork out of sculpting an artificial limb, but this technology is still in the early stages.

## UPPER LIMBS: REACHING FOR A NEW WORLD

The loss of an arm or hand may be more difficult to adjust to than the loss of a leg. Not only is it more visible, but the complicated function of a hand is much harder to duplicate than a leg or a foot.

The good news is that even upper extremity amputees have more options today than ever before. At one time, a hook was the only prosthesis available to someone who lost an arm or hand. Myoelectric arms more closely resemble the human arm and hand and are more cosmetically pleasing than hooks. Controlled electronically by muscle movement, myoelectrics were developed in the 1960s and are available in proportionally-controlled designs. The proportional control allows movement of the arm and hand at different speeds, depending on the amputee's muscle movement.

Early fitting is the key to successful prosthetic use for those who have lost arms, whether you choose a hook or a myoelectric arm. Going more than a few months without a prosthesis greatly reduces the amputee's success rate. Why? You mentally become one-handed, learning to do everything with the remaining hand. Then, it becomes a chore to relearn everything with a prosthesis. If you learn initially with a prosthesis, it becomes more second nature.

Early fitting with a passive hand is especially important for babies born without limbs. A baby can begin wearing a prosthesis by three to four months. Fitted after that, a child might reject the prosthesis as a foreign object and resist wearing it.

Just as with lower extremity amputations, the more joints that are removed, the harder it is for the amputee to adapt. Generally, a below-the-elbow amputee will have an easier time learning to use a prosthesis than an above-the-elbow amputee. The elbow function and the rotary movement of the shoulder are both lost when the amputation is above the elbow.

Also, if the residual limb is left excessively long – as with disarticulations at the wrist and elbow – there is a problem with the space required for the artificial joint. Often the lower forearm must be made shorter to compensate for the length after a joint is attached to the prosthesis. Shoulder disarticulation amputees have problems similar to those with hip-disarticulations – a big shoulder socket normally has to wrap around the shoulder. Recently, however, smaller shoulder cap designs have been

developed, reducing the size of the prosthetic shoulder socket.

Hooks, switch-controlled electronic arms, myoelectric arms and combinations are all available. Hooks are usually body-powered and are operated by cables attached to a harness strapped around the shoulders. Movement of the shoulder opens and closes some hooks, while others are electronically powered.

Alternatively, myoelectric arms are muscle-controlled. A small electrode in the arm socket picks up electrical signals as the muscles in the residual limb contract, which in turn triggers operation of the elbow, wrist and fingers. For instance, one muscle group initiates opening of the hand, while another group closes the hand. It takes some training and effort to learn to use the muscles that operate the arms and hands. We recommend physical and occupational therapy for most patients who have lost arms – especially for those with high level amputations, like shoulder disarticulations. It is often difficult to find a physical therapist who has experience with myoelectric arms, since these amputations are not as common. It may take some research to find an experienced therapist.

The elbow can be myoelectric or switch-controlled. Frequently, hybrid (combination) systems are used, with a switch-controlled elbow, but myoelectric wrist and fingers. Many adaptations can be made to a myoelectric prosthesis.

We prefer myoelectrics over hooks for two simple reasons: if you're going to wear an upper body prosthesis, a hand is more accepted than a hook in our society, and most things are made for the shape of hands – not hooks. With advanced technology, myoelectrics are much more functional as well. The grip of a myoelectric hand is much stronger than a hook, which usually depends on rubber bands to close it. Amputees also find they can do many things with myoelectric hands that they can't do with hooks. However, even the best myoelectric hand is only able to duplicate a small portion of what the actual human hand can do. Yet what it can do is significant and practical for a person who has lost a hand.

Frankly, hook versus hand is a center of controversy. Many physicians, prosthetists, and patients debate the issue. Some professionals are dogmatic about prescribing use of a hook, because they are used to hooks and feel myoelectric hands are too expensive and break down too frequently. While the trend is to myoelectrics, many people are able to use hooks effectively in

their work and do not want to change.

Ken Whitten, who lost both his arms, and Chuck Tiemann, who lost one, both say it's important to them not to look like "Captain Hook." For that reason, they both chose myoelectrics over hooks. Both like their myoelectric arms and hands because they look more natural – but both have gone through the frustration of breaking the mechanical arms as they tested the limits of the prostheses. Myoelectrics work well but are far from perfect. Mechanical failure is one of the drawbacks.

Upper extremity prosthetics have come a long way and are constantly being improved. But there is still much research to be done to even begin to come close to mimicking the function of a real human hand. Despite that, many people have found a great deal of success with myoelectric arms and hands. And with the right attitude, you can learn to use and accept a myoelectric armor hand as a part of your body.



## CHILD AMPUTEES

One mother says she couldn't bear to look at her new baby who was born without a leg. Another fears what family and friends will say when they see the tiny limbless infant. Yet another blames herself and is so angry that she can only sit and cry. These feelings are not uncommon, most parents are devastated when a child is born without an arm or leg. Initially, there is a lot of guilt and soul-searching. Every parent expects nothing less than a "perfect" newborn.

It is equally traumatic when a child is diagnosed with cancer or injured in an accident. A parent probably faces no greater emotional dilemma than that of deciding whether the arm or leg of a son or daughter should be amputated. In the final analysis, it may come down to amputating the limb or losing the child. And there are no easy answers. In many cases, the child handles it better than the parents.

The best advice is to realize you're not alone, and there is hope. Parents who have gone through the experience say watching their children grow up as amputees isn't nearly as bad as they originally imagined. Many times parents anticipate problems that never even materialize. The toughest part is accepting the amputation and treating a child amputee as you would any other child. Love your son or daughter with all your heart and offer the support that's needed, but don't become overindulgent just because of the loss of a limb. Coddling and spoiling will only slow the child's journey to acceptance of the amputation and deny growth of healthy, positive self-esteem.

Children who are fitted early with prosthetic limbs almost always accept them and do quite well. They run, jump, bike, participate in sports, hang out with their friends and grow up too fast – just like other kids. Generally, they learn to do most everything, even though sometimes they have to do it a little differently.

In recent years, we have developed a cosmetic and functional infant prosthesis that weighs as little as two ounces. That compares with the older prostheses which weighed two to four pounds. It's called the Oklahoma Infant Leg (OIL) and utilizes expanded polyethylene to form a one-piece, ultra-light jointed leg. It provides flexibility in the socket, as well as the joints, and is available for all amputation levels. Designed for the 3-month to

12-month age group, it is great for those early developmental stages of infancy, crawling, and later, beginning walking. The prosthesis is soft, waterproof and can be made to smell like baby powder, which seems to make acceptance of the artificial leg a little easier.

It's critical that mom and dad accept the amputation. Many parents spend years blaming and questioning themselves – wondering if they did something that resulted in the amputation. But the “why” isn't really important. The solution is what's important. Parents need to get past the self-blame and pity stage if they are going to help their child. Sometimes that means counseling. One parent says she couldn't have gotten through it without help from a child psychologist. If that's what it takes, it's certainly appropriate. By all means, find someone with whom you can talk. You can't help your child if you remain bitter about the loss. A parent who has been through the experience can be especially supportive. Ask your doctor or prosthetist for the names of parents you might call, or check out the special support groups for parents.

## WHAT ABOUT FINANCIAL COSTS?

In the midst of all the emotional trauma of amputation, you also are forced to deal with the financial picture. The cost of a prosthesis varies, depending on the level of your amputation. Generally, the higher the amputation, the greater the cost. High tech componentry, advanced designs and special technical procedures also add to the cost. The cost of an electronic arm can be significantly higher than a leg. The same consumer rules apply when you purchase a prosthesis as when you buy anything else: if someone offers you a deal that sounds too good to be true, it probably is.

When you buy a prosthesis, realize that you are purchasing both a service and a product. Just as you want to make sure an auto dealership will be able to service your car, you need to have confidence in your prosthetic service. Service is especially important, because it is not only the future service but proper fitting when you first get your prosthesis. You are paying for experience, knowledge and expertise more so than you are with your car. You'd never buy a car without asking questions, so ask questions and get the answers before you settle on a prosthesis.

The bottom line is that you want a prosthesis that is comfortable, functional and fits your lifestyle. You can take charge of your prosthetic care by understanding a few basic things. The good news is that many insurance plans, including Medicare, pay for a portion of the cost of a prosthesis. To determine what your policy will pay, contact your insurance agent or group health plan division. Ask if prosthetics are covered and if there are any limitations. Your prosthetic center may even have a financial counselor or business office that can check on your insurance coverage for you.

Most importantly, find out what type of documentation you need to submit with your claim. All insurance companies require documentation of need. Your doctor will write a prescription for your prosthesis which will be the primary source for documentation. For that reason, it is important to communicate your lifestyle needs to your doctor and make sure he understands your entire health background. For instance, a heart condition or other medical problems that necessitate regular exercise certainly would justify your need for a particular type of prosthesis. Just saying that you dream of running again will not get the insurance company to pay for a high-tech running leg. You and your doctor will want to discuss your needs

at home and on the job as a part of documenting the need for a prosthesis. Documentation from allied health professionals, like your physical therapist and perhaps your prosthetist, may also be beneficial in establishing your case for payment. You should realize that with rising health costs, insurance companies are constantly looking at cost containment, so your case of need must be well documented if you expect payment.

You may also want to find out what your avenues of appeal are if payment is denied. You are fully justified in asking “why” if your insurance company refuses payment for a portion of your prosthetic care. It may be a simple breakdown in communication of your needs. If you are covered by a group plan, ask your employer to go to bat for you. Insurance companies are highly competitive and their clients tend to have some leverage in payment of justified claims. Medicare will pay for a portion of the cost of prostheses, although benefits are restricted. Currently, benefits are available through the Veteran’s Administration but are sometimes limited.

So, what if you don’t have insurance or your insurance benefits don’t cover prosthetic care? There is still help available. Check on medical assistance through Medicaid or your state vocational rehabilitation program. In some states, medical assistance is also available through non-profit agencies or charities.

## **GRIEVING AND GETTING ON WITH LIFE**

There are no simple formulas for dealing emotionally with the loss of a limb. And there is nothing wrong with grieving. In fact, it is a healthy part of inner healing after an amputation. Everyone grieves in his or her own way. Some amputees say crying, or even screaming at the top of their lungs, helps release a lot of anger and frustration that accompanies tragedy.

Grief and denial are very natural first steps for an amputee. Acknowledging the grief and anger is important as you begin the journey to acceptance of the amputation. And again, it all boils down to acceptance. You need to admit to yourself that you have suffered a loss and that it is painful. Grieve over the loss. Then, put it behind you. Look toward the future with hope, but live in today.

How you feel about yourself should be controlled by only one person – you. Don't let a stubborn sense of pride stand in your way, and don't let someone else's yardstick of success measure your life or sense of self-worth. Sometimes we are too self-critical and try to measure up to someone else's definition of what we "ought" to be, which can be self-defeating. More so than at any other time in your life, you need to learn now to value yourself for who you are – and never forget that you are okay just the way you are.

Don't be surprised if just when you think you're getting a grip on the situation, you suffer a set-back or two. During your hospital stay, where a round-the-clock staff serves your needs, you may be lulled into a false sense of independence. Things seem easier then. Many amputees report that returning home is a real shock when they suddenly discover their house and previous way of living doesn't necessarily fit the lifestyle of an amputee. You may have a two-story house, your bathroom may not be arranged so you can maneuver easily, and even getting up out of that easy chair to go to the kitchen may now seem like an enormous task. But it's nothing you can't manage with time. Remember, time is your ally – emotionally and physically you are going to get better with time.

You may face depression and anxiety over the changes you need to make in your life. You may feel like your life is out of control. There may be a feeling of helplessness and even shame over your new physical appearance. That's all very common. You may need counseling. Despair or extended depression can lead to thoughts of suicide in some cases. Don't wait until

then to get help. Every amputee needs someone to talk to, and some may need a professional counselor, therapist or pastor.

You should understand that the changes an amputee goes through also affect the family, so family members may find professional counseling helpful as well. You needn't be ashamed of that.

Family members can provide a real source of strength and support for an amputee or, unfortunately, they can add to the struggles, making the person psychologically, physically and emotionally dependent. Caring family members may try to do everything for the amputee, not realizing they set the stage for the person to feel like – and become – an invalid. The most important ingredient to family readjustment is communication. Take time to talk about the amputation with your loved ones; share your feelings, as well as hopes and dreams. It may help to have one or two particularly supportive members of the family involved in discussions with your doctor and prosthetist.

And what about talking to your children about your amputation? Some parents are hesitant, but some go overboard trying to explain what has happened. It's important to remember to give children "age-appropriate" information. You don't want to scare them so that they have nightmares. On the other hand, you want to give them enough information that they aren't afraid they're going to lose you. Talk to them as you would about other things happening in your life. Answer their questions. But most importantly, don't let your amputation stop you from enjoying those special moments together.

Amputation is a life-changing experience. Some people are better equipped to deal with it than others, just as some people are better able to deal with the death of a loved one or close friend. In fact, some amputees compare the grief that you go through after an amputation with the death of a close friend or relative. It can be very traumatic, and you may experience a roller coaster of emotions.

One of the keys to getting back into life after amputation is to put things in perspective and deal with one thing at a time. There's no need to feel like you have to be perfect at every task. Again, don't be so critical of yourself. You don't have to be bigger than life to be a success just because you are an amputee. Enjoy the successes – no matter how small – and don't dwell on the setbacks. If you constantly feel you have to "prove" yourself, you'll only

end up adding additional unnecessary stress to your life. And who needs that? Such an outlook on life will be frustrating and difficult for you, as well as for those around you. Remember, the goal is to make steady progress – not to do everything perfectly. It is a continuing process. You can't turn everything around in five minutes, five days or even five months. Give yourself some time.

You need to look at the amputation not as an end to life, but the beginning of a new stage in life. Sure, there will be changes, but those changes need not all be negative. Many amputees report discovery of a greater enjoyment and appreciation of life after an amputation – along with a greater appreciation for many things people take for granted. Why? Rather than focusing on the “I can'ts,” they choose to embrace the possibilities of all that life has to offer.

For some people, the road to acceptance leads them on a spiritual journey that puts them much more in touch with what life is all about. We've found that amputees who are firmly grounded in a spiritual faith seem to do better and adjust more quickly. With God as a companion, they don't seem to experience that deep sense of “aloneness” that some other amputees struggle with. Their personal faith sustains and strengthens them through the toughest hours.

Some amputees do not speak directly of God, but they admit their survival and success hinges on calling upon an indescribable inner strength which each person possesses. Those who call upon that inner strength, whether or not they connect it with God, tend to be highly motivated and committed to making life as an amputee happy and fulfilling. The journey of each amputee is similar, but no two are the same. Only you can ultimately decide which the direction in which you will travel.

As an amputee, you can do most anything you did before, although you may not do it exactly the same way. There's usually no need to give up driving, working, dating, sports, hobbies or recreational activities just because you are an amputee. Decide what you want to do and try it. Sometimes you may have to force yourself to get back into an activity. You may be self-conscious about being an amputee, especially at first. But how you approach an activity will influence how others respond to you. In other words, should you decide to live like an invalid, people will tend to treat you that way. If you decide to live with amputation as one of life's challenges,

people will most likely treat you as they always did. Only you can determine when you will put self-pity aside and move ahead. To some amputees the word “depression” is only another word for “self-pity.” That may sound harsh at first, but self-pity only turns you inward, thinking of “poor me,” and that leads to depression. It can be a vicious cycle. You have to get out of that cycle – focus on something larger than yourself. Being depressed and feeling sorry for yourself won’t change the fact that you are an amputee. But wallowing in pity will certainly cripple you for life.

“The key is that in my own mind I don’t set myself apart from everyone else,” says one amputee. She simply doesn’t put herself in the “amputee category” but sees herself as a whole person. Developing that confidence and positive self-esteem is not something that just happens a week, a month or even a year after an amputation. For some people, it comes quite easily, but most of us have to work at it and cultivate it.

Self-confidence and a sense of wholeness is not dependent on the fact that you wear a prosthesis. Naturally, we see more people who wear artificial limbs, but some amputees choose not to – more often those who have lost arms than legs. Those people still have full, rich lives and find wholeness without limbs. What feels comfortable for one amputee may not be right for another. To many people, a prosthesis becomes like a part of the body. It’s incorporated into the self-image, and the amputee doesn’t want to be without it. Whatever the choice – with or without a prosthesis – it does not make an amputee any more or less whole as a human being.

As you work on confidence and feelings of self-worth, you may find valuable information and new friends through an amputee support group. Such support groups are growing across the nation. Even if there isn’t one in your community, the various groups have newsletters and can give you names of other amputees to call. But your total support group need not be confined to amputees. Counselors often tell people who are having difficulty facing any life change that they should get involved. You can find new friends through church or community organizations. Some people have discovered volunteer work – an opportunity to help someone else – is a step toward personal healing. As they help others in need, they also help themselves to heal emotionally.

You may be hesitant to take the risk to make new acquaintances at first, especially if you are looking for a dating relationship. But again, if you can



relax and be yourself, most likely others will accept you as you are.

We've talked with many amputees who are bothered by people who stare at them. How do you deal with that? We think you have to realize that people have a natural curiosity about anything or anybody that is different. They aren't necessarily staring because they find you ugly. After all, aren't you inclined to take that second glance if you see someone who is taller, shorter or more beautiful than the norm? If people have questions, you can provide honest answers. Why not educate them a little? You have a wealth of knowledge to share. If you feel at ease with yourself, they likely will feel at ease also.

If a relationship or friendship fails, it's not going to be just because you are an amputee. Don't take it personally . . . look at the fact that these things happen every day to all of us. You may meet the occasional rude character who is so biased he can't accept anyone who is different, but chalk that person up as narrow-minded – like you would if you weren't an amputee – and go on. On the other hand, don't use amputation as a scapegoat. It may be easy to blame shortcomings, whether in a relationship or at a job, on the fact you are an amputee. You'll only be cheating yourself.

So what about male/female relationships? Invariably, amputees have questions about sexual intimacy. Normally, there is no physical reason for avoiding an intimate relationship. If you are married or have been in a long-term relationship, most amputees say the answer is communication with your partner. One amputee said she struggled with the fact that she and her husband began to develop more of a brother-sister relationship, avoiding intimacy after her amputation. It was a matter of communicating. Her husband was simply afraid he might hurt her residual limb. Often for women, this is a time when they must re-establish those feelings of femininity, while men want to prove that they are still masculine.

Amputee Ivy Gunter admits her initial reaction was to ignore her residual limb. "It took me almost a year to stand in front of a full-length mirror," she adds. Those kinds of feelings can translate into fear of what your mate or companion will feel and make you question whether you will ever again be sexually attractive. "When I first lost my leg, it was all so new. My first thought was that my husband Don would leave...that the physical appearance of a wife with one leg would simply be too much for him and that he might leave me," says Ivy. "My presentation into the bedroom

changed from the allure of slinking in dressed in a Christian Dior gown, to wheeling into the room in my wheelchair, crutching in, hopping – or even crawling in. I was determined to regain the sensuality and sexuality that I once had.” Sensuality and sexuality are sensitive subjects – and it may take some time for you to work through your feelings. Try to be honest and open with yourself, as well as with your mate.

What about children? Many female amputees are concerned about pregnancy. One may wonder if she can even get pregnant, while another has doubts about carrying a child to full term. In most cases, an amputation should have nothing to do with whether you can have children. Of course, pregnancy means additional weight and volume changes. It may necessitate prosthetic socket changes, but most women continue to wear their prostheses throughout pregnancy.

Returning to work may or may not be a traumatic experience, depending on what type of work you do. Many amputees find a whole new support group among their peers at work. If you have to find a new job, you may have feelings of self-doubt rekindled when you have to include on a job application that you are an amputee. Don't let that deter your ambition. If you are qualified for the job, go after it.

Other than job applications, you are not obliged to announce to everyone you work with that you are an amputee. One patient said a co-worker never knew she was an amputee. He noticed she limped occasionally but thought it was just an injured knee or something. Even when people ask about your leg or arm, you are not compelled to go into a complete medical history. An elaborate explanation isn't always necessary. Again, your attitude will affect those around you and how they respond to you. If you do decide to share your story, many times people gain a new respect for you – that in spite of an amputation, you have persevered and overcome many hurdles.

We have found that amputees have had such defining experiences that their maturity levels far exceed those of able-bodied persons the same age. Having dealt with amputation has so defined their characters and broadened their perspectives of themselves and others that we want to “grow” in the same way they have. We want to share time with them and be with them, and we think other people feel the same way. Amputation is not a drawback; it can be an advantage in relationships.

Regardless of what happens in our lives, we are learning that the only

person you can really change is yourself. Developing a positive attitude means putting the loss of a limb in perspective – looking at it alongside all the other things that are important to you. Put your life in perspective and focus on what you can do, instead of what you can't do. It's good advice for amputees, as well as the rest of us. Learning to accept our strengths and weaknesses, while cultivating a positive self-concept, is a long road for many people. But that is exactly what many of the amputees in *You're Not Alone* have struggled with. They have courageously shared their intimate journeys in their stories, and we hope you will take time to read each of them.

We encourage you to first select stories about people with amputations similar to yours, but don't forget to read the others for additional advice from amputees who have been through it all – the feelings, the frustrations, and the struggles mixed with success, the changes and the journey to new life. Each amputee has a special wisdom and insight to share that will help you cope, stretch, grow – become.

**KEN WHITTEN, 40**

## **It's a Two-Handed World**

*He was working for a power company when a bizarre accident sent thousands of volts of electricity pulsating through his body. The electrocution forced amputation of the right arm below-the-elbow and left arm above-the-elbow.*

*He became one of the first to wear two myoelectric arms.*



Ken Whitten

The day was strange from the start. I was chief of the underground crew for Duncan Oklahoma Power and Light. But that October day, the company was pulling new overhead lines from one of the power substations. They asked our underground crew to help the overhead crew.

The foreman went over the details of the job. I spent much of the morning at the trailer where we unrolled the large spool of wire that was to be strung. We worked several hours and stopped for a short coffee break. Afterward, we had to splice one of the lines, but the line had to be hung so that the splice was not over the roadway. Since I had more climbing experience, I volunteered to climb the pole to pull the splice down.

I didn't know the safety guards had slipped or that the line was carrying 7620 volts of electricity. All of the lines were supposed to be dead.

I grabbed the line. I don't recall feeling anything. The next thing I remember was awaking on the road as crew members went through rescue procedures. I drifted in and out of consciousness as the helicopter flew me to the hospital at Duncan.

Emergency room doctors had to cut off my work gloves. I remember looking at my hands. I didn't think they looked so bad. They packed them in ice. I talked briefly with my supervisor. The next thing I knew, I was on a chopper headed for Baptist Burn Center in Oklahoma City. I heard someone say the flight would take 30 to 40 minutes. Then, I was out.

At the burn center, they placed me on a gurney and rolled me into a room with a big bathtub. They stripped off my clothes. It was embarrassing. I asked for a towel to cover myself as 10 to 15 doctors and nurses stood looking at me.

Later, I awoke in the intensive care unit. The doctors told me I had to make a decision. They wanted to cut off my hands. They told me gangrene would set in if they didn't. "Well, take them off," I told them, as I fell back asleep. I wasn't thinking about losing my hands then, but about pulling through...about staying alive. I don't remember waking again until after the operation.

My wife Alicia had to make arrangements for the surgery. I don't know how long it was before I awoke again in ICU. I was thirsty. I reached out to grab a glass of ice water on my bedside table. I couldn't do it. My hands were

gone. I couldn't even get a drink of water. It made me mad, and I started to cry.

I wasn't bitter or mad at any particular person, but I wanted to know what happened. As I asked questions about the accident, they told me my friend Carl was dead. The accident that had left me with no hands had taken Carl's life. He was only four poles away from me at the time – at the trailer where I had been only shortly before the accident.

The doctors kept me on a high-powered painkiller. Most of the time, I only felt the pressure of the swollen limbs. I had a lot of what they told me were phantom sensations. I'd think my hands were there – I'd reach out for everything, but I couldn't grasp anything. The only real pain I remember was when they cleaned the wounds and cut away the dead skin. Then, they can't give you enough medication to take the pain away.

I was in the hospital 36 days. As the days wore on, I began to realize the number of things I could no longer do for myself...things I had to ask others to do for me. Little things, like dab my runny nose. Or, when I went to the bathroom and I had to ring for the nurse to wipe me. It was humiliating. It's those little things that people don't think about that really bother you.

A psychologist visited me, wanting to talk about the accident and what I was feeling. I was stubborn. I didn't much want to talk to him. He kept asking me how I felt about losing my arms. I was upset – what did he want me to say? I had friends who came to talk with me. I didn't want to talk about the accident with a stranger.

I wasn't at all sure how my three kids were going to react. They hadn't seen me since the accident, so Alicia was going to bring them to the hospital. I didn't know what I would do or say. I just kept thinking about how my boy loved baseball. How was I going to play ball with him? How was I going to do all the things with the kids that I used to? When they arrived, I met them at the door. The three of them ran and gave me big hugs. I cried. All they cared about was that I was up and walking and they could see me again. They knew Carl was dead.

Of course like all kids, they were curious. My three-year-old daughter wanted to know how long it would be until my hands grew back. But I think by the time they left the hospital, they were satisfied that I was going to be okay.

Sometime during the second week of my hospital stay, an occupational

therapist made me a cuff to go on my arm. With it, I was able to eat and brush my teeth. As I felt better, I began to feel cooped up. I worked out in the hospital weight room, using weights on my legs. The doctors weren't too keen on that idea, however.

I didn't think too much about artificial limbs. No one talked about prostheses. Frankly, as I lay there in the hospital bed, my biggest concern was that while I was there and away from my job, the bills were piling up. How was I going to pay for all this?

In the mean time, a lot of my friends were researching what was available for me in the world of prosthetics. During my third week in the hospital, a prosthetist paid me a visit. We discussed the options of myoelectric arms or hooks. Few people in the United States had ever worn two myoelectric arms, and everyone kept telling me it would be too hard. They said I'd be too confused because the arm muscles make the hands work, and it would be hard to work two arms. They kept telling me I needed at least one hook.

But there really wasn't anyone around who had experienced what I was going through. No one could tell me what it was going to be like...how I could function without hands...or how I could go back to work. Few people have lost both hands. One amputee who had lost one arm came to see me, but his visits only depressed me. He had a myoelectric arm, but he wasn't very encouraging. When I got out of the hospital, I wanted to be able to do everything I'd done before. He just wanted to sit in an office and do paperwork.

The real test came when I was allowed to leave the hospital for Thanksgiving. It all hit me then. I was faced with the reality of life with out my hands. All the family was gathered at our home for the holiday dinner. I had my cuff, but Alicia still had to cut my meat and help feed me. It was tough being around all the family...kind of embarrassing. I wanted to be back to normal and do everything I always did. There were things I wanted to get done around the house, but I couldn't. It was so frustrating. My hands had quit, but my brain hadn't stopped. I couldn't take it – I wanted to go back to the hospital.

Three or four days before I was to be permanently dismissed from the hospital, the doctors discovered the muscle in my lower left arm didn't function. For weeks, they had been finding dead tissue. They re-amputated the left arm at the elbow. Little did I know it would be the first of several

surgeries, including a bone spur operation and a revision surgery that would allow room for a myoelectric elbow. I ended up with the left arm amputated above the elbow and the right arm below the elbow. I began to think the amputations would never end.

It was tough leaving the hospital. While I was there, the nurses did everything for me. I knew from my experience at Thanksgiving that things weren't going to be as easy at home. One of the first things I did when I got home was go out to the barn. In addition to my job at the power company, I farmed. I just walked and walked around the barn. I thought about all the things that needed to be done ... all the things I couldn't do. One day I tried wearing a hook. As I gazed at my shadow against the barn door, it looked like a huge dagger. That was all for the hook.

I was determined this was not going to get the best of me. Within two weeks, I was driving the car. I'd just put my arms in the steering wheel and go. I wanted to see how people were going to react. I wanted to get back into circulation. All along, I knew I'd go back to work. I wanted to work so something like this didn't happen to anyone else.

It was July of the following year when I got my first temporary prosthesis on my right arm, but it was February before all the surgeries were complete and I had two working myoelectric arms. Just getting two new prosthetic arms couldn't solve all my problems though. It takes a lot of muscle control to use the arms, and it takes a lot of practice. I remember sitting for hours picking up potato chips with my new hands or crushing soda cans. I'd have Alicia toss dimes on the table, and I'd try to pick them up. I wanted to see what I could do.

Some things I learned easily, like writing. Other things took a lot more patience...patience I didn't have. I remember standing in the barn several times and getting so mad I thought I was going to go crazy. I'd be trying to do something simple like fix the lawn mower. All I needed to do was turn the screwdriver, but I couldn't do it with my immobile prosthetic wrists. Then, I'd be doing something else and a hand would break. Or, I'd fire up the chain saw and it would interfere with the battery-operated hands. One day, I got so mad I beat the arm against the barn wall. This is a two-handed world. Everything is built for the human hand.

Why...why did this happen to me? Why didn't I get to die? Why was I left on earth to survive with something less than I came in with? I didn't



understand why it all happened to me. At the same time, I'd always preached to the kids not to give up. How could I show them not to give up? How could I live what I preached?

Then one day I pulled into the parking lot at the doctor's office. A lady with a walker was struggling to get out of her car, so I went to help her. I was wearing a long-sleeved shirt, so it wasn't until we reached the office door that she noticed something wrong with my arms. "Oh, I see you've got problems, too," she said. I guess I realized then that I could still help someone else.

Even if you can do things for yourself, it doesn't stop other people from assuming you can't. I still had my job at the power company, but it was a fight to get them to let me go back to work because of the company's insurance firm. I had been classified as 100 percent disabled. First, they didn't understand why I was going back to work. When I convinced them I was going to work, they insisted on a driver's license that said I was disabled. I went to the highway patrol station to get the license changed. After driving with me, the officer wanted to know why I was even there, because I did everything correctly. The only restrictions on the new license were turn signals on the steering column and I have to wear both arms when driving.

It's those little things that degrade people who have lost limbs and keep them from going back into society to work. After the accident, I went back to work doing what I'd always done, except I didn't climb poles. Since my boss retired, I'm now foreman. When I wear long-sleeved shirts or jackets, most people don't notice the artificial arms unless they hear the battery-operated hands move. When I wear short sleeves, people are amazed that the myoelectric arms look so real. Of course, kids ask lots of questions, especially when I coach baseball or go camping with the scouts.

What I missed most after I lost my hands was feeling my kids when I picked them up. I'd lift them up for a hug, but I couldn't feel them in my hands. I miss the softness of my little girl's skin and being able to touch my wife at night. But my family has supported me through it all. I don't know how I would have made it without Alicia. Just after the accident, doctors told me stories about other burn patients whose wives couldn't handle their amputations and left them. I worried whether Alicia would want to stick with me, but she has always been there for me. My main regret is that I still have to depend on her for a lot of things.

It bothers me that while I'm my own person during the day when I have my arms on, I'm always dependent on my wife to help me in and out of my arms. The arms have to be pulled on with socket socks, so I can't get them on by myself.

When I'm wearing my arms, I feel like a whole person. I look in the mirror, and I look normal. But at night when I'm walking around the house without my arms, and I catch a glimpse of myself in the mirror, I always complain to Alicia how different I look. I just want to look normal.

I may never come to grips with having someone help me do things that I used to be able to do myself. I still want to be able to do everything, and every day is a new challenge. I work with my prosthetist a lot, and so far, he's been able to make changes in the arms and hands to help me do whatever I wanted to try. From the beginning, he worked very closely with my doctors on the revision surgery to make sure I'd be able to get the best use of the myoelectric arms. He added a ball joint at my wrist so I can scratch my ear or comb my hair. I think he likes the challenge, too, and both of us want to see how far we can go to improve the arms and, therefore improve my way of life.

LAURA MCCLURE, 20

## Meet My Friend Sam

*It seemed like a simple sprained knee, but it didn't get better. The diagnosis: cancer. At age 14, her right leg was amputated above the knee and she suffered the dehumanizing effects of chemotherapy. Yet out of tragedy grew not only a desire to run but a new passion for life.*



Laura McClure

I'd like you to meet Sam. We were first introduced when I was a teenager. Sam is my artificial leg. I was 14 and a freshman in high school in Waverly, Tennessee. I started at a new school that year, so I had lots of new friends. I even had a boyfriend.

I was in gym class when I fell against the bleachers and sprained my knee. It hurt, and after two weeks, it wasn't getting any better. My father was a physician, so he heard all my complaints, but he didn't seem too concerned.

As time passed, my knee got worse. It began to give out when I was walking, and I couldn't walk up steps. My dad decided to take me to the hospital for X-rays. Not that he was too concerned about it...it was more to pacify me.

He looked at the X-rays, shrugged his shoulders and tried to convince me it didn't look like anything serious. But that night when he called a friend of his who was an orthopedic doctor in Nashville, I realized just how concerned he was. It was 9 p.m. on a Sunday when Dad said he wanted me to see the doctor the following morning.

Something wasn't right. I called my best friend Mary Anne and told her I was afraid something was really wrong with my leg. My dad didn't call friends in the middle of the night to make doctors' appointments.

The next day, I went to Nashville to the doctor. He did a few more X-rays and poked around on my knee. When he was finished, he said it was nothing to worry about. He gave it some name I could never pronounce or remember, and told me it would go away with time.

But as I was getting dressed, he came back to the examining room. He asked if he could make just one more X-ray...maybe get another opinion from another doctor. That afternoon, he told me I might have a tumor in my leg.

I really didn't know what that meant. He said there was a 10 percent chance that the tumor might be malignant. At the time, I didn't even know what malignant meant. When I questioned him, he said there was a slight chance I had cancer. Cancer! I thought that was something only old people got. The doctor said it was a slim chance I had cancer and he didn't seem overly concerned.

But the next day I found myself on a plane to the Mayo Clinic in Minnesota. Mayo is a 14-floor hospital. I think I saw every floor in three days. I didn't feel comfortable there. The doctors were all strangers and they

did about a dozen more X-rays.

I ended up in a tiny waiting room...waiting for the diagnosis. The doctor came in...sat down...and waited several minutes before saying anything. I remember watching my father's expression. The doctor looked straight at me. "You've been diagnosed with osteogenic sarcoma, a malignant bone tumor," he said. The diagnosis would need to be confirmed by a biopsy. If it proved malignant, he wanted to amputate my leg above the knee.

I'd never felt like that before. I started to cry. I saw tears running down my father's face. I never would have thought the cure for cancer would be amputating your leg. I thought that was inhumane...something cruel. I thought people lost their legs in car accidents. This couldn't possibly be a cure for a disease. Amputation. It sounded more like a disease than a cure.

We didn't do the biopsy in Minnesota. We returned home and went to Memphis. My father decided the biopsy would be done there, and if the amputation had to be done, it would be done there also.

A couple of weeks went by. It was December 17, and my Christmas present was a biopsy the next day. As I sat in the hospital, I wondered if I'd have one or two legs the next day...and how many friends I'd have left. I was sure I wouldn't have a boyfriend anymore. My friends stopped by the hospital, but they didn't seem to know what to say to me. I think that hurt worse than anything. They weren't trying to be mean, but they didn't know what to say.

The next morning when I returned from surgery, I remember the orderly lifting me into bed. "I still have two legs, I can feel them," I thought to myself.

"They didn't amputate my leg," I told my mother. "Yes, honey ...they did," she said. She was wrong. I didn't believe her...not until she pulled the covers back and let me feel. I reached down and I felt around my thigh. To my horror, as I felt farther, there was nothing – just an empty space where my leg had been.

The following day, a very pretty lady entered my hospital room. She was pushing a wheelchair and carrying a metal pipe with a size 10 mannequin foot attached. "My God, I hope that's not my leg," I thought. I hadn't thought much about what they'd give me to replace what they took.

"This is your training leg," the lady said, smiling. She explained that she was the physical therapist and was going to teach me how to walk on crutches and use the training leg. I thought she was crazy, but she finally

talked me into getting into the wheelchair.

She wheeled me to the physical therapy room. “This can be very easy or very difficult, depending on how much work you want to do,” she said. “You can feel sorry for yourself and stay in a wheelchair, or you can go on with the life you were living if you do what I say.”

In a day, I learned how to stand again. She attached the metal pipe to my cast. She taught me how to drag the pipe and foot along and walk between the parallel bars. I was excited. I was even more excited when she taught me how to walk with crutches.

A week later I left the hospital with my metal pipe, mannequin foot and crutches. I had learned how to unlock the knee, making it work like a real knee. I was in good spirits.

My friends were at my home to greet me. They still didn’t know what to say, but that was all right because they were talking and happy to see me. Even my boyfriend was there. He kissed me on the cheek and told me it didn’t matter...he liked the size 10 foot.

Christmas passed, and I thought the worst was over. But when January arrived, I went to St. Jude’s Children’s Research Center in Memphis. It is a hospital for children with cancer. I didn’t know the doctors wanted to do anything besides amputate my leg. I thought I was cured because the part of my leg with the cancer was gone. Was I wrong!

We were in another little waiting room. I knew something bad was going to happen. The doctor said I ran the risk of still having cancer cells in my body – cells that wouldn’t necessarily show up on an X-ray. He wanted me to begin a 44-week, experimental chemotherapy program as soon as possible. He explained the side effects of the chemotherapy...nausea, diarrhea, mouth ulcers...none of it sounded good. Then, he mentioned I’d lose my hair. Lose my hair! No way. I fought it tooth and nail – I didn’t want to take chemotherapy.

After the first treatment, my fever shot up to 104 degrees. I didn’t get out of bed for four days. It felt like the double flu. Gradually, I felt better. But as I ran my hand through my hair, it fell out by the handful. I think losing my hair was the most dehumanizing thing that happened to me. Not only did I have an artificial leg with a mannequin foot, now I was bald. I was beginning to feel like I was no longer a real person. Everything in the hospital was sterile. They didn’t let me have flowers and I couldn’t even keep my stuffed

animals with me.

While I was confined to the hospital, I continued physical therapy. There were times I didn't feel like being out of bed. But there were other kids there who were amputees and had cancer. We all walked around with our I.V. poles, the chemotherapy rushing through our veins. It's hard to describe what went on, how we all got through it. Some people probably would think it was sick humor. We had races in the halls, pushing our I.V. poles as we went. We made bets on how many times we'd fall. We also bet on who could go the longest without throwing up from the chemotherapy.

We made it as fun as possible. Everyone's leg had a name. I named mine Sam. We were afraid to look at things from the serious side. We might not make it. We took one day at a time...one step at a time.

I finally made it through chemotherapy. And I had my new artificial leg with a soft, sculptured cover. From across the room, it looked really nice. I could wear skirts, and when I put on blue jeans, my leg had a shape again. It made me feel like a girl again. I felt feminine.

But getting a leg that fit well was a problem. It was a tedious process. They'd fix one thing, and something else would be wrong. I'd walk, and it would rub blisters. It hurt. I felt like the leg was the only thing holding me back...the only thing keeping me from getting on with my life. The prosthetist would work on the leg, but nothing seemed to help.

I told my parents I wasn't going to wear an artificial leg anymore. It was easier to get around on crutches. They were really upset. My father started searching for someone who might be able to fit me with a leg. He found a prosthetist in the middle of nowhere...Oklahoma! The prosthetist had made legs for Ted Kennedy, Jr., and a fashion model named Ivy. I decided to give it one more shot.

The fitting took a couple of weeks in Oklahoma. I still had blisters at first. There were minor problems, but I went home with a leg I could walk on. I learned how to tighten my leg muscles so I didn't limp so badly. I started wearing shorts even in the public malls. People still knew I had an artificial leg, but it looked nice. I walked with less of a limp and didn't feel as self-conscious as before. I realized when I didn't feel self-conscious, others didn't feel self-conscious about talking to me.

I'd worn the leg for a year when I told my father that I wanted to learn to run. My first prosthetist had told me to tone down my expectations...they

were too high. He told me I'd never run, only sort of hop. But I went back to my new prosthetist for a leg that would let me run – a leg I could climb trees and fall off a bike with. The indestructible leg is what I wanted.

He built me one, but it wasn't very pretty...with a leather cover and hard foam. It had a hole in the back where you could see the three-inch knee unit. The prosthetist took me to the park as soon as it was built. He was holding my hand and walking beside me...walking faster and faster until I could no longer keep up. He kept pulling me along. I started to fall, but I caught myself and kept on. Suddenly, I realized I wasn't walking...I was running. I'll never forget what it felt like to run again after more than two years.

I had met another amputee who told me about athletic competitions for persons with disabilities, so I began training. I'd never run competitively before, but I signed up for the 100-meter dash in the U.S. Amputee Nationals. I did well enough to land a spot on an international team. Being an athlete became an important part of my life. We traveled to Australia, England and Canada to compete. I usually competed with other above-the-knee amputees. Occasionally, I'd end up in a race with someone who had lost a leg below-the-knee, which can be pretty discouraging since an above-the-knee amputee can never run as fast or as far as a below-the-knee amputee.

I practiced and trained. I think I inspired others. And others inspired me. My goal was to learn to do everything for myself. I was selected to go to Seoul, Korea, for the U.S. Disabled Olympics as a sprint runner. Those 25 seconds it took to get down the track in Korea in front of 10,000 people were the biggest moments in my life. The run was also my greatest accomplishment. I ran my personal best time, but I didn't come in first. I beat a few people...a few beat me. But what was important was that I made it there.

After that, I knew I could do anything. My senior year in high school, I was an athletic trainer for the football team and was in lots of extracurricular activities. I did everything I think I would have done had I not lost my leg and then some. Life meant more to me. I'd had to fight so hard to do everyday things...to be an everyday person. I knew when I graduated from high school and was accepted at college, I'd be okay. I'd battled cancer, and I'd be all right.

That doesn't mean there weren't struggles. There are still struggles. There



are days when my artificial leg doesn't quite fit. When it fits, I'm on top of the world. I think the hardest thing about having an artificial leg is fear... fear that people won't like me or will think of me as disabled. I think because I lost my leg, I want to be more than I ever wanted to be.

As a college junior, I still have some of the same fears, but I'm learning some of them are unfounded. I used to think no guy would ever think I was pretty and that I'd never have a serious relationship because guys would think I'd be a burden. That simply isn't true. My boyfriend and I have a strong relationship. Without him, I don't think my confidence level would be where it is.

I met my boyfriend after track practice my freshman year. I was wearing a leg that looked a good deal like that metal pipe that so horrified me when I first had my leg amputated. It's a high-tech leg without a cover. I like it so much; I wear it everywhere.

My boyfriend tells me to this day that one of the most attractive things about me was my willingness to accept what had happened to me...to make it a part of my life, but not a problem in my life. He's one of the most supportive people in my life. He and my best girlfriend won't let me sit on my rear and give up on doing a task they think I can do. But my boyfriend is also there to put his arms around me when he realizes I've run into a wall and hit my limitations.

Yes, there are limitations, even though I choose not to focus on them. I don't have the same endurance I once did. I can't run as fast as I would with a real leg. Sometimes, I still get blisters or I lose my balance. But I look at it from the perspective that everybody has bad days. Everyone sits down and cries once in a while. And that's okay. My bad days may be because something went wrong with my artificial leg...or one too many people stared at me at the mall. Those are the times when I need that friend to say, "Hey, get back up! There are a lot of people worse off than you." That's what my boyfriend and best girlfriend do for me.

The most frustrating part of being an amputee is having your leg worked on. You have to learn to communicate with your prosthetist. Even at that, your leg isn't always going to fit correctly, particularly if you lose weight like I did. Most college freshmen gain 15 pounds, but I lost 15 pounds. When I did, my leg literally fell off. It's taken time to get the leg to fit again because I lost a lot of muscle volume, changing the shape of the leg. It was like starting

over. My prosthetist and I screamed at each other and probably would have thrown things had something been handy. But we kept at it, kept trying. Eventually, things like that work out, but they don't work out on their own. You get them worked out only if you're willing to work at it.

If I could take all the knowledge I've gained, all the friends I've made, all the places I've been and trade it back in for my leg...no, I wouldn't do it. I've gained an appreciation and love for life...a passion to live, to be happy and be the best I can. I often

think, "What would I tell someone who is going to become an amputee?" Someone once told me to do the best I could despite the fact that I lost a leg. But I think that attitude sells you short. I believe you can do anything you want to do, keeping in mind you may have to do it a little differently, or it may take a little longer. But once you learn how, it will mean more to you.

Perhaps most importantly, you have to really get to know your artificial leg. Sam and I get along great. We've developed quite a relationship over the years. Someone with all their limbs might not understand when I say that Sam is my friend. But how can he not be? We're together all the time – he's a part of me!

**MIKE ROBERTS, 28**

## **Jerk Is a Four-Letter Word**

*Struck by a car while attempting to fix a flat tire, both his legs were amputated above the knee. As a 21-year-old amputee, he questioned his masculinity as he suffered severe depression. But after grieving the loss of his limbs, he discovered that there's something worse than being an amputee.*



Mike Roberts

It was a typical autumn day in September. Or at least so I thought. I had driven to Baltimore that weekend to visit family and was returning home to Washington, D.C. I didn't know what lay ahead on that road...or that I would spend the first of many nights in the hospital as I began a long road to physical and emotional recovery.

As I headed into D.C., I was about five miles from my apartment when I came upon road construction where two lanes of the interstate were being repaved. I struck an object in the road and ended up with a flat tire. I got out to change the tire. I was standing at the rear of my car with a spare tire when I was struck by another vehicle. I was crushed between the two cars, my legs partially amputated.

I don't remember the actual collision. My first recollection is of the emergency room. It was the strangest feeling I believe I've ever had. It was almost like a dream. I knew I was talking to doctors and nurses – but it never registered that since I was talking to them, I was in a hospital. The nurses asked my name, address, and phone number. Just before I slipped into unconsciousness, they asked me to move my legs. I remember trying with all my might to move my legs, but they wouldn't move no matter how hard I tried. Then I was out.

Suddenly, I was awakened by a doctor who was physically shaking me. He introduced himself and said I was at an emergency room in a hospital near Washington, D.C., because I'd been in an automobile accident. Then he said they would have to amputate both my legs or I'd be dead by morning.

I can remember thinking, "Wow, I don't remember what happened, but I'm in real bad shape." He shoved a consent form in front of my face and I made a lazy attempt to sign it. I realized then that I was going to be an amputee, but it was a choice of losing my legs or my life. "Okay, let's just get this over with," I told the doctor.

I awoke the next morning in intensive care. What an experience! I was 21 and had never been in a hospital before...now I had every machine known to man attached to my body. It was overwhelming.

I remembered the conversation with the doctor. As I looked down toward the foot of the bed, the blood-soaked sheets were a vivid reminder that I was now an amputee. The doctors had a tough time trying to keep blood in me. It ran out about as fast as they pumped it in. As I looked to my left and then to my right, there were intravenous lines on both sides. I had all kinds of

electrodes, monitors and hoses. I drifted back to sleep.

It wasn't long until I was rudely awakened. I had accidentally disconnected a heart electrode. An alarm sent a rush of nurses bursting into my room to check me. It really scared me because I hadn't realized my physical condition was so fragile. For the first time I remember thinking I might die. After four days, I was moved to the orthopedic floor to begin what would be the toughest weeks of my life. At that point, I wasn't too worried about not having legs. I was in such intense pain that I just wanted my body to heal. The pain was so gripping that I recall lying in bed, trembling as if I had the chills. A nurse would give me a shot of pain killer and I'd sleep for a few hours.

The doctor said I'd spend six to eight weeks in orthopedics if there were no other complications. "What was he talking about?" I thought to myself. "I've never spent one night in the hospital before. I don't know who they are talking about, but I'm not spending six to eight weeks in a hospital." As it turned out, I was released from the hospital three weeks to the day after the accident.

It was after my discharge that my feelings that I was an inadequate person began to surface. The hospital was barrier-free. I didn't have to do anything for myself. When I wanted a snack, I rang the bell. When I wanted a soda, I rang the bell. When I needed to go to the bathroom, I rang the bell. At home, the bell was the first thing to go. My mom provided the best care she could, but I wanted more. I always wondered why she had to stop at midnight. It wasn't the round-the-clock care that I had come to depend on.

Frustration seemed to spark my feelings of inadequacy. Frustration over no longer being able to spring out of bed and use the bathroom or get a drink of water...frustration over having to use a wheelchair...and, worse still, frustration at not having legs from five inches above each knee. As I look back, I can see the distinct emotional stages I went through.

As the anger mounted my first month home, I went through denial. I thought, "This is so terrible – it really isn't happening." Then came the "Why me?" stage. I kept asking myself, "Out of all the people in the world, why did this happen to me?" That was a tough question and I really haven't answered it to this day. Accidents, like what happened to me, occur without any good reason.

What followed was depression. I could feel myself sinking deeper and

deeper into depression. It was compounded by the fact that I normally wasn't a depressed person. I found myself being depressed that I was depressed, if that makes any sense. I didn't know what the hell was going on. I'd sleep for hours on end. Anyone within speaking distance was a target for one of my tongue lashings. I went through a period of not being able to do anything but cry when I awoke each morning. I always had been a bright, go-getter person. I was not used to feeling like this.

About that time, I met another bilateral, above-the-knee amputee who was about my age. I'll never forget that first meeting. He was full of positive energy and enthusiasm. He bounced down my basement steps, hopped into a chair, stuck out his hand and told me his name was Jim Leatherman. The funny thing was that he reminded me of myself...before the accident. I sat there in amazement.

Jim helped me see that I could still be a positive person full of energy and capable of doing things. He made me see that I shouldn't be so down on myself. "I've got some good news and some bad news," Jim told me. "The bad news is that your legs aren't going to grow back. The good news is that the quality of your life isn't going to be compromised just because you are an amputee." He was absolutely right.

Jim taught me the "amputee lessons." He told me I had to forget the way I used to do things because now I had to do them a little differently. Things like going up and down steps...and hopping up on the kitchen cabinet to grab a glass of water. Being the avid sports enthusiast that I am, Jim introduced me to wheelchair athletics. I haven't been the same since. Wheelchair athletics was my vehicle to discovering that what I can do is more important than what I cannot do.

As I have done some advocacy work with other amputees the last several years, I have tried to promote that philosophy. When a person goes through a disabling injury, he or she tends to focus on what can't be done, because that is what's most apparent. The human mind is an amazing thing – but no one ever wrote an owner's manual for it. I discovered what occupies your mind is what is most real to you. By concentrating on my abilities, rather than my disabilities, my abilities became most real in my mind. It sounds almost too simple to be true – but it is. And with that philosophy, I have experienced many successes. Most recently, I became a successful prosthetic user.

My doctor always told me that as a bilateral above-the-knee amputee, I would never walk. In my heart, I knew that I could, if I could find a piece of equipment worth using. I did finally in May 1989 and now I can walk without canes or crutches.

I learned many lessons during my recovery. I discovered a lot about human nature and a lot about myself. Unfortunately, I was slow to learn some lessons. My biggest regret is how I chose to deal with relationships – particularly relationships with women. At the time of the accident, I had a girlfriend who was everything anyone could want. Our relationship had cooled somewhat before the accident because she lived in Baltimore and I had just moved to a Washington, D.C., suburb. She couldn't believe what had happened to me and still cared a great deal for me. She stuck by me through thick and thin. What did I do? I rewarded her affections with nothing but heartache.

I questioned her motives. "Did she think she might get some money out of the deal? Why would someone that attractive stay with a guy who didn't have legs?" I asked myself. It didn't dawn on me that the fact that I didn't have my legs didn't matter to her.

Once I was physically able, I set out to prove my masculinity... to prove that I still had what it takes to be a man. I wanted to know if women would still find me sexually attractive. It was a big concern for a 21-year-old guy whose priorities were all mixed up. As it turned out, women did find me sexually attractive and I steadily reinforced that point for the next two years. Eventually, my girlfriend had her heart broken so many times that she told me to take a hike. It wasn't until later that I realized what I had done.

I discovered there is something much worse than being handicapped – single-syllable disabilities are much worse than multisyllable ones. "Jerk" is a four-letter word that has more limitations than being an amputee.

**GEORGIE MAXFIELD, 57**  
**A Whole New World**

*Riding a motorcycle on a mountain pass, she was struck by a car. The accident forced the amputation of her left leg above-the-knee. At age 53, she began searching for a prosthesis that was bearable to use. She formed an amputee support group to learn and help others experiencing similar struggles.*



Georgia Maxfield and husband Don -  
round dancing!



I'd been riding motorcycles since I was 15. My husband Don and I had ridden and backpacked through most of the western United States. We had ridden to Alaska and played in the glaciers ...traveled the entire perimeter of Mexico, living on beaches and climbing Mayan ruins. In June of 1986, we were on a Sunday ride in a nearby Nevada mountain pass when I rounded a curve to find a vehicle driving in the middle of the highway...headed straight at me. The driver apparently didn't see me. With a cliff on one side and a wall of rock on the other, the choices weren't good. The car hit me.

On impact, my left leg was broken in seven places and deeply severed; my right leg was broken above the knee. My pelvis was separated and my left arm was broken. I must have been thrown over the top of the car. As fate would have it, a nurse was riding in the car behind me. She put a tourniquet on my leg and saved my life.

Don was on his cycle ahead of me. I had dropped farther behind than usual because I had a new motorcycle and was being extra cautious. When he noticed I was no longer in sight, he turned around to locate me. He found me lying in a pool of blood in the middle of the highway with one leg over my head in an almost impossible position. It was a horror for him to face. We had lived, worked and played together for 31 years. Now he had to hold my head, still in the helmet, and talk me into staying alive until the ambulance arrived.

The ambulance stopped at the first little town to do blood transfusions and then I was transported via helicopter to Reno. There wasn't room in the helicopter, so Don had to drive into Reno. That must have been a nightmare for him.

At the hospital, doctors told me I would lose my leg. I couldn't agree to that! I sat upright in the bed arguing with them until my son Mike arrived. "Baby, don't let them take my leg. I can't live like that," I begged Mike. "Mom, there's nothing they can do; there is nothing left to save," he told me. I finally consented to the amputation. At that moment, I believe I gave up and fell back on the bed...maybe I passed out. At least that's how I remembered it, but months later I read the medical reports and no one in that condition was sitting up in bed.

They amputated my left leg above-the-knee. With such extensive damage, they didn't expect me to live. And I had no desire to. Don, our sons, my dad

and friends came to see me, but I barely knew they were there. When I couldn't or didn't die, doctors began piecing me back together, wheeling me in and out of the operating room day after day for seven operations. I wasn't much interested in it all, but it did seem like dying was taking an awfully long time. My first real memory is of the horrible phantom pain. I knew the leg was gone, but it felt as if someone was twisting my foot off at the ankle. I didn't know then what it was. No one told me anything about phantom pain. I just thought I was crazy and asked for stronger pain medication. I didn't mention this insanity to anyone. Doctors and nurses should explain phantom pain to their patients.

I was in intensive care for three weeks and spent a total of three months in the hospital. My family and friends helped me make it through one day at a time. Then my dad suffered a heart attack. We were in the same hospital, one floor apart. My parents lived with us because of ill health. Mother had died the year before and Dad was 88.

Dad died just a month after I was released from the hospital. He had a heart attack in his room at our home. I fought to give him CPR from my wheelchair while Don dialed 911. I made burial arrangements and attended his funeral in a wheelchair, all the time feeling as though my accident had contributed to his death.

Hospitals are arranged for handicapped people. Going home was the shocker. It was hard or impossible to do anything. Everything I saw reminded me of the life we had led before. Shoes in the closet made me cry. Depression lived at our house, and it felt like a great, black hole. I contemplated suicide. Dying looked good compared to this. I kept asking myself, "Why the hell did they save me, and how can anyone accept being in this condition? You can bleed to death in four lousy minutes, so why couldn't they just have left me alone that long?"

I can't truthfully say how, but Don's strength was there, and only the fear of hurting him more made living necessary. I do remember making one decision: "I'll give it one year. If I can't become a productive human being in a year, I'm checking out."

I met my first temporary prosthesis that October. It was a white plastic, adjustable, fits-all, fits-nobody socket with a black pipe, hinge-like knee and SACH foot. It was the ugliest thing I'd ever seen. It was cumbersome and awkward...and I was crushed.

Looks fell by the wayside really fast. I was thrilled to stand between the bars and totter forward. Walking and movement were what was important. First it was with a walker, then the trauma of using crutches, followed by a balancing act between two canes. Wow! I had the beginning stages whipped. Nobody told me I'd spend the next six months inching along like that, waiting for the stump to heal and Medicaid to approve a permanent limb. I had a million miles to go.

About that time I decided to stop thinking in terms of pain. I decided it was a sensation, a new sensation. When I thought in terms of pain, I held myself back.

I had a residual limb that was difficult to fit. The stump was 11 inches long, but there was only six inches of bone with five inches of soft tissue on the bottom. A long and deeply recessed skin graft covered the top of the thigh. My doctor felt I needed special attention and sent me to Los Angeles for evaluation. The evaluation cost \$400, and no one prepared us for that. My brother paid for it since the facility didn't take Medicaid. I quickly discovered a good leg was going to cost a lot more than we had imagined.

Once back home, I began searching for another amputee – someone who might have some information about prosthetics. I couldn't afford to "learn" at the going rate. I found two amputees – a lady with a hip-disarticulation and a lady who was a below-the-knee amputee. They gave me all the information they had.

Armed with new insight, I urged my doctor to send me to Denver to the prosthetist my friend recommended. The prosthetist was a delight to know. We became instant friends, and he arranged for my husband and me to attend an amputee support group. He created a special socket to protect my scar tissue. It was a hard quadrilateral socket with a hydraulic knee and Kingsley foot, all weighing just over 10 pounds.

In this type of socket, the entire body weight is supported by the pelvic bone, which moves up and down on a hard shelf with each step. The hip is rather loose and migrates out to the side. My stance was very wide, and I had a severe shoulder dip. I believed I could learn to overcome all of that. Within a month, I gave up both canes. I was reasonably mobile, but the more I walked, the greater the energy output...and the more I would sweat, which contributed to a growing infection in my scar tissue. Revision surgery was necessary in August 1987 after I had used the leg three months.

Revision surgery is akin to re-amputation. A plastic surgeon removed the skin graft area and shortened the stump to reduce the swinging mass of soft tissue. I spent six weeks in a wheelchair.

Interwoven during this time was the growth of the Northern Nevada Amputee Support Group, born from our original group of three. As amputees, we learned from each other and were amazed to find how few amputees had ever spoken to another amputee outside a prosthetic facility. And we came to realize that we, the prosthetic users, knew almost nothing about the products our lives revolved around. Prosthetists, the gods of this world to us, all speak a foreign language.

Getting the support group going wasn't an easy task since doctors, prosthetists and hospitals must hold records confidential and won't give out names and addresses of patients. I practically chased amputees down the street when I saw them...and suddenly, I did see them. "Had they been invisible to me before?" I wondered.

Our amputee support group now numbers nearly 200. We have educational meetings and share prosthetic information through our meetings, newsletter and video library. We make hospital visits, help with family adjustments, work with a "buddy" system and raise funds to help with the purchase and repair of prosthetic devices and wheelchairs. We've made mistakes along the way, but our community support base continues to grow.

During my recuperation after the revision surgery, I had time to study videotapes and information that made me realize there were other above-the-knee amputees who could walk circles around me. Since my quad socket would no longer fit the revised stump, my doctor sent me to a prominent West Coast medical facility...a prosthetic engineering department that stayed abreast of the latest in artificial limbs. With financial help from Medicaid, Vocational Rehabilitation and Hill Burton Assistance, I was fitted with a state-of-the-art, lightweight CAT-CAM...a super-duper leg. It was a big deal, and Don and I were happy people.

I found a lot to like about my new leg: its light weight of just six pounds, the foot, ankle and knee. Everything was fine except the socket.

Beware...all CAT-CAM sockets are not the same. I discovered the socket is a product of each individual prosthetist. As I continued to use the socket, Don and I attended several amputee conferences and studied the

different sockets worn by amputees we had seen on videotape. No matter what anyone chose to call it, the socket I had was a glorified quadrilateral with attempted pelvic containment. My rather soft thigh tissue twisted and wrenched in the inner thigh area with every step, while the pelvic bone worked its way off the edge of the socket.

Eventually, I was back to blood and blisters. My activity level was greatly reduced – no dancing, no tennis, no camping or hiking. A cyst that developed near the pelvic bone meant I finally could no longer wear the leg.

The components were still serviceable, but I had to have a new socket. Medicaid wouldn't fund it, so we begged and borrowed from relatives to buy a new socket produced in Reno. It was another version of CAT-CAM. The prosthetist created a socket that didn't breed cysts and blisters, for which I was grateful. (He also made me a shower leg that I could even wear into the lake, making swimming a pleasure again.)

But as I wore it, the socket still twisted around the inner thigh, causing a burning, irritated mass. My hip still migrated out to the side and stayed there. I decided my problems were unsolvable and I'd have to adjust my lifestyle. Life became timed in short spurts of action. I leaned on the grocery carts to take some weight off the leg while I shopped. At home, I used the walls, halls, furniture, kitchen counter-top – anything to relieve the strain. I had no balance, and bruises became a way of life.

Here I was an encyclopedia of prosthetic knowledge, none of which seemed to help me. I decided it was all a pack of lies. The videos were made of "special people," athletic stars who were paid to perform and lied through their teeth about the comfort. I felt like it compared to the quack miracle cures – all hype and no delivery. Don't misunderstand. The prosthetists I encountered gave me their best. I do not feel they took advantage of me. Each of them tried, but they were limited by their experience. Still the money was gone, Medicaid refused further payment, and I didn't have a leg I could use. If these special legs existed, I decided they were saving them for someone else.

About that time, I attended a prosthetic convention where Donna Kennedy, another amputee, was featured. She had tissue problems with her stump that were similar to mine, but she had found success with a leg built by Oklahoma City prosthetist John Sabolich. Once I was able to contact her, I realized there was still hope. I also knew there was no more money for

another leg.

With a great deal of fear and trepidation, my husband and I borrowed money against our home. It was about all we had left after all the travel, hospital and medical expenses. It was a difficult time of life to be going into debt, but we felt it was worth the investment. My husband and I drove from Reno to Oklahoma City in our 1961 pickup, pulling our son's old camper. We lived in that trailer for a month. It was a trip filled with love and hope. "We're off to see the Wizard, the wonderful Wizard of Oz," I sang as we drove. And I prayed it was true.

The day we arrived, the prosthetist went to work and the casting and fitting of a new socket went quickly. Adjusting to the pressure of a true total pelvic containment, however, was something else. Uncomfortable as it was, it felt good because I was stable – the socket really fit. The difficulty with the pelvic pressure was slowly adjusted until I felt fine walking or standing, but I still found it uncomfortable to sit because my tailbone hurt. My prosthetist urged me to endure, explaining that too would get better. After a month or so, it did.

One day, the prosthetist was teaching four other above-the-knee amputees to run in the parking lot, so I gave it a try. I didn't run fast or well, but it was the fastest movement I had experienced in four years. Don videotaped us all. It was thrilling. Later, we went to a park to ride bikes. Some went horseback riding or played tennis to test their limbs, but Don and I went to flea markets, an amusement park and the auto races. Doesn't sound like handicapped activity, does it?

After four years, all the legs and travel expenses came to well over \$40,000 – but I finally had a leg that looked good, let me walk and let me be the person I wanted to be. The mental, physical and emotional wear and tear are beyond evaluation. I wanted to share my story in hopes that someone will be spared the strain of learning everything the hard way, as I did. Don and I thought long and hard about advice we would attempt to offer (because all advice can be dangerous), but we feel these points deserve attention when you choose a person and place to make an artificial limb:

- Beware of the term CAT-CAM because anyone can use it. There are as many variations of the socket as there are prosthetic facilities.

- Observe the personality and disposition of the prosthetist you select. Volatile temperament is not a desirable trait. Cool, calm and collected people get the job done.
- Ask to meet and talk privately with some of the prosthetist's patients – people with your type of amputation who are using the components you are interested in.
- Learn to speak the prosthetic language. It isn't difficult. Your prosthetist can teach you if you let him know you don't understand.
- Establish and maintain communication. Remember, no one can feel what is happening to your body except you. Guess work hurts both parties.

Today, I have a good, strong prosthesis that is improving my life. My activity level is approaching normal. I feel better about my existence and future.

In September 1990, Don and I returned to round dancing, our first time on the dance floor since the accident. Round dancing is a stylized version of ballroom dancing, done by couples moving around the room in a circular motion. It's the Fred-Astaire-and-Ginger-Rogers stuff. We love it. We'd been dancing for 25 years before the accident and even taught round dancing.

We're starting over with a class, relearning not just the steps and maneuvers but the body mechanics. And we're making adjustments for a few movements I can't do. It is challenging, but it's wonderful to accomplish something personally important to us as a couple. We're dancing, laughing, talking and enjoying the company of our friends.

There are people who still find it difficult to be comfortable in my presence because of the amputation. Whether they can overcome that remains to be seen. But I no longer waste my emotional stamina trying to make myself acceptable. A hunk of flesh is gone, but I'm still a mind, soul and being to be considered and acknowledged. If Don and I can recover from the amputation, surely other people can, too. Thank God the bothered souls are few and our loved ones are many.

The amputee support group continues to grow, keeping me busy. Don is one of the most vital forces in it. We have met and enjoyed many phenomenal people. I was proud to be elected to the board of directors of

the Amputee Coalition of America and hope to serve a useful purpose in the national organization. I urge every amputee to reach out and contact a support group or other amputees. The benefits are many. After all, life is learning and sharing...and even amputation is just another learning experience.



# GABRIELLA CLABES, 2 1/2

(As told by her parents, Brandon and Sandy)

## She's Our Hero

*When she was born, all her father could think of was how beautiful his daughter was. The parents of two little boys, they had no idea what lay ahead as they dealt with her PFFD*



Gabriella Clabes

*From Brandon:*

We learned about Gabriella in the early months of Sandy's pregnancy. The baby's left femur was much shorter than the right. Why is a mystery. During an ultrasound, the technician was suddenly quiet and we knew that wasn't good.

After many more ultra sounds, tests, and doctor visits, we were told that our baby daughter suffered from PFFD(proximal femoral focal deficiency). Only Gabriella's hip, femur and knee joint were affected, and by the time she was born, her left femur was 60 percent shorter than the right.

*Sandy:*

It was the worst time of my life. I was so shocked that we were even having another baby, let alone that something was wrong. But when we found out about the PFFD, I was somewhat relieved. I had thought it was osteogenesis imperfecta, where bones break very easily. Life can become almost abnormal for some people with this disability.

*Brandon:*

When she was born, she looked so perfect and such a gift from God. But I was so angry at God. I didn't understand why this had happened in our family, especially to my baby daughter. I felt helpless; I couldn't fix it. I saw it as a tragedy, but my pastors and friends helped me see all of the blessings she would bring. I worried about her because I know what it's like dealing with being different. I was born with a cleft lip and palate so I've had to deal with being different through personal experience.

*Sandy:*

I wasn't angry; I was scared to death. I was afraid many other things would be wrong. I felt inadequate and guilty. I was sure that God meant to give her to someone stronger. But the moment I held her in my arms, I was sure I was the best mom for her and now I can't imagine life without her.

We investigated all the options available for a child with PFFD- limb lengthening, Van Ness Rotation. We knew we wanted to give her the ability to function as normally as possible but our decision meant surgery and having her fitted with a prosthesis. The foot on her affected shorter leg would have to be amputated.

Emotionally it was the hardest decision we have ever made. But now we

know for sure that it was the right decision for Gabby. She wants to try everything. And we let her, although we're fearful at times. Our attitude with her has always been "better to have tried and failed than never to have tried at all." She never fails; she just finds another way to accomplish the task. We also have two boys, Collin, 9, and Morgan, 6, and she tries to do everything they do.

I recently met a young lady who also has a PFFD abnormality in our doctor's office. She was a great help to me. I had so many questions for her and she answered every one. I wanted to know how things were for her in high school, dating and just being a young woman. I wanted to know about her marriage and what kind of activities she participates in now. She spent a lot of time with me and was very reassuring.

Recently Gabby was fitted with a new prosthesis. She put the leg on and refused to take it off although I was supposed to check hourly for pressure points. She didn't take it off till bedtime and even then she slept with it by her side the first night.

Gabby's our hero. She's been through several surgeries and long months in a body cast. You can see the fighting spirit in her eyes; I wish we all had an ounce of her courage. She is full of inspiration and hope. She's a "girly" girl and loves tea parties, Barbies, her babies, swimming, and Barney videos, but still a tomboy following her big brothers. If she could choose her vacation spot, it would be the bathtub. Gabriella is a normal two-year-old and now wants to ride a tricycle and eventually a bicycle. We're not sure how we're going to arrange that since right now she doesn't have a knee joint, but I'm sure we'll figure something out.

We feel so blessed to have her. We want others to hear her story and know how normal life can be for someone with a gift or a difference. While we know that Gabriella will have some challenges ahead, we also believe that she will continue to be the blessing that keeps this family centered in a very confusing world. God never promised that life would be perfect, but what we may view as perfect is not always so. We all have our burdens to carry, our own handicaps to bear; the only difference for Gabby is that we can see hers.

*It's not known what causes PFFD, but the congenital anomaly is characterized by abnormal development of the femur, hip socket and knee joint. PFFD is a rare abnormality affecting only one in 200,000 births.*

*Although only Gabriella's hip, femur and knee joint are affected, this anomaly is often accompanied by another missing limb, fingers, a hand and/or facial deformities, and the hip is usually involved in various ways.*

JACQUELINE ANN TAYLOR, 28

## Rubber Bands and Paper Clips

*Doctors don't know what caused her to be born without arms or legs. Many babies with such severe birth defects are institutionalized, but her family took her home, loved her, and treated her like their other children. She hasn't let the lack of limbs deter her from pursuing a career in law.*



Jacqueline Ann Taylor

The snow and ice that covered the ground in Oklahoma City in February were only the first of many challenges my parents would face that day. By some miracle, my mom made it to the hospital in time to deliver me, her fourth child. It was apparent from the beginning, however, that I was not like the other children in my family.

After my mom regained consciousness from the anesthesia, the doctor came in to tell her that her new baby girl had been born without limbs. Worse yet, no one knew why. The next few days must have seemed like a lifetime for my parents who, with the help of the doctors, had to decide what to do.

The doctors, of course, had to advise my parents of the full list of options. These ranged from giving me up for adoption to institutionalization. Finally, one doctor told them, “Just take her home and love her – she will be fine.” Fortunately for me, they did.

While my childhood was often lonely and difficult, it had some wonderful bright spots woven through it as well. My siblings, Jerry, Doug and Kay, were all quite a bit older than me, but Kay and Doug played with me often and taught me to sit up and climb stairs on my own. Other tricks that Doug taught me were not so constructive in my parents’ view.

One spring day when I was about 3-years-old, Doug climbed out of his second-story bedroom window to sun himself on the roof – with me in tow. He had me yell for Mom until she came out in the backyard to see where I was. When she looked up and saw us on the roof, she nearly had a heart attack! Doug and I laughed hysterically. That was a great moment.

Almost two years later, in January of 1967, Doug severely and permanently injured his midbrain when a car hit the motorcycle he was riding. He had gotten the motorcycle on his 16th birthday – less than a month before. Doug existed in a nursing home in a persistent vegetative state for the next 18 years. His loss is but another example of the hardships our family has faced over the years.

Next to my mom and my siblings, my maternal grandparents probably did the most to shape who I am today. My Grandma Viola was the kindest and wisest woman I ever knew. None of her grandchildren will forget the love she gave to everyone around her.

Grandad Evert was the perfect contrast to Grandma. Although loving, he was feisty and liked to tell his grand kids tall tales about anything that came

into his mind. He was also a retired school teacher and a garage inventor. One early “adaptive device” he made for me was an extended crayon holder, which he made by wrapping rubber bands around the crayons and placing them in the ends of spent Roman Candle firecrackers. His motto was, “If you can’t put it together with rubber bands and paper clips, you don’t need it.” My granddad taught me to read and write before I entered kindergarten. That advantage helped me gain confidence in my abilities, which I would need growing up with a severe disability. Grandma and Granddad also made me feel loved and accepted by taking me wherever they went, proudly introducing me to all of their friends. In their own way, they greatly reduced the attitudinal barriers about disability among all the people they knew.

When I reached school age, my parents had the financial resources to send me to private school. This was fortunate, because at that time the Oklahoma City Public Schools did not mainstream students with disabilities with able-bodied students. In fact, I would have been placed in a classroom with profoundly mentally disabled children. Although it would have been easier and cheaper to place me in public school, my family knew that a good education was my only chance for future independence.

Despite the wonderful learning environment I had in elementary school, I was often sad and lonely because I had few friends. Kids are very physical at that age, and they don’t understand how to relate to a peer who cannot be physical with them. I did have a couple of very close friends growing up, however. One is still a friend today. We have shared so much that whenever we see one another, no matter how long we have been apart, we can talk as if we’ve never been separated.

While my disability alienated me from many of the kids at school, I met other childhood friends because of my disability. These were kids who, like me, went to rehabilitation hospitals for prostheses and/or therapy. But because the field of children’s prosthetics was still developing in the early 1960s, only certain centers in the United States were specializing in child amputees. Unfortunately, Oklahoma did not have such a center, so I had to travel out of state.

My first significant encounter with prosthetics came at age four when I traveled to Grand Rapids, Michigan, to the Amputee Clinic at Mary Free Bed Hospital. At the time, it was one of the most innovative centers in the country for children’s prosthetics. Although my mom took me to Michigan,

she had to leave me there for several weeks while I was fitted with prosthetic arms. That was my first time away from home without my family, and I think it was much harder on them than it was on me.

Much to everyone's surprise, I contracted chicken pox from another patient at the hospital and had to stay in quarantine for over a week. That was the pits! Once the mini-epidemic was over however, I began to learn how to use what would be my first pair of arms.

Because I have only shoulders and no residual arms, the prosthetic arms were held on by plastic caps, which were molded from a plaster cast to fit over my upper body. These early arms were unusual in that their movements were powered by carbon dioxide stored in miniature tanks on the back of the plastic caps. The gas traveled to the motors of the arms via a system of plastic tubing, and aside from the irritating noise it made as it moved through the tubes, it was quite effective. Later, arms that I used, powered by cadmium batteries, never worked efficiently.

I could make the arms go up, or make the hook open by pressing small switches inside the caps with my shoulders. Although there were three switches for each arm, I quickly mastered them and was able to write, feed myself with a spoon and grasp some objects. Before I got the arms, I relied on someone else to feed me, and I wrote with a pencil held in my mouth or between my shoulder and chin. When I started school, the arms were a conversation piece for several days. The kids were interested in how they worked compared to their own arms and hands. Soon everyone, including me, realized there was no comparison, and they became commonplace tools that simply changed the way I performed some tasks. Nevertheless, I made two pilgrimages per year to Mary Free Bed from the time I was 4 until I turned 13.

Because of the severity of my congenital disability, the doctors and prosthetists used me to try out the latest technology in artificial arms. I later decided to try my own experiment with walking on prosthetic legs, despite the protests of the doctors that this was unsafe because I could fall too easily. But as usual, I was determined and stubborn. This time the doctors were right, and I decided that I would stick to power wheelchairs or scooting around on the floor at home for mobility.

Even though I abandoned all prosthetics at age 13 (except the legs, which I wore and still wear for cosmetic purposes only) the trips to Michigan were



certainly not wasted. There, I finally realized that many other children had been born without limbs or had lost them in accidents at an early age. That realization was important, because I knew that I was not alone. We all learned so much from each other. I hope some of us can meet again through a Mary Free Bed reunion.

The other childhood experience that gave me a sense of being part of a group was attending the Easter Seal Handicamp in Idaho Springs, Colorado, for eight summers. Kids from Colorado and several surrounding states came to the camp each year for adapted activities such as swimming, horseback riding, archery and fishing. We also came for friendship in a place that was designed for us. For me, Colorado is still a magical place.

When I entered high school, I began to make many new friends. The impenetrable cliques of elementary school still existed, but many other students were open and friendly. Because I was happier socially, my grades improved, and I eventually graduated with honors.

Like all teenagers, I tested the boundaries of acceptable behavior which meant I got into trouble on a fairly regular basis. While I now know what grief I must have put my parents through, I am not sorry for the experience I gained. In fact, the period I went through in high school helped me to mellow and mature somewhat faster than many of my peers.

My college years were also quite fulfilling. I attended Scripps College in Claremont, California, where I majored in international relations. I elected to go away to school because I knew it was time for me to have my own identity, apart from my family. Scripps, a small women's college specializing in humanities, was the ideal place to learn independence while still feeling part of a closely-knit academic community.

Part of the independence that I had to learn was how to train and manage a personal assistant. My mom had undergone serious surgery about a month before I left for college, so my dad took me to California. Upon our arrival, Carolyn, the young woman who would be my personal assistant throughout my years at Scripps, met my father and me at the airport. She was a nurse's aide that my parents had arranged for through a southern California nurses' registry before my departure from Oklahoma. Carolyn was truly a gift. We became fast friends, and she also became good friends with Nancy, my best friend at college. As my personal assistant, Carolyn lived in the room adjoining mine in the dorm. She attended classes, ate the often deplorable

cafeteria food and went to the crowded parties with me. In my opinion, she deserves an honorary degree.

The most incredible part of my Scripps experience was my junior year abroad. As an international relations major, I had to choose a language in which to minor. I selected French because I had studied it for four years in high school. Eventually, I fought for and won the opportunity to attend the Scripps Year Abroad in Paris. Upon my arrival in France, I would soon discover why the professors were so reluctant to allow me to go.

The summer before I left, my mom and a friend of hers went to Paris to locate an accessible apartment for me. They succeeded in finding a new building that only had one step into the front door and a small elevator to reach the apartment. It was situated in the Montparnasse section of the city, where Sartre and Hemingway once practiced their arts. Believe it or not, that building was the most accessible one we ever saw in Paris.

A good friend of mine from Oklahoma City, who also knew French, went with me to Paris to be my roommate and personal assistant. Paris was beautiful but very difficult to negotiate in a wheelchair. The curbs were enormous and did not have curb ramps, so most of the time we traveled through the city by asking strangers to help us climb or descend several flights of stairs at the Metro subway station.

Throughout my stay, I wondered why I never saw one other person who used a wheelchair or anyone with a disability for that matter. I later discovered that at least some of the disabled people in France live in totally accessible suburbs outside of Paris. There, doors unlocked and opened, and lights turned on and off all with the push of a button. These towns were wonderful, but the residents were completely segregated from the rest of French society. The French government may pick up the tab for all of the physical needs of its citizens with disabilities, but the trade-off of segregation does not seem worth it to me.

During my year abroad, I took French classes with French students and my California classmates. I also spent time in cafes, museums, and traveling around the French countryside. When I returned, I could speak French fluently. The experience would not have been possible however without the help of the woman who ran the Year Abroad program in Paris and our landlady, who took us under their wings and allowed us to try everything, even if they feared we would fail.

Because the professors and staff made Scripps such a perfect environment in which to learn, I excelled academically. But after graduation, I discovered that I still didn't know what I wanted to be when I grew up, so I came back home to think it over. When the Independent Living Project in Norman offered me a job providing independent living services to others with disabilities, I jumped at the chance.

There, I became much more aware of the political issues faced by people with disabilities, such as funding for accessibility projects and Social Security disability payments, upon which a number of people depend. I worked at the project for two years and saw a lot of turmoil and change occur within it. Although the work was often stressful, it was also rewarding. I learned more through that job than I could ever give in return.

It's odd, but I actually don't remember why I eventually elected to go to law school. The world certainly has enough lawyers! But I wanted to give back to the disability community at least some of what it had given me. I wanted to be an advocate for groups and causes I believed were worthwhile.

Three years later, I reached my goal. I graduated from the University of Oklahoma College of Law in May 1990, passed the Oklahoma Bar Examination, and went to work for U.S. District Judge Wayne E. Alley in Oklahoma City. The judge arranged for the federal government to employ a full-time assistant at work for me. Fortunately, a good friend of mine, a paralegal who had already worked for me during law school, became my assistant. We both really enjoy the work because we can observe other attorneys and research many different types of cases without having to work with clients.

Other areas of my life are coming together, too. I recently bought a used van with a wheelchair lift, so I can now transport my power wheelchair. Also, a wonderful man and his wife from Dallas, Bill and Joyce Baughn, are helping me to become more independent by building inexpensive, ractical adaptive equipment. And through their contacts, we have arranged for some engineers with General Dynamics and Bell Helicopter in Texas to build a customized power chair. This chair will do all of the things that a regular power chair will do, plus the seat will go up and down so that I can look people in the eye, instead of in a much more familiar, yet uncomfortable place.

My sister Kay – who is now a cinematographer – and I are continuing to

work on a film about my life and about disability issues in general. We hope to have the film ready for distribution in two years. Finally, I am planning to get a service dog that will perform such tasks as retrieving dropped items, opening doors and pushing elevator buttons. I look forward to having my dog as soon as possible.

Knowing my love for travel, I expect to take another bar exam before my tenure with the judge ends, so that I can be ready to move to a new state and see what new adventures await me there. No matter what else can be said about my life, it is rarely ever dull.

MONA PARTHUM, 33

## Swept Into Another Life

*Caught in a tornado, she clung to a tree for dear life. Flying debris was embedded in her body, leading to infection that forced amputation of one leg above-the-knee and the other below-the-knee. She wore two prostheses with relative comfort until after her pregnancy, when she thought she'd never find artificial limbs that fit properly.*

I was on my way to a cake decorating class in Wichita Falls, Texas, when the wind began to blow. Debris began to batter my car. I'd seen pictures of a funnel cloud, and suddenly at age 22, I was facing one less than 100 yards in front of me. The sky turned a strange greenish-black. I got out of my car, but I got no farther than the median where I lay on the ground and held on to a small tree to keep from being swept away.

I slipped in and out of consciousness as the storm swirled around me and debris pelted my body. When it was over, I found myself sitting on the curb. A 2-by-4 had blown into my right leg, leaving my leg hanging by the skin. I screamed to a passing truck...at least I thought I was screaming. At first the driver didn't see me. Then he backed up, loaded me in his truck and took me to the hospital. I was the first of many casualties to arrive at the emergency room in the wake of the tornado. I guess the good Lord was looking after me. I was alive.

I kept telling the emergency room personnel my name, but they didn't understand. I thought I was saying my name, but somehow it wasn't coming out of my mouth right. I'd lost so much blood, the doctors weren't sure I'd live, and they still weren't sure who I was. As I lay on a gurney, they tagged my left foot: "Mona Rake (the name they thought I was saying), near death."

It was a few days later when I was told my right leg had been amputated below-the-knee. I don't remember my parents telling me. I was so heavily sedated that I only vaguely remember an amputee coming to my room to see me. I was hospitalized two weeks in Wichita Falls. Then, because the debris embedded in my skin caused so much infection, I was flown to Medical City in Dallas where I remained for nearly six months. My memory is foggy of those first two months because of the pain I was in and the medication I was

given. But my general daily routine included scraping the infected tissue from my left leg. The doctors just couldn't get enough of the infection out of my system, and my fever remained high. I ended up back in intensive care and later – on the operating table. To save my life, they amputated my left leg above-the-knee.

I wasn't aware of what was happening. My parents had to make the decision to amputate. I didn't know until a couple of days after the surgery when I asked my dad to scratch my knee. "Which knee?" he asked. "My left knee," I told him. "Honey, you don't have a left knee," he replied softly. As we talked about that conversation years later, my dad said it was all he could do to keep from bursting into tears.

The doctors continued to prescribe morphine along with Demerol for the extreme pain during the dressing changes. The Demerol depressed me, and I cried a lot. My mother knew that because of my depression I was unable to put up the kind of fight for life she knew I wanted to. Mother knew I didn't want to be sad and depressed all the time, so she asked the doctor to take me off Demerol. He was reluctant because of the amount of pain I was in, particularly when they changed my dressings.

"It's going to be okay," my mother said as she looked at me. "When you scream, I'll scream. When you cry, I'll cry. We'll get through it together." And we did. When they changed my dressings, my mother and I screamed and cried into my pillow. I squeezed her hand and she squeezed mine. My parents knew what I would want...they made the decisions when I couldn't.

But after one dressing change without Demerol, the doctor explained to my mom how nerves were being exposed each time they changed the dressing and she consented for medication to be used as long as it was something other than Demerol. That was fine.

By August, I had undergone more than 30 operations. I was taken each day to a huge whirlpool of medicated water designed to kill the infection. Normally, they lowered and raised me from a stretcher, but then the day came when I was to sit up in a wheelchair after my whirlpool treatment. It was the first time I had really taken a look at my self. I remember looking at my legs for the first time. It was the ugliest sight I had ever seen. I broke down and tears streamed down my face. But the physical therapist knew exactly what to say and helped me through what was the biggest hurdle I can remember.

For the first time, I started talking with my doctors about my amputations...asking questions about what my limitations would be...and if I would walk again. Also for the first time, I began to think that no man would ever want to look at me again. No one was ever going to think I was pretty.

But my doctors pushed me along. "You'll do whatever you want to do. The sky is the limit," they said. We started talking about artificial limbs and the doctors sent a lady who was an above-the-knee amputee to visit me. She made me realize that this was not the end of my life. I knew then I would walk and be independent again. I was fortunate that I had a lot of support from my family and friends. In my heart, I knew this had happened for a reason. I may not have known why yet, but God had a plan.

I was fitted with my first prostheses in August while I was still in the hospital. They were wonderful at the time. After all, they enabled me to walk and drive – two things some people thought I'd never do again. I remained in the Dallas area, living with an aunt and uncle for a month after I left the hospital, and I continued physical therapy three times each week. That November, I went back to my hometown of Henrietta, Texas, returned to work, and bought a new car. I never looked back.

I was still walking with canes or crutches. I'd only walk alone around the office or at home. But after six months, I put the canes and crutches in the closet.

I lived with my parents for 10 months, and I think my mother thought it was like having her teenager home again. She did almost everything for me because I was still so weak. At the time, I couldn't have cared less about dating. As long as I had my friends and family, I was fine. Besides, driving 20 miles to and from work after a long day really did me in. I usually crashed at night.

The following November, I moved out on my own and got an apartment. I met a guy in my apartment complex – we went out once and then became really good friends. We'd watch television together, play cards, just everything. He introduced me to a friend of his, whom I dated off and on. Dating never really was a problem. It was just that split second when I first met a guy that was somewhat uncomfortable. But if we talked for very long, I knew I could put him at ease. I decided if someone didn't like me, that was their problem.

At work, we listened to a disc jockey named J.D. Stone on our favorite radio station. I decided to call him one day to tell him what a blast it was listening to him. It turned out he banked in the same building where I worked, so he said he'd stop and see me sometime. I doubted it, but I'll never forget Friday the 13th in February 1981. He came into our office, and we hit it off right from the beginning. He asked me to the movies the following weekend. When he came to my apartment that night, I told him I had something I thought I should share with him. I explained that I had two artificial limbs. He couldn't believe it, but it didn't matter. John and I were married that December. Like the rest of my family, he's always been supportive and encourages me in anything I want to attempt.

In March 1982, I was fitted with what was supposed to be an above-the-knee CAT-CAM prosthesis on my left leg. It was lighter, but it was still a hard quad socket that felt like I was sitting on a rock. My right leg still had a strap that held the prosthesis on at the knee. The prostheses were definitely more comfortable than my original pair, and I had no major problems wearing them until I became pregnant in April 1985. That August, we learned we were expecting not one, but two babies. I started retaining fluid during my fifth month and couldn't wear my above-the-knee prosthesis at all. I began using a wheelchair. I could still do most everything. I could have walked with crutches, but I was more comfortable with the wheelchair, partly because I didn't want to take a chance of endangering the babies by falling. My doctor prescribed strict bed rest in October to prolong my pregnancy so the twins wouldn't arrive too early. Having children wasn't something I (or my doctor) was sure I would ever be able to do. And after so many surgeries, my doctor wasn't sure if I could withstand a normal delivery or if I would need a Caesarean. To everyone's surprise, I delivered two small, but healthy girls, Stephanie and Marissa, normally on November 6, 1985.

After losing the majority of the 45 pounds I gained during pregnancy, I made an appointment the following August to be fitted with new prostheses. I once again was fitted with a hard quad above-the-knee socket on my left leg and had a strap across my right knee that held on my below-the-knee prosthesis. These prostheses were horrible. Even people at work said my below-the-knee prosthesis looked like a tree stump. Both sockets fit so poorly that I had more sores in the year that followed than I had had the entire time I had been an amputee. I could walk on the artificial legs, but I



couldn't wait to rip the moff as soon as I got home from work.

The prosthetist kept blaming it on my pregnancy. How could that be...he wasn't trying to remake my old legs...these were new legs. I had a second below-the-knee leg made, but it didn't help. My husband recalled the name of the prosthetist who developed the CAT-CAM prosthesis, and I called to talk with him. I went through a hassle with the insurance company and the Texas Rehabilitation Commission concerning payment for the new limbs before I made an appointment with the prosthetist. I had my permanent legs by September. I was fitted with a light-weight, comfortable CAT-CAM above-the-knee prosthesis on my left leg. And my below-the-knee prosthesis was no longer held on by a strap, but with a rubber sleeve. The new flexible feet allow more stability when walking, especially up inclines and stairs.

I'm now proud of the way I look and walk. I do things that I've been unable to do since 1979...like mow the yard, ride a bicycle and I was able to keep up with two very active little girls. The only problem I have is an occasional breakdown of scar tissue during the hot summer months. I know how much it helped me to talk with other amputees, because only they really know what you are going through. I've talked with several amputees in the hospitals in Dallas since 1979, and John and I have gone as a couple to talk with some. One lady with a below-the-knee amputation was particularly concerned that her husband would never want to touch her again and her kids wouldn't love her. John told her that her husband should love her for what she was on the inside. We stayed in touch with the family for months. Helping others is such a good feeling.

In April 1979, when I was nearly swept away by that tornado, I felt alone. I felt like no one knew what I was going through. Now I know I'm not alone. I'm a strong person and will grow stronger with the help of God, my family, and friends.

## JEREMIAH MAXEY, 6

(As told by his mother Evelyn)

# Bubby's "Canacal"

*She and her husband looked forward to the birth of twins, but her joy turned to sadness when their baby boy had medical complications that threatened to end his short life. Miraculously, he survived, but there were problems with his arms. Doctors said amputation of the right arm below-the-elbow and part of the left hand was the only answer.*



Jeremiah Maxey and his twin sister  
Danelle double-up on the slide.

The twins were born in Casper, Wyoming, on July 20, 1984. They arrived a month early by Caesarean section. The doctor and I had suspected for some time that some thing might be wrong with baby "B."

I awoke in the recovery room a few hours after surgery. It was apparent from the look on my husband Glenn's face that something was wrong with one of the babies. "Did baby "B" make it?" I asked. In a shaky voice, he said: "We have a boy and a girl...and the little boy has some problems."

I fell apart. I asked him what was wrong. "The doctors don't know what it is, but he has some problems with his arms and amass on his left side." The doctors had contacted Children's Hospital in Denver, and a medical team was being flown in to get the baby. I wanted to see Jeremiah, as we had decided to call him. He was on life support, so I had to go to the nursery to see him. Dragging my I.V. and still half-sedated, I made my way to the nursery. There he was...so tiny and beautiful. With both arms covered, tubes running into his small body and his face covered with an oxygen mask, he was still precious. I just knew he had to make it. At that moment, my only thoughts were on him, leaving my baby girl – small, but perfect – without the attention a beautiful newborn deserves.

The Denver medical team arrived, and I saw what I feared might be the last glimpse of my son as they rushed him to a small jet. My husband went with Jeremiah, while I stayed in the hospital with Danelle.

When Danelle and I were released, we went to Denver. We stayed at the Ronald McDonald House and spent most of our time at Jeremiah's bedside in the intensive care unit. The doctors discovered he had too many platelets in his blood, and his whole system had clotted. The worst clotting was in his arms and kidneys. They put him on Heparin to thin the blood, but doctors offered little hope that Jeremiah would survive. They feared a clot could move to his heart, lungs or brain, but that didn't happen. It was our first miracle.

The days passed, and Jeremiah was getting better. Weeks passed, and his general health continued to improve. At the same time, his arms were getting worse. His right arm was turning black, along with his left index finger and forearm. I had a very hard time seeing what I did not want to see. We had come so far, and every day was a big step. He was still on oxygen and had to be fed through a tube, but he was getting better. I just couldn't face the fact that blood to his arms, especially the right one, had been cut off too

long and they were not going to get better. I had taken Danelle with me to the hospital cafeteria one day. As I returned, the mother of the child in the crib next to Jeremiah's crib said the doctors had brought an orthopedic surgeon to see him. "I heard about Jeremiah's arm, and I'm so sorry!" she said. "What do you mean?" I replied, in shock. She started to cry and went to get the nurse.

"We were waiting for your husband to come from Wyoming this evening to tell you," the nurse explained. And I knew what I had tried to deny was about to happen. I just couldn't deal with it. The nurse said Jeremiah was scheduled for surgery at 7 a.m. Monday to amputate his right arm below the elbow and part of his badly damaged left hand.

Jeremiah hadn't even reached five pounds yet – I couldn't believe this was happening. Doctors said the gangrene was so bad it was becoming a threat to his recovery. I prayed: "God, please don't let this happen; please take my arms, my legs, my life but not my baby's." We had come so close to losing him six weeks earlier and now I was losing a part of him.

"Mrs. Maxey, it's all the better that if it has to happen, it happens now," the doctors said, trying to comfort me. "He will never suffer the mental anguish or worry. You and your husband will do that for him. And all his energy will be spent on recovery."

But I still wanted to change this...it just couldn't be. I was an emotional mess. The hospital staff psychologist talked with my husband and me. She was used to dealing with "why my child" parents. She gave us the best advice anyone could offer at the time. "Go ahead and cry, throw a fit, be mad and grieve," she told us. "When he comes out of that operating room, his arm will be gone. As in death, it's final, gone forever. The only way to heal is to grieve, mourn. Then you come to accept your loss and start to recover." I cried and questioned "why?" and I worked through all the normal things you do when faced with a loss. Monday came and all I could think of was "Please God, let him live through this surgery...he's so small and has been through so much...please, please, let him live!"

Five hours later, the doctors came out of surgery and said Jeremiah was on the way to the recovery room. We could see him in a little while. I was so happy to have my twins...both of them. I put the loss of his right arm and part of his left hand in perspective for the first time since it had all started.

Soon after he recovered from surgery, our lives started getting back to

normal – or what would become normal from then on. After not having any children for 10 years, and now having twins, “normal” took on a whole new meaning. Jeremiah returned to Denver Children’s Hospital every other week for the first year. It was a five hour drive from our Wyoming home. He went through four surgeries on his left hand and had a cast for six months as doctors tried to stretch tendons and straighten the damaged fingers.

Jeremiah was first fitted with a passive mitt at six months and wore a hook for four years. His hand specialist started talking about myoelectrics to replace the hook, in part because the fingers on the left hand had been so badly damaged. Jeremiah was fitted with his myoelectric hand at age five, and it’s the best thing that’s ever happened to him. He adapted to using the myoelectric hand fairly quickly, although he had to relearn some of the things he had been doing with the hook. He’s able to do so much more, and it helped improve his self-image as he started school and began dealing with other children.

Jeremiah and his sister are quite a team. Danelle is a real defender when it comes to her brother. They are very close. They were playing outside at a friend’s house one day. Some neighborhood kids told Jeremiah his arm looked stupid, so he went inside to play Nintendo. But Danelle would not let it drop. She told the kids they were very rude and that Bubby’s “canacal” (what she calls his myoelectric hand) was not stupid! She came home very upset, telling her dad and me about the incident.

“That’s okay, Sissy,” Jeremiah said. “Those kids just don’t know some people have two arms and some don’t. But it’s really okay because we’re all different.”

Out of the mouths of babes...there’s nothing like a reminder that everything really is okay.

**PETER THOMAS, 27**

## **Don't Listen to Anyone**

*At age 10, both of his legs were severed below-the knees in a car accident. Snow skiing gave him a renewed sense of freedom, independence and pride. He excelled in college and went on to law school. Now he is an advocate for the disabled on Capitol Hill and has a world of practical advice on how to make the most of a physical challenge.*



Peter Thomas

I was in intensive care three to four days after both of my legs were amputated below-the-knees. A man who had read about my automobile accident came to visit me. As we talked, the man unbuttoned his pants and literally jumped out of them and up on to the bed beside me. I was shocked. I hadn't even realized that he was an amputee. "I'm a great golfer, have a family and everything!" he said. "If I can do it, so can you."

It's a moment that I'll never forget. It was a turning point in my life. He made me understand that I didn't have to look or act like an amputee. What I did or became was entirely up to me.

After 17 years of living with two artificial legs, the best advice I can give to anyone with a physical challenge is simple: don't listen to anyone except yourself. You are limited only by your attitude and determination, not by your particular physical situation and certainly not by what someone else thinks you can or cannot accomplish. The visit by the stranger was proof of that.

Having said that you are not limited by your physical circumstances, I must say the loss of both my legs below-the-knees at age 10 was a relatively minor handicap when compared with other disabilities. I was young and adapted to my amputations rather quickly. I still had mobility in my knees, and my stumps (or paws, as my girlfriend calls them) were in good condition. When I think of the tremendous accomplishments of people who have lost their knees or arms, are paralyzed or blind, I realize I have it pretty easy.

Lest you think dealing with two artificial legs day after day is a cakewalk, I must say there were times when I'd rather sit and stare at the wall than endure the pain of getting up to turn on the television. When you think about it, I walk on stilts, suspended a foot above the ground. Regardless of how well they fit, there is going to be some degree of pain at some point. When there's pain, think of how fortunate you are to be mobile – then, see a good prosthetist. In the early days after my amputations, I encountered pain frequently, but it seemed to fade once I had some success with my physical challenge.

Some people who genuinely love and care for you are so careful not to get your hopes up that they wind up telling you all the things you "can't" do. These good-hearted people will wait on you, comfort you and not encourage you to challenge yourself – all in an attempt to ease your pain. What they

don't realize is that the loss of a limb can soon become a handicap or disability, rather than a physical challenge in an amputee's mind. And the difference is more than semantic; it is attitudinal. A "physical challenge" is an obstacle to be positively challenged and overcome. A "handicap" immediately assumes an inferiority to the rest, while a "disability" emphasizes an inability to do something. Once your amputation becomes a handicap or disability, the psychological effects of the loss can be devastating.

I was fortunate to have two positive and supportive parents and a close-knit family that didn't cater to my physical limitations. My father used to secretly walk behind me at the shopping mall and then say, "You're limping to the left." I hated it at the time, but I developed a straight gait.

I also became immersed in a quality group of friends who constantly treated me like "one of the boys." If there was an activity that I felt was physically prohibitive, I was never left out nor was the activity cancelled. Instead, my friends found some way to incorporate me into the activity. In time, people begin to see you as a friend or family member – not as a disabled friend or family member. I can think of no greater compliment than when an old friend seriously asks me if my new shoes are too tight or if my feet are cold. When you and your artificial limb become one in your mind and in the minds of others, in a sense you become whole again.

While I believe it would be inappropriate – perhaps even unhealthy – to refuse to accept your amputation, try not to let it consume and encompass your existence. There are millions of factors that make you what you are. Put your physical challenge in perspective and move on with your life. If you negatively take advantage of your disability, you eventually will be liked by few and resented by many. That type of behavior reinforces handicap stereotypes and prompts people to treat the physically-challenged population with pity instead of respect and encouragement. However, please don't confuse exploiting one's handicap with capitalizing upon your physical challenge.

By capitalizing upon your physical challenge, you adapt your daily life to your physical limitations and opportunities will inevitably come your way. I have capitalized on my physical challenge, and my life has been richer and more exciting than I could have imagined.

Before my amputation in fifth grade, I was only interested in one thing: soccer. As I struggled through my first few years with artificial limbs, I



learned to walk well, occasionally played contact sports with friends and constantly rode my bicycle. But as organized sports began to take most of the time of my junior high friends, I knew I had to adapt to and capitalize on my physical circumstances.

At the time, the technological inadequacy of my limbs prevented me from running fast enough to keep up with any junior-high athletic team. I became the football manager, but I had a real desire to be more active. I auditioned for and landed leading roles in school plays. Because few people in the audience knew of my disability, I was applauded for my performance as Mr. Bumble in the play "Oliver," and not for being a handicapped performer. This was a triumph. But in the words of Tom Cruise in the movie "Top Gun," I felt the "need for speed."

Bill Denby, widely recognized as the Vietnam veteran basketball player in the DuPont commercial, taught me how to snow ski when I was 14. Skiing turned out to be my conduit to a new way of life. I raced in slalom, giant slalom, downhill and cross country competitions. I won 11 gold and silver medals over a four-year period in the National Handicap Ski Championships held in Winter Park, Colorado. With travel expenses paid for by local civic organizations and my equipment donated by manufacturers, there was nothing to keep me from whizzing past my able-bodied friends with the wind whipping through my hair. Skiing provided an unparalleled feeling of freedom, independence and pride that began to encompass every facet of my life.

I began to excel in my high school studies, and as a senior was elected class president. Because of my physical circumstances, I took high school seriously and looked toward a good college to help land a career with a decent wage but without strenuous physical demands. I received a settlement for my accident which assured that I could attend college. I set my sights on Boston College and was accepted by early decision. I know that my physical challenge positively affected the college's decision to admit me – not because they wanted to give the handicapped kid a chance, but because I had accomplished a significant amount during my adolescence despite my handicap. I had, in effect, capitalized on my physical challenge and turned it to my advantage.

I'll let you in on a little secret: If you are unassuming and humble...if you disregard your physical limitations and carry a good attitude, living life the

way a good-spirited, able-bodied person would...people are in awe of you even if you have done nothing spectacular. It's like Helen Hayes said: "At my age, people admire you for just being alive." The same is true of someone who seems to get along as well as, if not better than, everyone else but who has a physical challenge most would consider insurmountable. People admire you for just being "normal" and will extend themselves more acutely than they usually would. This is when opportunities arise that would not if not for your physical challenge. Capitalize on these opportunities with a positive attitude, and your life will be enhanced by your physical challenge.

I learned the most about being physically challenged during my years at Boston College. I rejected the "handicapped room" and opted for unadulterated dorm life. Initially, I received some pretty uncomfortable looks in the common showers when 6-foot-5-inch football players would walk in and see me on my knees at 4-foot- 5-inches. My ice-breaking line was always the same: "Just call me Neil." It seemed to relax them long enough for them to realize that I was approachable and just like any other freshman. My roommates quickly adapted and took full advantage of my car privileges for late-night pizza runs. And for the first time, I experienced being with a woman and not being treated differently when my artificial legs were off for the night. I realized a woman could be attracted to me and consider my artificial legs as an interesting, even positive, attribute instead of an impediment to a meaningful relationship. Through all of this, I learned the value of having very good friends and the support generated from those relationships.

In addition to graduating cum laude from Boston College, I served first as chairman of the student senate and later as president of the student body. I represented the 8,500 students on the University Board of Trustees and was selected to represent Boston College as the One Millionth Graduate from an American Jesuit College or University. As chairman of the handicapped committee, I conceived and organized the first Handicap Awareness Day. Subtitled "Sensitivity '86," students simulated a handicap for a day to personally experience accessibility obstacles. The highlight of the day was a speech given by Teddy Kennedy, Jr., who is physically challenged and an accomplished amputee athlete.

It was then that Georgetown University Law School ignored my rather mediocre standardized test scores and accepted me to law school. I had

entitled my application essay: “Adversity, Adjustment, Action, Achievement.” I surprised the director of admissions by striding into his office to ask whether I had been admitted. Once he realized the rather brash person in his office was a double amputee, I suspect that he made his decision on the spot. It was not because I had artificial legs that I was accepted to law school.

Again, it was because my accomplishments were on a par with other applicants who had not encountered a physical challenge. Two artificial legs were just the icing on the cake – or, in his words, “a great gimmick.”

I moved to Washington, D.C., rented a two-bedroom apartment and began looking for a roommate. I wanted a person who pulls into first day classes at law school with no apartment and no plan. I found two such drifters and developed a fantastic group of friends who were every bit as understanding and supportive as my college buddies and my hometown friends. I struck up a relationship with a beautiful woman who could not have been more accepting of my physical challenge.

Some amputees speak of the prejudice and discrimination they encounter, but I have personally experienced little of that except when I’ve been wheelchair-bound after an occasional revision surgery. I have noticed a major difference in how people treat me when I’m in a wheelchair versus when I’m on my limbs. They want to cater to your needs and coddle you. They don’t mind inconveniencing everyone else if it is better for the guy or gal in the wheelchair. To me, this seems like an unhealthy attitude that only reinforces handicap stereotypes.

It was in law school that I became involved in a non-profit, disability advocacy organization called the American State-of-the-Art Prosthetic Association, which has an office in Washington, D.C. The group, comprised of prosthetists, orthotists and consumers, strives to benefit amputees and disabled individuals by technologically advancing the state of prosthetic and orthotic devices. I became consumer vice-president and lobbied on Capitol Hill for legislation to benefit amputees and the disabled. The legislation was signed into law in November 1990.

As a result of the legislation, a National Center for Medical Rehabilitation Research will be established at the National Institutes of Health to coordinate, conduct and support research on medical rehabilitation, including research on the development of orthotic and prosthetic devices.

I became involved in the organization because I felt many amputees were

not satisfied with their artificial limbs, and I felt I was in a position to help. I encourage you to get involved, too. The support of all amputees and consumers of orthotic and prosthetic devices is needed to assure continued progress in these fields. But if amputee advocacy organizations are not for you, I encourage you to get involved in sports, clubs or organizations that interest you. In the words of NIKE, "Just Do It!" The worst thing you can do is to sit on the sidelines and let everyone else have all the fun.

I've had 11 sets of artificial limbs in 17 years and have experimented with just about every type of limb on the market. I have seen my 10-pound leather and rawhide, stiff-ankled, thigh-corsetted leg become a two-and-a-half pound carbon fiber, multi-axial limb, complete with soft "skin" and toes to match. There have been many technological advances in the past decade that have helped amputees. But there remains a vast gap between what is available from different prosthetists and orthotists. Some have led the way to new fitting techniques and material application, but others continue to produce and fit the same old devices.

A new amputee or orthotic user needs to understand there are choices. Ask questions. Talk to more than one prosthetist and even other amputees. Tell the prosthetist about your activities and goals, and place the burden on him to come up with a device that meets your needs. If he can't or won't, the answer is simple: go to someone who will.

There are very few amputees who cannot be fitted with prosthetic devices. Make sure you exhaust your options before deciding not to obtain a prosthesis.

But even if you can't wear a prosthesis or choose not to, your life can be as fulfilling as anyone else's life. All it takes is a positive attitude and a lot of determination, because these are your only two limits. I can say unequivocally that, were it not for my capitalizing upon my physical challenge, I would not have lived my life to its fullest. I choose to listen only to myself and to words of encouragement from family and friends.

And so I say to you, when someone says that you can't do something – be it a task, a sport or whatever – flash them a grin and then proceed to conquer your physical challenge. Don't listen to them – because they are wrong. Don't listen to anyone except yourself!

**JOYCE BAUGHN, 52**

## **Facing Life with Confidence**

*At age 6, her arms were amputated below the elbows when she was run over by a train. She used prosthetic hooks until a control cable broke, then she discovered she could do everything without prostheses. She and her husband Bill launched the first amputee support group in North Texas.*



Joyce Baughn

I was born and grew up in and around Sweetwater, a small West Texas town, divided by several sets of railroad tracks. This geographical fact had a lasting impact on my life.

One beautiful day in May, as I was on my way home from my grandmother's house where I had been playing after school, I found a train stopped across the street. It never occurred to me to walk the block or so necessary to go around the train. I was only 6-years-old, and this was the only route I knew. I soon became impatient with waiting, and a solution occurred to me. If I crawled under the train and out the other side, I could be on my way. The idea frightened me, but as I continued to wait, its appeal increased.

After looking around to make sure I was unobserved, I crawled under the train. Just then I heard the jerking sound that boxcars make when they start to move, and I knew I was trapped. I lay very still and waited for the train to pass not realizing my hands were across the rail. Only after it had passed over me did I realize that I had lost both my arms below-the-elbows.

Fortunately, two soldiers, who were waiting in their car for the train to pass, saw me under the train and were ready to use their belts as tourniquets as soon as the train passed over me. They rushed me to the local hospital where our family doctor did the necessary surgery in the emergency room. He really did a fantastic job – I've never needed further surgery, nor have I experienced phantom sensation. I was in the hospital 11 days.

After my arms healed, I was taken to McCloskey Hospital in Temple, Texas. At that time, as WorldWar II neared the end, it was being used by the military for combat veterans. There, I was fitted with prostheses that had child-size split hooks. After they were built, they were shipped to my home and arrived early in August, in time for my seventh birthday.

With only a month until school started, I had to work hard to learn to use the new prostheses. I have very loving parents, but my mother is also a very disciplined lady. She was told that I had to learn to use hooks, so she did her part to see that I did. Each morning I was dressed for the day, and this included putting on the hooks. They only came off when it was time to get ready for bed. I went back to school that fall with the rest of my classmates. I could print, eat and do the few things required of a second-grader.

In the summer between third and fourth grade, one of my control cables broke. Replacing it was not easy because there were no prosthetic facilities in

Sweetwater in the late 1940s – there probably still aren't. And society was not so mobile then. Besides, there was no real urgency since I wasn't in school.

As I went without prostheses, I used my arms to do things. By using both arms, I could grasp and manipulate things. It quickly became apparent to my parents that I was learning to do everything that I had been doing with hooks plus things I hadn't been able to do with them. Using my arms was easier for me. It required less energy, and it was certainly more comfortable. The biggest advantage to using my arms instead of hooks was that I retained my sense of touch...I was no longer totally removed from everything around me. The control cable never did get fixed.

Looking back, I wonder what my schoolmates thought. The last day of first grade, I had hands. When I started second grade, I had hooks. The last day of third grade, I was using hooks, and when I started fourth grade, I was using my arms. Some of them must have been confused, but I don't ever remember being made to feel different or unwelcome.

Life continued for me much as it did for my friends. I learned new skills about the same time as others my age – with a few exceptions. The things I wanted to do such as drive, I learned to do. Things I really wasn't motivated to do, I postponed learning – such as ironing and becoming functionally independent. I only learned to dress and take care of myself when I left home to go to college. Accepting help at home from family was one thing. Needing help from others was something else.

One area in which I was slow to develop was socially. I do not blame this on my lack of hands. I was and still am shy. The difference is that today I work at overcoming this tendency. I was more interested in reading a book than being with people. I dated some, but I wasn't very comfortable with men, so I decided they were more trouble than they were worth.

My love of reading influenced my career choice. I recognized that I needed to prepare myself to make a living...I would make a lousy waitress! I had worked in the library in high school and college, so I decided to become a librarian. After getting a bachelor's degree in English with a minor in psychology, I received a master's degree in library science. For several years, I worked as a cataloger in various college and public libraries in Illinois, Massachusetts, Oklahoma, Texas and Florida. I liked to travel, and this seemed like a good way to do it.

I enjoyed living alone. I had an apartment, a car, my job and friends. I could be alone or not – as I chose. I didn't think things could be better... then I met Bill Baughn. He is so totally different from anyone I have ever met. That is one of the reasons he fascinates me and perhaps what has enabled me to view life from a different perspective. I do know my growth curve took off like a rocket when we met. He is truly my other half.

Bill is a theatrical technician and was active in that field until recently. We traveled a lot with his work and I "retired" for a while. Being retired enabled me to pursue some untried interests. I became interested in genealogy, made some redwood burl clocks, learned to do needlepoint and tried stained glass using the copper foil method. I enjoyed retirement, but it was time to move on and "grow" so me more.

We moved to Dallas to be near my family and more or less settled down. I went back to work but didn't go back to library science. I had "done" that and was ready to try something different. I went to work for a parts distributor where I have worked in several positions from pricing invoices to back orders and expediting accounts receivable and accounts payable. I discovered I am very good at payables and enjoy it – in spite of the fact that I barely passed math in school.

Bill is a skilled woodworker. He had just gotten his first lathe and we decided to do some arts and crafts shows – though we both had some reservations. I had never worked with the public before. Our reservations were totally groundless. Not only did people accept me as a sales lady, but they were ready to believe I had done the work! That was an ego boost, and it encouraged my interest in learning to work the lathe. We acquired a second lathe and Bill taught me wood turning. There is real satisfaction in producing a piece that someone is willing to buy.

A friend got us started going to the PALS group, an organization for parents of limb-deficient children. Most of the children have birth defects and are being treated at Scottish Rite Hospital. I feel that by being there with my husband, I can encourage by example even when the questions aren't asked. And I am always open to questions at the meetings.

The amputee support movement had started, but there was no organization in Dallas. There was talk, but no action. Bill and I decided the time had come, and the only way to get something going was to jump into it. We called a meeting for anyone interested, and the North Texas Amputee



Support Group was born. We have been involved with it ever since and feel a real commitment to helping other amputees adjust to their new lifestyles, and in some cases, come up with methods of adapting.

I have been asked the secret to my successful adjustment to life as an amputee. I believe it was the way my parents raised me. At the time of my accident, they wished the train had killed me – not because they didn't love me, but because they did. They couldn't imagine how I would be able to do anything and didn't want a life of helplessness and dependency for me.

Since I didn't die, they took me home to love and do whatever was necessary...for however long it was needed. Fortunately, it wasn't long before they saw they were wrong in their initial assumptions. They allowed me to grow and develop at my own pace, and they treated me the same as they treated my two sisters. There was never any question in my mind about their love and acceptance of me. Because of this, I grew up with a feeling of self-worth that enabled me to face life with confidence.

## TEDDY ALVIS, 21

# A Brief Detour

*A week after high school graduation, he was looking forward to college life. A head-on crash took the lives of two friends and left him a bilateral amputee. Although he walks with two prostheses, he has renewed his self-confidence playing wheelchair basketball.*



Tony Alvis

My spirits were high. I was 18 years old and had just graduated from Murphy High School in Mobile, Alabama. Two friends and I were on our way to take a look at the University of Alabama campus, where we thought we might spend our college years. I was planning a career in broadcasting and wanted to be a disc jockey.

It was a rainy June day in 1987. We were on a two-lane highway when a tractor-trailer rig came speeding right toward us. It hit us head-on.

I was taken to a hospital in Birmingham, where I later learned that both my friends had been killed. I was badly burned, especially my legs, and my left thigh was broken. For three days, the doctor worked to save my legs. But there was nothing that could be done. The doctor talked to my folks and me about amputation. I signed the papers for the surgery and told the doctor to do the best he could. My left leg was amputated above-the-knee and my right leg below-the-knee.

I can't say that I was angry about the amputations. It's difficult to remember all the emotions I felt. At the time, I was more devastated by the loss of my friends than the loss of my legs.

I was in the hospital 47 days. During that time, several amputees visited me. They encouraged me even though the doctor told me it would be at least a year before I'd be able to walk again.

During my hospitalization, I began physical therapy, which I continued as an outpatient at the rehabilitation center even after I went home. I'll never forget that first time I was in the swimming pool for therapy. There in the water I felt like I was standing again. For the first time since the accident, I felt like I was on two feet. It was a wonderful feeling.

I kept up my therapy two to three times each week. Because of my burns, it was a long healing process. I wasn't fitted with my first artificial legs until February 1988. I had another friend who had lost his legs during the Vietnam War. He took a look at my legs and said they looked just like the wartime design.

They were conventional, old-style prostheses with metal side joints. Strings laced up the leg. I had so much scar tissue that the prosthetist wanted to take as much pressure as possible off the ends of my legs. That meant I wore moderately heavy straps and a waist belt. I started out with big wool socks over my stumps and leather sockets that fit high over the hip area.

It took me about two months to learn how to walk with my prostheses. I began walking between the parallel bars, progressed to crutches and then to a cane. I took one step at a time and didn't rush because every step was painful. The scar tissue and skin grafts continued to cause me problems...I had to be very careful how I walked to keep the skin from breaking down. I learned how to use the legs fairly well.

It wasn't long after my amputations that a friend introduced me to wheelchair basketball. That was probably one of the keys to my recovery. I had played basketball all my life and was on the high school baseball and golf teams. I just loved sports. The basketball court is where I regained a lot of my self-confidence. I realized my life would go on...and I could still play basketball. My first time on the court was a powerful, emotional experience. Playing from a wheelchair is different, but overall it was an excellent experience. Now, our team plays November through February against teams from all across the southern part of the United States.

I began college during the fall of 1988 at the University of South Alabama. I'd walk on my prostheses, but after a time my scar tissue would break down again, and I'd end up back in a wheelchair.

Going back to school wasn't a tough decision since I knew my life was headed toward a career in the radio industry. College students are probably more accepting of the disabled than some other people, although there is still a lot to be done to make campus buildings more accessible to the handicapped. Of course, some people do stare. You've just got to say "the hell with them" and go on. If they are going to stare, they are going to stare, and you just have to get over that. And there are some busy-bodies who have all kinds of questions. I sometimes tell them I was in a shark attack or something else. That usually leaves them a little stunned, but they don't ask anymore questions!

A college friend told me about a prosthetist who was making legs that helped amputees run. I saw a videotape of all the things other amputees could do and got on a plane to see if I could be fitted with better prostheses. I was excited about the possibilities.

I still had a rod in my left thigh, which the doctor wanted to remove. I had it taken out, but then I re-broke the thigh. It meant my leg went back into a cast, and I spent nine more months in a wheelchair, so the legs had to wait awhile. There are no words to describe being confined to a wheelchair. I

don't think you really appreciate all that people in wheelchairs go through until you've been there.

It was February 1990 before I got my new legs. Now I have silicone socket inserts that protect the areas that were burned on my legs. I can walk longer without the skin breaking apart.

The most exciting things about my new legs are the hydraulic knees. I knew the minute I stood up with the new knees how much less effort it was going to take to walk. Now I can stand up straight and am better supported so I don't fall. With suction sockets on my prostheses, I don't have to mess with the belts, so it's easier to put on my legs.

The new legs have made me a lot more mobile. I was able to walk to class every day last semester. I just don't have the problems when I walk like I did before. I still have episodes of phantom pain, but in a way, I like the phantom pain because I can still sense the feeling in my feet. Sometimes a twinge of pain wakes me up at night, so I squeeze the leg to try to cut off the circulation and stop the pain.

Occasionally I have a down day, but I won't let myself wallow in self-pity. I believe all things happen for a reason and events in our lives are predetermined. I never blame God for that. God gave me a brain and a heart. I believe you have to do the best with what you've got. I guess I could say "the hell with everything" and give up, but that would be self-destructive.

I enjoy playing wheelchair basketball, and with my new legs I can now stand to play golf. Also I continue to play the drums whenever I can. I used to be in a band, and I still enjoy sitting in at the drums to play a little blues or rock and roll. There are some things I can't do, but for the most part, things haven't changed all that much since I became an amputee.

I know different people react to things differently. Other amputees have told me that their girlfriends left them because they lost their legs. That's just a part of it. If someone doesn't like you for who you are, then you can't be close to them anyway. I've seen a lot of people who are a lot worse off than I am. I just thank God I am alive. I think getting to know other amputees has helped me realize we're not so different from anyone else.

**GLEND A STANDEVEN, 35**  
**To Prove the Doctor Wrong**

*The pain in her right hip awakened her at night. Following surgery to remove a tumor, she was told there was no malignancy. But a lump that appeared later led her back to the doctor. It was cancer. Doctors removed her leg, hip and pelvis. One doctor told her she'd never walk.*



Glenda Standeven, hemipelvectomy  
amputee, and son Kevin.

Photo by Jean Konda-Witte, Chilliwack  
Times

My first clue that something was wrong with my hip came innocently enough. I was having trouble sleeping on my right side. I'd awaken during the night with a nagging pain deep inside my hip. The pain would subside during the day only to return at night when I slept on my right side. I tried exercise and took up jogging, which only seemed to aggravate the problem.

My family physician began to treat me for bursitis in my hip, but the pain grew worse. I went to a chiropractor but on my third visit, he insisted I go for X-rays. He said there was something very wrong with my hip – it wasn't bursitis or anything he could fix.

I was an active 31-year-old, so I was relieved when the X-rays revealed it was only a small bone fragment that had broken away from the head of the femur causing the irritation I felt. But my relief was short-lived. The femur head had deteriorated because a tumor had destroyed almost the entire hip joint.

My first biopsy was in May. I was stunned and numb when they told me it was cancer. People die from cancer. The surgeon reassured me that it was not a virulent type of cancer. I would be given a replacement hip, a portion of my pelvis would be removed, and a bone transplant done. The healing process would be long, but I was young and healthy.

The day of my surgery, I was optimistic but scared. The only other time I had spent the night in a hospital was to have my baby. I opened my eyes after surgery to find my husband holding my hand. "You've still got your own hip. They didn't have to do the surgery," he told me. I couldn't believe my ears!

They hadn't found what they expected based on the CAT scan and X-rays. The tumor had spread deep into my pelvis and resembled grains of rice. The pathologist diagnosed the new tumor as malignant, but the surgeon said it was benign. So they did the only thing they could. They removed as much of the tumor as was visible, hollowed out the femur head and reattached my thigh muscle to the bone with a metal screw while they sent the tumor off for further evaluation.

It was more than a week before the biopsy report came back. They sent it to labs in Canada and across the U.S. The strange new tumor was benign. We were sure it was some sort of a miracle! We didn't stop to question the results, but we were grateful I wouldn't need hip replacement surgery.

Months later, after going for physical therapy twice a week to strengthen

my leg, I noticed a small lump on the site of the original biopsy. “Just scar tissue,” I was told. But the lump seemed to be growing. I was determined not to let my worries overwhelm me, but I went to my specialist for one more CAT scan before my husband and I began trying to have another baby. When the scan results came back, my surgeon was concerned. There was definitely a growth there. Another biopsy was scheduled.

The biopsy was done in December. It was a malignant growth that would not respond to chemotherapy or radiation. My only option was surgery. At first I thought the doctor meant he would just remove the tumor. As he explained the surgery in detail, I went into shock. He said my leg would have to be removed. “This can’t be happening,” I thought. “It’s only a small, egg-size lump on my hip. How could I lose my whole leg? And not just my leg. They want to take the hip and pelvis on my right side, too.”

The doctor said time was critical. The cancer could spread to my lungs. I didn’t understand how a tumor on my hip could affect my lungs. Christmas was only days away, but he wanted me in the hospital immediately. I had a 3-year-old son, and I didn’t want to spend Christmas in the hospital without a leg. That was no gift to a small child. I told my doctor I wanted Christmas and New Year’s with my family. My three married sisters, my parents, and our family always celebrated Christmas together. The doctor wasn’t making any guarantees that even with surgery tomorrow that I’d be there next year. I figured two weeks with my family to prepare and pray was not asking too much. I’m glad I took the time. It brought me spiritual peace and strength. And it brought our family even closer.

On January 6, after a 10-month struggle, I lost my leg, hip and pelvis to cancer. The surgical name for it was a hemi-pelvectomy.

The night before my surgery, I lay in my hospital bed stroking my sick leg and saying my good-byes. Losing my leg wasn’t a hard decision to make. I had a son and wonderful husband who loved me very much. Losing a leg would be a small price to pay to stay alive and be with my family. My favorite nurse came into the room. She started to cry when I told her I felt I should throw a farewell party for my leg. The surgery seemed to affect people who were close to me more than it did me. I think my faith in God and my family’s support gave me incredible strength and determination.

I awoke to pain after surgery – incredible, unbearable pain. I’d given birth to a 9 pound, 2 ounce child, but this pain was consuming and unending. I



was totally unprepared for it. They gave me morphine, but that was horrible, too. After the third day of floating in and out of pain and not being able to think or see clearly, I had them reduce the dosage. It was a wise decision because I've since learned how drug dependency becomes a problem for many amputees.

Nobody had warned me about the pain. If I had been able to talk to another amputee, maybe I would have been more prepared. I had assumed once my sick leg was gone, the pain would be gone. Was I wrong! The phantom pain was worse than the ache my leg caused before it was amputated. I kept a journal the first four months after the surgery. My entry from January 28, reads:

*The phantom pain is like electric shocks zapping you out of nowhere, and you never know where they'll hit. Mostly, they seem to be around my foot for some reason. That's where the "popcorn" pain is, too. The popcorn pain is like popcorn popping inside my skin and trying to pop out. It feels really gross! The electric shocks...run up and down my leg with such force I want to scream...It starts off slow, then builds to a zinging climax...and there's a vise pain...like my foot is being crushed by a vise...Then there are the cramps. How do you get rid of a muscle cramp when there's no muscle to rub? When you stand up, the blood rushes to the stump, so it pounds like crazy. When you lie down, the blood rushes away, and the electric shocks zoom in...When I say the pain never goes away, that's sort of a lie because for five or 10 seconds, the pain will stop, and it's like a beacon in the dark showing me the way it's going to be someday. Someday soon, God willing!*

That was written only two weeks after the surgery. Honestly, that incredible phantom pain is nothing more than a vague memory now. I've found most amputees continue to suffer occasional "zingers," but nothing like the first few weeks after surgery. Patience is the best medicine. That and lots of hugs from family and friends. I found prayer, meditation, visualization and relaxation helped me get through it one day at a time. No doctor can prepare an amputee for those zingers. But it's not just in the head. It's real pain. I thank God for the rehabilitation center that taught me how to deal with the pain other than by taking drugs.

After my surgery, a doctor came into my room to examine me. I'd never

seen him before. I wasn't particularly impressed by his bedside manner, but I was trying to be cooperative. He informed me that I shouldn't get any "funny ideas" about ever walking again because it just wasn't possible for someone with an amputation to my extent. If I did walk, it would be with such a horrible, lurching gait that I would be embarrassed wherever I went, he said. At this, he stood up and imitated what my walk would look like. I wanted to die. But he made me so angry that I stuck out my chin and said, "Maybe you would walk that way, but I certainly would not!" I waited until he was out of the room before I collapsed in tears in my husband's arms. Until then, I had no doubts about getting an artificial limb and walking. I desperately wanted to prove him wrong.

About a month after my surgery, I was sent to a rehabilitation center in Vancouver. The center was like a life preserver to a drowning person. There, they taught me how to use an artificial leg. More than that, they taught me to have confidence in myself. I was not handicapped. I became "physically challenged."

I threw away all the painkillers and sleeping pills. I had a rough weekend of withdrawal symptoms, but my family put up with my crankiness and irritability. Everyone knew how much I hated being dependent on drugs, so I had a lot of support when I decided to quit taking them. I found the more I exercised, the less the pain bothered me. By bedtime, I was so tired that I didn't need the pills to sleep. A special relaxation class taught me to escape the pain, and I could use those techniques when I needed them.

My husband and I enrolled in a three-day seminar at the HOPE Cancer Center in Vancouver. We discovered my fears about dying and feeling helpless against my cancer were quite normal. They showed me how to fight back against my disease through meditation and visualization. I was armed and ready to get well. Nothing would stand in my way. I was exercising more than I ever had in my life. My weight dropped to 109 pounds, too thin for my 5 foot 9 inch height, but when I returned home to my own good cooking, I soon regained the weight. I looked and felt better than I had in years.

After three months at the rehab center, I was sent home to begin my life as an amputee wife and mother. I never dreamed doing all those ordinary tasks again would feel so rewarding and fulfilling. My husband Rick and I started a cancer support group to teach other cancer survivors to fight back

with meditation, relaxation and visualization techniques. The group also was wonderful therapy for me as an amputee.

My phantom pain was slowly disappearing until it seemed that one morning I awoke, and the pain was gone. It was wonderful to be free of pain. But one thing still bothered me –my prosthesis.

My new leg just wasn't living up to my expectations. It rubbed me raw and was terribly uncomfortable. I needed crutches even when I was wearing the leg. I didn't know an artificial leg could be comfortable and functional. I just assumed the discomfort was to be expected. Back then, I didn't know better.

It wasn't long before I discovered that I could go faster on my crutches without my leg. So Peggy, as we affectionately called my prosthesis, spent more and more time parked in the closet. I became more and more comfortable going places without her.

One day, my son Kevin and I went to a water park. I crutched into the washroom with him at my side. It was filled with a bus load of foreign tourists. As I entered the room, there was silence. They stood open-mouthed, wide-eyed, staring at me. I was uncomfortable, to say the least. For my son's sake, I decided to hold my head high. As I washed my hands and fixed my hair, Kevin was getting anxious to go. "Mom, everyone is staring," he said. I replied, "Yes, honey, I noticed that. What do you think they are looking at?" He looked up at me with such innocence and love and said, "Beats me. Let's get out of here!" That's how all my family treated me. I'm still Glenda on the inside. Only my outside packaging has changed.

Through it all, I discovered maintaining a sense of humor is a must for an amputee. When my leg squeaks a little, I quip, "Hmmm. Must be a quart low." One above-the-knee amputee friend was getting out of the lake when some kids asked her what had happened to her leg. She never missed a beat. "Sharks," she said. With a smile and a joke, you can set the tone for how others will accept you. If you let it become a burden or an embarrassment to you, others will sense your discomfort and be uncomfortable around you.

I gradually forgot about wearing a prosthesis. I wore my leg only to church (and prayed the sermons were short), weddings and social functions. The pain wasn't worth the cosmetic appeal. But it bothered me so because I wanted to prove that certain doctor wrong.

I refused to let the loss of the leg slow me down much. Skiing was a sport

I enjoyed before the amputation, and I found I enjoyed it even more on one leg. The sense of freedom...of gliding...of going fast like you're running...is almost overwhelming. I was frightened at first, but the instructors soon had me skiing better on one leg than I ever had on two. I even won two silver medals in the British Columbia Winter Games.

I also met a wonderful girl Louise Henriouille who had been an above-the-knee amputee for 13 years. We both loved to ski and became fast friends. She spent many weekends at our house. Together, we tried "amputee racquetball" and devised our own set of rules. Then, we bought toe clips for our bikes. Without our prostheses, we went bike riding around the neighborhood. There were a lot of double-takes, but I think we inspired a lot of able bodied neighbors to get out and enjoy life. When we went to the beach, Louise and I hopped down to the water, and we got more than our share of strange looks. I like to think people admired our courage and determination. Maybe, just maybe, they're a little more grateful for all they've taken for granted.

About a year ago, a friend saw a television program about a prosthetic center in Oklahoma. She contacted my sister, who sent for information. A video showed a girl with the same type of surgery I had who was walking with a cane. The smile on her face made me determined to get a prosthesis like she wore.

My Vancouver prosthetist checked into it, but said he couldn't duplicate the design. However, he was willing to learn new techniques. If I arranged coverage for the cost of a new leg, he would accompany me to learn how the special silicone socket was made. Our local medical program was not willing to spend that kind of money on a new limb, but after six long months of red tape, I was given permission to get the leg. Insurance covered 80 percent of the cost of the leg, and the Canadian Cancer Society gave me \$1200 to help with airfare and hotel costs. My parents gave me \$1000, and I was set to go. What made the trip even more urgent was that I was two months pregnant and a prosthesis was available that could be adapted to fit my growing shape. I arrived at the prosthetist's office looking for a miracle.

The news media covered my story on province-wide television. I was determined not to let my family and friends down. I was going to go home with my crutches in a bag...no matter how hard I had to try. As it was, I didn't have to try too hard. My new leg was ready in just under three weeks.

When I boarded the plane for home, I walked with just a cane. My family was there to meet me at the airport. We all cried as my little boy ran up to meet me, and I was able to bend over and pick him up for the first time in almost three years. I didn't have to drop my crutches or settle for a hug around the leg any more. As the media and others watched, I even waltzed with my father. My husband and I walked out of the airport arm-in-arm, also something we hadn't done in nearly three years. It was the miracle we had prayed for. I had proven that doctor wrong.

Now when I go shopping, people don't stare or ask rude questions. They just think I have a sore leg. They couldn't be more wrong. My leg doesn't hurt at all. I'm fortunate I'm able to wear my prosthesis even though I'm six months pregnant. The only drawback is that my torso is contained inside the silicone socket, so I'm the only one who can feel the baby kicking. The baby will be here soon. And who knows...I may walk into the delivery room and fulfill another dream. All I know for sure is that with faith and determination, all things really are possible.

*Editor's note: Glenda did walk into the hospital wearing her prosthesis, and on November 8 gave birth naturally to a 7-pound, 14-ounce baby boy. Mother and son are doing great.*

**PATTY BATTRUM, 63**

# **Angels Watching Over Me**

*She was living an active and fulfilling life as a wife, mother, grandmother and community volunteer. Then an aneurysm and multiple operations changed the life she once knew. She lost her leg but not her spirit.*



Patty and Dick Battrum

Losing my leg was the result of a long series of operations. It started with an abdominal aortic aneurysm. Despite trying to repair my hereditarily narrow arteries, I still had reduced blood flow to my foot and consequently doctors had to amputate just below my left knee.

It isn't anything anyone ever expects to happen. And when it does happen, it takes a long time to sink in that it really happened to you. But I had an amazing experience in the hospital that made me know I've never been alone. Ever.

Right after the amputation, my husband Dick was taking a nap in my room. We were both so tired; it was a grueling experience for both of us. I was sitting up in bed when a lovely young lady came in and asked me if I was okay. She was dressed like all the nurses and I thought she was checking on my leg. I said I was fine, but really I wasn't. I was quietly weeping.

"Are you sure you're okay?" she asked me. And I told her, "Actually, no I'm not sure." Then – I'll never forget this – she took me in her arms and let me cry it out. She said "I promise you you're going to be okay. I don't want you to ever forget that I'm promising you that."

After she left, I began to feel a real sense of peace. And I was so glad when she came back at 5:30 the next morning. Again she promised me I'd be okay. Dick was awake this time and asked her name. She told us it was Jill. Then she said, "I've got to get back upstairs and finish my work."

When another nurse came in, I asked her to tell me how to get in touch with Jill so I could write her a thank-you note.

"Who's Jill?" the nurse asked me.

"The young lady who was just in here," I said.

"What young lady?" she said. "Honey, I'm the only one on the floor. There hasn't been anyone here but me."

They tore the hospital apart looking for this woman. The doctors couldn't find her; the nurses couldn't find her. No one could find Jill anywhere. And so I think she was an angel – a messenger. It wasn't because I was special; it was because God knew I wouldn't be afraid to pass this story on to other people so they will know they aren't alone, either.

I know other people have been helped by my losing my leg. I don't know how and it isn't my place to know that. But I've asked the Lord to use me as His instrument in this world any way He wants to use me. I didn't want to lose my leg, but I survived it and that's the biggest thing. Whatever it is I'm

saying and doing, I'm doing it because God wants me to. He's using my situation for His purposes. It isn't important for me to know why this happened to me, it's only important to know that God will help others as well as myself because of it.

When you have a disability of some kind, it makes it easier for people to say to you that "Hey, I have this problem and I don't know how to deal with it." Somehow it always comes out that it's not the worst thing in the world.

I think all of us have to deal with something. You don't have any choice. It's going to happen. But if you can wake up in the morning and say "I'm going to have a positive day!" a sense of joy comes from knowing God is in charge.

It helps to have a sense of humor, too. I'll never forget when Dick and I went to a conference at the Thompson Retreat Center in St. Louis. Dick pulled the car up so I could get out at the front door. When I swung my leg out of the car to put it onto the pavement, it went flying. People stood there with their mouths wide open. What can you do? You chase down the leg and put it back on. And be sure to give everyone a dazzling smile. That was before I was fitted with a good leg.

Having a good prosthesis gave me back my life. I want to do a lot of things. I want to be a good wife. I want to be a good mother. I want to be a good grandmother. With my old leg, I couldn't. But my new leg gave me my life back so that I could contribute to our life as a family.

After I lost my leg, the two things I missed most were riding escalators – I love to shop – and walking on the beach. The first time I took a walk on the sand with my new leg, I took my dog Mackie and walked out to the water. I walked very slowly and very carefully. And then when I got as far as I thought I should go, I turned around and thought, "Oh, well. I wonder if I'm going to get back now..." But it felt so good to be doing it. I wasn't afraid to try.

I like that my prosthetic leg looks the same as my other. It feels like skin; it's soft and patterned after my real leg. That's important to a woman. No matter if you're 180 years old, you want to look as good as you can. Particularly if you have a good-looking husband like I've got. I came to Scott Sabolich a year and a half after struggling with a bad prosthesis and searching for something better. My physical therapist gave me a video about the company, and it was the light at the end of the tunnel. I knew if someone



could ski and run and do all the things they were doing, the least I could do was get up and walk.

I'm the Princess and the Pea, but thanks to Scott Sabolich, I'm finally able to walk comfortably. It takes a tremendous amount of patience and know-how to treat amputees, but there's no one at Scott Sabolich who doesn't care. Everyone there has a vision to make life better, and they're doing that better than anyone I know. My limitations seem to be disappearing one by one. I'm never going to be a long distance walker, but I can sure walk as far as I need to.

One of the things I'd really like to do with my life is to help someone who's sitting out there in a wheelchair just like I was doing. Someone who has no idea what can be done...who has no idea of how they can be helped...who has probably said "I'm just not going to get up again because it hurts too much." It doesn't have to hurt. And you can live life again. To know I could get my hopes and dreams back – it's given me the passion to help others who need it.

## SARAH EAST, 11

(and her mother Brenda)

# Oops, an Alligator Got Me!

*Born without her left leg, her parents worried what the future would hold... would she be accepted by other children? Once she had a prosthesis, nothing could stop her. In fact, her dreams of running led to improvements in artificial limbs that helped other amputees run.*



Sarah East

*From Sarah:*

I've never had two legs. Sometimes that's hard, but most of the time I don't think about it. I still play softball and run with my brothers and sisters.

One thing I don't like is that my parents won't let me play basketball. I can't go swimming with both legs, and in the summer, only one leg gets tan.

Sometimes kids make fun of me or stare, and I want to beat them up. Sometimes I just tell them, "Why don't you take a picture . . . it lasts longer." Little kids are curious about my leg. I tell them I got it stuck in a blender or an alligator ate it. They get funny looks on their faces.

*From her mother:*

Sarah was our third child. Like any mother, I was praying for a healthy baby. I had no reason to suspect my baby would be any thing but perfect. I'd had a healthy pregnancy with no complaints other than the usual nausea and aches that go along with it.

My labor pains were already five minutes apart when my husband Carl and I started for the hospital at 2 a.m. In a few hours, Sarah was born. As I lay in the delivery room, I heard a healthy cry. The doctor told me I had a girl. I should have known something was wrong when he didn't let me see the baby. It wasn't the normal routine. As they gave me a painkiller to knock me out, I went to sleep thinking I had a perfect little baby girl.

When I awoke four hours later, my room was crowded with people . . . my parents, brother, Carl and Carl's mother. Carl's mother never had visited me at the hospital before. I should have found that strange. Our pediatrician came into my hospital room.

"You know there is a problem with the baby," he said. His words shocked me. "What problem? What's wrong?" I gasped. No one had told me anything was wrong; he just assumed I already knew. The doctor explained that Sarah had been born without her left leg but otherwise was a healthy baby. He asked if I wanted to see her.

"No, I don't want to see her at all," I sobbed. I didn't think I could bear it. The pediatrician assured me there was no retardation and that with an artificial limb my baby Sarah would live a normal life. After a few minutes, I gave in. I wanted to see my baby.

They brought her from the nursery...screaming her head off. But the moment the nurse placed her in my arms, her crying ceased. I cried harder.

I continued to cry, not understanding why this had happened to my baby. The doctor had no answer either. I later discovered that other children like Sarah were born to mothers who had taken the same medication I had for morning sickness. But we had no clue when she first was born. Sarah had her left leg down to the knee, where a tiny, three-toed foot was attached. I cried so much those three days in the hospital that the doctor threatened to give me medication that would knock me out unless I stopped. There was no one else who could tell me what it was like to have a child with one leg and that it would be okay. Fear...anger...guilt. I experienced them all at once as I sat in my hospital bed gazing at Sarah.

“What will her life be like? Will other people accept her, and what will she do?” I kept wondering. I was afraid of how others would respond when they saw her. Some people really are afraid of handicapped people. I remember stopping at a friend’s house on the way home from the hospital. I pulled back the blanket so my friend could see Sarah’s leg.

“Brenda, that’s not so bad,” she said. She didn’t faint or drop dead or anything. No one has ever looked at Sarah and been disgusted.

My husband told our two older children that Sarah had been born without a leg. They cried. They were really scared. It was hard for all of us those first few weeks. Carl felt guilty and was fearful, too. We just kind of closed ourselves off, not talking much about it. But Carl and I did agree that whatever Sarah needed, she would have...even if it meant sacrificing other things. We also agreed we couldn’t baby her. We had to treat her just like our other children.

One of our first trips out in public was to church. The people there were great. Of course, they expressed their sorrow, but none of them were horrified. Some of the older ladies wanted to know what we were going to do. I simply told them, “She’s all right now and she is healthy. When she’s older, we will take care of it.” One funny incident occurred when we took six-week-old Sarah to a photographer. He was making such a fuss over what a beautiful baby she was. He kept wanting to uncover her legs. His mouth dropped open in shock when he pulled back the blanket. I don’t think he knew what to say.

As we adjusted, I still had days when I looked at Sarah and just cried. (Sometimes, I still do.) I just didn’t know what she was going to do. But as time went by and I looked at other amputees, I realized they had gone on

with their lives, so I knew there was hope. Sometimes, I just have to stop and give myself a little pep talk.

Our older kids, Daniel and Chandra, were so excited about their new sister. They loved her so much and wagged her around like a little puppy. They were very protective of her and still are.

The doctors had told us Sarah could be fitted for a prosthesis as soon as she started pulling up. She crawled earlier than most babies and was pulling up at four months of age. It was nearly Thanksgiving, and we were ready for an appointment with the orthopedist. We were referred to Children's Hospital in Oklahoma City, but we couldn't get an appointment until February. The waiting was frustrating. I wanted to do something to help her right then.

We started going to children's clinics that February. It was both helpful and hurtful. I was able to talk to other parents who had similar experiences and that helped. But the clinics involved a bunch of doctors standing around arguing about what should be done with my child. It seemed so impersonal. That was not only frustrating – it hurt.

We saw the prosthetist the same day we first visited the orthopedist. He fitted Sarah with a leg that utilized the little foot to hold it on, but he cautioned that she probably wouldn't be able to walk right away. She surprised us all when they put the leg on and she took her first steps. Carl and I were encouraged.

But my joy turned to tears the next day when I put the leg on her. She'd crawl and it would fall off. I must have put it back on six times in 15 minutes. I called the prosthetist, and we went back to have it fixed. It was all new to him, too. Sarah was the first little one with whom he had worked.

Sarah walked by herself at 15 months. She walked stiff-legged, but she really got around. Believe me, she could go.

The following July, doctors wanted to operate to remove the little foot that was attached to Sarah's leg. It would allow for better fitting of a prosthesis. But the doctor wanted me to put her in the hospital on her birthday. It had waited this long; it could wait a few more weeks. The hospital was no place to spend your second birthday.

I was still leery of the surgery, but the pediatrician examined Sarah and thought she could handle it both physically and emotionally. We decided to go ahead with the operation while she was young. She would heal quickly.

We tried to tell her what was going to happen...that it would hurt...but mommy and daddy would be there with her.

The doctor removed the foot and a bone that was growing out the side of her leg. They gave her pain medication, but only the first day after the surgery. She had a big, bulky bandage on her leg. She cried, but it was hard to pick her up to comfort her without causing her more pain. I guess she finally got accustomed to the pain. Carl would take her for rides in the little red wagons that were used to transport children around the hospital. She'd try to kick the nurses as she went by. We couldn't figure it out, so we asked her why she did that. "They hurt me," she answered. Sarah thought the nurses had caused her all the pain.

The doctor put the leg in a cast before we left the hospital. But it fell off as soon as we were home. I took her back to the doctor, who showed me how to wrap it. I became really good at wrapping the leg. Two to three months later she got her first bent-knee prosthesis.

Even though Sarah was doing well, I still wondered what it would be like when she started school. Kids can be so cruel. When she was not yet two years old, Daniel wanted to take her to kindergarten as his "show and tell." We went, and the kids were fascinated. Sarah was the only amputee in our small town. I think being around her has helped other children to be more accepting of people with handicaps.

Sarah was only 3-years-old when she told prosthetist John Sabolich that she wanted to run. He looked at her and said, "But Sarah, you are an amputee. Amputees don't normally run." She was undaunted. "If you would make me something better, I could run. I could run fast," she told him. He videotaped her trying to run with her old prosthesis and discovered she was trying to run step-over-step. That was something above-the-knee amputees just didn't do.

To help her, Sabolich developed the OKC running cable. Sarah loved it. It made the knee snap out faster, so her leg was there when she was ready to take her next running step. Sarah just took off! She was the first above-the-knee amputee to run normally, step-over-step. She could keep up with her friends. She raced her brothers and sisters, played ball and jumped off the porch. It was great to watch her. I knew then nothing was going to hold her back...nothing was going to stop her. I think the running really gave her a lot more confidence. It brought her out into the world and made her feel like

she could accomplish anything.

As Sarah has grown, Carl and I have tried to stick with our pledge to treat her like our other children. Sometimes it's hard to let her do things when we think she might get hurt. She learned to ride a bike in first grade. At first, she refused to wear her prosthesis because she could pedal with one leg. After a while, she learned to ride with an artificial leg like other kids ride with both legs. It was a scary experience for Carl and me. We live at the top of a hill. There were a lot of rocks and gravel at the bottom of the hill, and we were afraid for her. Despite our cautioning, she took off down the hill...like any other kid. She landed face down in the gravel. She looked like she'd been beaten, and she missed a few days of school. But within a few days, she was back on her bike. She still falls, but she gets right up and goes again. That's the way we have raised her all her life.

Probably one of the hardest moments for me came when Sarah was in second or third grade. We'd weathered a lot of the bumps and gotten through most everything...or so I thought. One day, Sarah looked up at me and asked, "What does it feel like to have two legs?" I wanted to burst into tears. For Sarah's sake, I knew I couldn't. I wasn't sure what to tell her. "You know what it feels like on your right leg?" I asked her. "Well, just imagine your left leg feeling the same way. That's what it feels like." The answer seemed to satisfy her, and she has never asked that question again.

When Sarah was six, there was another addition to our family. But this time, it was a set of two. The twins were born perfectly healthy. They grew up playing with Sarah, never thinking about her leg. It wasn't until almost three years later, when she was standing in a doorway, that one of them noticed she didn't have a leg. "Sissy, where's the rest of your leg?" Zachary said. He just stood there feeling her stump, with wonder in his eyes.

Sarah is a little upset with her dad and me now because we won't let her play basketball or soccer. We just don't think she could keep up with soccer. We know she can play basketball, but we are afraid she might damage her good knee playing competitive basketball. She always has done everything the other children did in physical education classes. Other than those two things, we've tried to let her do whatever she wanted to try. We had to modify what we said to her when she was little. If we said, "You can't do that," she'd set out to prove she could. We had to learn to say, "We don't want you to do that."

Now, she helps with chores just like the other children. If she wants to get out of work, she may complain about her leg hurting. It's like any child who feigns illness to get out of work. We try to be fair with all our children. But from time to time, there is some jealousy among the older children who may feel Sarah is getting away with something because she has one leg. I know there are times when we're overly protective of Sarah, but by the same token, if she needs a spanking, she gets one.

Sarah's growth spurts are our biggest problems right now. It is impossible to keep her comfortably fitted in a prosthesis. She will wear a leg for a few weeks, and then it's too short or too tight. We've always tried to get by for 18 months before we replaced a leg. The prosthetist has worked to make little adjustments that allow her to wear it longer. In fourth grade, Sarah refused to go get a new leg fitted until school was out for the summer. She often misses school when she is having a leg fitted, but that year, she wanted to get the perfect attendance award at school.

I think whenever you have a special child, you always worry... about the future, about what kind of job she will be able to get, if any man will ever love her and marry her and if she'll be able to have a family. I've grown with Sarah over the years. But it doesn't mean that I've stopped worrying about her. She still weighs heavy on my heart, but the logical part of me says she'll be able to do anything she wants. And she'll probably do it better than other people. She's just more determined.



**BILL MURRAY, 58**

## **Easy for You to Say**

*After he lost his left leg to diabetes, he spent a day feeling sorry for himself. He took a week off to rest. And then he dedicated his life to helping others who have lost limbs.*



**Bill Murray**

In 1988, I took a job as a radar instructor for the Federal Aviation Administration, and we moved from Indianapolis to Oklahoma. I was only there about six months when I developed extreme pain in my feet. I was diagnosed as a diabetic but managed to control the disease and stayed on the job until 1995.

In 1997, I developed a diabetic-based disease in my right foot called Charcot Marie Tooth syndrome. The nerves in my foot stopped controlling my impulses and collapsed in a pile, leaving my right foot distorted. I wound up in a series of casts over a 20-month period. I lost my little toe and the outside portion of my foot. Six months later, the doctors took the next three toes, leaving me with only my big toe on that side.

It was a painful experience, and I remember asking the doctor if he thought it could happen to my left foot. He assured me he'd never seen it occur in both feet on anyone.

But just a year later, the nerves in my left foot were starting to do the same thing.

I was hospitalized in February 1999 with a serious infection and on February 20, I was told I was going to lose the left leg below-the-knee. I knew it was coming in a way. I thought I was prepared for it because I had done a lot of research – I've always controlled all my medications and I knew what the disease was all about. We made arrangements to do the amputation March 9.

A prosthetist came to the hospital prior to my losing my leg. He gave me some literature and a video and prepared me physically for what was going to happen. He gave me some exercises to help strengthen my leg, which I began immediately. I thought I had everything under control. I thought I had taken care of everything. Then I opened up some of the literature.

It said that the first shock would come when you look down to the bottom of the bed and the blanket is lying on the bed instead of your leg. It was 11 p.m., and I was all by myself. I told myself, "I'm not going to dwell on this." But I read on. The brochure said the next shock will come when you have to unbandage what's left of your leg by yourself.

I had prepared myself so well – I was so rational – Dr. Janssen will cut here, sew here, and it will be all over. I hadn't thought past that. I hadn't thought at all what it would be like after the surgery. So I had to start preparing myself all over again.

With a name like Bill Murray you know I've got to be a comedian. That's what helped me get through it. Right before surgery (in front of my two ministers, my two sons – Bill, Jr. and Eric – my wife Judy, and four or five people from church) I grabbed Dr. Janssen by the neck of his scrubs, pulled him down to within an inch of my face and said, "Are you really going to do this, Doc, or are you just pulling my leg?"

He's a pretty serious, business-like physician, but he just lost it. Everyone cracked up.

Then he asked me, "Anything else?"

"Yes, I want a t-bone steak for dinner," I said.

"How do you know you'll feel like eating?" he asked.

I told him, "Are you kidding me? I love steak! I'd give my left leg for a t-bone!"

Losing part of your body is difficult. But if the alternative is death, then there's no question. I got over pitying myself pretty quickly. On my first day in rehab, I was very irritable and in a lot of pain. I had a miserable move in the rain from the hospital to the rehab center and on a bumpy road. I let the nurse know I didn't want to be there. I told them I wanted to eat my dinner alone in my room. They told me I'd be eating in the cafeteria just like everyone else on the unit. I got across the hall to the cafeteria and I was in the best shape of 30-some people in the room. So I lost the "poor me's" pretty quickly.

I took myself out of service for one week after rehab and that was it. In fact, as assistant director of Canadian County Emergency Management, I was chasing funnel clouds without a leg or prosthesis on May 3, 1999, in the infamous Oklahoma City tornadoes. I didn't let my leg loss slow me down too much.

My family has been great about this. My 4-year-old granddaughter treated my wound, and all my grandchildren wanted to see it immediately. We didn't hide anything from them. Now when they see someone with no arms or legs in a wheelchair, they don't stare; they go over and talk to them. They tell them, "I'm sorry you're sick. You're worse than my grandfather. I'll pray for you." Kids don't see anything wrong with me. They think it's cool. It's different but not weird. The Bible says by your children you shall be taught. Now I have a lot of adults used to it, too. Education is the secret.

With my prosthesis, I get around well enough that I can shock people. I

see a lot of bitter people. There's no sense in blaming. I don't blame the Lord. The best thing for me to do is try to help other people. And it helps me just as much as it helps them. So I spend a whole lot of time talking to people who are going to or have just lost a limb.

When I go in to see them for the first time, I always wear long pants. And I carry a clipboard like I'm a social worker or a psychologist. And I talk with them. And invariably, something will come up like, "Easy for you to say. Why don't you have your leg cut off?" That's when I show them. They look at me and their mouth falls open. And I pretty much shock them into silence. It does the trick. I tell them that one minute after I got my new leg I walked 100 feet. And I'm a big guy; I weigh 250 pounds. If I can do it there's no reason anyone else can't.

One guy I helped weighed 500 pounds. He lost his grandchildren, lost his fiancé, and his grandmother had died. He was absolutely depressed. People said he wouldn't walk but I said, "I'll have him up in two months." And he was. He just needed someone to listen.

I'm in real or phantom pain 24 hours a day, so I get depressed sometimes, too. But I just try to turn that over to the Lord. I spend late nights tinkering with my ham radio, my trains, my computers or on my radio telescope, listening to Jupiter and all the stars and planets sing. I don't know any other way to do it other than finding someone else that needs help.

The most important person to come through all this is my loving wife Judy. Without her tolerance and help it would have been much harder. Married 39 years and still in love!

The biggest thing I tell people is, "Don't give up." You still have a lot of life left. But when all else fails, turn to the Lord.

**PRESTON CROSS, 36**

## **Helping Others Helped Me**

*A 27-year-old diabetic, he underwent a simple operation on a broken nose. An overdose of anesthesia set in motion a series of medical maladies, one of which resulted in the amputation of both legs below his knees. He took up a career he had once abandoned, counseling others in crisis.*



Preston Cross

As I rounded second base that game, I could see the play at third was going to be close. I would have to slide to keep from being put out. As I slid, the third baseman made the tag – right in the middle of my face. The blow broke my nose. Doctors suggested rhinoplasty, a 30-minute operation, to clear up the breathing and sinus problems that resulted from the accident. No problem. Except for being diabetic, I was a healthy 27-year-old.

But something went wrong during surgery. I received too much anesthetic. Protein spilled into my urine, and my blood pressure shot up to stroke level. They weren't sure why I'd received too much anesthetic, but afterward they told me there was kidney damage. In three to five years, I would need a kidney transplant or dialysis. It was only three months later that my kidneys failed. I began dialysis and felt fortunate when doctors found a kidney donor after a few months

The transplant was successful, and I was back to work at my sales job with General Foods within six weeks. What I didn't know was that I had contracted a deadly virus through the donated kidney that would send me back to the hospital. CMV, as it is called, kills 85 percent of the people who contract it. I was in a coma for 14 days, paralyzed from the neck down. My weight dropped from 155 to 105 pounds in two weeks. At one point, doctors gave me less than a one percent chance of seeing the next sunrise.

Fortunately, God was with me and I survived. After a lot of physical therapy, I was back on my feet. But the high-powered antibiotics I was being treated with were experimental. They led to a reduction in both the size of the arteries and amount of blood flowing to my extremities. A year after I left the hospital, I was recuperating from the virus when I was told my right leg would have to be amputated below the knee because of gangrene.

When I awoke from the amputation, I kept thinking that maybe the doctors had been able to do something during surgery... maybe my foot was still there. But as I looked down the bed to where your foot normally causes a peak in the sheet, the sheet was flat. I knew it was gone. I cried. I went through all the stages of grief.

The phantom pain was unbelievable. It was the same pain I had felt before the surgery. Normally, diabetics experience numbness in their limbs, but I had already gone through excruciating pain in my foot. Now the foot was gone, but the pain was still there. I was eating pain killers like M&Ms.

The worst time was at night...2 a.m., when everything was quiet at the

hospital. There was no one around. No one to talk to. I didn't want to call someone at that hour and bother them, but I just wanted to hear someone's voice. I was desperately lonely, and I cried "why me?" to God.

I went through physical therapy and got a prosthesis that let me walk. I was doing well with the new artificial leg...and even played softball eventually. When I first got the leg, however, I relied on my crutches. I didn't think that little leg could possibly hold me up. But one day the phone rang, and instinctively, I got up to answer it. As I turned back around, I discovered I had left my crutches behind me. I could walk on the leg.

I think it takes different amputees different amounts of time to "turn the corner," so to speak...to realize there is life after amputation. It was a couple of months after the amputation that I really came to realize that even though I'd lost a leg, the real Preston wasn't gone. I had refused to be seen in shorts publicly up to that time, but one day I wore shorts to the store. I got a lot of stares, but it didn't bother me. I knew I was coming to grips with being an amputee.

Just as I was learning what it meant to have lost one limb, my left leg turned bad. Doctors told me it would have to be removed. My wife Patti and my mother were with me when the doctors told me the second amputation was needed to remove the leg below the knee. I was devastated. I think it was easier physically to deal with the second amputation because I knew what to expect. But emotionally, it was harder. I was ready to give up. Every time I saw a doctor, I was told something else had to be removed. I was seeing parts of my body erased inch by inch. My life was nothing but a series of operations. I pictured myself sitting in a wheelchair for the rest of my life. I was in my early 30s...a time when life is really supposed to be kicking off.

I believe losing a limb is harder than losing a friend or relative to death. It's like a part of you is dead and being taken away. I thought of suicide several times over the course of all my surgeries. But I decided that was the easy way out. I'd been through a lot, and I'd make it through this. Life was too important.

I wasn't through yet at the hospital. The medication I was taking to maintain the kidney transplant led to different ailments and infections. I suffered a heart attack and had to have open heart surgery a year later. Later, I made two more trips to the operating room to remove fingers from both hands because of vascular disease brought about by the diabetes. I felt

likemy life was out of control. Everyone likes to have some control over life...to be able to say “no.”But I couldn’t stop what was happening. It still is tough to visualize myself as whole sometimes. But I keep a good outlook – it’s all I’ve got. I don’t have my body, but what I have to offer people are my thoughts and personality.

I had begun volunteer work as a counselor at a local hospital shortly after my kidney transplant. I majored in social work in college, but I never pursued a counseling career because at the time, it just didn’t pay enough money. Being at the hospital, however, I saw people who were much worse than I and who were suffering a lot more.

After my amputations, I began to visit with other amputees at the hospital and at a prosthetic firm. Helping the mended up helping me also. As I shared what I had gone through...how I’d made it, it helped them. But as I shared my story, I found new strength by being able to talk to someone about my feelings and emotions. Communicating...sharing what’s bothering you with friends, family and especially your spouse – that’s one of the hardest things to do, but one of the most vital.

The amputations and all the physical problems kept my family in a state of turmoil. I have two daughters,Alicia and Kelli, who never really have known their daddy when he was healthy. They’d have a big day in their lives and I’d be off to the hospital. My wife Patti and I have spent half our married lives dealing with my medical problems. We endured great emotional and financial burdens. It almost wrecked our marriage. We even filed for divorce, but we decided we’d been through so much,we’d try to get through this.

I know it sounds chauvinistic, but it was hard to reverse roles with my wife. Suddenly, she was the breadwinner. I was at home with the cleaning and the cooking. It just wasn’t the way we had planned it. I was supposed to be working to support my family,while she wanted to stay home with the girls. Of course, I wondered why my wife would even want to stay with me because of my physical appearance.

Through it all,my faith in God sustained me. As I’ve talked to other amputees, they repeatedly share an overriding sense of a spiritual being that’s helped them through their traumas. Family and friends are great support, but sometimes you are by yourself. You need to cry. You’re searching for answers to your questions. God has given me strength and purpose. He was there at those 2 a.m. hours when I was lonely.



It seems people are always in a hurry. There's that old adage about stopping to "smell the roses," but few actually do. When you endure such physical infirmities, you have to slow down. You've got time to think about things. I discovered how many times I blew it...how many things I took for granted. I realized that fighting for money, job or status isn't what is important. I think I have come to understand why we are really here.

*Editor's note: Despite continuing critical health problems, Preston rarely felt sorry for himself, and he always went out of his way to help other amputees find meaning in their lives. He felt strongly about sharing his story in this book but never had the opportunity to see it in print. Complications from advanced diabetes ultimately led to a heart attack which took Preston from us. He was an inspiration to all who knew him, and he will be greatly missed.*

**BILL NIENABER, 65**

## **Finding the Right Leg**

*A telephone company marketing manager for a five-state area, he led an active life. He and his wife were avid snow and water skiers. At age 63, a malignant tumor was found behind his left knee. He refused to let the amputation of his leg at the hip sideline him from the life he loved.*

My wife and I were skiing Vail in late winter 1987. I was looking forward to hitting the slopes at the top of the mountain. But as I sat down on the lift that morning, my left leg felt as if I were sitting on my fist. There was a hard knot behind my knee.

I waited until we returned home to St. Louis to consult a doctor. On the way to the hospital for a biopsy, I remember thinking, “So I’ve got a lump in my leg; I’ll just have it taken out.” The biopsy showed I had a malignant tumor. It was way up inside the leg, and there was no telling how long it had been there. The doctor, who was a friend and neighbor, looked me squarely in the eye and said, “Bill, we take the leg off for this type of thing.” I was in shock.

My wife June was at work. I waited until she came home that evening to break the news. I sat her down on the couch and told her what the doctor said. We sat and cried. It was several days before we began to overcome the shock. It was hard to accept that I might lose my leg, but I was glad the doctor told me up front what was likely to happen. We thought about it for a month, trying to decide what we should do. I don’t know what I would have done without my wife.

Then the doctor began pushing me to get treatment. He said we shouldn’t fool around with the cancer any longer. I checked into the hospital for an aggressive program of chemotherapy. They put a tube into an artery under my left armand ran it all the way down my side to the tumor in my leg. I underwent chemotherapy for three days. As the treatments continued, I felt awful. Nasty is the only word to describe chemotherapy. I couldn’t eat – the food just wouldn’t go down.

The third night I awoke screaming. I had a chemo burn on my groin. The chemicals were burning from the inside out. The pain was so intense, they

gave me four shots of morphine. Nothing phased it. They stopped the chemotherapy.

I went home after a few days but returned to the hospital every day for radiation treatments. The radiation continued for 25 days as the doctors hoped to shrink the tumor, but a follow-up MRI scan revealed that the treatments had failed. It was then that the oncologist and surgeon recommended amputation. But I wasn't ready to have the leg off just because they said so. I got opinions from two other doctors.

I was told that the back of my leg could be removed and the tumor taken out. I'd have to wear a brace, and the leg wouldn't be worth much, but I would be able to walk on it. But if they removed the leg, there would be enough flesh to make a good stump for a prosthesis.

In addition, the doctors were concerned that by not removing the entire leg, there was a risk the tumor would grow back. If that happened after the back of the leg had been removed and it had to be amputated later, it would mean grafting skin from my back to close up the stump. I told them I'd sleep on it. Two days later, I told them to take the leg off. I wanted to be done with it and get on with my life. But it took a month to get the radiation out of my system so they could operate.

While I was waiting, I wanted to talk to someone about a prosthesis. I didn't want to wait until the leg was gone. That's the way I am. When I'm building a house or working on a project, I'm always thinking about the next step. I was involved in volunteer work through my job, and I was familiar with the Shriners' Children's Hospital in St. Louis. I figured if anyone knew about artificial limbs, they would. No one had offered me information on a prosthesis.

I asked a friend at work who was a Shriner to help me. He introduced me to a prosthetist who had been in the business 35 years and who also was an amputee. I figured he must know what he's doing. I told him I was going to lose my leg and asked him to make me a prosthesis.

It was summer 1988. I wanted to go to the lake to ski one last time with two legs. We belong to a group of water skiers that gets together every summer at Norfolk Lake in Arkansas. I always had done trick water skiing, and my wife and I even did acrobatics in which she stood on my shoulders while I was skiing. I was still under the phone company's insurance program, and the insurance company didn't want me to leave the city with

my pending surgery. My doctor said that was ridiculous and wrote the insurance company a letter asking them to give me a break since I was going to lose my leg.

I still was weak from the radiation and my hair was thin, but I was determined to go. I skied barefoot and slalom and also swam. It wasn't as hard to get through it physically as it was mentally and emotionally. I love water skiing. As I tried to enjoy the trip, I kept thinking, "I may not be able to do this ever again."

But I was surrounded by friends and family who were hoping only for the best for me. Everyone was teary-eyed as my wife and I prepared to leave. It even broke up my one really macho buddy, who thought he could never cry.

I returned to St. Louis where I checked into the hospital. The next day, they took my leg off. They did a hip disarticulation, removing the leg at the hip socket. They were afraid that leaving any of the thigh would increase the risk the cancer might return.

I awoke from the operation in good spirits. It was over then, and I was ready to regroup and get my body going again. By the second day, I had a trapeze over my bed, and I was doing chin-ups. I didn't have a great deal of pain from the surgery, but I had intense phantom pain. Even when I went home, those sensations in my leg that wasn't there kept me awake at night. I'd lay in bed watching television into the wee hours of the morning until I was so exhausted that I'd finally fall asleep.

When my leg was sufficiently healed, I went to the prosthetist for my first fitting of my artificial leg. He did the casting, and about two weeks later, I got my leg. He worked with me and showed me how to throw my hip out to make my leg kick out. I did it as soon as he put the leg on me, but it was uncomfortable and awkward. And I hated the way my walk looked. He told me I would just have to get used to it.

That was impossible. The socket was like a hard bucket, always pressing in on me. I was constantly in misery. I'd wear the leg when I had to...to a party or special function and when I went back to work. At work, I was running an office of about 70 people, so I was on my feet all day. It really was uncomfortable trying to walk on the leg. After about three weeks, I thought: "Why am I doing this? It's not worth it. I'll just retire. I've got 42 years in."

Later, my brother was reading National Geographic. He said, "Hey, you've got to read this." There was a picture of a guy who weighs about 200 pounds

running with two artificial legs. Of course, he had his upper legs. I knew that made fitting the prostheses easier. The guy had lightweight legs of space-age material and energy-storing feet. I figured I had to talk to the prosthetist who was able to do that.

I talked to the insurance company. They had paid for the total cost of my first leg but would cover only 80 percent if I wanted another leg. I decided it was worth it. I traveled to Oklahoma City to the Sabolich Center, the same place Ted Kennedy, Jr., had been fitted. I figured, as a Kennedy, he could go anywhere, so I'd give this place a try.

The new socket is a lot softer. I am no longer tormented by the socket burning around my hip bone. With a special spring on my leg, I don't have to throw my hip out anymore to get my leg to kick out. When I put my weight down on my foot, that loads the spring. When I relax, my foot steps up. I no longer look weird walking down the street. If I'd had this prosthesis before, I might not have retired.

I still do everything I want; I've rigged things to compensate. Before I lost my leg, I welded a handle on my three-wheeler and my tractor so I could shift gears by hand instead of with my foot. I wanted all that done before I lost my leg so I wouldn't have to call someone to do it. I drive a four-wheel Bronco and an all-terrain vehicle. I maintain five acres, and I mow the grass...I can do almost anything. I have given up my mountain bike. I could put a strap on the pedal and ride with my artificial leg, but I'm used to riding pretty fast. I don't want to tear up my good leg.

Last winter was my first time on snow skis with one leg. I took lessons from an instructor who had worked with other amputees, and by the third day I was skiing from the top of the mountain. I raced a course I'd raced before. I used to do it in 28 seconds, but it took me 58 seconds. They still gave me a gold medal...for courage.

I want to stay active in sports. I've been back up on one water ski too. I taught myself to ski barefoot once before, and now I'm going to try that on one foot. I know it can be done. I plan to use a boom on the side of the boat, instead of a ski rope.

I decided from the start that it doesn't do any good to sit around and cry once your leg is gone. You just go downhill, and your body wastes away. Then there's no place to go but down. People gave me books about cancer and amputees that talked about being down and depressed, but I never really

was. I'm starting a support group now, but not necessarily for those who are down. It's to help people find the right kind of prosthesis from the very start. I want to share what I went through and what I learned. I want to tell them to look around to find what works for them. It's important if you want to get your body going again and get on with your life.

# MARIJA TOPALOVIC, 14

## A Prayer For Peace

*Trapped in a war of aggression in Bosnia, a single mortar shell explosion blew off both her legs above-the-knee and killed her father. A U.S. missionary found her in the midst of countless injured Croatians and sought to make her wish to walk again come true.*



Marija Topalovic

My life in Bosnia was much like any teenager's – that is, before the war. My hometown of Vitez was a lovely city. I was in seventh grade when the Serbian aggressors came.

There is no comparing war-torn Bosnia today and the Bosnia I knew before the war. When the fighting began, the schools were shut down. Sometimes when the bombing stopped, we would return to classes. When I stopped going to school, it was like I wasn't living any more. We had no contact with the outside world. Our lives centered around “who got killed today” and “whose funeral was yesterday.”

It was two days before Christmas 1993 when my father and I left the house where we were living to return to our family home, by then in ruins. Our home was one of many left in shambles after repeated bombings, but the basement where we had stored some baking pans and other Christmas things was still there. We thought keeping some of the holiday traditions would ease the pain of the war.

Because of the continued sniper fire, we only dared to go out when it was foggy or at night. With the cover of darkness, my father and I set out on the 15-minute walk to the house, by then very near the front line of the fighting. I was going to gather the things from the basement, and my father wanted to drop off some food for my brother and some of the soldiers. One of our neighbors yelled to us that we had better get out of there because the shelling was starting again. We heard explosions and ran toward a barn for shelter.

Suddenly, a strange twinge-like electricity shot through my body as I went flying up into the air. Back on the ground, I could only feel a gritty sand in my mouth. I started screaming to my father, “Help me, Father, help me!” It seemed like I was yelling for five minutes or more. There was no answer. I could only hear him breathing heavily. My brother had seen the blast and heard my screams, so he came running. I remember he kept slapping me. I guess I fainted or was in shock. Then, a few feet away, my brother lifted my father's head and held him. My father murmured painfully “good-bye,” and then he was dead.

I felt like it was all a dream. Some soldiers were carrying me. I asked them where my legs were. “It's okay. Another soldier is carrying them.” There was too much shelling to safely bring a car for me, so the soldiers carried me across town to a Catholic church that had been converted to a hospital.



It was dark in the hospital. There was no electricity, so the doctors and nurses had to do everything by candlelight. I looked down at my left leg; I still had a knee, but the crushed bone was sticking out. The church was not equipped to be a hospital, so all the patients were in one large room. The beds were made of wood and very uncomfortable. I could not believe this was happening. I screamed out when the medicine no longer eased the pain.

Of course, my mother didn't know what had happened. My uncle went to get her. He told her I had been critically wounded, but he didn't tell her that I had lost both legs until she arrived at the hospital. I knew in my heart that the hospital situation was not good in Bosnia, and I was sure I'd never walk again. One of the doctors was very encouraging though. "Sure, you'll get some legs, and you will walk again," he told me. I really wasn't convinced but I had to hope.

An American who was visiting the hospital one day stopped to talk with me. All I knew was that he was in Bosnia to bring food and relief supplies for our people. We knew we were getting help, but we really didn't know where the food was coming from. The man turned out to be Larry Jones of Feed The Children, a charity devoted to serving children in need around the world. When he promised he would help me, I didn't realize he meant I would be flying halfway around the world to the United States.

After some days passed, I was taken to a hospital in Italy, for further treatment. Larry Jones saw me on a news program as I was being transported to the hospital. After that, things began to happen quickly. Another man from Feed The Children contacted my family and made arrangements for my mother, three of my sisters and me to be brought to the United States. I had no idea traveling to America would take so long. I wasn't sure exactly what was going to happen, but the trip and the kindness of the people turned out to be more than I ever wished for.

When we arrived in New York, there were reporters and television cameras. I could not believe I was getting all this attention. They had so many questions. There were more reporters and questions on our stop in Dallas and later in Oklahoma City. They wanted to know if I felt America should become more involved in the war in Bosnia. Yes, I wanted America to help my country. "Food is nice, but somebody needs to do something about the fighting," I told them.

In Oklahoma City, I was scared – scared the fitting of my artificial legs

would be painful. I still had doubts about walking. Arrangements had been made for me to be fitted with new legs at the Sabolich Prosthetic and Research Center. It was there I saw a picture of a model who had lost one of her legs. Her leg was beautiful. That's what I wanted – pretty legs.

I began a series of physical therapy workouts, and there were measurements and castings for my legs. The pain I had feared didn't happen. I watched videos of other amputees and met some girls who had been born without legs. The visit with the girls was the first time I thought that I might really walk again and that there would be a life after having my legs blown off. I wanted to get my pretty legs and wear a mini skirt – or maybe a super mini!

It wasn't long until the first phase of my legs was complete. Once again, the cameras and the people were there to see me walk. I was excited and scared at the same time. I looked down at two pink tennis shoes on my artificial feet. The temporary legs weren't really pretty, but I couldn't wait to feel something underneath me when I stood up and to walk again. The prosthetist helped to steady me as I took my first steps holding the railings on either side. It was amazing – I was walking, and I felt like I had been reborn! I was so excited that I let go of the railings, turned and raised my hands over my head in celebration. I reached out to hug the prosthetist as tears ran down my face, and I realized that something good had come out of something so very horrifying.

I was relieved. I'd seen others who had lost legs in the war in Bosnia, and they will never walk again. I knew I was the lucky one. Even as I was taking my first steps, I thought of others left behind in my homeland, including some of my family. I continue to pray every night that somehow peace will come to Bosnia. I pray there will be no more children who lose their legs or their fathers – no more who suffer as I did.

*Editor's Note: Marija has remained in the United States to complete her education. Her mother and sisters returned to Bosnia.*

**CASSIE CHAMBLESS, 10**  
**She's Never Said "I Can't"**

*Pitcher for the Oklahoma Magic and roller blading champ of Timber Creek Drive in Tuttle, Oklahoma, this fourth grader isn't afraid of all the studying it's going to take to reach her goal of being a veterinarian or prosthetist when she gets older. And thanks to her lightweight, comfortable leg – which helps her run, bike, skate, ski, swim and play 80 games of fast-pitch softball a year – she's not afraid of much.*



Cassie Shambless

*From Cassie's mom Barbara:*

Cassie will try anything. She's never, ever said, "I can't."

Cassie was born with a birth defect that left her right leg considerably shorter than the left. Her fibula bone didn't extend all the way to her knee, her ankle wasn't correctly fused, and she was missing several critical bones in her foot. Orthopedic specialists recommended amputation.

When the doctor first said the word "amputation," I remember gasping, "Oh,my!" But as a lab tech in pediatric oncology at Children's Hospital, nothing really shocked me. It wasn't a tough decision. What they said made sense and because of the kids I work with, I knew how amputees can get around. We knew it was the right thing for her.

*Cassie's dad Kevin:*

It goes through every parent's mind when they're faced with an amputation: "Am I doing the right thing?" But we knew the alternative – the years of surgery, trying to stretch the leg out – would be so painful and maybe unsuccessful, so we felt good about our decision.

*Barbara:*

They amputated at the ankle when she was 9-months-old. It was tough at first, but babies compensate a lot. And she did fine with her new artificial leg. She never tried to take it off, she never even seemed to mind. She took her first steps by herself the day before her first birthday. My younger daughter Audra walked about then too, so obviously the lost limb didn't delay Cassie at all.

Since Cassie's first fitting for a prosthesis, the staff at Sabolich have been like family to us. They're really super people. We feel confident that they're working to do the best they can with Cassie. They do a lot of research and keep presenting cutting-edge technology. I like that they know about Cassie's sports and give her specialized care.

She's missing something very important to her life, so it's a priority for us that she get the best possible care.

So far, Cassie gets a new leg every year, so we're grateful for good insurance. This past year, she finally weighed enough to get an energy storing, spring-loaded foot designed to mimic the motions of the real human foot. The old feet were breaking a lot – during softball season she

probably broke one a month. They were always amazed to see us again at Sabolich, but I don't think you should tone down a kid's activity.

*Kevin:*

I'm so proud of everything Cassie has done, especially in softball. She's pretty amazing. One of her old coaches just told me the other day, "Not only does she just participate, she's a ballplayer." A lot of it has to do with just growing up that way. She works hard at it and it's all she knows.

*Barbara:*

Cassie is strong – not just physically, but emotionally. There was probably a week when she was 3-years-old and wondering when she was going to grow a new foot like the other kids, but other than that, she's used to it.

Every time she gets a new leg, she is ready to put it on and get rid of the old one. We were told that younger kids have a hard time giving up their old artificial limbs because they become a part of them. But she's always adapted to them really easily. She has a good self-image; she can handle it. She wears shorts, sandals, skirts, even swimsuits. And Tuttle is a small town – everyone's used to it. We don't ever let her think she's handicapped. Once when it was really crowded at the zoo she offered to take off her leg so we could get a better parking place, but we just laughed. We don't let her get away with it. And usually she doesn't try.

*Cassie:*

The kids in my class treat me like a normal kid. They don't treat me like I'm a handicapped person; my teacher doesn't seat me in the front row because I'm an amputee. I just sit with everyone else and do what they do. It makes it easy for me.

*Barbara:*

My goal is for Cassie to lead a normal, happy life. But I know she'll never let this hold her back from doing anything. If she wants to participate in something like the Paralympics, we'll support it completely. But right now she's happy playing softball and running around with her friends, and that's all that matters. She's only 10; she's still my little girl.

*Kevin:*

We're behind her 100 percent. Whatever she wants to do, I don't think

there's any limit.

*Cassie:*

I still don't know whether to be a prosthetist or a veterinarian when I grow up. I love animals so much and I'm the best at giving our dog Coco his medicine. But if I were a prosthetist, I could help kids who are my age now, and I would have the experience to know just what they need. That would be great.

*You might have spotted Cassie – bright eyes, long brown hair and loads of freckles – on an episode about kids with artificial limbs for Nick News on Nickelodeon children's channel. For her part, Cassie says she has no limitations, no fear and no idea why people are making such a big fuss about her. "I don't even think about my leg," she says. "It's easy to forget it's there."*

**RICHARD TRULSON, 59**

# **Still Flying High**

*Even the loss of his legs below-the-knee couldn't take away his larger-than-life spirit. Nor could it keep him from what he loved.*



**Richard Trulson**

*Photo courtesy of Sam Buchanan*

It was really hot that day and my brother-in-law and I were building a barbeque pit. Suddenly, something went wrong and I felt it slip. It fell on top of me and crushed both my legs. My brother-in-law tied off the injuries with some cording and got me into his truck. My wife Loretta was out running errands so I called my son from the truck and asked him to call his mother to meet me at the hospital. But I told him not to worry her.

Now some might find that my level head that day was a little strange, but I'm a pretty tough kind-of guy. I even called the hospital to ask for an emergency team to meet me there. When we got to the hospital and I talked to the doctor, I knew the legs had been crushed and couldn't be attached. So I told the him, "Cut 'em off even, doc, so I can walk even." By the time Loretta got to the hospital, I could see how upset and scared she was. So I joked with her, "Ah, heck honey, at least I won't have to bend down to kiss you anymore."

Later, that same doctor told me that it would be at least a year and a half before I would be up walking. But I fooled him. I was up and walking in just 13 weeks. Even before I got my legs, I was back at work in a wheelchair. No matter what, I never gave up. It didn't get me down; it just slowed me down. One thing about it, I never have to worry about athlete's foot, cutting my toenails, or making sure my shoes fit.

Seven months later, I bought a refurbished motor home on the Internet and Loretta and I took off for Alaska. The following year we went to California and all points in between. All the time though when we were in Alaska, it was hard to have fun and enjoy it because my legs were so painful. It was a reminder though about just how fragile life is and how we should enjoy every minute we have here. I realized I just wanted to spend time with Loretta traveling all over the United States and enjoy ourselves. And that's just what we did.

Just down the road from where I live, it turns out there is another amputee who has lost his leg below-the-knee and an arm. It's Chuck Tiemann and he advised me to go to Oklahoma for my prostheses. It was the best decision I ever made. I can walk now without pain and feel like I can do most anything I want to do. My prosthetist and I have become good friends. He's like a brother tome. Now there was only one thing I really missed. All my life, I have flown small planes. Even when I was a little boy, my dad would come home from work and take me flying in the afternoon. Loretta



and I own a small airport in Ardmore, AL, and we worked side-by-side as airplane mechanics. I wanted so much to fly again. There's nothing like seeing God's beauty from the air – watching the leaves change color in the fall and the countryside after a snowfall. Just nothing like it!

I found a little plane on the Internet and stopped on the way home to Alabama from one of our trips to see it. I bought it right then and there. I was sure I'd be able to fly it just like it was with mechanical brakes, but I got FFA approval and added hydraulic brakes. It's as old as I am and it has to be hand-propped.

My Oklahoma prosthetist was even there in Alabama three years to the date of my accident when I flew for the first time. All my friends and family were there, even the news media. It felt so great when I took off and circled the field. What a feeling!!!

I circled around once, touched down and took off again. I wasn't quite ready to stop. But when I landed, I couldn't stop the tears. They just overflowed. And when I got out of the plane, Loretta ran into my arms. She was crying too. And so were most of the people there.

Since that day, I have flown on short trips all around Alabama. Soon I hope to fly to Oklahoma and have some new legs made. And Loretta and I have updated the RV and are planning a trip back to Alaska. My legs fit much better this time and are more comfortable, so our trip will be more fun.

My 5-year-old niece Katelynn is a huge inspiration to me. I would always save Jello and grapes for her when I was in the hospital and she would visit. She even suggested the lamination for the covers of my sockets. Dolphins, Nemo and pictures of her.

My other inspiration is Loretta. I know I'm a tough guy, but thinking about her just makes me get teary. We've been married for 35 years. She's stuck by me and been there for me whenever I needed her. Through the bad times, the good times, the hard times, she's been right here.

**PAT SHAUGHNESSY, 50**

## **On My Last Leg**

*At age 34, he was bound for a preaching mission in South Korea when a bomb exploded at the Los Angeles Airport. His right leg was blown off above-the-knee and the left leg severely injured. His unwavering faith in God gave him strength to deal with the amputation. He returned to his pulpit four months later and has since traveled worldwide*

It was August 6, 1974. I had left Phoenix the day before and was killing time in the Los Angeles Airport, waiting to board my flight to Seoul, Korea. I was looking forward to the 30 days I'd spend preaching in three Korean cities. It was an honor for a young preacher.

I was standing near the Pan Am ticket counter, reading an international travel schedule. I had no idea that less than 25 feet away was a baggage locker loaded with plastic explosives.

It was 8:10 a.m. The locker exploded! One second I was standing, the next I was on my left side on the floor...lying in a pool of blood...fighting for my life. Pain shot through my body.

The ensuing scene is one that remains graphically painted on the canvas of my mind. People and debris everywhere. My friend and traveling companion Won Yong Koh had stepped into the men's room and was spared from the blast. His wife and children were also uninjured. But around me were 33 injured bystanders and nearest to me...two people lay dead from the explosion.

I had been blown 29 feet from where I had originally stood. I looked down toward my feet. My pant legs were gone. I could see the left leg. Not a pretty sight. It looked as if someone had placed a couple of pounds of raw hamburger meat on the inside of my left knee. I couldn't see my right leg. There was no flesh below the mid-thigh. It had been blown off.

Two thoughts flashed through my mind as I lay waiting for help. First, I worried about my family in Phoenix. I was afraid someone might knock on the door and tell my wife that her husband had been blown up. Secondly, I knew that God had allowed this to happen for a reason...and he would take care of me.

Don't misunderstand...I hurt and groaned under the piercing pain. I wasn't sure that I might not be ushered into the presence of God at any moment. But there was a strength – an inner strength – that sustained me. Someone said that we react to stimuli of life based on what we believe. I believe the Bible is uniquely inspired by God...absolutely trustworthy, authoritative and relevant. My reaction to the incredible pain was based upon my beliefs.

I believe the Bible teaches us that with God there are no accidents, only incidents. This was only an incident. I felt a sense of security because I knew God was in control. In Romans 8:28, the Bible tells us: “We know that in all things God works for the good of those who love Him, who have been called according to His purpose.”

It was time for a mid-term exam in my life. At age 34, I was pastoring a growing church in Phoenix. I was in the best physical condition of my life. God was asking me if I really, really believed that part about “all things.” I did. And it was that confidence in God that gave me strength beyond myself.

I was taken to Hawthorne Community Hospital, where doctors gave me only a 40 percent chance of surviving before they took me to surgery. They upgraded my condition, giving me a 50 percent survival chance after operating on my legs. I was young, athletic and strong. My right leg was amputated about 10 inches below the hip. I had four fractures in the left leg and two in the ankle. I awoke in intensive care. I looked down at the sheet... now a flat sheet...where my right leg used to be. Funny how we take so many things for granted. But when you lose something, somehow what you have left seems to take on a more valuable role in your life.

Since my body had suffered such shock and trauma, the doctors expected me to be in the intensive care unit for a week. I was there little more than a day. Hospital officials told the press my recovery was “miraculous.” I later learned that I was the closest person to the bomb who survived.

My family flew in from Phoenix. They were very supportive. But my 2-year-old daughter was a bit confused about where my right leg had gone. Once she thought she had found it under the bed. “It” was the sand bags used to put my left leg in traction.

I spent a couple of months in the Los Angeles hospital before I was transferred to a hospital in Phoenix. There I got my first glimpse of the world of prosthetics. What a scary experience. A prosthetist came to my

room saying he was going to take me to the prosthetic center to fit me with an artificial limb. As he rolled me into the center, I thought I was in a house of horrors. "Surely this must be where Frankenstein lives," I thought. Hands, feet and legs were hanging all over. It was a psychological thing that I had to get over. I think it's a psychological hurdle all amputees have to overcome.

Even before I got my finished leg, I had my first public outing as an amputee. A friend of mine coached the Phoenix hockey team and gave me tickets to a game. The doctors made me a foam leg to fill out my pant leg. They attached a shoe. I went to the hockey game in a wheelchair and sat in the handicapped section for the first time. I didn't feel very secure. After all, I had one foam leg, and the other one was broken in six places.

It wasn't long until I was fitted with a quadrilateral socket and artificial leg. It had a steel brace that came up around the hip with a belt to hold it on. Every time I bent over, the metal brace dug into my body. The leg weighed about 17 pounds, but I was up and walking. I walked with a cane for about a month until I felt stable. I went back to church to preach the Sunday after I left the hospital...new leg, cane and all.

I guess the hardest thing to change is your attitude about other people helping you. Becoming an amputee takes away some of your pride. When I first came home from the hospital, I had to learn to depend on my wife for some things I'd always done for myself in the past. Finally, I swallowed my pride, realizing that people who really loved me really did want to help.

Although I was walking, I wasn't walking well. It seemed like the leg was too long or too short each time it was worked on. Eventually, I had another leg built by a different prosthetist. The new leg was better, although the hard socket was always uncomfortable and I still had pain in my stump. It's a chronic pain that remains with me, but like a toothache, I've gotten used to it.

I've had several legs since 1974. Each one has made it possible for me to continue a fairly normal life. I've been to Korea three times since the day the bomb exploded and have traveled to 30 countries to preach the gospel. I've stood in my own Phoenix pulpit three times on a Sunday morning and again in the evening to preach.

I always got around on the hard socket, but it hurt. I couldn't wait to get home and take it off. It was painful to walk and painful to sit. It wasn't until 1989 that I discovered there was something better...a lighter leg that wasn't

painful to wear. Now, I can even jog with it! I can wear my leg from the time I get up in the morning until I go to bed. After all these years, it is hard to believe such a thing exists.

I am grateful for each day on my new leg. I thank God for life and healing and that someone has taken the time to learn to make artificial limbs that make life more enjoyable for people like me...people who are on their last leg.

**HOLLEY HOWARD, 53**

## **Sometimes I Just Have to Laugh**

*At age 21, she was an attractive, vivacious young adult looking forward to a dance career. A freak boating accident resulted in amputation of her left leg below-the-knee. After years of pain and life on crutches, she had revision surgery to remove her knee, but still encountered setbacks and struggled to find an artificial leg she could wear.*



**Holley Howard**

I just have to see the funny side of things, especially losing my leg. I know it's serious but when your life changes as drastically as mine did, I have to look at the positive side. In 1981, my lifelong dream of becoming a dancer and dance instructor was about to come true. Everything seemed to be going my way.

A friend and I were celebrating the Fourth of July weekend in typical Tyler, Texas, fashion at the lake. Some people laugh when I say I was practically raised in water, but I'd been swimming since I was a toddler and water skiing since age 8. I felt completely at home in the water, especially at Lake Tyler. I had no idea a nightmare about to unfold would change the rest of my life.

Sarah and I were out cruising in my family's boat. I was driving when suddenly something caused the boat to pitch. The impact was incredible, and Sarah was tossed across the boat into me. Before either of us could react, we were thrown from the boat into the water. We don't know why, but the boat went into a spin running over us several times.

I was treading water, holding onto Sarah, and screaming for help. It's strange how at such a terrifying moment you can find humor, but a comedy routine from an old Bill Cosby album kept running through my mind. He tells a story about God talking to Noah. Noah was questioning God about preparing for the great flood. God kept asking, "Noah, how long can you tread water?" It sounds crazy, but I kept thinking, "Holley, how long can you tread water?"

A fisherman had seen the accident, and he came to our rescue. It was a miracle. As he pulled me toward the small fishing boat, I lost my grasp on Sarah and saw her go under water. Just as miraculous as the fisherman's appearance, another man seemed to appear from nowhere and dived in from his boat to save Sarah. The fisherman laid me flat on the bottom of his boat and placed Sarah lengthwise on top of me. At the time, I remember thinking, "It's bad enough to be cut up like a sausage, much less have Sarah stretched out on top of me." But the reality was that the pressure from her body was acting like a tourniquet and keeping me from bleeding to death. The whole rescue was as if the hand of God reached down to take charge.

It was a painful trip to shore, and the long wait for an ambulance was excruciating. We both were losing a lot of blood as we lay in the bottom of the boat. When the ambulance did arrive, I lost consciousness as they picked

me up from the bottom of the boat. The coolness of the air-conditioned ambulance revived me, and the ambulance attendant warned me that if I lost consciousness again, I might not regain it!

I spent months in and out of hospitals, in body casts and having more than 30 surgeries. Long days, long nights and lots of pain followed those surgeries and a three-month hospital stay. I was in traction throughout the whole ordeal. There were days the doctors didn't know if I'd make it.

In the beginning, doctors truly believed my leg could be saved. I remember my dad fighting back tears as he told me my leg was going to have to be amputated. As a Shriner, he had helped take care of many children at the Shriner's Hospitals. He knew full well the impact this would have on the rest of my life. I knew that a one-legged person would probably never teach dance, much less operate her own dance studio. I tried to make a joke – after all, they say laughter is the best medicine. “Well, at least I'll always be able to find a parking spot in handicap parking,” I quipped. We laughed and it relieved the tension.

I can remember all my cheery-faced family and friends, hoping to say something that would keep my spirits up. “Gee, you look just the same from the waist up,” one remarked. “Why, I saw a guy who ran all the way across the country on a wooden leg,” said another. “A wooden leg...ugh,” I thought. It was not an optimistic outlook for someone who had always felt her legs were her best asset.

When you lose a leg, you lose a lot more than a limb. There is an initial loss of spirit...an inner spirit you must rekindle to get going again. It's kind of your survival instinct. It helps you overcome obstacles and put things into perspective. I know I wouldn't have gotten through it all without that special inner strength. I think it's that inner spirit that helps me remember so many of the funny times and forget the really painful ones.

I went home from the hospital in a body cast from below my breast down my left leg. I looked awful. I went through a stage where I wasn't sure I'd ever go out in public again. But after a couple of months of being confined at home, I changed my mind. Most of my friends were home for the holidays, and I grew tired of hearing about the fun they were having while I sat home playing “pitiful Paula.” I wanted to be with them, but I had one real dilemma – how to dress around my inflexible body cast. My mom made me some maxi skirts that covered the cast. I looked like a cross between Mrs.



Butterworth and the Statue of Liberty. Because I couldn't bend, I could hardly get into a car without a T-top. Honestly, my dad bought a van for the family just so they could tote me around.

While I was recuperating at home, the doctor sent a physical therapist to work with me to try to loosen up my knee. I was in a body cast and traction so long that the knee doctors had worked so hard to save was frozen and useless. Sarah, already a patient of this particular therapist, had told me how much she enjoyed and admired him. The first day Eddie came to my home, I met him at the door. I know I must have looked less than attractive wearing a body cast – with no hair. My hair had fallen out from all the trauma and anesthesia. I don't know when I realized that I was enjoying the physical therapist more than the therapy, but Eddie and I both admit the attraction was there from the start. However, our relationship was strictly patient/therapist – until my last therapy appointment when Eddie surprised me with a bouquet of roses and wished me luck on getting my first artificial leg at a rehabilitation center in Houston, Texas.

Because of my fractured hip, I was unable to walk on my new prosthesis, so I was still getting around on crutches. When I went out with friends and people saw me on crutches, they usually assumed I had broken my leg. If I told them the real story, some acted like I was kidding. I think it was easier for them that way. While I was in Houston, I had my first date since the accident. I had just gotten my below-the-knee prosthesis, and my date knew I had an artificial leg. I was trying to make everyone feel completely at ease with my situation. We went to a concert. First there were what seemed like thousands of steps. Then, the seats were about 12 inches apart. "Oh great. How do I sit down?" I thought. My knee wouldn't bend enough for me to sit normally, so I had to take my prosthesis off. I asked my date if he would mind helping me hold it during the concert. Are we talking awkward or what!

Eddie started calling me while I was in Houston. By October, we had dated more than six months and decided to get married. He's been behind me all the way and has encouraged me to "go for it" when it came to anything I wanted to try. There have been some real setbacks along the way because of my struggle to find a prosthesis I could wear, but he's been there through it all. Needless to say, he is an answer to prayer.

At this time, I was still a below-the-knee amputee and struggling to wear

a prosthesis. It wasn't at all like I thought it would be. I was in so much pain and was limited as to how many hours a day I could wear it. It was easier to go places on crutches than to deal with the discomfort and hindrance of an artificial leg.

Sure, I'd prefer to walk into a room and blend in with the crowd, not stand out as a one-legged person. There have been times I've panicked before going to a party or social function. But I try to get a grip by telling myself, "I may be the only person there on one leg, but I'm going to be the best person there on one leg." As long as I feel good about myself and my appearance, I've fought the battle and won. When I wallow in self-pity, it's no one else's fault that I feel uncomfortable because I've made myself uncomfortable. I've had my share of stares from John Q. Public, but I've found the best thing to do is stare right back at Holley Howard volunteers countless hours for non-profit agencies in Tyler, Texas. Photo courtesy of David White people until they realize I do feel their stares and don't appreciate them. If I hold my head in shame, then they have won.

I'm sure my two sons will probably look back on their childhoods one day and realize I did things differently than other moms. It's hard because you're with your children and you don't want to embarrass them. So often your children don't want their friends to know they have a mother, let alone a one-legged mother. I remember being on crutches without my leg and kids would be on the floor looking up my dress trying to find my leg. My boys would yell, "It's gone!" Now they will warn their friends before I gets out of the pool, "Don't worry when my mother gets out of the water; she doesn't have a leg."

For many years, I couldn't find a prosthesis that worked for me because they were all so painful and I suffered from many skin breakdowns. But I wanted to do things with my family. I couldn't go to an amusement park like Six Flags without being pushed in a wheelchair. I wanted to dance with my husband and wear whatever I wanted. I would see success stories on television about amputees and I would think to myself, why can't I do anything like that.

One day Eddie handed me an article about Ted Kennedy, Jr., and how he went to Oklahoma City for his prosthesis. I still suffered from breakdowns and my knee was almost non-functional. I visited with some of the Oklahoma prosthetist's above-the-knee patients. They were biking, running

and doing things I had been forced to give up. That was all I needed. I called Eddie and told him I wanted that revision surgery he had been suggesting.

Three weeks later, I had my knee amputated. I was excited about the possibility that I could be fully active again, and everyone was pulling for me. Six weeks after the surgery, I began walking on a temporary above-the-knee prosthesis. It was different from the way I had been taught to walk on my below-the-knee prosthesis, but I was determined. My first clue that something was wrong with my residual limb came one day when I stepped down on my prosthesis and felt a knife-like pain in the bottom of my stump. I couldn't move without pain. I returned to the doctor who ran a test, but found nothing. Finally, after months of heartache, I realized I was probably going to have to have another revision surgery. Out of desperation, my dad tracked down a surgeon in Memphis who specialized in amputations. The doctor recommended surgery. I was sure my problems would be over if he could fix what was wrong with my stump. Six weeks after he operated, the pain hadn't subsided. The doctor was shocked, and I was once again deflated. What had started out as a simple above-the-knee revision surgery had turned into a nightmare. I could no longer wear any prosthesis.

I was beaten and downtrodden. I remember getting a newsletter about a high-tech prosthesis. An article in the newsletter featured a girl who had been fitted for her leg the same time I was. Now, she was riding a bicycle – and I was still on crutches. Nothing I did seemed to work. I needed to take a break from the whole prosthetic fitting process. Even though I wasn't ready to throw in the towel, I made myself accept the reality that I might never be comfortable wearing a prosthesis.

Since I was on crutches for so long, I decided I would get a little creative. Eddie and I were going to a gala event known as the Rose Ball. I couldn't imagine getting all dressed up in a formal gown only to hang on to my ratty, metal crutches. So for fun, I

took my crutches to a paint and body shop where I had them painted in high gloss black and trimmed in gold. Then, I glued on about 300 rhinestones. They turned out great! Instead of detracting from my appearance, they became a wonderful accessory. People didn't seem to notice I was on crutches. I had so much fun dancing on one leg that night that a week later a friend told me she thought I had been wearing a prosthesis. I fooled her!

The prosthetist spent hours and hours working to fit me with a new leg, but the tissue on my stump hurt even when I wasn't wearing a prosthesis. He finally was able to design a suction socket that pulled the painful tissue away from the bone. This kept me from putting pressure on the sore area when I walked. Gradually, I began to wear the leg. But I'm convinced that it was the Lord who ultimately healed my leg. It was July 1989, and the sore tissue began to ache so badly that I was forced to take off my prosthesis. Even with that, the pain grew worse. I'm sure I was having muscle spasms at the bottom of my stump. It hurt so much that I called the doctor for pain medication, and I sat up most of the night with my stump packed in ice. Miraculously, the next day the pain was gone. Something changed that night, and I've never had pain like that since. Finally, I was on my way to attaining all the goals I had originally set when I took the plunge and decided to have my knee amputated. For the first time in years, I was comfortable and really over my setbacks. Trusting in the Lord and a lot of patience had paid off at last.

Now I can do nearly anything I want to. I still don't run but I ride my bike, dance with my husband, and walk into a room with two legs. And I love to ski. I think you have to keep trying until you find what works for you. I know I had to. It's never easy or as quick as it sounds. Getting the right fit and the right componentry is not simple. And it's going to have to be replaced. It's like a car. It breaks down. And you need time to heal. It's tiring and it can be smooth or sometimes it isn't. Each person should do it for themselves.

For the longest time, I couldn't go back to the lake. The very idea was too much for me. I finally realized though that my accident had taken the joy out of the lives of my family and me. I decided I wasn't going to let that happen any more. After my boys were born, Eddie and I realized that we really missed the lake and I had to get over that fear. I realized I wanted to experience that joy again. Sometimes you just have to face that fear.



Holley Howard volunteers countless hours for non-profit agencies in Tyler, Texas. Photo courtesy of David White.

**DAINA BRADLEY, 20**  
**April 19, 1995 The Oklahoma  
City Bombing...My Story**

*Victimized in one of the worst terrorist acts ever committed in the United States, her mother, daughter and son were killed and her leg was amputated to rescue her from death.*



Daina Bradley publicly expresses her feelings about her losses for the first time since the Oklahoma City bombing.

I rose early to get my children, Peachlyn, three, and Gabreon, four months, ready for the day. My mother, sister and I headed out early to the Alfred P. Murrah Federal Building on April 19 to get a Social Security card for Gabreon. Remembering the long lines, we got there early in hopes of beating the crowd.

The Murrah building was buzzing with activity as employees started the day and customers began forming lines. My mother saved a place in line and my sister Felysha watched the children while I filled out the paperwork.

Suddenly, there was a bright flash of light. The last thing I remember seeing is my sister picking up a pen, and then I was slammed to the floor with rubble piled on me and all around me.

I screamed. I could hear a loud, whirring sound, which turned out to be severed electric lines. My daughter was screaming “Mommy, Mommy” and my son was crying. It was crazy as other people in the building were moaning, crying and screaming for help.

Then I heard a series of loud crashes as the nine stories of the Murrah building fell on top of me and my family. The floor I was lying on collapsed, and I slid to what I later learned was the basement.

I could no longer hear the voices crying out. I could no longer hear my mother, daughter or son. My sister began moaning, “Mom, help me...” while I lay with my left arm pinned beneath the rubble and my right leg trapped under a slab of concrete. I couldn’t help myself or my sister because I couldn’t move. Soon, cold water began filling the space I was in, and I knew that if it continued to rise, I would freeze to death or drown.

Emergency rescue workers arrived and began to pull people from the building. I could hear them, but I could not see them. I began screaming for help as the terror of it all began to sink in.

A fireman arrived and immediately started talking to me. In a calm, caring voice he let me know that rescue workers were trying to get me out. Finally – some hope in what seemed to be a hopeless situation. In an instant, that would all be shattered.

The screaming started again. This time it was directed toward the rescue workers. There was another bomb and everyone began running. I begged for the fireman to stay. He promised he would return to help me.

They left me for what seemed like forever, and I waited silently for the bomb to explode. I did not blame them for saving their lives, but I thought it

was the end of mine.

It turned out to be a bomb scare, and rescue workers returned and began the painstaking work to release me from what felt like a tomb. I was trapped in a coffin-size cave with a slab of concrete pinning my leg and another huge chunk only 18 inches from my face. I was buried so deep in debris it took <sup>1</sup>/<sub>2</sub>hours just to lower oxygen and a blanket to me.

They began by freeing my arm which was without circulation the five hours it took them to remove the rubble. There was some relief when it was finally loose, but my leg was going to be more difficult. They began talking about amputating, and I said no. I didn't want to lose my leg.

Finally I realized there was no other way. My survival instincts set in, and I wanted to do whatever it took to make it out alive. The rescue team began preparing to save me at all costs.

I had lost so much blood that doctors were unable to administer an anesthetic and were able to give me only a pain killer for the operation that would save my life. The procedure began with the smallest doctor climbing headfirst into the hole with several scalpels. The doctor amputated my leg in a mere 10 minutes. I do not remember the horror of the operation, nor do I remember my screaming that rescue workers say still haunts them. I only know the doctors saved my life, and I am forever grateful.

It was after I was taken to the hospital that I found out my sister was alive and in a rehabilitation hospital. She was in critical condition and may have suffered severe brain damage. My mother and daughter were not in any hospital; they were dead. My son had not been found.

Suddenly, losing a leg was not the most painful aspect of my life. In only a few minutes, I had lost my mother, daughter, my sister as I knew her and possibly my son.

As rescue teams from around the country worked night and day to find any remaining survivors, I attended my mother's and daughter's funeral with a faint hope that Gabreon had lived.

The funeral is a blur. My body had been badly burned and bruised. I wore a bandana to cover my burned-off hair. I had no strength. I just wanted to go back in time. I wanted my mother, daughter and son to be with me, or I wanted to be with them.

After the funeral, I began going through the motions of a living person, but I was not. Friends and family were taking the steps for me. We had never



known anyone who had lost a limb, so the search for a prosthetic center began. My aunt was a nurse and knew of a place where they made artificial limbs.

I arrived at the prosthetic center in the same dress and bandana I had worn to the funeral, still not knowing if the life I was left with was worth living. Just talking took most of my strength. I felt like I had been lifted from my tomb in the battered Murrah building only to be placed in another from which I would never escape.

I was admitted to Jim Thorpe Rehabilitation Hospital, and I began physical therapy for my arm and leg, along with daily trips to the prosthetic center.

The people and patients at the prosthetic center were nice. There were other amputees who were able to show me I would be able to walk and even run in time. I began making some progress, like talking before being spoken to and even laughing. Everyone was doing what they could to pull me out of the fog I was living in.

The operation that took my leg may have been primitive, but it left me with a residual limb that was healing fast. After my stitches were removed, I was fitted with a temporary prosthesis...a special one. My prosthetists found out I liked Mickey Mouse, and everyone at the center joined together to get permission from Disney to have Mickey Mouse laminated on my leg. I couldn't believe they had done this for me – it was wonderful!

I took my first steps only weeks after the accident. Then I received news of my son: Gabreon's body had been identified as one of what would ultimately be 168 victims found in the Murrah Building explosion.

Preparation for another funeral began, and the realization set in that both of my children were dead. The mental pain became more intense than any physical pain, but I was still trying to hold on. This time I not only attended the funeral, I was able to walk to it.

This is when living became even more difficult. Deep depression left me with no motivation. Walking didn't seem to matter as much when I would never see my children or mother again. I was discharged from the rehabilitation hospital, and the tasks of daily life set in. I didn't care. I didn't even want to live most of the time.

I was angry at God and everyone else who still had their family. Why me? Why my family and my leg?

People around the country continued to reach out and help me. A lady from California Donna Jackson, whom I had never met, raised more than \$20,000 for my prosthetic needs. No matter how hard I tried to escape, I was pulled back by people like her who refused to let me give up and die. My dream of my daughter being a model and my son being a football player will remain only that – a dream – but my life is moving forward.

I am still struggling and have only just returned to the prosthetic center. I know there is a long road ahead, but the thought of running and playing with children again helps keep me going. Gabe Bruce, Gabreon's father and my fiancé, has been by my side every step of the way. We share the grief of our losses, and he is a constant source of strength when I am weak.



Pausing for a moment of silence in honor of the victims, federal workers stare up at the bombed-out Murrah Building in Oklahoma City.

©1995. Oklahoma Publishing Company. From the April 27, 1995 issue of The Daily Oklahoman.



Daina Bradley walks with Donna Jackson, from California, who raised money for Daina's prosthetic needs.



**TAYLOR FOUST, 6**

# **I Got to Play with the Kids**

*She was just a baby when she lost both her legs and part of her right hand to a bacterial infection.*

*She lost her mother shortly after. But now with two new prostheses and a family who loves her, she's gained what she wanted most in life – a chance to be just like the other kids.*



Taylor Foust practices her ballet technique.

*Taylor's adoptive mother Jeanette:*

Taylor came to live with us when she was 2-years-old. I was her teacher in Christian preschool, and her mother said she couldn't take care of her anymore. She asked us to take her – which we were glad to do because we'd already fallen in love with her.

When she was just 1-year-old, Taylor was diagnosed with meningeal toxemia, which is a bacterial meningitis that destroyed her legs and part of her hand. Both her legs and the fingers on her right hand were amputated.

*Taylor:*

Now I'm 6. I'm in the first grade and I'm in dance. We get to do exercise, mat, ballet and tap. I like it. It makes me feel like I'm enjoying myself. For tap, the dance I like best is called "You Can Do Anything."

*Jeanette:*

With her legs at the time, she was falling every few steps. After reading the book, *You're Not Alone*, we decided to see what Scott Sabolich could do for her. And it's made all the difference.

Taylor has a very short residual leg below her right knee, but she had always been placed in an above-the-knee prosthesis. It was heavy, hard to maneuver and uncomfortable. Scott Sabolich decided to experiment with a below-the-knee prosthesis for Taylor, not knowing if it would work because her short residual limb. But it did work.

The prosthesis on her left leg comes above-the-knee, but now it's softer, more flexible and comfortable. She's come a long way, and Scott has helped her so much.

*Taylor:*

Scott's neat; he made my legs. He's wonderful. Before I got my legs, I was just sitting down at the edge of the playground watching the kids play because I couldn't keep up. Then I got my legs and I got to play with the kids.

*Jeanette:*

The best thing a parent can do is be supportive, always let their child know they can be anything they want to be. The more comfortable the parents are, the more comfortable the child is going to be.

It's hard when Taylor wants to do things that are hard for her, when she wants to keep up with other children and she's a little slower. But she does really well. We try to encourage her in everything. She may have to find a different way to do things, but she does what she wants to do. I see a wonderful future for Taylor. She's determined and she's smart. She's going to do whatever she wants.

*Taylor:*

When I grow up I want to be a teacher.



Taylor and prosthetist Scott Sabolich

**TIM MCCARTHEY, 26**

## **There's Not Anything I Can't Do**

*After only a few weeks as a new officer, he received a Letter of Commendation and a Valor of Service Award for his brave assist in a robbery. He dedicated his life to being a police officer. But then a suspect evading police ran him over.*

*Now he dedicates himself to helping other amputees.*



Tim McCarthy



In an instant, I went from being a bad-ass cop to being barely able to do anything on my own. It's hard to go from doing anything you want and being good at it, to being unable to walk or function.

While I was laying on the ground immediately after I was hit, all the other officers went into action. I remember hearing one of my best friends yell my name. I remember seeing him ride by me, taking off after the guy who hit me. Another one of my good friends put pressure on the damaged part of my leg. Other friends were there; I was trying to sit up and see what was going on with my leg. They were holding me down by the shoulders. When I think back on it, I'm really glad they wouldn't let me up. If I had seen the damage to my leg, I probably wouldn't have dealt with it as well as I have. These guys are the best friends I'll ever have.

They went through the worst time of my life with me. Along with the fire department, fellow officers raised \$40,000 to cover expenses beyond my worker's compensation.

My leg traveled about 150 feet before it came to rest. The suspect made it about 300 feet. My leg arrived at the hospital on ice. Doctors looked at it but decided there was way too much damage to reattach it. They decided to amputate above-the-knee.

While I was in the hospital, Craig Gavras, an ex-police officer from Dallas and the director of Limbs for Life, came to see me. As fellow officers and amputees, we immediately clicked and became close friends. Since then I've been helping Craig raise money for Limbs for Life which buys prosthetics for amputees who can't afford them.

Three and a half months after I lost my leg, Craig asked me to join him on the Project 50 Bike Ride. It was a five-and-a-half-day journey over 225 miles. We wanted to raise \$60,000 for 50 amputees to get new prostheses. The idea was to go 40 miles a day and ride from Oklahoma City to a ceremony on the 50-yard line at the Dallas Cowboys game.

I told Craig I'd try, but I didn't think I'd ride very far – I figured I'd make it about 50 miles. The first day I rode the whole way. I didn't think I could do it the second day, but again I rode all day. And I ended up riding the whole way...just three and a half months after I lost my leg. Even more amazing, we ended up raising \$80,000 – \$20,000 more than our goal.

Life as an amputee is different from life with your limb, but it's still a good life. You do things differently, but you still do things you did before. It's a

life-changing experience, but it's not a life ending experience. It definitely makes you appreciate what you had. It might slow you down a little, but you build back up to where you were.

The worst part about becoming an amputee was just being unable to get around and having to rely on people. But that ended after I received my prosthesis, and now I do things just like I used to. Shoot, I do everything now. I can run, I ride bicycles, lift weights – there's not anything I can't do.

**COLLEEN VALDERAMA, 36**

## **Armed With Determination**

*She was a ninth-grader when the doctor's discovery of a malignant tumor in her right arm led to amputation at the shoulder. She hated the cosmetic arm and hook, so she learned to do everything left-handed. No one ever really denied her abilities until she applied to nursing school. "People just won't accept a one-armed nurse," she was told.*



Colleen Valderama

At age 14, I was active in my Oklahoma City junior high school band and drama productions. I was working on a backdrop for an upcoming play when a big piece of scenery fell, striking me on the right shoulder.

My parents had the doctor examine me, and he treated me for bursitis for about three weeks. But the pain wouldn't go away. It kept me awake at night. There apparently was no circulation in the arm. I would hold my arm under hot water – as hot as I could get out of the bathroom tap – just to ease the pain. When my mother discovered what I was doing, she took me back to the doctor. After an X-ray revealed a tumor, the doctor sent me to a surgeon for a biopsy. I had the biopsy on a Friday, in April 1969. By then, I was in horrible pain.

There was never any option other than amputation. My parents came to me and explained that the cancerous tumor would continue to grow and spread throughout my body if the arm was not removed. Without the amputation, I would be dead within six weeks. Actually, there was never a choice because I was hurting so much. All I wanted was for the pain to stop.

From the time of the biopsy, I was hospitalized and under heavy sedation. My family was there for me, as they were throughout recovery. I remember Hap and Jeanette, my older brother and sister, would just get really silly and make me laugh. They stayed by my bedside and helped me focus on something besides the pain. They constantly massaged my hand to ease the pain that remained with me day and night. The following Monday, the doctor amputated my right arm at the shoulder. The tumor was on the humerus bone, midway between the shoulder and elbow.

I remember waking up in the recovery room. I could see my cousin, a hospital intern, standing at the foot of the bed. My legs and left arm had been tied down and I had a tube in my throat which made it impossible to talk. "Please untie my legs," I tried to say. I didn't understand why they were putting me through all that.

Later, back in my room, I was horrified . . . not that they had removed my arm, but that they had cut off my breasts. There were bandages from my clavicle down to my waist and I thought my breasts were gone. No one ever mentioned it and I was too embarrassed to ask. Boy, was I relieved when they changed the dressing and I could see my breasts were still there!

The phantom pain was horrible immediately after the surgery. It was hard to believe that I could still feel the arm and the pain as if it had never been

cut off. For weeks after the amputation, this phantom pain prevented me from sleeping. The harder I tried to relax, the worse the sensations became, until I was in tears and near hysteria. After many agonizing weeks of sleepless nights, I began to realize the sensations weren't going to end, so I needed to find a way to live and sleep with them. Thanks to the patience and help of my mother, I began learning to focus on relaxation of my body and muscles until I became calm and less anxious. The phantom pain became more bearable as I relaxed. Finally I drifted into much-needed sleep. I still use relaxation techniques to help me sleep when phantom pain bothers me.

I didn't focus too much on my arm being gone those first few days. My grandmother had made me a dress for 89er Day, an annual celebration in Oklahoma. She brought it to the hospital for me to try on. When I slipped it on, the sleeve on the right side hung flat. I think that was the first time I noticed my arm was gone. At the time, it didn't matter. I was so happy to see the dress that I didn't worry about a missing arm.

In the late 1960s, they didn't do much chemotherapy following amputations like they often do now, but I went through a series of steroid treatments and was kept out of school. I had to have a home bound teacher because the doctor was afraid my immune system couldn't handle any germs I might pick up at school. It was a difficult time.

Two months later, my parents took me to the prosthetist to be fitted with a cosmetic arm and hook. That was a nasty experience. We were shown to a dismal room where lots of artificial arms and legs hung on the walls. "This is gross," I thought. "I don't want to wear any of these." I flatly refused and cried as my parents took me home. I told them I was never going back to the prosthetist.

When we got home, my mother called our family doctor. He had a close relationship with our family and didn't mind telling me what he thought. He said I had to stop acting this way...that my parents had been through enough, and I didn't need to give them anything else to worry about. I had to rehabilitate myself and do whatever I could do. I guess it was good advice, although I wasn't so sure at the time. Later, while I was in my room feeling sorry for myself, I decided I could either stay in my room forever or I could join the human race again. I chose the latter.

It helped that I had two brothers and a sister who weren't about to cut me any slack. They made it plain that I could do things for myself, or I could sit

around and feel sorry for myself for the rest of my life. They certainly weren't going to do everything for me. My dad probably would have carried me everywhere and been my right arm. Looking back, it was a good thing he was busy with work – for both our sakes.

One of my brothers was ambidextrous and worked hard to help me learn to write with my left hand. “Anyone, even someone as stupid as you, can learn to write left-handed,” he goaded me.

Some of my friends in band and drama stayed in touch over that summer following the amputation. They didn't ask many questions at that age. They just wanted to see that I wasn't dying. It didn't matter that I was without an arm.

Things changed when I went to high school the following year. No matter who you are, high school is an awkward time, and it was even more so for me. I didn't make friends easily. Hap was a senior then. He insisted I join the pep club and attend other school functions; otherwise, I probably wouldn't have participated in anything. At the time, I thought he was being really mean to me.

I had been fitted with a special shoulder, cosmetic arm and hook. I had therapy at Children's Hospital where they taught me how to move my arm up and down at the elbow. But because the arm was amputated at the shoulder, I didn't get a lot of use out of the artificial limb. Normally, the cable that makes the hook work is operated by moving the arm, but since my arm was amputated at the shoulder, I had no arm to move. I wore the prosthesis to school only once. “Forget it,” I said after that. I always thought it was stupid to wear something that wasn't useful. I tossed the arm in the closet and informed my family I wasn't going to wear it, no matter how much they begged. I didn't date in high school. My brothers took me to lots of places with their friends – I was one of the “buddies.” It did hurt, however, when girls tried to make friends with me just to get introduced to my good-looking brothers. It was also painful when I didn't have a date for the prom. But for the most part, I was a feminist before feminists were “in.” Frankly, I thought most guys were pretty stupid, and I certainly wasn't going to let a guy tell me what to do.

After I graduated from high school, I went through a vocational rehabilitation program. I had my sights set on becoming a nurse but was told there was no way I would be capable. Program officials suggested

horticulture.

I wouldn't give up my dream. I applied to nursing schools at the University of Oklahoma and Central State University, but they wouldn't even talk to me once they found out I only had one arm. I remember a doctor who was examining me as part of a follow-up exam. He scoffed at the very idea that I wanted to be a nurse. "It will never happen," he said. Later, after I became a nurse, I was speaking to a group at a clinic where he happened to be in attendance. As I spoke, I looked him straight in the eye. "I can remember being told by a doctor that I would never get through nursing school," I said. "I'd like to let that doctor know that I did, and I'm doing quite nicely."

It was a long road. People were very "anti" when it came to a one-armed person. Handicaps just weren't accepted in the 1970s, and that made me mad. My ability to survive wasn't in my arms and legs. I had been brought up with the idea that you were more than your body...you existed because of what was in your mind and your heart. People only limit you when you accept their evaluation of you. I had to keep trying.

In 1973, I was accepted into the nursing program at Oklahoma State Technical University in Oklahoma City. The only stipulation was that I would have to wear an arm. School officials felt the public would accept me if I had an artificial arm and hook.

I agreed, but it meant relearning everything. I'd gotten used to doing everything with my left hand. It was hard to make myself use a hook. I had to pick up things, make beds and hold instruments with my hook. I had a supervising instructor who was always there to remind me if I forgot to use my hook. Yes, sometimes I spent more time in the lab than my nursing classmates. I'd do things over and over until I got them right. But once I mastered them, I never forgot them. I graduated from the nursing program with an associate degree in nursing in 1976. I was a registered nurse at last!

My first job was at University Hospital in Oklahoma City. The hospital was short-staffed the day I began work, so I was thrown right into the regular routine. People were amazed at how many things I could do. Most people just can't imagine life without two hands. It's as if they think it affects your mind because your brain would surely short-circuit without two hands!

Sure, there are things I can't do as quickly as I would like, but we all have our strengths and weaknesses. As nurses, we share the load. I help others

when I'm better at something, and in return, they help me.

After a year on the job, I wanted to travel. I joined the Peace Corps in 1977, thinking I could travel and still make a difference.

The people in Brazil were surprised to encounter a one-armed nurse. They were not accustomed to people with handicaps, let alone one working as a professional. Normally, anyone with a missing body part or an illness did not work! People without limbs or those with disabilities were beggars in the streets. It was an opportunity to show people I was more than just a person with a handicap. The people treated me with respect and courtesy, yet looked at me with awe because I was working as a nurse.

I spent the next several years working and traveling. I'd work to make some money, then put my things in storage, sell my car and be off. I guess having cancer at such an early age made me realize I'd better live for today. I traveled around Europe and tried to live in Spain several times in the early 1980s. In many ways, I lived life my own way. If I wanted to do something, I would do it, never thinking "I can't" because I only have one arm.

I took a couple of years off from nursing to work in the family oil business. It was during this time I met Alvaro, who became my husband. I was taking Spanish lessons from his aunt. The fact I didn't have an arm didn't seem to affect him. The hardest thing for us was that we were both independent and hard-headed. We still struggle with that in our marriage.

We now have three boys: Chris, 2, Alex, 5, and Simon, 6. I've never had any real problem managing the children that two armed mothers don't experience. As a mother, sometimes you need 10 hands to keep up! I remember during my third pregnancy, I cried because I didn't see how I would be able to hold on to another baby and still keep my other two boys with me. I soon found out I did things just like any other mother with three kids. I tried to move fast and keep a firm grip on them at all times, even if I had to use my feet or mouth!

Now that I have a myoelectric arm, elbow and hand, the children are particularly fascinated. It doesn't bother them that I have only one real arm. I laugh when I think my youngest is going to grow up thinking everyone takes off one arm and stores it in the drawer overnight!

Getting my myoelectric prosthesis wasn't easy, however. I had returned to full-time nursing at Presbyterian Hospital in Oklahoma City when I went to the prosthetist to see about getting such an arm. It was quite expensive, and



the insurance company flatly told me they would not pay for it.

Frankly, I would have given up. What was I going to do if insurance wouldn't cover the cost? But my hospital supervisor wouldn't let me toss in the towel. "When you wanted to get into nursing, what did they tell you? Only you can decide if you want to do battle with them," she told me. A local television reporter did a story on my problem. Money came in from across the state, and a firefighter in Altus even offered to give me his myoelectric arm.

I had heard of, but never met, Doug Bonds several years before from a nurse friend who had cared for him. He had battled the same kind of cancer I did and lost his arm also. His cancer had recurred, so he wasn't going to be able to use his myoelectric arm. When he heard my plight on the news, he contacted me immediately.

Doug gave me his arm, wanting to know someone would wear it and get good use out of it. It was a real joy to meet him and receive his special gift. It wasn't only receiving the arm that mattered to me – but meeting someone who had experienced many of the same feelings I had over the years. We shared humor that bordered on crazy, but we both agreed that's what helps you survive. He gave me more than an arm. He gave me the knowledge he had overcome many hurdles and never given up!

The prosthetist was able to use parts from Doug's myoelectric arm, but he still had to build a shoulder so I could wear it. The insurance company wouldn't pay for the shoulder either. It seems many insurance companies only want to give amputees the minimum required in a prosthesis – not what might improve the quality of life. I believe a person has the right to have the very best prosthesis available if you are determined to use it.

It took many calls from my attorney to get the insurance company to pay for the shoulder. I'm grateful for my friends at work who stood behind me and those who donated money to help me get the arm. The donations have helped cover what the insurance didn't and will help pay for servicing the arm. I don't know what I would have done without that support system. I was ready to give up. When you are told "no" over and over, you get mentally tired and begin to wonder if it's worth it. It becomes too much to deal with – like running up against a brick wall repeatedly.

The arm is like a part of my uniform now, and I have changed my mind entirely about the use of prosthetics. I never would have believed the arm

could make me feel this different about myself. I love it when I look in the mirror and my clothes fit better.

I've even gone out dancing – something I never would have done with a hook. The arm is not only cosmetically pleasing, it's also functional.

The arm works off electrodes. When I flex my shoulder and chest muscles, the arm moves electronically. I can do a lot more than I ever could with a hook. Many times, instruments would just slip through the hook, but I have control and strength with my new hand.

Before, people saw my hook first. Now, they see my face first. They see me as a person first. I never have liked being described as “the one-armed nurse.” I'm a person, not a nurse with an artificial arm. People at work say they can tell a real difference in me. The arm looks really natural.

At work, it's not “my arm,” but “our arm.” Everyone is excited for me. The first day I wore it, one doctor insisted on seeing how it worked. I was learning how to use it, so I was hesitant when he wanted to shake hands. I did and the hand kept squeezing until he was in tears. The harder he tried to take his hand away, the harder my myoelectric hand squeezed. I had to relax so the hand would relax. I think he probably had bruises. There have been several instances when the hand wouldn't open. It's not funny at the time, but later I usually laugh.

Of course, there are some drawbacks with the new arm. I began to have more phantom pain again when I started wearing it and had to practice relaxation techniques to lessen the sensations. There is never going to be an artificial arm that will replace my real arm—there just isn't. There are electrical problems with the myoelectric arm, and sometimes I really get frustrated. I was at work once when the arm locked in the “up” position, and the battery just kept running. I was so mad that I wanted to break the thing. I was ready to throw the arm out the window, but I didn't. I counted to 10, took many deep breaths and tried again. But all in all, the arm is still better than the cable-and-hook system of 20 years ago, and it is certainly better than not having an arm at all.

I've come a long way since those days as a teenager when I refused to even discuss wearing a prosthesis. I wouldn't be where I am today without the support of my friends, co-workers and family. I'm glad they didn't let me give up, and I hope I never will.

EMILY BAUM, 80

## My Family Kept Me Going

*Blood clots led to amputation of both her legs – first one above-the-knee and later the other below-the-knee. After the first amputation, she wanted to give up...to die. But her family kept encouraging her, and now she is determined to enjoy life.*

I knew I had a problem with blood circulation and hardening of the arteries, and my doctor had me on all kinds of blood thinners to prevent clots. But when I was 73, I began developing blood clots in my left leg. My heel became ulcerated, and I had a growing pain in the leg.

The doctors tried several bypasses in my leg, but nothing worked. My foot turned black, and I knew then I would probably lose my leg. The leg was amputated above-the-knee because that was the first place doctors could find good tissue and circulation.

After the amputation, I didn't want to live. I refused to eat. I wasted away to 90-some pounds. I didn't want to live and be a vegetable. It depressed me when I hopped up out of bed at night to go the bathroom, only to fall flat on my face because I didn't have a leg. Life just didn't seem worth the trouble. My children, the doctors, and a psychiatrist talked to me and encouraged me everyday. It was my children who finally talked me into living. Later, I was glad I'd made that decision because I just got along beautifully with a prosthesis and the aid of canes. I drove the car, lived alone, shopped and did everything I wanted.

I didn't know then I would one day lose the other leg. In fact, I was walking so well I thought I'd never have any problem with the right leg. The doctor was checking it regularly for any problems. Then in 1990, I developed an ingrown toenail that wouldn't heal. Ulcers began to form on my leg. I had a woman who came each day to put hot packs on my ulcers. Thinking the deterioration could be retarded, doctors tried several bypasses on the leg. They didn't help, and the foot began to turn blue. Gangrene was spreading rapidly, and I was told if I wanted to save my knee, an immediate amputation was necessary. In February 1991, doctors amputated my right leg below-the-knee.

I went through many of the same feelings I had felt after the first amputation. I was determined I would not go through life as a vegetable in a wheelchair. I didn't want to be half a person. I knew I'd have to change my whole lifestyle with the loss of both legs, and I didn't think life would be worth living. Once again, it was my family that kept me motivated. The children gave me the will and the desire to live.

They remain concerned about my comfort and have all pitched in to help me adapt my home to make things easier for me. My son took the doors off the bathrooms to accommodate the wheelchair and rearranged my bedroom to make it easier to get around with the walker. My daughter reorganized my kitchen, placing pans and utensils where I could better reach them. I'm having some cushions made to raise the seats of some of my chairs to make it easier to get up from a sitting position. The children have even checked with the woman who helps me weekly to make sure she gets me out of the house frequently so I don't get depressed. I still have "down" times from time to time when I ask, "Why did I deserve this?" But the times are short, and I can usually pull myself out of the dumps by getting tied up in a book or television program, or by calling to talk to someone. My children phone at least once a week – sometimes twice – and that is a big boost.

I have a woman who comes four days each week to help me with the things I am not able to do. I think if I had help more often, I might become too dependent. I still do a lot of things for myself, like bathing and laundry.

Even though the second amputation was only four months ago, I already have my below-the-knee prosthesis. I had to have it if I was going to walk, so I was pretty anxious. I get around with a walker now – I'll probably always use it. It tires me to walk a long distance, but I think it will make a difference once my new stump is completely healed. I want to go to the mall to see just how far I can walk without the wheelchair. Of course, there are still things I regret that I will never be able to do again. I could have my car adapted for an amputee, but I may just give up driving. I haven't decided. My bridge club friends told me not to worry about driving – they'd take me to the store or to bridge club.

I had phantom pain with the first amputation, and I'm still having phantom pain in the right leg. I feel like I have a foot with a sore ankle. I just try to concentrate on something else when it bothers me – like a book or a TV program.

When I got my second prosthesis, I was on television news. I was at the rehabilitation center and was totally unprepared for the interview – I even had to borrow a pair of slacks for the filming that day. The news crew was amazed that someone who was 80 and had two artificial legs could walk. However, I was disappointed in what the media said on the air that night. What I wanted to tell everyone was that there is a whole new world out there for amputees or anybody who is disabled. There are wonderful rehabilitation centers where you can go for help. While I was at one, I saw so many people come in unable to eat, feed themselves or walk. In the short time I was there, I saw the same people feed themselves and walk out of the center. So, it can be done. There is help, and there is hope. I'm proof of that. It can be done, but you have to want to do it! I did it and am getting along nicely.

**ROGER DAKIN, 32**

## **Never Two Bad Days**

*To a firefighter, grass fires are routine. But out of the smoke that day came a car that would change his life. An accident left him without both his legs above-the-knee. He refused to let the amputations get him down and kept in shape through weight lifting.*



Roger Dakin taking a walk through the park with daughter, Kristine.

I was just sitting down to a late lunch at a Sedgwick County fire station on that November day in 1989. It was 2:10 p.m. when the fire alarm sounded. Lt. Stuart Segraves and I rushed to put on our bunker gear. As we drove to the fire, we joked about missing lunch again, all because of a grass fire. I didn't know that for me this would be more than a routine grass fire.

The fire scene was approximately six miles from the station. More than a mile away from the fire, we could already see thick, gray-white smoke. There weren't any fire hydrants out that far, so Stuart called for a second tank truck to help supply water.

At the scene, visibility was only four to six feet. We drove slowly through the dense smoke to try to find where the fire began. Stuart called the sheriff's office for traffic control. Once we located the origin of the fire, we drove back to the head of the fire to begin extinguishing the blaze. We turned the engine into the wind, about 20 yards in front of the smoke. Stuart jumped out and pulled the booster line while I charged the pump to get water to him as soon as possible. Routinely, I got back into the truck to drive so we could "run and pump." Stuart walked along the side of the truck extinguishing the fire.

But the smoke got thicker. I could no longer see Stuart in my side mirror. I set the brake, locked the wheels, got out and walked around the truck to locate him. He was about 30 feet off the roadway fighting the fire. I told him I could no longer see him, so he would have to yell or hit the side of the truck when he was ready to move.

I was thinking how exceptionally smoky the fire was as I stepped onto the roadway behind the truck. Out of the corner of my eye, I caught a glimpse of something in the smoke. The next instant, I was upside-down, pinned between the front of a car and the engine tail board. My legs were behind me embedded in the grill of the car. The impact completely knocked me out of my bunker boots. The engine was shoved forward 22 feet. The front of the car was pushed straight up into the air, and the motor was sticking up.

"Stuart...Stuart...help me," I yelled. He had trouble finding me in the smoke. The pain was indescribable. I just prayed to the Lord not to let me die. I wanted to see my little girl, Kristine, again. She was only 18 months old.

After assessing me and the driver of the car, Stuart called dispatch. He told them he had a motor vehicle/pedestrian accident with a firefighter down. On his authority, they launched a Life Watch helicopter. Two more

engines were dispatched for fire control.

I could hear the pump still running on the truck. Stuart returned with the medical kit to try to stabilize me. "Get my legs down off this car. Get me down," I kept telling him. "You know I can't do that," he said, as he tried to calm me. Had he moved me, I probably would have bled to death.

But as we stayed in the smoky roadway, I think we were both painfully aware that if that one driver had ventured through the smoke, another might. We could both be killed.

Within a few minutes, firefighter Alfred Pressnel arrived at the scene with the second tank truck. He pulled across the roadway sideways about 25 yards back to block further traffic. Alfred knelt beside me to take my pulse and check my respiration. He was surprised to find me conscious and alert. Alfred and Stuart continued to check my injuries. Remarkably, only my legs were hurt. But there were multiple open fractures and massive tissue damage to both legs. The left leg had been crushed to such an extent that it was hanging only by soft tissue.

Capt. Jim Shavers, firefighter Bob Conger, and the EMS unit arrived. The EMS team started two IVs and removed my legs from the vehicle grill. They rolled me onto a spine board and applied mast trousers, a shock garment that also would stop the loss of blood. I never looked down at my legs. That way I could get by thinking they were just broken.

The helicopter arrived, and they rushed to get me loaded. I had been at the scene of many accidents and wanted to be a good patient, so I tried to do as they told me. The pain was still there, but I was tired. I felt like I couldn't go any farther. I wanted to go to sleep. I knew I was experiencing shock. They kept telling me I had to stay awake. I wanted to go to sleep so badly.

The Life Watch technicians were in touch with HCA Wesley Medical Center in Wichita. "We're on our way with a code red trauma alert," I heard a technician tell the hospital. I knew that meant I was just short of dead.

We landed at the hospital just 20 minutes after the accident. They prepped me for the operating room. When they removed the mast pants in surgery, the left leg just fell off. Doctors worked eight hours to save my right leg. But after the operation, the bleeding wouldn't stop. I went back in for a second surgery to amputate the right leg.

In the intensive care unit, I was covered with a sheet held up in a tent-like fashion. I really didn't think about looking at my legs because I could feel



them. There was crushing pain. “I wonder if I’ll lose both my legs?” I remarked to my wife Kathy. She was shocked. She thought they already had told me, so she went to get the doctor.

“Roger, we had to take them both,” the doctor told me.

“Okay, then what do I have to do now?” I asked. He looked puzzled. “Do you understand what I said?” he questioned.

“Sure...I know both of my legs are gone, and they aren’t coming back,” I replied. “So, what do I do now?”

I guess I’d already made an unconscious decision about how I was going to deal with the amputations. I could get mad and depressed, or I could get over it. I chose to get over it.

That doesn’t mean it was easy. There were three more debriding surgeries to remove infection. And the phantom pain was incredible. It was really weird feeling such intense pain in legs that weren’t even there. I averaged about four to five shots of Demerol each day for 70 days.

I had been in the hospital for a little more than two weeks when I began physical therapy. The therapist wanted to test my upper body strength. By the time I’d finished the session of cable crossovers, dips and a variety of balance exercises, she said I was already stronger than she would have wanted to make me. I was weak and had lost a lot of strength by my standards, but compared to the normal accident victim, I was quite strong.

I had been lifting weights for the last eight years. I usually worked out more than two hours each day – five to six days per week. At the time of the accident, I was 6 foot 2 inches and weighed 220 pounds with only 6 percent body fat. I was in better shape than the average person. The therapist also commented on my extraordinary attitude for someone who had been through such a trauma. I told her I knew I could live out my life and be depressed and in a bad mood, or I could live out my life trying to cope and make something good out of it. The fact that my legs were gone would never change. I chose to be happy.

It’s not that I didn’t care about losing my legs...I surely did. And there’s nothing – no prostheses – that can replace my real legs. Even with artificial limbs, there are still a bunch of things I can’t do...like squat. If I bend both artificial knees at once, I fall on the floor. But I just don’t think about that every day.

While I was in the hospital, I had to tell myself not to be mean to the

nurses or the doctors, not to take it out on anyone who just came in the room and not to be mad at the lady who hit me. I just was in the wrong place at the wrong time. I'd been raised in a family that always went to church. My mother taught me that God has a plan for everything that happens, and "I can do all things through Christ who strengthens me" (Philippians 4:13). I had tremendous support from my family, friends and fellow firefighters...letters and cards came from churches and pastors I'd never heard of. They were all praying for me. They believed that would help and so did I.

It was hard on Kathy. She had a really tough time accepting the accident. But as long as my spirits were up and I was "just Roger" she did okay. I wasn't sure about my daughter. I didn't let her come to the hospital for more than a week after the accident, until all the tubes were out of me. It would have scared her to death.

She was so young she really doesn't remember me with legs. In fact, she sees pictures of me before the accident and says, "How can this be daddy? Daddy doesn't have legs."

I left the hospital January 11, 1990. My first outing was a trip to the gym the very next day. I didn't get much of a workout but I did give it a try. People wondered why I went and some of the guys just stood around and stared at me. But the fact that I had been in such good shape is what kept me alive. I wanted to get back into shape again. I'd lost 75 pounds. Granted, some of that was legs, but I wanted to get back to weight lifting. The guys at the gym were afraid I would roll off the bench because it is difficult to balance when you don't have any feet on the floor.

Of course, getting the blood flowing again meant increasing the pain but with weight lifting you hit pain barriers all the time. You have to teach yourself to handle the pain. Over the eight years I'd been lifting, I had gotten to where the pain was secondary. I learned to block it out. I think that helped me at the time of the accident. I was able to have some control over the pain.

It was March before I got my first artificial limbs – "stubbies," as they are called. They were real short, square-footed legs that help you regain balance and confidence in walking. They also helped toughen the stumps. I took right off walking on them. My prosthetist couldn't believe how well I walked on them the first day. I went home with the short legs to practice walking,

standing, turning and going up and down stairs to get ready to try some taller, permanent prostheses.

One of the first places I went on my stubbies was the softball field. I had played ball and coached for years. I stood in the batter's box and hit the ball. I even tried running to first base.

I went back to the prosthetist for my permanent legs just after Easter. I put them on and was six feet tall again. It was odd because I'd gotten used to looking up to people on my stubbies. Now I looked down on some people, just as I had before the accident. The prosthetist told me it would take awhile to get used to balancing on the higher legs. But I started walking around the office complex with the aid of a cane as soon as I put them on. I was told to wear the artificial limbs four to five hours each day to get used to them.

My first day home, I wore them 14-15 hours. I went to a softball tournament. I walked everywhere. I guess subconsciously I was trying to prove something...that this was not going to get me down. I had been told if I wore the legs too long I might develop painful blisters. I did. I think it was me against the pain. I was not about to let it or those legs beat me by making me fall down until I quit.

I had some real struggles with the new legs. It was a hot summer and my legs lost some volume so I couldn't wear the prostheses because they just didn't fit. I remember one time I wore the legs to a softball game where I was scorekeeper. One of the legs kept slipping off. After the game, I came out of the dugout, took off my leg and threw it. I was really mad.

Now I've gained back some of the weight I had lost in the hospital and the legs don't fit again. But I'm just waiting for the weight to level off so I can go to the prosthetist for adjustments. It is frustrating and I get mad if one of the leg malfunctions. But most of the time I'm fine and things are fairly easy.

I'm just not the "why me?" type of person. I won't allow myself to dwell on that. I know I will have bad days. But Lord willing, I won't have two in row. I guess the only thing I really feel bad about is not being able to go back to work as a firefighter. The accident robbed me of that. It was one thing I really enjoyed and wanted to do for a career. I won't go to work in a fire department office because that's not what I originally hired on to do. I hired on to help people. I liked doing that and I enjoyed fighting fires. I do plan to go back to work but it will have to be a job where I get up everyday looking forward to work, like I did at the fire department. I hope something good

can come out of all this, that I can help someone who has had an accident like me...someone who can look at me and say, "Man, he has a good outlook on life and I want to be like that." I believe once you get it in your head that you want to do well, you will. Every cloud has a silver lining. You just have to find it.

RON, 51

## Twelve Steps to Acceptance

*A truck accident caused the loss of his left leg below-the-knee. There were 12 long years of alcohol and drug abuse along with three attempted suicides before he surrendered his will and his life to the care of God. With God's help, he finally accepted the amputation and himself. Now he's pursuing a career as a drug and alcohol counselor.*

I was an active person and enjoyed hunting, fishing, camping and just tramping through the woods with my three children when I was home between my coast-to-coast runs as a cross country trucker.

In June 1973, I was a member of a two-man truck team. I must have had a premonition that something was going to happen because I didn't really want to make that trip. But we were coming up on a contract negotiation period, and I was afraid I might be out of a job for a time if we went on strike. I needed the extra money I'd earn from the trip. My partner was driving on an eastern Tennessee highway while I was resting in the sleeping berth when the accident occurred. I awoke underneath the truck with one wheel on my chest. Someone kept screaming and I thought to myself, "Why don't they just shut up?" I finally realized I was the one screaming.

A woman had crawled under the truck and was holding my head up out of the diesel fuel. I kept feeling some sort of mass under my shoulder. It was uncomfortable and I kept trying to move it. It turned out to be my left leg, bent and twisted up under me. As I lay there trapped underneath the truck for more than five hours, it became apparent to me that the leg would have to be amputated.

I didn't have a great deal of pain; doctors later said it was because I was in shock. I was conscious and talked coherently to the ambulance technicians on the 30-mile ride to the hospital. I remember telling them, "I've never been in a vehicle like this before, so how about turning on the siren?" They kept telling me to lie still, that I didn't need to see everything that was going on. I was taken to a hospital in Kingsport, Tennessee. Fortunately, it was a tri-state trauma center, so they were equipped to handle accidents like mine.

I had an eerie feeling as they rolled me down the hall on a gurney. There

were all these faces looking down at me. They had an internist and a fine orthopedic surgeon standing by. The doctors told me I was going into surgery and my leg would have to be amputated – they weren't sure how high because the bones were crushed and they would just have to see how much of the leg could be saved. I signed the release forms and went into surgery not knowing how much of my leg would be left when I awoke. I was lucky. By pinning the bone, doctors amputated at mid-calf and were able to leave my knee.

It's kind of weird after surgery. When you raise your head up and look down your bed, you normally expect to see two feet sticking up. But after an amputation, you raise your head and all you see is one foot sticking up. You see the other leg going down so far, but nothing at the end of it. It's hard to describe the feelings. So many things ran through my mind. "What's happened to me? What am I going to do now? How am I going to make a living for the family? I don't even want to live..." There were millions of questions, but no one who could give me any answers.

Doctors weren't sure I was going to survive, so they didn't focus on helping me recover emotionally from the amputation. In addition to the amputation, my chest had been crushed, causing one lung to collapse. Both arms and my other leg were broken, and there was significant damage to the internal organs. During my hospital stay, a woman who was a double amputee came to visit me. She told me as an amputee I could do whatever I wanted to do. That was the only counseling or help I received, and she was the only one who told me I could still do anything I wanted.

I was in the Tennessee hospital two weeks before I was flown back home to an Oklahoma City hospital. There I met an orthopedic doctor who probably did more for me than anyone. He made me mad. I hated that man. I guess he could sense that I was starting to feel sorry for myself. He was an old battlefield surgeon from World War II and went to work on me with a little reverse psychology.

I'll never forget how he grabbed the end of my stump, twisted it around and shoved it toward my face. "Look at this. This is what you're going to have to live with," he said. "You're going to be a cripple for the rest of your life. You're going to be out on the corner selling pencils to make a living."

It worked. Nothing he could have said or done would have made me more angry. "I'm going to walk out of here," I told him flatly. "I want a leg

built so I can walk out of this place. I'm not going to ride out in a wheelchair."

A prosthetist came to the hospital to cast my leg for an artificial limb. I walked out of there 30 days after the accident. I didn't walk very well, but I walked. I swore then that I wouldn't let anything or anyone stop me. I practiced walking hour after hour and even wore a path across my yard in an attempt to walk with a natural stride so most people wouldn't notice anything was wrong.

Learning to walk with a prosthesis was nothing compared to learning to accept the amputation. That, I just couldn't do. I was addicted to morphine when I came out of the hospital and a relative continued to get me the drug illegally. I had been a heavy drinker before the accident, so the morphine dependency came easily. My morphine supply ran out after a couple of years, so I turned to street drugs...whatever I could get at the time.

I combated what I first thought was physical pain with drugs and alcohol. Only later did I understand what I was feeling was emotional pain. The pain came from many sources. My wife at that time told me I was repulsive to look at. She said she couldn't stand to see me lying in bed with just one leg. Whether it was my drug and alcohol abuse or my physical appearance, I had become repulsive to her. Worse yet, I was ashamed of my appearance. I didn't want people to know there was something wrong with me. I did everything I could to hide it. I tried to prove to myself that I was still whole. I wasn't going to be a handicapped person!

Compounding my feelings of inadequacy was the fact that my employer wouldn't let me drive a truck after the accident. The company wanted to give me a desk job. My supervisor called me a cripple and said there was no place for a "handicapped" driver with the company. Being told that nearly did me in. I overdosed on drugs and alcohol in two attempts at taking my own life and ended up in a hospital psychiatric ward for 90 days. I was just tired of me, tired of being put down, and tired of being called a cripple. Doctors told me then I had an alcohol and drug problem, and if I would just quit, that would take care of many of my problems. But I didn't quit. I was drinking within 24 hours after I left the hospital.

My wife and my employer only reinforced the bad feelings I already had about myself. The bottom line was that I couldn't accept me. I didn't like seeing myself in parts. I let the feelings of other people dominate me, and

they only reinforced the thought that was buried within me: that I was nothing. I could have adapted to the physical challenge of the amputation, but the emotional trauma wouldn't let me. Using alcohol and drugs was my way of hiding my feelings from other people. I hid my emotions and thoughts about being an amputee for 12 years, from 1973 to 1985. I filed a discrimination suit against my employer, which took more than three years to settle out of court. During the suit, I took a leave of absence from the company. Ironically, the only job I could get in the interim was driving a truck in California. That was fine with me because I wanted to prove to myself that I could still drive a truck, which I did from the summer of 1980 until February 1984.

My drinking and drug use continued, and eventually I turned to cocaine. Once I had given up on myself, drinking and drugs seemed to me to be the only answer. But no matter how much I thought I was hiding from the outside world, I still had to face me on the inside. I nearly overdosed a third time in 1983.

I moved back to Oklahoma City in 1984. In 1985, I finally realized I needed help. I drove all the way to Shawnee, a small town outside Oklahoma City, to my first Alcoholics Anonymous meeting. It's funny – you don't want anyone to know you're going to an AA meeting, but it never bothers you when your name is in the paper for driving under the influence. I was reaching out. I just wanted someone to say, "Hey, you're okay."

I made the decision to quit drinking in July 1985 and checked into a drug and alcohol treatment center that August. I was drunk when I checked in. I think that's probably the only way I could have done it at the time. I went through four days of "detox" and was in treatment a total of 30 days. That was the beginning of acceptance. I had to get off the drugs and alcohol before I realized all the pain was in my head. It was emotional pain, not physical pain, that was killing me. I carried that injury for 12 years, and it hurt like hell all that time. But when I gave up and asked God for help, I finally quit hurting. I had to accept that this was the way it was. I was an amputee and that was not going to change. Part of that acceptance was learning I didn't have to hide my amputation from people.

"You've never told anyone about your leg being gone, have you?" one treatment center counselor questioned me. I said, "No," and he asked "Why?" I couldn't really explain to him, except I didn't want anyone to



know. "Someday you will," the counselor told me.

I think that was the beginning of understanding who I was... that just because I was an amputee didn't mean I was any less than the next person, and I could be just as much as I wanted to be. I saw that same counselor again several years later. He was the guest speaker at an Oklahoma City AA meeting. I walked into the meeting in sneakers and shorts. He didn't say anything directly to me, but just looked at me and smiled, taking note of the shorts. I knew what he was thinking... "Someday you will."

For the first time, through a support group of other patients at the treatment center, I was able to talk about me – my fears and anxieties. Being able to talk about it made the difference. Many of my self-doubts and fears ceased being problems.

That doesn't mean acceptance came overnight. Just wearing shorts in public was a big deal to me. I had to work up to it. I started wearing them to work in the backyard and eventually graduated to the front yard. Initially, I looked around to make sure no one was watching.

I had remarried in 1978. I can honestly say now that I never really knew my wife, Ruth, the first seven years we were married. But she was my biggest booster in treatment. She has always accepted me for who I was. More importantly, she had patience until I was able to accept me.

After I was sober, Ruth and I joined the Catholic church. They were signing people up at church to walk in the CROP Hunger Walk. "Hey Ron, why don't you sign up?" one of the girls asked. Before I could answer, another woman said, "Oh, he can't do that." So, of course, I signed up. My wife asked what I had done. "I signed us up to walk," I laughed. We participated in that 10-mile walk for three consecutive years. I walk four miles a day now. I started that when I was preparing for the first CROP Walk and Ruth chided me, saying "You hardly walk to the mailbox and you're going to go 10 miles?" Of course, there are a lot of people who practically fall over doing double takes when they see me out walking in my shorts.

Ruth has been a constant source of support, something I needed from the beginning. Having someone to talk to is so important. I have several support groups now, including AA and the church, but it's really important for amputees to have the opportunity to share with each other what they are going through... what they can and cannot do.

I have a lot of pride in me now. I'm proud of the many things I've been

able to accomplish in the last few years. Now, I'm able to accept that an amputation doesn't mean I'm a cripple. It doesn't mean I'm disabled. I am only limited in some areas. And I discovered that sometimes I am limited only by what I think I can't do. I remarked to my prosthetist one day that about the only thing I really couldn't do was run. "Sure you can," he said. I tried it, and I can run, but it seems a little awkward. Right now, I run at night because I'm not ready yet to let other people see me do that. I still want to make sure I can do something right before I do it in front of anyone. Eventually, I'll get around to jogging in the daytime.

It's ongoing. You have to try some things to find out you can do them for sure. Like dancing...It may not be easy and it may not be graceful, but I can still dance. A lot of people may think I can't dance, but I think I can dance. That's how I see me now. Before, I didn't even want to see me.

I've adapted the things I do to the point that I don't think much about being an amputee anymore. I've found that I need to be me, not what other people want me to be. I can't worry about their expectations. I've grown comfortable with who I am. I've accepted me. Sure, there are "down" days... days when I see someone walking with two legs and envy the fact he has two ankles. That's negative thinking, and I have to get away from that. That's one thing I've learned through AA – when I get negative, I've got to get back on the positive side. I have a sponsor I call when I get down. I've found my problem quits being a problem when I can share it with somebody.

Now, I'm working at a hardware store and going to school. I literally drank my way out of college 32 years ago, but I'm back studying sociology. I plan to go into drug and alcohol abuse counseling and hope to work in the penitentiary system. It's needed so badly in the prisons. People in there have problems they can't deal with – just like I used to have – but they don't have the avenues of help I had. I hope I can make a difference.

As a part of all I've been through, I found out I can do most anything if I try. I just didn't try for 12 years. Drugs and alcohol made it easier – easier to hide behind and easier to accept what others thought of me. Even now, everything isn't perfect. I work toward my goals, and I know I'm going to have problems. But if I can accept me today, then I can take care of tomorrow.

*Editor's note: In keeping with the tradition of Alcoholics Anonymous, we are*

*not using Ron's last name.*

**DOUG BROOKS, 47**  
**I'm a Lucky Guy**

*As president of Brinker International, he was a busy man in charge of 75,000 employees in more than a thousand Chili's, Macaroni Grill and On The Border restaurants around the world. Then a freak accident changed things – but fortunately not his energy level or zest for life.*



Doug Brooks

It was a hot day in Plano, Texas, July 1998. I got up early and decided to sneak in a run before my wife Holly woke up. At 7 a.m. it was already blazing as I headed out on one of the 20 different paths I took through my neighborhood. Running was my passion. I was training for the New York Marathon. I had already run in the 1992 Chicago Marathon when I was 40 and I was itching to try another 26.2-mile race.

I told myself I was only going to go five miles. Just a quick run and be done with it. When I was a mile from my house, a Lincoln Continental made a U-turn beside me in the street. He didn't see a van coming the other way. When the vehicles collided, the van bounced off the car, slammed into me and pushed me into a brick wall. I was trapped in a pile of brick rubble.

Unfortunately, I didn't lose consciousness. I looked down and saw my left foot hanging. I could smell the tires.

One of the first things I saw was this woman coming around her house screaming into the cell phone in her hand. The guy driving the van stood over me screaming in Spanish. Right before the ambulance carted me away, I had the screaming woman call my wife and tell her what happened.

A doctor in the emergency room told Holly, "If he lives, he'll lose his leg." I lost 30 pints of blood that day. They ended up air lifting me to Dallas. I had six surgeries as they tried for a week and a half to save my leg. Finally they had to take it, and I lost my left leg above-the-knee.

Holly's strength never wavered. She was my rock. My teenage sons, Kyle and Taylor, were there, my brothers and sisters came. Friends stopped in by the dozen. But when I was alone in my hospital bed, I looked down and I cried.

Of course it turns your world topsy-turvy. It's 90 percent mental to get over it. Luckily the visitors kept coming.

Norman Brinker, my boss, is friends with Ross Perot. They were having dinner one night and Norman was talking about me. Both Ross and Norman were going to the hospital to visit friends, so Ross asked Norman if he could join him and come by and see me first. Imagine my surprise. I'm laying in my bed and in walks Ross Perot with my boss. Ross encouraged me to go to Oklahoma City as soon as I could to see Sabolich about a prosthetic leg. He told me there was no other place in the world beside Sabolich to go for prosthetics. He had helped veterans with lost limbs get their arms and legs there. At the time, I thanked him politely thinking surely there would be

something right in Dallas, but he turned out to be absolutely right.

Another celebrity visitor I had in my hospital room was Craig Gavras, director of Limbs for Life. Limbs for Life raises money for amputees who can't afford prostheses. When he heard about my accident, he started ringing my phone in the first few weeks. I didn't want to talk to him. I didn't know him, I didn't feel much like talking. My wife encouraged me to talk to him when he called back again. He ended up being such an incredible force in my life. My mentor. I can't believe I tried to ignore him. Craig is missing a leg, too – lost it in the line of duty as a police officer in Dallas. He helped me so much, especially to learn how to help others.

I was happy to finally leave the hospital, but the real battle doesn't start until you go back to the real world. Craig told me the worst part is going home because you're a stranger in your own house. Showering, moving around all the obstacles – it's all strange and has to be relearned.

It was bleak at times. I had depression. Late at night and early in the morning when you're all alone is the worst. I won't lie. There were times I bawled my eyes out. There was a lot to fight through. I lost my father in a different freak accident – the 1959 Braniff plane crash – and memories of that were haunting me, too. But I'm a lucky guy. I have a wonderful job. Wonderful support. A great wife. Great kids. A great life. My family and my faith in Jesus Christ got me through it.

I went back to work really soon, even had meetings at my house while I was recuperating. If you don't have something to keep your mind busy, it's dangerous. No one wants to come to your pity party.

As for sports and my other activities, losing a leg hasn't stopped me from that. One of the things my son Taylor said he was so mad about was that losing a leg meant losing his dad in all our favorite outdoor sports. He asked Holly, "Does this mean Dad can't go snow skiing or play golf with us?" A year and half later we spent the holidays skiing in Winter Park. And I rode in the Project 50 Bike Ride in the fall of 1999 with Craig and Tim McCarthy, another cop who lost his leg in the line of duty. I joined them in Gainesville, Texas, and rode the almost 100 miles to Dallas with them.

We raised \$80,000 for amputees who can't afford new limbs. Our next project is the Byron Nelson Charity Golf Tournament to raise money for Limbs for Life. And now my wife and I are on the board of directors of Limbs for Life. We're so grateful to Craig who brought me into a whole new

world of what can be done for amputees.

At first I thought losing a leg might slow me down. I remember when it came time for our annual canoe trip with our friends down the Guadalupe River, I told everyone, "Well, I guess the canoe trip is out." We'd made that trip every year for 20 years. It was tradition. My friends and wife had one word for that – "Bull!" They told me "we're not going to let this lost leg change things...you're going with us." I couldn't get out of it. It was life as normal and it turned out to be a wonderful trip.

Actually, everything is wonderful when you have people to encourage you. You can still have a terrific life even if you've been through a terrible accident. Life is precious, so you've got to enjoy it.





**DONALD “BUTCH” WYMAN, 37**

## **A Spirit That Wouldn't Quit**

*Alone on a mountain cutting trees for lumber to build a new home, he was trapped when a mammoth oak tree fell on him, crushing his left leg. Faced with certain death unless he freed himself, he cut off his lower leg below-the-knee with a pocket knife. His “I can do” attitude has helped him deal with the loss.*



Donald “Butch” Wyman

My wife and I were going to build our dream home in the Pennsylvania woods. To cut the costs, we decided we would do as much of the construction ourselves as we could. As an employee of a strip mining company, I was used to taking down trees to clear an area. The company let me borrow the equipment, and I stayed after my regular shift to cut some trees that would be turned into lumber for our home.

The woods became quiet as the others on the strip mining crew headed home late that July afternoon in 1993. I turned to go back down the hillside with my chain saw, never expecting the serenity soon would be shattered, and I would face a life or death decision.

I had my eye on a big oak tree. I had cut hundreds of trees, so I should have known better. The top of that particular tree was slightly bowed because it had been wedged between several other trees on the ground. As I cut, the trunk suddenly snapped! I was Donald "Butch" Wyman knocked to the ground, and my lower left leg was pinned under the tree. The tree was more than 30 inches in diameter. As soon as it hit me, I knew I was trapped. I couldn't move my leg, and there was no way that tree was going to budge.

I couldn't cut the tree away because of the diameter, so I started digging around my leg hoping I could open up enough space under the tree to pull it out. At the same time, I was screaming for help. I'd dig a little and scream a little. But my cries for help rang hollow in the woods. No one could hear me. I kept frantically digging, first with my chain saw blade to loosen the soil. When the saw ran out of gas, I used my hands to scoop away the dirt. I just knew I could do it – until I hit a rock. Then I had to deal with the fact that there was no way I was going to free my leg.

I was kind of panicky, but I knew I couldn't let myself lose control. I didn't want to pass out. Part of the bone was sticking out of my blood-soaked pant leg. A pool of blood was beginning to form on the ground. I don't know what made me think of it as an option, but it came to me that since my leg was already broken, I could cut through the flesh and leave my leg there. I pulled out a pocketknife. It was horribly dull, so I sharpened it on a piece of rock and cut my pant leg away to see how badly I was hurt.

I prayed for a little while. I decided I could either stay there and maybe bleed to death, or I could go for it. I decided I had to go for it. I took the rope off my chain saw and tied it around my leg like a tourniquet, hoping that would deaden the feeling in my leg. I scratched the knife across my leg,

and it wasn't too painful. As soon as I started to cut though, I hit a nerve, and it was just like there wasn't a tourniquet at all. I didn't think I was going to be able to do it. For a few minutes, I wasn't sure what to do. But there really was no other option. I had too much to live for –my wife Janet and son Brian. I closed my eyes and began to cut. It was an agonizing pain, and I'm not sure why I didn't faint at that point. I just tried to concentrate. Finally,my leg was free!

Leaving the lower part of my leg pinned beneath the tree, I began the uphill climb to my bulldozer which was about 135 feet away. I was hanging on to the tourniquet as I crawled up the hill and into the dozer. I used the dozer to drive myself the remaining 1,500 feet to my truck. Once in the truck, I used a metal file to push in the clutch when I shifted, all the time holding on to the tourniquet to suppress as much of the bleeding as possible. As I drove, I was praying to find someone – anyone – who could send for help. No one was home at the first farmhouse I came to. I passed yet a second vacant house before I saw children playing in the yard of another. I pulled over and started yelling for help.

As the farmer neared my truck, I screamed, "Help me. I'm bleeding to death. I cut my leg off." I kept trying to lift my leg up off the seat to show him. He ran inside to call an ambulance, but I knew we were still a good distance from the hospital, and time wasn't on my side. I asked him to drive me to meet the ambulance. We took off, but by that point I was growing weary. Knowing I had to stay awake, I began retelling my story of all I had been through to get that far. We met the rescue squad, and they immediately wanted to give me something for the pain, but I declined. I wanted to know what was going on and to stay in control. One of the rescue people asked where to find the rest of my leg, so I hastily sketched a map to help them locate it. That gave me hope that the leg could be reattached.

But it wasn't meant to be. They found the leg and delivered it to the hospital only about 30 minutes after I arrived. It was unsuitable for reattachment because it had been too badly crushed by the tree. The doctor joked that I was not a very good surgeon. As luck would have it, one of the best surgeons in the country was at Punxsutawney Hospital. He had experience with amputations during the war. He cleaned up my self-amputation, and I was left with six to seven inches of leg below-the-knee .

I worried about my wife and how she would react. I asked the hospital

not to tell her I had lost my leg. They called Janet and told her I had been in an accident and injured my leg. Maybe it was a sixth sense or something, but out of the blue she asked, “He didn’t lose his leg, did he?” They didn’t confirm that for her until she reached the hospital.

Janet and Brian have been there for me all the way. I kept a positive outlook which helped them. Some people ask how I kept up my spirits. Things happen in life, and you just go on from there. I lost a leg but was happy to be alive and to be there with my family.

I was hospitalized for six days and was scheduled to go to a rehab center about 30 miles away. Probably the hardest thing to understand was all the media attention. They were camped out at the hospital, and fortunately the hospital public relations staff kept them at bay that first week. Janet and I decided they weren’t going to go away, so we picked out several we thought were reputable and agreed to tell our story. We figured if we shared the story, the media would go away. At first I was reluctant, but as I realized how my story was helping other people, I almost felt obligated to share the details.

In fact, when I say I never let the amputation get me down, there actually were a few days when I dwelled on “Why me, God?” I can remember being in the rehab hospital on a Saturday – no treatments, nothing to do, and Janet had errands so she didn’t visit that day. I began to think about how Brian and I used to run in the backyard. I could visualize us racing and myself with no leg. I had to deal with the idea that those days were gone forever.

As my story became highly publicized, I began to get stacks of mail. There were letters from people all over saying pretty much the same thing – that they had troubles in their lives they didn’t think they could handle until they read my story. It was then I came to a realization that God was using me as a tool to help other people with their troubles. What they didn’t know was that their letters also were helping me.

Exactly a month after the accident, I was fitted with a temporary prosthesis. Even though it was a little uncomfortable, it was great to look down and see two feet on the floor. Of course, I had expectations that this was going to be a miracle leg, and I was going to put it on and take off walking. It wasn’t quite that easy. Even after two weeks of pretty much taking baby steps to relearn how to walk with the prosthesis, it was not really comfortable. My surgery was so recent, and I had a lot of healing to do to get past the tenderness and cut nerve endings. My prosthetist tried to encourage

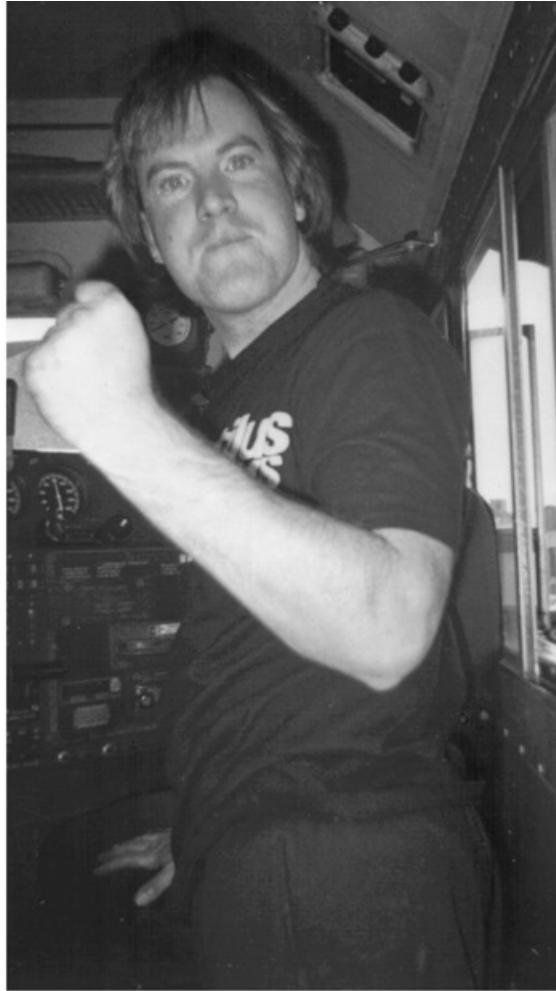
me not to take it too fast, but I was determined to be walking for my wife's birthday that month, and I did exactly that.

I continued to use my temporary prosthesis and, as I healed, the leg felt better and better. I returned to work three months after the accident and was fitted with my permanent prosthesis in January 1994. I actually got two legs. One is a more rugged sports leg I can wear to work. It's durable and has a shock absorber and spring foot. My second leg is designed to look like my real leg, with closely matched skin tone and simulated hair.

I guess I've looked at the loss of my leg as more of a minor setback. I knew from the outset that some how my family and I would get through this ordeal and we'd go on from there. Mine is a story, though, that if I heard it, I'd say, "I can't believe that. I could never do that." But I did. It all boils down to an overpowering will to live. I just couldn't give up.

**BRENT POLANCHEK, 27**  
**Shattered Dreams**

*He was living out his lifelong dream of working on the railroad when a boxcar sheared off both of his legs at the upper thigh level. Now, with two artificial limbs, his sights are set once again on becoming an engineer*



Brent Polanchek, bilateral above-the-knee amputee, showing his enthusiasm after his first climb back onto the engine with his new prostheses.

I took my first ride on a train when I was 4 or 5, and I was hooked. That's all I ever wanted to do – be an engineer. As soon as I turned 18, I started putting in applications and sending letters everywhere in hopes of landing a job on the railroad. It took more than seven years, but in July 1988 my dream came true. I began working as a brakeman for the railroad in Portland, Oregon.

By June of the following year, I had worked my way up to switch foreman. I was working the graveyard shift, usually on the job from midnight until noon. This particular night, it was only 15 or 20 minutes until quitting time. I didn't know the next few moments would forever change my life.

It happened in an instant. One second I was standing; the next I was on the ground. I'll never forget the sound the wheels of the train made as they ran over me, like metal crunching a 2-by-4. Like in a dream, the cars kept coming – one, two and then three. But I was conscious, and I knew exactly what had happened. I knew that my legs had been cut off.

The third car dragged me more than 60 feet. It finally stopped, but I still was pinned under the one wheel. I raised my head and saw one of my legs in the middle of the track, a couple of feet away.

I thought, "This is it. I'm going to die." All I wanted to do was go to sleep as the paramedics struggled to keep me awake and worked to keep me alive.

I don't remember the helicopter flight to the hospital. I only remember the pain of sliding off the carrying board onto the operating table. I woke up in a hospital room. I didn't know if it was the same day or days later. I don't remember the few minutes before the accident or about 10 days afterward.

I'd always said if something terrible like this happened to me, I'd rather be dead. I wanted to kill myself.

The sense of loss was overpowering...lying there in a bed, knowing I didn't have any legs, that I couldn't walk and I couldn't run. I knew I couldn't go back to being a brakeman or a switchman anymore. And I knew no matter how badly I wanted them back, I couldn't have my legs again.

The doctors were encouraging. From the very beginning they told me I could be fitted with artificial legs that would let me walk again. I listened, but the fact was when I went to sleep and when I woke up, I still didn't have any legs. I felt my life was over. My family tried to help keep my spirits up. I did fairly well when they were there during the day, but after the lights went out and I was alone, I wanted to somehow slip off into the next world. I

wanted to kill myself. If there had been any way – a pair of scissors or a gun – I would have done it. I thought of pills, but I didn't have any and I couldn't get out of bed. I was on morphine, which took the edge off the pain, but couldn't relieve it entirely. The pain of the original amputation was surpassed only by the pain after the skin graft operations. They had taken all the skin off my back to patch my legs and the fingers on my left hand, which also had been amputated by the train wheels. The pain was incredible – like lying on a cookie sheet with a gas flame underneath.

Several days after the second skin graft, I was loaded into a wheelchair for my first ride outside the hospital since the accident. Tears ran down my face as I got my first glimpse of grass. Green grass. I could see it, but I couldn't get up and go over to it. I cried because I knew even with artificial legs that I'd never again be able to feel the tickle of the grass between my toes.

I cried a lot those first few weeks. Maybe that was therapeutic. I needed to get the grieving out of my system. Calls from friends I hadn't heard from in a long time would trigger yet another round of tears. The memories of things we did together...things I'd never be able to do again...came flooding back.

While I was in the hospital, a workman was installing an intercom system. He told me about a friend who also had lost both of his legs. He gave me Roger Charter's phone number. I called him. During the first part of the call, I cried and he listened.

"You can do it. There is hope," Roger told me. "You can get fitted with legs and do a lot of the things you used to do. Just don't give up."

Talking to Roger and others gave me hope. I sent for information from the prosthetics facility where Roger had been fitted with legs. I saw a videotape of Roger running. "My God, look at that guy. He's lost both his legs, and he's not walking – he's running," I gasped. Something changed inside me. I saw Roger and other people who had faced the same kind of catastrophe that I had, and I knew I wasn't alone. If they could make it, so could I.

I was dismissed from the hospital even before my legs were completely healed. I didn't know then that I would be in for yet a third skin graft on my right leg. It was six months before my legs were healed and I could consider getting my first prostheses.

At the time of my accident, my fiancée Kathy and I were looking forward



to a big November wedding. I couldn't imagine that she would still want me, but she said I was still the same person, whether I could walk or not. We moved the wedding date up and we were married in a small ceremony by the Justice of the Peace on August 22. I couldn't have made it through those first weeks and months without her.

I had talked with a couple of prosthetists while I was in the hospital. One offered very little hope, telling me that my residual limbs were so short that I was going to need big belts and metal hip joints to even hold on a pair of artificial legs. I wanted to punch him out. I'd seen Roger run. I wanted to be able to slip my legs on and go. To be honest, I thought it was going to be easier than it was. Somehow in the back of my mind, I thought a prosthetist was going to make me a pair of these magical legs, and I was going to put them on, stand up and go cruising.

I wanted to go to the Oklahoma prosthetist who fitted Roger, but a local prosthetist assured me he could do anything they could do in Oklahoma City. And looking at the practical side of it, he was close if I needed anything fixed.

I was fitted with my first legs in January 1990. But even after a few months, I could wear them only 30 minutes at a time. And the pain was excruciating. I know the prosthetist wanted to help me, but he didn't have a lot of experience fitting amputees with so little of their legs left.

It was July when I arrived at the Oklahoma Sabolich Center. Within a few days, I was up on stubbies. First I walked with canes, and I was surprised when the prosthetist told me to walk without them. And never in my wildest dreams did I expect to be climbing stairs. In those little short legs, I went up and down the stairs outside the office. Those stairs were bigger than me. I wasn't sure about it at first, but once I did it, I knew nothing could stop me. I felt like my life had been handed back to me.

To be an engineer, you've got to climb stairs to get up on the engine. And I was climbing stairs. I knew that in time –maybe not that day or the next – I would realize my dream of being an engineer. I knew I could do it.

With my desire and the help of my prosthetist, I knew I could do whatever I wanted. I could finally see that keeping a positive attitude was paying off, despite the months of agony and frustration. I'm not kidding myself. I know there will still be down days, but those are becoming fewer and further between. Some days, I still wake up and think, "Geez, another

day without legs,” but the next day will be better.

A lot of positive things have happened since the accident. I have spoken with and know many wonderful people, other amputees, I wouldn't have known otherwise. I think I can finally see the light at the end of the tunnel, and this time it's not a train.

Now, I'm just living for the day when the phone will ring, and it's going to be someone calling me like I called Roger. It's going to give me the opportunity to tell that person what I went through, and I'll be able to help someone like Roger and other people helped me.

# RODERICK GREEN, 21

## “That’s Who I Am...”

*Born ninth in a family of 11 children, when it comes to sprinting, Roderick Green is usually more likely to be at the head of the pack. Despite the amputation of his right leg below-the-knee when he was 2, he went on to earn an NAIA college basketball scholarship and three medals at the 2000 Paralympics in Sydney, Australia.*



Paralympic silver and bronze medalist  
Roderick Green

I was born in West Monroe, Louisiana, and grew up in a big family, 11 kids in all. I was two years old when doctors removed my right leg below-the-knee because it didn't have an ankle or fibula. Six months later, I was fitted for my first prosthesis. And that's who I am. The prosthesis is a part of me; it's all I can remember.

My family and friends helped me out. They didn't make me feel different from any other kid. Besides, with 10 other brothers and sisters running around, there was no time to feel sorry for yourself. You had to get up and move or you didn't get seconds.

We were all into sports, but since I was seven years younger than my next oldest sibling, I was in school by myself and had to make it on my own. I had to make a name for myself and find my own way. My older siblings did taekwondo, baseball, boxing and football. But basketball and track were mine.

The toughest time I can remember is when I started to grow, around the age of 10. I got taller, gained weight and the blisters on my residual leg were incredible. Sometimes I was on the bench for two to three weeks with a sore leg. But I kept at it. Finally, when I was 17, I hooked up with Scott Sabolich and was fitted for a new prosthesis and the comfort has been great ever since. The prosthesis has a flow-like, mineral-based gel liner completely form fitted to my residual limb. It's an ultra-light composite carbon leg, and the difference in weight is tremendous. Plus the foot is smoother, handles the pounding better and allows me to walk without a limp. With the skin-like covering, you can barely tell my legs apart.

As far as anyone knows, I'm the first amputee to receive an NAIA college basketball scholarship. I play for Oklahoma Christian University. It's exciting and such an honor. But my real love is track. I love the challenge of an individual sport. On the basketball court, you can play hard, but the game can be decided by someone else...someone else can always take the last shot. In track, if you lose, it's all on you.

When I decided to try and make the U.S. Paralympic team, I had to work just as hard as – if not harder than – an able-bodied Olympian. I took a year off school and spent four to six hours working out every day. I had to watch every morsel I ate, and lift weights, practice sprints and push myself harder than ever before. I was absolutely concentrated on my dream. I wasn't really arrogant, but I definitely had a hard-nosed style. Practicing at the track, I

was there to do business, not chat and hang out.

And then we got to Sydney. Olympic Stadium was a sight to behold – it was incredible to have that many people supporting you. You feel jittery all the time because at any moment you can mess up and all those people are watching. But finishing the race...to look up and see your name on the board – that had to be the greatest feeling of the whole trip – to know you're top three in the world in what you do. It's a perfect reminder that hard work and dedication will take you far in life. Like my dad always said, "A whole lotta God and a little hard work and you can do anything." He was right – I ended up bringing home a silver in the 200-meter run, and two bronze medals for the long jump and the 400-meter run. In the 400 prelims, I broke the U.S. record with a time of 55.40 seconds.

My long-range plans include getting my physical education and nutrition degree and eventually becoming a college coach in basketball or track. But for now, I'm hooked on running. I'm constantly in training – for the nationals in Virginia, an international meet in Canada and the Paralympic Revival in Germany. I'm training for a lot – for the bragging rights, to keep the respect I've earned, and most of all, so I can get the right sponsorship and move somewhere warmer and train year round! I train because I can't help it. Just like my leg, that's who I am.

**RICHARD REYNOLDS, 58**

## **Working Through the Anger**

*A prominent businessman and mayor, no one would guess he is an amputee. At age 44, bone cancer forced amputation of his left leg below-the-knee. During the year that followed, he endured chemotherapy and dealt with an anger that nearly consumed his life.*



Richard Reynolds,  
Mayor of Norman, Oklahoma

I was a runner. I ran every day to stay in shape, but my ankle kept bothering me. The nagging pain in my leg ultimately made me decide to see the doctor. Thank goodness I was a runner and kept irritating the leg so it forced me to do something about it.

The pain was caused by a tumor in my ankle. The doctor could tell from the X-ray that the tumor had grown into the bone. It most likely was malignant. But he assured me what it wouldn't be – osteogenic sarcoma. That type of bone cancer generally is found in children younger than 18 or adults more than 65 years of age...usually. I was 44, but the final diagnosis was osteogenic sarcoma.

My physician in Norman, Oklahoma, sent me to a doctor at the Oklahoma Health Sciences Center in Oklahoma City. The doctor there said my leg needed to be amputated seven inches below-the-knee. Originally, I'd been told the leg would have to be removed above-the-knee. At the time, I didn't know anything about amputations and didn't realize the difference in losing one joint or two. I Richard Reynolds, didn't realize how lucky I was.

When I first was told I had cancer and would lose part of my leg, I was scared...not so much that I would die, but of the unknown. I didn't know what I was facing. Just the thought of having a portion of my body cut off was difficult to accept. Something like that reinforces all the negative feelings you have about yourself. I was afraid I'd be less of a person, be less acceptable to other people.

Besides fright, I was consumed by a terrible anger. I tried to cover it up with humor sometimes, but I was angry – with myself and with everybody else. I didn't know why this happened to me. I didn't deserve it. I vented my anger at the doctor, my family, people at work ...everyone and anyone. I wasn't a pleasant person to be around. And it was an anger that didn't go away overnight.

About 10 days after they discovered the tumor, I went into surgery for the amputation. When I awoke, I was in a lot of pain. I had a cast on my leg along with ice packs, and they kept me pretty sedated. It wasn't so bad when I was in medicated "never-never land." I had pain from the surgery and some phantom pain. I never could quite figure out where the phantom pain was coming from, but it didn't go away easily. I still have a little phantom pain even now.

My leg was in a cast for the first few weeks. I had to sleep on my back, and

I felt like I was in a straitjacket. After the cast came off, I was more comfortable. Six weeks after the amputation, I was fitted with a temporary prosthesis.

About the same time I was getting the leg, I began chemotherapy. Initially I was hospitalized, but later I took treatments on an outpatient basis. When you have something like cancer, your whole life revolves around it. I'd have treatments for five straight days. They started me on five different drugs and later reduced it to three. The drugs all made me sick. I'd be totally out of commission during the treatment days. I'd get up, throw up and go back to sleep. But I was determined not to let the chemo run my entire life. I was back at work as soon as treatments were over...until the next round.

I had owned a Norman car dealership for a number of years and didn't like to be away from work. I lost my hair after the first round of chemotherapy, but I refused to wear a hat or a wig even to work. I'd never worn either before, and I didn't intend to start. Losing my hair was one thing, but the chemotherapy also strips your color. My color was ghastly. Even my hands were blue. I went to a business meeting and guys I'd known for years didn't even recognize me.

As I lost the leg, began chemotherapy and tried to keep some normalcy in my life, I was still tormented by anger. Working through the anger was probably as difficult as working through the physical aspects of amputation. I knew I had to do something to resolve my problems. Suicide. I thought that might be an answer. I figured out every imaginable way – gun, gas, drowning. For the first three months, I dealt with that scenario over and over in my mind. But I came to the conclusion that I could not do that. I couldn't take my own life.

One day my doctor visited me while I was at the hospital for chemotherapy. I lashed out at him. I don't even recall what I was complaining about...something going on in the hospital. He listened. "You know you're not going to die. You don't have to worry about that," he said reassuringly. That made a big impression. I didn't think I was scared of dying, but maybe I was harboring that fear subconsciously. Somehow, him telling me I wasn't going to die helped make my anger more manageable.

As the months of chemotherapy wore on, I'd be expecting to begin treatments on a certain day, only to be told that my white cell count was too low. Treatment would have to wait a week. My body just wasn't recovering



fast enough between treatments. It kept my life pretty mixed up, and it was just one more aggravation that kept me angry. But that was only part of it. Every time I went for a chemo treatment, I had to sit in the waiting room and listen to all these sick people talking about their ailments. "I am so tired of listening to these people. I've got my own problems," I told a nurse. "You know why they talk like that, don't you?" she replied. "That's their lives now. That's all they know. They don't know anything but cancer and dealing with their health problems."

She understood my need to get away from that and suggested I come for treatment in the early morning before the center opened. She knew what I was going through.

I knew I couldn't go on being angry with my kids and everyone else. I had to face up to the fact that I had lost a leg and that I had to go through chemotherapy. Once I got to that point, the anger started to subside. It helped that I had a good friend at work I could talk to. She listened as I talked it out. I think every amputee needs someone to talk to. You just can't go through it alone.

I came to realize that I could sit there and cry and lament over this thing, or I could put it away...make it less important in my mind and get on with the things I really wanted to do. It seemed fruitless to sit and cry. No matter how hard I cried, I wasn't going to grow another leg. It was a waste of time and energy.

The amputation, the months of chemotherapy, the anger – the whole ordeal took its toll on my family. The kids dealt with the amputation pretty well once they knew I wasn't going to die. But my wife couldn't accept it. She'd just turn her head and wouldn't look at my leg. I guess that was the only way she could handle it. We never talked about the amputation. Our marriage ended in divorce in 1980, four years after the amputation.

The end of chemotherapy was a milestone. The anger was finally coming to an end, and I started getting well again. I guess the only thing I worried about in the back of my mind was how I was going to get along with my prosthesis. But I did well. I have a regular socket that fits like an old glove. The only problem I've ever had is holding the leg on. I wear an elastic sheath, but if it touches my skin, I tend to blister. So I wear extra socks to protect my skin and the leg has a tendency to slip out of the socket because of that.

I've been amazed at the changes in technology over the years. When I

first got my leg, I'd have a pain in the right hip after walking a lot. But now, I have a new foot that has a spring in the toe. I don't have to work as hard at walking, and there is no pain.

And I have walked a lot, especially when I decided to run for mayor in 1986. Seeking public office was something I'd always wanted to do. I'd reached a point in my business where I felt I had the time. I hit the campaign trail on foot. I served two three-year terms as mayor of Norman. I campaigned door-to-door during both elections.

As mayor, I was constantly in the public eye. Not everyone knows I a man amputee so when I did a television show on amputees about three years ago, a lot of people were surprised. Even today, sometimes I'm taken aback when people ask about the television program and say they didn't know I had an artificial leg. It makes me feel good they don't notice. They just take for granted I have two legs.

I discovered I could do most everything I wanted to do. I don't run much anymore, but I ride my bike and keep up with guys who are a lot younger. I've even done some dancing.

I think the toughest thing about being an amputee is the unknown. You don't know what to expect because you've never been an amputee. You need to cry and work through all the emotions, but you also need someone to talk to about it...another amputee. I was once asked to go to the hospital to talk to a young man who had lost his leg in a motorcycle accident. No one had ever told him he could get up and dance again one day. He thought at age 20 he was a goner, and he would be bedridden for the rest of his life. He was shocked when I told him he'd dance again...if he wanted to. When you learn your life really isn't going to be all that inconvenienced, that's a big turning point.

# CHUCK TIEMANN, 35

## Miracles Still Happen

*He was working as a lineman for a rural electric company when a live wire sent 7,200 volts of electricity through his body, ultimately resulting in the loss of his left arm and right leg. Refusing to be sidelined by the amputations, he now puts the latest prosthetic devices to the test.*



Chuck Tiemann

I recently finished the grueling Bay to Breakers race in San Francisco, a 7½-mile uphill pavement-pounder that challenges even the most able-bodied runner. My time wasn't as good as I had hoped, but I finished the race, and I know I'll better my time next year.

The fact that I ran the race at all may have surprised those who don't know me. But for me it was another opportunity to show that amputees can lead normal lives. That's something I've done since I became an amputee in 1980.

It was a typical, windy spring day in May. I was working as a lineman for Kay Rural Electric Company in north central Oklahoma. We were upgrading part of the electrical system. Nothing had gone right all day. The job wasn't ready when our construction crew of five arrived. I shut off the 762-volt line, while another crew mate was to kill the 7200-volt line. There was a mix-up in communication. The line with 7200 volts was not dead.

I climbed the pole and can remember reaching out and touching the line. I screamed. There was a bluish flash; then everything went black. The next thing I knew, the crew foreman was with me atop the 35-foot pole. He and another crew member had started pole-top rescue. I was conscious as they lowered me down a hand line.

I was scared to go back to sleep after they got me off the pole. I knew I was hurt. I felt I had to keep talking and call the shots. They put me in the line truck and arranged to meet the ambulance. First, the truck was stuck in the mud, and later we had a blow-out, forcing rerouting of the ambulance. I remember the winding roads, the blue silos and the trees flashing by, and I just kept talking.

A favorite hymn popped into my head, and I repeated the words from "Love Lifted Me" over and over in my mind. It gave me a sense of peace, and by the time we arrived at the Ponca City hospital, I knew everything was going to be fine. Ironically the Sunday before, my wife and I had chosen to study the Bible at home rather than attend church. We turned to the book of Job. We did not know then how precious those lessons of patience would become over the next 10 weeks.

Doctors at the hospital emergency room said I had to go to a burn center in Oklahoma City or Tulsa. My family was nearer to Oklahoma City, but that burn center was full. It was perhaps a blessing in disguise, since we later found out that Tulsa's Hillcrest Burn Center was rated one of the top in the

nation. Even with that, the prognosis was not good. The doctors were honest. They said I had only a 10 percent chance of surviving the first 24 hours.

Their first goal was to get me through that critical period and to save the armand leg, if possible. The accident affected my left arm, which touched the line, and my right leg, which was grounded. The electricity had blown off my right metatarsal bone.

The first night, doctors split open my leg and arm. My limbs were very swollen and they had to cut away the charred, dead skin. There was no discussion of amputation at that point, partly because electricity stays in your system as long as two weeks and can keep burning away the tissue.

Fortunately, I beat the odds. I came through the first night and doctors continued their efforts to save my limbs. I underwent skin grafts; there was intense pain with each of the surgeries. We fought for six weeks to keep the arm and leg, but the limbs were deteriorating. They turned black and hard. I know what it means to say a limb is dying. The smell is rank, much like spoiled bologna. I'm glad they did all they could to try to save my arm and leg because I never felt cheated. When it came time to discuss amputation, I was ready. On June 10, 1980, doctors amputated my right leg below-the-knee and left arm below-the-elbow.

I went through some real emotional changes after the amputations. When you lose a limb, much less two, you feel ugly and mutilated. I wondered how I could ever again live in a two-armed, two legged society. The man in the next bed was a big inspiration, even though we came from different backgrounds and had different values. He had lost a leg earlier in his life and was hospitalized then for burns sustained in a house fire. I also had a great deal of support from my family and friends. I received well-wishes in 542 cards from people throughout the community. But one of my greatest sources of strength was the Bible. I kept looking for that miracle verse. The Lord didn't give me the answer right away. He made me read the first four gospels before I got to Romans 5:3-5 – verses that I stand on, which say: "We can rejoice, too, when we run into problems and trials for...they help us learn to be patient. And patience develops strength of character in us and helps us trust God more...Then, when that happens, we are able to hold our heads high no matter what happens and know that all is well, for we know how dearly God loves us..."

The nurses were good to me. Someone always stopped by just to chat, and my physical therapist even came in on Saturdays. I tried to learn everything about taking care of myself. I watched carefully to make sure my limbs were wrapped properly because I didn't want any infection.

Originally, the doctors told me I'd be in the burn center six months, so I was thrilled when I went home after 69 days. But it was hard to leave the hospital because I had made so many friends among the patients and staff. I spent the first night at the home of my in-laws.

It wasn't long until I went back to work at Kay Electric and even climbed a few poles. I think I had to prove that I wasn't handicapped. I would do crazy things in those early days to prove to the world that Chuck Tiemann wasn't handicapped. I'd always been active in sports, and I love baseball. I felt like this was the bottom of the ninth with two men out, and I was up to bat. I didn't want to let anyone down.

Four days after my release from the hospital, I celebrated my 25th birthday. I was never so glad to see a birthday. My wife Terri and I decided we had so many friends and family members who wanted to seem that we'd throw a big birthday party. We had more than 200 people. They just came in the front door and went out the back. Even though I didn't have my limbs, it was a real celebration.

I knew from the very beginning that I would get an artificial leg, but I didn't know what I would do about my arm. My first goals were to do the regular daily things like walk and hold my toothbrush...things I'd taken for granted in the past. My brother had a friend who begged me to try a myoelectric arm. Many amputees are first fitted with a hook and later, if they do well, with a myoelectric prosthesis. But Terri and I talked it over, and we were convinced myoelectric was the way to go.

I guess a visit by a man who wore a hook was what really made up my mind. "You've just got to have an 'I don't give a damn' attitude when people stare at you in the grocery store. Kids especially will stare and say, 'Oooohh, look at that man with the hook,'" he told me. "But there's a good joke you can use at cookouts. You can surprise your guests and pick up the hot grill." I knew there had to be more to life than that. I wanted a myoelectric arm.

I had a prosthetic leg five weeks after the amputation, and within a couple of weeks, I was walking two miles each day. Because I worked hard at perfecting my gait, a lot of people couldn't tell I had an artificial leg. I

watched videotapes of my walk, I practiced in front of a full-length mirror and Terri checked my posture. I wanted to walk as naturally as possible.

I guess you could say I am the perfect amputee, if there is such a thing. My amputations were below-the-knee and below-the-elbow, which are the best levels for adapting to and using prostheses. But, having lost one of each, I can say unequivocally that I would rather have lost both legs than an arm. The loss of an arm is so much more visible. And learning to use an artificial arm is harder and requires more patience than working with an artificial leg.

Still, I worked hard at using the hand, and within three months I was doing things the man with the hook never dreamed of. I was picking up everything from popcorn to five-gallon buckets of water. Every time I'd learn something new, I'd call my prosthetist and say, "Guess what I just did?" I was ready to get everything back. I wanted to see what I could do and do everything the best that I could.

Terri was my backbone. She encouraged me all the way. I remember once after I had my prosthetic leg, I was sitting in the living room and asked Terri to get me a drink of water. She pointed her finger at me and said, "No, I won't. I'm not going to do anything you're capable of doing for yourself. I didn't marry a handicapped person, and you're not going to be that way. You've always loved sports, and you're going to do that, too. Sure, you're going to be like a baby and you'll have to learn things over, but you're going to adapt, and you're going to do it. Do you understand me?"

I said, "Yes, ma'am." I appreciated that. We'd been married five years and that probably was the first time I really respected her for who she was.

*From Chuck's wife Terri:*

The night of the accident, I went to the chapel at the hospital, got down on my hands and knees and cried out to God. He gave me a song, "One Day at a Time," and for 70 days I stood on that song. Then I turned to my great support team—my mom, my dad and my sister, and friends and co-workers, my minister and my faith in God. My parents really gave me strength – they said I had to be strong and they modeled strength for me.

I talked to other amputees and their spouses and it helped to be able to ask them questions. You just wanted someone to give you a hug and tell you everything was going to be all right. My dad said, in time, things would be fine, but life as I knew it before May 1, 1980, no longer existed, so I had to

get tough and figure out how to live life and make it work. I wanted someone to come to my pity party and feel sorry for me, but he wouldn't do that. He knew what I needed and he was right.

I was also counseled by family services at the hospital and one thing I learned was that Chuck and I would be able to get through this with tough love. They told me I should make him do the things he was able to do and not baby him. I was supposed to support and encourage him, but not pity him or try to do his daily tasks for him. It was difficult, but it worked. I pushed him and we've never looked back.

*From Chuck:*

Terri was right. I'd always been an athlete, so I tried out for the softball team. The guys said, "We know you can hit, you can run and you can catch, but don't you think it would be better if you coached? You could fall and hurt yourself." I didn't want people to treat me differently because I had lost an arm or leg! If I had dropped the ball before, it was no big deal, an error. But if I dropped it now, they thought, "Well, he's lost an arm, and that's the best he can do." It seems amputees can't make errors if they want to fit into society again. Because that was the way I felt, I was always trying to prove myself.

After I got my arm, I was really fired up. It was a modern-day miracle. I went to Enid, Oklahoma, to show it off. I was trying to impress one orthopedic surgeon when he turned to me and said, "What the hell are you going to do, Chuck – try to change the world?" I told him, "No, but I'm going to change my little corner of it." But from that point on my attitude is what changed. I realize now that I was going too fast.

Still, I want to be all that I can, the best that I can. I believe firmly that if you say you can – or you say you can't – you're right. So I've been dubbed sort of a guinea pig for the latest in prosthetic devices. Whenever a manufacturer has something new that might make life easier for amputees, I try it. Good or bad, whatever I do today is going to affect what's available in the future. If somebody didn't do it, we'd all still have hooks and wooden legs.

Artificial limbs have changed so much since I was first fitted with prostheses. My first leg weighed seven pounds, while the one I have now weighs only a little more than two pounds. Now the leg is totally adjustable, and I have a flexible foot. Actually, I've got three feet – one with a cowboy



boot on it, one with a dress shoe and one with a tennis shoe.

Of course, I like to test a prosthesis the “Chuck Tiemann way.” I don’t like the manufacturer or prosthetist to tell me what I can’t do with it. They told me my leg wasn’t waterproof – that if I stepped in a hole of water when I was hunting it was okay, but not to submerge it. I wear the leg water skiing and dry it off when I’m through. I’ve never had a problem. A prosthesis needs to be dependable. More than that, it needs to be good enough to make an amputee equal to a guy who has both legs.

I left the electric company in 1984 and returned to school to pursue my degree. That always had been the plan. I received a degree in rehabilitation counseling, but I discovered I didn’t have the patience to work with people who weren’t motivated or willing to try, so I returned to school for a teaching degree. I taught only one year because of the lack of support for education by the state legislature.

Now one of my first loves is talking to groups – like schoolchildren and other amputees – about what it’s like to be an amputee. I talk to kids about my “toy arm” or “toy leg.” I let them touch the artificial limbs. The kids can relate it to Barbie or G.I. Joe, and they are fascinated. Now, if they stare, it’s because they are in awe – not because I’m some deformed man with a hook.

When I speak at schools, I always focus on the dangers of electricity. The point I like to make is to never, ever go near a downed power line. Never climb a tree with a power line going through it. The minimum line voltage on the uninsulated lines is 7200 volts.

I have a number of aspirations. Someday, I’d like to publish my own book on using prosthetics and possibly do a movie for Disney and meet some of those ingenious people who design those mechanically animated dolls and characters. I believe Disney and NASA could help make tremendous advancements in digital and flexible motions for prosthetics that are more life-like.

My greatest goal is to establish a fund for the distribution of state-of-the-art prostheses for children. I pray that God shows me the way and gives me the strength to do the things He wants me to do. I have been successful only because I love life and because God is in control of everything.

Of all the achievements that I have been able to accomplish, the greatest is that I have been able to be a regular dad, work a regular job and be a positive influence on the three greatest joys in life – my children, Kendall,

Kristin and Kim. Handicap is in the mind, it's not physical. You can be whatever you want to be.



Chuck Tiemann gives daughter Kim a big swing.

**LAURIE ARRIGONI, 27**

## **Never Let It Define You**

*At 16, she was diagnosed as having a malignant tumor in her knee. Her leg had to be amputated above-the-knee. But she never let the loss of a limb keep her from the dream of owning a New York City boutique.*



Laurie Arrigoni

I'd just gotten my driver's license. That was the most important thing in the world to me at age 16 as a high school sophomore. It was Memorial Day weekend. I was planting flowers in my mother's yard.

I noticed a pain in my knee. I didn't think much about it at the time, but the soreness didn't go away, and the knee became swollen. I'd been treated for a knee injury while playing high school sports, so I figured it was nothing serious. My parents made an appointment for me to see the orthopedic surgeon who had treated me previously. By the time I saw him a few days later, I could barely walk.

The doctor X-rayed the knee and said it was probably a bone infection. At least that's what he told me. He wanted to do a biopsy. I had more important things on my mind – final exams and the prom. I'd been invited to the prom by the hottest guy at school, and now I had to call and turn him down because I had to have a biopsy.

The doctor told me the tumor was malignant. So, what did I do? I got out my high school biology book to check that out. I still didn't think much about it. It was beyond my comprehension that you couldn't just remove the tumor.

In mid-June, I began an aggressive program of chemotherapy at Memorial Sloan Kettering Hospital. I know some people will say something like that is devastating, but it didn't hit me like a ton of bricks at the time. It was more like a process, one step at a time. I went along, sorting it out with the doctors. My parents were there for me all the way. I didn't know it at the time, but they were doing a lot of background research on my condition.

Doctors amputated my leg above-the-knee on July 9. The pain after surgery was excruciating. But the amputation was something that was over. Not so with the chemotherapy...it made the surgery seem almost secondary. I really concentrated on just getting through the chemo. It was relentless – like there was no end in sight. I felt if I could survive the chemotherapy, I could survive anything. And I could get through life without one leg.

It was a tough summer, though. Most of my friends were getting summer jobs for the first time, but I was in the hospital. After the surgery, I had an immediate-fit prosthesis. When I woke up, I had a pole and cast so I was up walking within a couple of days. When school started that September, I didn't miss a beat. I was back in class even though I would miss a week at a time to take chemotherapy. I had a great group of friends and a family who

never treated me all that differently.

My mother kept wanting me to go to the prosthetist to be fitted with a permanent leg, but I kept putting it off. I was busy with school and my friends. My mother was a nervous wreck because I was driving to school – but you don't need a left leg to drive! I got my first permanent leg six to eight months after the surgery. I can't remember a day that I didn't get up and put the leg on and walk around.

When I was feeling good, I led a pretty normal life. But there were weeks with the chemotherapy that I couldn't get out of bed. Originally, doctors told me I would have chemotherapy six to nine months, but it ended up being 14 months. I was hospitalized once because my blood count was so low. The doctors at Kettering are pretty hard core and pretty straight with you. When I woke up that Saturday, I flippantly asked my doctor what he was doing there on his day off. "Well, you almost died last night, so I thought I'd better check up on you today," he told me.

Maybe I was naive, but I don't think so. Somehow I just always knew that I was going to get through it. My mother and I went through it together. And I think I had some sort of inner strength that helped me all the way. Still, there was no expressway to the end of chemo.

Of course, when my blood count was low, the doctor would send me home with instructions to stay away from places where I might pick up a virus or infection – like movie theaters and shopping malls. So, where did I go on Friday night? To the movies with my friends, of course.

I finished my junior and senior years in high school and applied for admission to Boston College. One of the high school guidance counselors kept trying to steer me to a local college – maybe she thought I needed to be near a doctor or my home for some reason.

I have to admit that going to college wasn't as easy as I expected. Boston College has a huge campus, and there was lots of snow that year. The snow and ice reached a point where I just couldn't walk around anymore. I had lost one leg, and I sure didn't need to break the other. I can remember calling my dad and telling him I wasn't sure things were going to work out at school. He offered to buy me a golf cart. I told him "No, no, no." I didn't want something that set me apart. I wanted to be normal.

Eventually, I learned the ins and outs – which staircase to avoid because of the flood of people and where to get keys to elevators. And a friend of

mine who was an athlete gave me a tip for making it around in the ice and snow. He suggested cleats. I'd never thought of it before. Of course it worked, so I walked all over on the ice that winter with cleats strapped to the bottom of my boots. I found I could make do; there were little ways.

During my sophomore and junior years, I worked at Saks Fifth Avenue. I graduated from Boston College in with a bachelor of arts degree, and I set my sights on opening my own business. I don't think my amputation changed the direction of my life much. I never wanted a career in ballet or anything like that. I just never let the loss of the leg define what I wanted to do or be. After working and getting some further retailing experience at a couple of New York boutiques, I opened my own boutique called Sola (meaning "on your own") located in Manhattan.

From the beginning, when I went to work, I never looked at my leg as a handicap. There would be those typical questions on job applications, asking if I had any physical impairment that would prohibit me from performing my job. I answered "no." I can stand on my feet for eight hours a day just like anyone else. In fact, I can do it better than some people. Owning my own shop hasn't changed how active I am either. It's not a desk job – I've never had a desk job. In fact, my shop has a spiral staircase down to the stockroom. Some people are surprised when I say, "It's no problem!"

Of course, being in the fashion industry, looks mean a lot. I have to wear short skirts... I live in New York. So, I have a beautiful foam leg. Sometimes I think maybe it looks better than the real leg. I'm very visible, and the store is open seven days a week. I like it that way. It's what keeps me going. I've always been a great walker, and I walk well with my prosthesis. I walk to work, I shuffle through the crowds to ride on New York subways; I don't just sit around.

Sometimes, people ask what I did to my leg. I've never really come up with a good answer to that question. If you tell them you lost the leg to cancer, they turn red-faced and feel like they've made a grand faux pas. I tried making up things that I thought would make it easier. I told one guy that I hurt it hang gliding in Mexico. Wouldn't you know it, he was a hang glider and started asking me questions about the sport! That answer just didn't seem to work. If it's a cocktail party, I usually just say, "Oh, nothing; it's fine," and go on.

I've learned to run with my artificial leg the last couple of years. I have

some friends in an amputee support group, ASPIRE, and we go to the gym for a vigorous workout three times a week. We exercise right along with all the able-bodied folks, and it's a lot tougher workout than many of my two-legged friends can do. I have a sports leg now that I wear for running or when I go to the beach or participate in something more active. The sports leg is not as cosmetic, but it looks okay and it can take a lot more abuse. Of course, it wouldn't be the thing I'd wear with a skirt.

I choose to wear flat shoes even with my skirts. Some women have interchangeable feet or adjust their feet for different heel heights. There was a time when I wore 4-inch heels, but I never felt comfortable and I never walked as well. I wear flats even if it's a black tie affair. I have the perfect pair of little black satin flats. High heels aren't important to me.

Actually, my foam leg looks so good that it's really funny when I go through the metal detectors at airports. I always tell them that I have a brace that will set the alarm off, so they have me step to one side to do a hand search. One security official kept looking at my leg, touching it. "Where is it? I can't see it," she said.

It seems that prostheses just get better and better every year. I can remember my first leg. It was an old wooden leg with hinges. I don't know how I got around on that thing, but the leg never slowed me down. Whether you're an amputee or not, I've always believed you set your own limitations – it's all up to you.

**GABRI BUCKINGHAM, 20**

# **Never Say I Can't Walk**

*As an 18-year-old college freshman, her life was filled with promise until the discovery of a malignant tumor in her pelvic bone. She endured months of grueling chemotherapy as doctors tried to shrink the tumor. Ultimately, her left leg had to be amputated at the pelvis. Her doctor said she'd never walk again.*

I had finished one semester at the community college in Powell, Wyoming, 20 miles from my hometown of Cody. I was just back on campus after Christmas break when I noticed pain in my inner thigh. I thought it was a nerve spasm and figured it would go away. But it didn't.

My mom worked as a receptionist in a doctor's office, so she made me an appointment. The doctor checked me for vitamin deficiencies, but the results were normal. I was referred to an orthopedic physician, who thought it might be the sciatic nerve, but he couldn't find anything.

I returned to school, but the pain grew worse. I could barely limp to class. All the time, I was doing aerobics, thinking that would loosen it up. I returned to the doctor when the pain persisted; he X-rayed the leg but didn't find much. He off-handedly mentioned a shadow on the X-ray. He said it might be a benign tumor or a cyst.

Maybe we should have known then that something was wrong. The doctor didn't want to touch it. He wanted us to go to Billings, Montana, for further diagnosis. I just wanted to go back to school.

My mom and I made the trip to Billings to see the other doctor on the first day of spring break. We talked about it on the trip. I think we were both kind of scared of what we might find out. We had to wait all day to see the doctor. He was the first doctor to mention cancer.

When he said the word cancer, my mom and I started bawling. I felt like the walls of that little examining room were closing in on me. The doctor said a biopsy was needed. If it was a benign tumor or a cyst, it would be removed. If it was cancer, they would need to determine its size and how to treat it – it would mean removing part of the pelvic bone. He wanted us to go to Salt Lake City, but we didn't want to fly all that way if it was just a cyst. He finally agreed to do the biopsy, after consulting with the Salt Lake City



surgeon on the best placement of the incision in case I needed further surgery.

He wanted to do the biopsy the next day. We returned home to gather our things and call the family. I told my boyfriend Mike. Mike and I met during the fall semester at school. We had dated four or five months, and our families had grown very close. Mike, my mom and I set out for Billings the next morning. Later in the day, other family members came to be with us.

I didn't know what to expect. I was scared. After surgery I awoke early from the anesthesia. Before I could even focus, the doctor told me it was cancer. I cried, but I really didn't know then what it meant to have cancer. I was in a lot of pain because they had to cut through a lot of muscle to get to the tumor.

It was that night before I talked with Mike. He took it really hard. I think he thought I was just going to disappear right before his eyes ...that I was going to die. Mike stayed in the room with me that night while my mom slept in the waiting room. Mom said she'd come in and Mike would be standing by my bed staring at me as I slept.

I was never afraid Mike would walk out of my life because I had cancer, but he was afraid I was going to leave him. He thought I wasn't going to want him around, that I was going to dump him.

Since it was cancer, I was referred to an orthopedic surgeon in Salt Lake City. We stayed with a friend of my mother's and that made it easier. It seemed through out my treatments there always was something or someone there to give us strength.

The doctor eased my some of fears when he said I had osteogenic sarcoma, a very common kind of cancer in young people. He had treated it before, so that made me feel good. No one mentioned amputation. The doctor planned to remove part of the pelvic bone. I would have a limp and the leg would be a little shorter. We were optimistic.

The following day was consumed by tests from morning to night. The last test revealed the tumor was bigger than the other scans had shown. The doctor told me to go home to begin chemotherapy; surgery was impossible at that time.

We went back to Cody. Mike and his friend Lee came up to be with me. We stayed at the Ronald McDonald House in Billings and watched movies that night. My mom and the three of us stayed in a room with two twin

beds.

I checked into the hospital and started chemotherapy the next day. I don't remember much about the first round of chemo except that I got sick. Mom stayed with me at the hospital. One of my older sisters took care of me after I was released from the hospital. Three days later, I saw a Billings oncologist, who said I needed a type of chemotherapy that required close monitoring of blood levels. It couldn't be done in Billings, so we'd have to go back to Salt Lake City. We flew out the next day.

That second treatment wasn't so bad. I really didn't get sick. They put me in a room with a girl a year or two younger who had the same type of tumor and the same chemotherapy. She was ahead of me in the treatment. She slept through most treatments, but once we did talk. She was scared she was going to lose her leg. I felt really bad for her because someday I'd be well, but she'd be walking around on crutches for the rest of her life. I was really naive. I didn't have any idea I could lose my leg, too. It never entered my mind.

My hospital roommate and I became good friends, and we still write to each other. But the best part of that hospital stay was that her mom was with her. It helped my mom a lot. Finally, there was someone who could understand...someone who could answer some of her questions. She was as scared as I was and wanted to protect me, but she couldn't if she didn't get some answers.

Most of my 11 treatments were in Salt Lake City. My mom, Mike and I made the trips. Mike's dad encouraged him not to take a summer job so he could be with me. His family was very supportive.

The worst part of chemotherapy was losing my hair. When I noticed my hair falling out, I only washed it every three days, brushed it once in the morning and plastered it with hair spray. I could only take that for a week. I took a shower one day and I pulled as much hair out as I could. I called my mom and asked her to come home and shave the rest of it off. I wore baseball caps in every color I could find. I couldn't stand my wig. It wasn't me. It was hard because people stared. Eventually, I decided I wouldn't let the cancer rule what I did and keep me from going out and having fun.

By the next-to-the-last treatment, the pain was totally gone, and I didn't limp anymore. We thought that was a good sign. The doctors wanted to see if the tumor had shrunk. But it hadn't. The tumor board was to meet and consider three options: radiation, chemotherapy injected directly into the

tumor, or amputation. That was the first mention of amputation. We went home to wait for their recommendation.

The doctors agreed amputation was the only option that could assure getting all the cancer. I thought, "All right, if I have to have an amputation, I want it done now, next week." But they wouldn't do it because my blood count was down.

The day before my surgery, we went to the amusement park. I put the amputation out of my mind. As long as I was with someone, everything was okay. The more I was alone, the more I thought to myself, "It's all your fault; maybe if you weren't thinking these things, you'd be all right. Maybe you want to have cancer."

When I arrived at the hospital, there was a shortage of nurses, and the ward I was supposed to be in was full. I ended up in the neurological ward. I wanted a private room, so my mom and Mike could stay with me, but only a double room was available. That night, Mike was telling me good night when a nurse asked if I wanted to stay in the VIP room. It was great... plush carpeting, mahogany wood, marble counters in the bathroom and a view of the entire city. I tried to relax, just to spend some time with Mike. Then, my doctor came in and bluntly told me there was a chance the cancer was inoperable. If I awoke with a leg after surgery, it had spread too far to amputate.

The doctor expected the surgery to last four hours, but it took eight. He did a hemi-pelvectomy, removing the pelvic bone on the left side, along with the leg. I had no bone below my rib cage.

I came out of the surgery screaming. I don't remember pain from the incision, but I had terrible phantom pain. They had used my thigh muscle to fold back and reconstruct a stump where my hip had been, so it felt like my leg was twisted behind my back. In the middle of the night, I'd try to pull my leg out from underneath me, but of course I couldn't because it wasn't there.

The whole ordeal depressed me. I don't think anything can really prepare you for the phantom pain. They've taken away your leg, but you still have pain as if it's there. The physical therapist had a hard time getting me out of bed. I was mad, not that I had lost my leg, but that I was having all the phantom pain. I don't know if the pain killers helped or if it went away on its own. Eventually, the intense pain went away. I still have phantom pain, but nothing like that.

My orthopedic surgeon said there was no way I'd be able to walk with a prosthesis without crutches. He'd never seen a person with a hemipelvectomy walk. He didn't want me to get my hopes up only to be disappointed.

I went back to school on crutches, and I got special permission from the school to use a four-wheeler on campus. I still had six follow-up chemo treatments. It was really hard going back to school where I had been popular and having people seem like that. It does a lot to your self-esteem. I wanted to tape a picture to my shirt that showed me when I was whole...when I had a leg and hair.

You grow up fast when you have cancer. Sometimes I wished I could take away the cancer and be who I was before. Sometimes Mike and I would fight. I think when your life is consumed by fighting cancer, after so long you forget how to have fun. I forgot what it was like to go out with my friends, to go to a dance, to laugh with them and joke with them. You kind of have to relearn that while your life has revolved around cancer, the lives of your friends have kept going. It's really hard, and I still have to work at it.

I became proficient at using the crutches, but the following spring I thought the doctor might be wrong about me never walking with an artificial leg. I felt really strong, and I could still control the thigh muscle that now formed my hip. When I was in the hospital for one of my follow-up chemo treatments, my original orthopedic doctor checked me. He agreed. He thought I could walk with an artificial limb. And after he looked at my spine, which was curving badly from standing on one leg all the time, he said I had to get a leg even if I couldn't use it without crutches. Otherwise, I faced life in a wheelchair.

Even when Mom and I made the trip to Oklahoma City to get my prosthesis, we weren't sure I'd be able to walk. I remember the prosthetist coming in and showing me all the different parts of the leg and different feet. He asked if I had any questions. "Well, am I going to be able to walk?" I asked. "What are you doing here if you aren't?" he replied. We were beaming.

It wasn't easy though. I expected to get this leg and go. The second day I had the leg, I went to them all. With this leg, if you bend down, you have to go all the way back up. I bent over to look at some watches and fell to the floor. My mom wouldn't help me because she knew she wouldn't always be around to pick me up, and I had to learn to do it myself. It took awhile to

learn my limitations. Most of the time, I use my cane. I can walk without it, but it's my security.

After I was walking, I made it a point to talk to the doctor who told me I never would walk. "Don't ever tell anyone again they cannot walk. It just isn't fair to them," I said. He said he was sorry. He'd never seen anyone like me walk before.

I finished my fourth semester at the community college in Powell after I got my leg. Then, Mike and I transferred to Northern Colorado University. During the summer, I worked with physically handicapped kids. I plan to graduate with a psychology degree and eventually work in a hospital as a counselor for cancer patients, especially amputees. I know what they're going through. And I know better than anyone that while you're going through it, the very best help is having someone to talk to.

## EARLE CONNOR, 24

# You've Got To Trust

*Losing a leg at 3 months of age did nothing to dampen Earle Connor's spirit for sports – hockey, baseball, tennis and basketball. No one who knew him was surprised when he made a name for himself internationally as an athlete. The only surprise was the sport – track and field. Just a year after he started running, he broke the world record in the 100-meter run to become the world's fastest above-the-knee amputee.*



Earle Connor gets an adjustment on his sprinting leg from Scott Sabolich, CP.

I was missing my left fibula when I was born and lost my leg above-the-knee when I was 3-months-old. For most children that would drastically change their life; I was an exception. Growing up in rural Saskatchewan, Canada, all my friends played sports. I had it in my heart to compete and once I started playing, I never let it go.

Being the only amputee around, I had no idea playing hockey, baseball, tennis and basketball at an elite level was unusual. There was no difference to me. I was treated like any other kid, and my parents enrolled me in sports when I was fresh and young and nobody knew any better. It was natural. Like many Canadian kids, I dreamed of playing in the NHL. I made the provincial tennis team and led my high school basketball team to a number three provincial ranking. About the only sport I didn't do was track.

Relaxing in front of the television one day in late August 1996, I was flipping through the stations when I came across the Paralympics. I had heard of the Paralympic Games, but since I was so successful at able-bodied sports, I wondered why I would want to participate in the disabled games. The next event scheduled was the above-knee amputee 100-meter race, and since that's my disability, I thought I would watch. The winner – and at that time, world record holder Lucas Christian – won easily. What caught my attention was the last place finisher's time of 15.19 seconds. I knew that I could easily cover 100 meters in a quicker time. It was then and there that I decided to give track a go.

Just a year later, I won the 100-meter race at the Paralympic Revival in Duderstadt, Germany, with a world record time of 13:18. Four years later, I brought home a gold medal from the 2000 Paralympics in Sydney in the 100-meter run. I once again broke the world record (which I'd set the day before in the prelims) with a new time of 12.61. I also won a silver in the 200-meter finals. What an incredible honor for me. Track has become my passion as well as my job. I was named the Canadian Disabled Athlete of the Year in 1997, 1998 and 1999, and in August 2000, I was inducted into Calgary's Sport's Hall of Fame. I have lost only one race with above-knee amputees over the last three seasons. What a journey it has been since I "stumbled" onto the Paralympics just four years ago. It has challenged me and completely changed the direction in my life.

Now I live a comfortable life-style as a full-time athlete, but if I were to lose, it wouldn't be as good. That's a lot of pressure, but it doesn't take the joy

out of it. In fact, I thrive on it. I hardly ever slack off –my mental makeup doesn't allow it.

I use that personal drive to help other amputees get to the level of active lifestyle I've achieved. I teach them that it's all about trust. Earle Connor wins the gold in the 100-meter at the 2000 Paralympic Games in Sydney, Australia. You've got to trust your prosthetic leg as much as you do your real leg. You have to get to know it so well that you get to a point where you don't even think about it. You have to believe in it.

You can break your real leg as easily as you can your prosthesis, and it hurts a lot more, too. If I bump my prosthetic leg, I instinctively say "oww!" That's how much trust I have in it. Tome, it's just my leg. Amputees must reach that level, and if they do, their lifestyle will be drastically improved.

We're lucky technology is making it easier for amputees to walk with grace and ease. The first few years, my prosthesis was basically a peg leg. The hardware slowly improved, and now carbon fiber technology has made a big difference in the weight and flexibility of the knee socket. And the energy-return foot is quicker, more comfortable and takes the brunt of many, many miles of pounding. Now I can train harder and longer – without resting, without adjusting. The average amputee can now walk or bike to the gym instead of taking a car. The biggest difference is just going up stairs instead of taking the elevator. What a relief to look at a staircase and not have to think "Oh brother, here we go again." It's a quality of life issue for many prosthesis users.

So my leg isn't my challenge. My challenge is to run fast. If I slow down, my life will change drastically. My income will be cut by 75 percent. I would lose all my titles and achievements. So I have a challenge to stay on top. I have pictures of my closest competitors on the walls of my bedroom to keep driving me. My e-mail address includes the numbers in my world record time. I live, eat, breathe and sleep running, 24/7. But I enjoy what I do. Every morning, I get excited about the day, about running, about breaking the world record again. I guess you could say every single day is another challenge!





Earle Connor wins the gold in the 100-meter at the 2000 Paralympic Games in Sydney, Australia

# Epilogue

The 38 people who shared their lives, their visions and their strength in this book had one thing in mind – to help you through a difficult time.

It's not easy. Acceptance is hard work. To go on and overcome isn't simple. It takes all the physical, emotional and spiritual energy you can muster.

Even if today is the worst day you have ever had, don't give up. Hold on with all you have. You will feel differently in time. Don't focus on the negative. Stay in the positive.

We hope that what we have shared helps you see the light at the end of the tunnel and reminds you that you are not alone.

# Glossary

**AE** – An amputation above-the-elbow.

**AK** – An amputation above-the-knee.

**Anterior** – The front part of your body.

**Adherent scar tissue** – Tissue that is stuck down, usually to the bone.

**Atrophy** – A reduction in muscle mass and strength.

**BE** – An amputation below-the-elbow.

**Bilateral** – A double amputation, involving two limbs.

**BK** – An amputation below-the-knee.

**Congenital anomaly** – An abnormality at birth, such as a missing limb or malformed limb.

**Cosmesis** – A word coined in the prosthetic field to describe the outer, aesthetic covering of a prosthesis.

**Disarticulation** – An amputation through a joint; commonly the hip, knee, ankle, elbow, wrist or shoulder.

**Endoskeletal prosthesis** – A prosthesis built more like a human skeleton, with support and componentry on the inside, and a cosmetic covering on the outside.

**Exoskeletal prosthesis** – A prosthesis that is hollow on the inside, with a hard outer surface, to bear weight.

**Donning and doffing** – Putting on and taking off a prosthesis.

**Hemi-pelvectomy** – An amputation where approximately half the pelvic bone is removed along with the leg.

**Hypertrophy** – An increase in muscle mass and strength.

**Ischial tuberosity** – The large sitting bone.

**Lateral** – To the side of the body; away from the middle of the body.

**Medial** – Toward the mid-line of the body.

**Myoelectrics** – Literally, muscle electric; technology used in prosthetics for upper-extremity amputees; used in prosthetic hands and elbows to control the prosthesis via muscle contraction utilizing

electrical signals from the muscles to the prosthetic device.

**Neuroma** – The end of a nerve left after amputation. It continues to grow in a circular pattern after amputation and can some times be troublesome, especially when trapped in scar tissue.

**Partial foot** – An amputation of the front part of the foot.

**Preparatory prosthesis** – Stage between temporary and permanent prosthesis, using transparent diagnostic test socket and special fitting techniques to accurately fit the prosthesis so problems can be eliminated before it is cloned for the permanent prosthesis.

**Prosthesis** – An artificial part of the body. In the case of an amputee, usually an armor leg. May be referred to as definitive or permanent.

**Prosthetics** – The systematic pursuit of providing cosmetic and/or functional restoration of missing human body parts.

**Prosthetist** – A person involved in the science and art of prosthetics; one who designs and fits artificial limbs.

**Posterior** – The back side of the body.

**Pylon** – Often what is referred to as a pole in a temporary prosthesis; the weight-bearing support shaft in an endoskeletal prosthesis.

**Ramus** – The middle portion of the pubic bone, in the crotch area.

**Residual limb** – Remaining portion of a limb after amputation.

**Shrinker** – A prosthetic reducer made of elastic material and designed to help control swelling of the residual limb.

**Socket** – The part of the prosthesis into which the residual limb fits.

**Stump** – A word commonly used to refer to the residual limb.

**Supracondyler suspension** – A method of holding on a prosthesis by clamping on above a joint.

**Symes** – An amputation through the ankle joint that retains the fatty heel pad portion.

**Temporary prosthesis** – A prosthesis made soon after an amputation as an inexpensive way to help retrain a person to walk

and balance while shrinking the residual limb.