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The Living Well With Limb Loss Magazine

## Financial Preparedness

Lifetime Cost of Prosthetics

Applying for Disability After an Amputation



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# Financial Preparedness

## Be Your Own Best Advocate

Bill Dupes, Editor-in-Chief



**For 30 years**, the Amputee Coalition has provided information and support to amputees, their families and healthcare providers. To further serve the needs of our constituency, we expanded our mission in 2005 to include an advocacy program to influence public policy regarding the fairness of prosthetic coverage.

The questions most frequently asked by amputees who contact the Amputee Coalition relate to requests for information about finding resources for financial assistance, and concerns about payment coverage for costs related to prosthetic fitting and associated services, home and vehicle modifications, and durable medical equipment (DME) such as wheelchairs, ramps and other adaptive devices. Despite the broad spectrum of questions, it all boils down to one central, universal concern – money.

Most financial experts advise to have at least six months of income set aside in a rainy-day fund in case of an emergency or job loss. But even that isn't enough for someone unable to return to work due to a serious disability or illness. And the truth is, nearly two-thirds of American families live from paycheck to paycheck.

A serious long-term illness or disability can have devastating, sometimes irreversible, effects on a family's financial well-being. In fact, the support of friends and family members are the most relied-on financial support resources – until those resources, too, are exhausted.

So, what can you do to ease the financial risks if you are one of the millions of people who must stop working each year because of a serious health condition? First, have hope – because there are things you can do to take control.

In times such as these, it's only human to feel afraid and overwhelmed. But asking for help is a sign of strength, and being your own best advocate can help you feel more in control.

This issue was designed with the intent of addressing at least some of the basic information you need to know to take steps to prepare for the future and deal with the present for the benefit of yourself and your family. We hope that you will find it both enjoyable and informative.

*"It is well to be prepared for life as it is,  
but it is better to be prepared to  
make life better than it is."*

~ Sargent Shriver, Politician and activist



### BE AN INFORMED READER

Editorial content (articles, news items, columns, editorials, etc.) in *inMotion* often contain healthcare information. As an informed reader, you should never make a decision about managing or treating your condition without consulting your own clinicians: They know you best.

Sometimes, in our interviews with people who are amputees, the person being interviewed will say something about his or her personal experience that may not be entirely consistent with standard practice. In these cases, we print what the person said because we think it gives readers insight into that individual's experience that we believe will resonate with others. But: We urge you to always check with your medical team before changing your own healthcare regimen.

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# I'mPOSSIBLE

**“LIFE IS NOT ABOUT FINDING YOURSELF. IT'S ABOUT CREATING YOURSELF.”**

Since she was a little girl, Carrie Davis knew she was unique. Born without her left arm, she often wondered “Why me?” She longed to be known for her contributions, not what she was missing.

A prosthetic wearer since she was nine months old and long-time Hanger Clinic patient, today Carrie is the face and personality of AMPOWER, the leading peer-to-peer support network for those living with limb loss or difference. Carrie finds the answer to “Why me?” through helping others.

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A Publication of the Amputee Coalition

*InMotion* magazine publishes unbiased journalism that seeks to “empower and motivate” living well and thriving with limb loss. The magazine targets amputees and their families and is provided free electronically to all friends of the Amputee Coalition and in hard copy to all subscribers. Each issue covers health, well-being, exercise, life issues and advocacy for amputees and their families. Stories showcase amputees living and thriving with limb loss and profile Amputee Coalition programs and services.

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**Our Mission** | To reach out to and empower people affected by limb loss to achieve their full potential through education, support and advocacy, and to promote limb loss prevention.

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## New Regulations for Financial Advisors May Bring More Transparency for Consumers

by Dan Ignaszewski

 For the Department of Labor's fact sheet on the rule as it was proposed, you're welcome to read more here: [dol.gov/ebsa/newsroom/fsconflictsofinterest.html](http://dol.gov/ebsa/newsroom/fsconflictsofinterest.html).

**L**ast year, the Obama administration's Department of Labor proposed a new regulation to address conflicts of interest in how consumers receive retirement advice. The rule was finalized on April 5, 2016 after extensive public comments. Essentially, the new regulation would expand the existing regulations for investment advice to also require retirement advisers to abide by a fiduciary standard. Expanding the fiduciary protections of the fiduciary standard to retirement advisors means that those individuals or firms that provide retirement advice can be regulated by the SEC or state security regulators to ensure they are putting their client's interest before their own.

Some of the changes outlined in the new rule include the following:

- Any individual receiving compensation for providing advice that is *individualized or specifically directed* to a particular plan sponsor (e.g., an employer with a retirement plan), plan participant or IRA owner for consideration in making a retirement investment decision is a fiduciary. Such decisions under the proposed rule could include, but are not limited to, what assets to purchase or sell and whether to rollover from an employer-based plan to an IRA. Being a fiduciary simply means that the adviser must provide impartial advice in their client's best interest and cannot accept any payments creating conflicts of

interest unless they qualify for an exemption intended to assure that the customer is adequately protected.

- The proposal carves out “retirement education” from the definition of retirement investment advice so that advisers can continue to provide general education on retirement saving across employment-based plans and IRAs without triggering the fiduciary duties. For example, retirement education could consist of general information about the mix of assets (stocks, bonds, etc.) an average person should have based on their age, income, and other circumstances, while avoiding suggesting specific stocks, bonds, or funds that should be a part of that mix.
- Under the proposed rule, the rule remains unchanged if an individual calls a broker or adviser and tells them exactly what they want to purchase without asking for advice. Because this type of transaction does not involve advice from the broker or adviser, the fiduciary responsibility to the client is exempted.

The Department of Labor produced studies before the rule was proposed that suggested consumers could save in excess of \$40 billion over the next 10 years with these changes in regulations. These studies were produced by a regulatory impact analysis and the bulk of the savings from the report is estimated based on the new regulation requiring a fiduciary responsibility.

While the administration touts these changes as an important consumer protection, there have been varying degrees of support and disagreement with the proposed rule. Many

financial advisors and organizations representing brokerage and asset management firms have expressed concern that the new regulation could result in reduced access to advice for consumers. With the new reporting requirements to monitor advisors and produce better disclosures about hidden costs, many of these organizations have expressed concern that in the short-term, the costs could increase for consumers as some of these costs get passed on. Others contend that these costs will level out over time and bring more transparency to the market. As recognition of some of these challenges, the final rule provided an expanded timeline for the regulations to go into effect. Many of the regulations will be enforced in April 2017, with full compliance expected by January 1, 2018.

Like any new rule or regulation, there’s likely some good and some bad. More protections and transparency for consumers are important safeguards to help people invest wisely, but potential added upfront costs for consumers and additional oversight of financial planners could make it more difficult for consumers to get retirement advice.

The rule was proposed last year and just recently finalized. It’s important for consumers to keep an eye on regulations like this; with the added transparency, consumers are strongly encouraged to work with their financial planners and do their research to determine the best retirement investments for their individual circumstance and how this proposed rule might impact their current and future retirement plan. 

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## events calendar

### May

#### HEALTHY VISION MONTH

[nei.nih.gov/hvm](http://nei.nih.gov/hvm)

#### NATIONAL OSTEOPOROSIS MONTH

[nof.org/nationalosteoporosismonth](http://nof.org/nationalosteoporosismonth)

#### NATIONAL PHYSICAL FITNESS AND SPORTS MONTH

[fitness.gov](http://fitness.gov)

#### OLDER AMERICANS MONTH

[acl.gov/NewsRoom/Observances/oam](http://acl.gov/NewsRoom/Observances/oam)

#### STROKE AWARENESS MONTH

[stroke.org](http://stroke.org)

#### TRAUMA AWARENESS MONTH

[nationaltraumainstitute.org](http://nationaltraumainstitute.org)

6 – 12

#### National Nurses Week

[nursingworld.org](http://nursingworld.org)

13

#### First Swing Clinic

Lemont, Illinois  
[opafonline.org](http://opafonline.org)

14

#### San Antonio Tour de Cure

San Antonio, Texas  
[diabetes.org](http://diabetes.org)

#### First Swing Clinic First Climb – First Stride

Seattle, Washington  
[opafonline.org](http://opafonline.org)

8 – 14

#### National Women's Health Week

[womenshealth.gov/nwhw](http://womenshealth.gov/nwhw)

25

#### National Senior Health & Fitness Day

[fitnessday.com](http://fitnessday.com)

**Note:** Dates listed for events are subject to change. Check Amputee Coalition online calendar and listed Web sites for current information.

### June

#### MEN'S HEALTH MONTH

[menshealthmonth.org](http://menshealthmonth.org)

#### NATIONAL FIREWORKS SAFETY MONTH

[fireworkssafety.org](http://fireworkssafety.org)

#### NATIONAL SAFETY MONTH

[nsc.org/Pages/JuneisNationalSafetyMonth.aspx](http://nsc.org/Pages/JuneisNationalSafetyMonth.aspx)

#### VISION RESEARCH MONTH

[preventblindness.org](http://preventblindness.org)

5

National Cancer Survivors Day  
[ncsdf.org](http://ncsdf.org)

9 – 11

#### Amputee Coalition

2016 National Conference  
Greensboro, North Carolina  
[amputee-coalition.org](http://amputee-coalition.org)

#### First Swim – First Dance

First Fit – First Climb  
Greensboro, North Carolina  
[opafonline.org](http://opafonline.org)

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#### Silicon Valley Tour de Cure

Palo Alto, California  
[diabetes.org](http://diabetes.org)

13 – 19

#### National Men's Health Week

[menshealthmonth.org/week](http://menshealthmonth.org/week)

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#### McKeever's First Ride

Versailles, Kentucky  
[opafonline.org](http://opafonline.org)

25

#### Fort Worth Tour de Cure

Fort Worth, Texas  
[diabetes.org](http://diabetes.org)

#### First Swim

Emmitsburg, Maryland  
[opafonline.org](http://opafonline.org)

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#### Wheelchair

Tennis Clinic  
Rock Hill, South Carolina  
[opafonline.org](http://opafonline.org)

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# WHO IS YOUR AMPUTEE HERO?



## FINDING BALANCE

by Rachel Handler

My hero is my mother. When I lost my leg at the age of 24, she supported me in every way possible, without letting me lose my independence.

Losing a limb can put a strain on your relationships with friends and family. But losing a limb as a young adult can be especially challenging when it comes to relationships with your parents.

I had a hard time determining how much help I actually needed, and how much help was just convenient and unnecessary. Living with my parents right after my amputation was necessary, but asking them for glasses of water every hour was not! My mom helped me regain confidence



in my ability to take care of myself and maintain my independence as a young adult.

After a few years as an amputee, I still have my good days and bad. Some bad days can stretch into bad weeks, and during those times she's always there to remind me to have hope – even when I haven't realized that I've lost it.

She's become active on the Amputee Coalition's Facebook page; she likes to know as much as me when it comes to prosthetic innovations. Amputees face so many choices when it comes to our socket and feet selections. I'm a worrier, and my mom is always there to help me make an informed decision and to be a sounding board for all of my concerns.

My mom believes in me – she believes in my dreams of being an actress and a singer. Without her love and support, I wouldn't be getting compliments like, "You've handled the loss of your leg so well!" Thanks to my mom, adapting to wearing a prosthetic leg has been more of an interesting journey and less of devastating loss. Thank you, Michelle Handler. 🌟

### Who is your amputee hero, and why?

Whether they're an amputee or not, the special person who inspires you to live well with limb loss can be a relative, a friend or someone you've never met. We invite you to send us an article (350 words or less) for consideration to be included in *inMotion* (editor@amputee-coalition.org).



# Prosthetist FINDER

## How Can It Help You?

The Amputee Coalition's mission is to reach out to and empower people affected by limb loss to achieve their full potential through education, support and advocacy, and to promote limb loss prevention.

To support this mission, the Amputee Coalition has developed many multimedia resources for people living with limb loss. The Amputee Coalition is the leading nonprofit organization in providing these resources in the U.S. and worldwide. Locally, support for an amputee comes from their prosthetist, a medical professional who specializes in the rehabilitation of amputees by designing, fabricating and fitting a prosthesis. Selecting an appropriate prosthetist can be confusing and challenging. The Amputee Coalition has worked hard to develop the most non-biased approaches to helping someone choose a prosthetist. The Amputee Coalition collaborated with the American Academy of Orthotists and Prosthetists (AAOP) to develop a nonbiased message on how to find a prosthetist:

1. Get information from an amputee peer.
2. Interview many prosthetists.
3. Find an office near you.
4. Ask family and friends to help.
5. Check credentials and education.

(Full Link: [amputee-coalition.org/wp-content/uploads/2014/11/lsp\\_aaop-prosthetic-patient-brochure\\_130115-040856.pdf](http://amputee-coalition.org/wp-content/uploads/2014/11/lsp_aaop-prosthetic-patient-brochure_130115-040856.pdf))

Empowering an amputee with impartial advice on how to find a prosthetist directly meets the mission of the Amputee Coalition, and is a service to help an amputee educate, advocate and seek local support for themselves and their prosthetic needs. The Amputee Coalition wants to help amputees find prosthetists that are personally right for them. The Amputee Coalition has partnered with a neutral, non-biased prosthetic amputee researcher to develop a Web site application called Prosthetist Finder ([prosthetistfinder.org](http://prosthetistfinder.org)), a *new* way to find a prosthetist.

The Amputee Coalition believes a prosthetist should be selected based on characteristics that best match *your* needs. The Prosthetist Finder gives you control over deciding which characteristics are important to *you*. The Prosthetist Finder app allows you to search for a prosthetist based on the characteristics advocated by the Amputee Coalition and AAOP.

Over the next five issues of *inMotion*, we will be discussing the importance of finding a prosthetist based on the Amputee Coalition and AAOP message, and how the Prosthetist Finder can help you find a prosthetist who best suits your personal needs. Please spread the word to your prosthetist and all of your peers about [prosthetistfinder.org](http://prosthetistfinder.org) so your prosthetist can enter his or her information, build the effectiveness, and be part of this exciting new Web site application.



## ProsthetistFinder.org



[amputee-coalition.org](http://amputee-coalition.org)

# Did You Know?

## THE AMPUTEE COALITION...

- Is a nonprofit organization
- Serves all amputees, regardless of age, race, religious affiliation or how they became an amputee
- Operates the Amputee Coalition Paddy Rossbach Youth Camp, a six-day traditional summer camp located in Ohio, for children age 10-17 years old from across the United States each summer
- In 2015, 110 children attended our youth camp – FREE of charge; thanks to our generous donors, we are able to pay for round-trip airline tickets and the full camp tuition
- Connects new amputees with a certified amputee peer visitor; individuals are matched based on similar level of amputation, age, sex and life experiences
- In 2015, our peer visitor program visited over 1,000 new amputees (an increase of 10 percent from 2014)
- Provides amputees with virtual support and networking opportunities through social media (the largest amputee social media outlet in the world)
- Publishes *inMotion*, a bimonthly magazine for amputees and caregivers, completely free of charge to subscribers
- Has a resource center that provides comprehensive information and connects people who need assistance to resources in their community
- Has a call center that provides real-time interaction with certified resource center specialists to help address issues, concerns or questions
- Holds at least three Limb Loss Education Days each year, with an average of 100 attendees at each event; each of these events has at least three educational sessions, a small vendor area and a lot of amputee networking opportunities
- Holds a National Conference annually, with approximately 1,000 attendees, including amputees, caregivers, family members, providers and industry professionals
- Will celebrate 30 years of serving the amputee community in 2016
- Established April as Limb Loss Awareness Month in 2012
- Established Show Your Mettle Day as the last Saturday in April to encourage amputees to show their courage and independence by showing their metal (prosthetic and assistive devices)
- Publishes *First Step*, a comprehensive resource guide on adapting to and living with limb loss, and remaining productive and independent
- Publishes a resource guide, *Insurance Coverage & Reimbursement: How to Be Your Own Advocate*, to help explain your insurance options, ensure you receive adequate prosthetic coverage, and empower you to play a role in your own healthcare
- Advocates on behalf of all amputees; in the face of growing challenges with insurance coverage, reasonable travel requirements and advancements in patient care and technology, we ensure amputees' voices are heard (#NotALuxury)
- Works with research partners to improve patient care (both physically and emotionally) for amputees, including our Well-Being project and PALS program
- Works with research partners to prevent primary and secondary limb loss, raise awareness of these issues and improve patient outcomes
- Provides scholarships to amputees (the Christina Skoski, MD, Scholarship and the Scott Decker, MD, Memorial Scholarship) to assist with college tuition, as well as the Bridge to Ability Scholarship to help new amputees attend our National Conference
- Works with over 250 support groups across the country.

## Support Our Mission

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# Exploring Cuba With Limb Loss

by Peter J. Purdy

# Cuba



**A**s our chartered flight landed in the Havana airport on a rainy Sunday, I was excited, imagining the adventures of exploring this island as it opens its doors to increasing numbers of American visitors. Yet, I wondered how difficult it would be to manage a two-week trip as a bilateral below-knee amputee.

To visit Cuba is to step back into a 50-year time warp, where horse-drawn taxis and bicycle rickshaws are major forms of transportation together with the legendary 1950s American Chevrolets that taxi tourists in the larger towns. At the same time, this time gap parallels the insensibilities about disability that existed in the United States before the 1990 Americans With Disability Act changed public policies and practices. In short, travelling with limb loss in Cuba today is consistently challenging, ever-surprising and often requires helping hands along the way.

In spite of evolving U.S. State Department policies vis-à-vis Cuba, Americans still must travel to Cuba under the aegis of people-to-people programs with an educational theme. In principle, seashore holidays on Cuba's legendary beaches are off-limits for Americans. Thus, the current tsunami of American visitors usually arrives in groups organized through *avanatour*, the

Cuban government agency responsible for arranging itineraries and logistics and providing guides.

The advantage of these programs is the variety of opportunities to interact with Cuban artists, musicians, architects, teachers, students, ranchers, fishermen and even workers crafting the famous Cuban cigars. Meals are often served in private homes, *Paladares*, part of the emerging small private enterprise permitted by the Cuban government. Similarly, *Casa Particularas* offer overnights in Cuban homes and, in small towns such as Trinidad, are the primary form of accommodation.

Visitors with limb loss are well-advised to bring a set of hiking poles to manage the cobblestone streets, the high curbsides, steep stairs with no railings and the narrow sidewalks with pot holes. Strong leg flexibility helps in mounting horse-drawn carriages and bicycle rickshaws needed to ply the small back streets of Old Havana, Camaguey, and Bayamo. Daily bathing is also a challenge: neither of the two five-star hotels provided bath benches, although other smaller hotels managed to find straw chairs to fit into the showers.

The rewards of a visit to Cuba are enormous. Cuban music abounds in the streets and restaurants, and visitors are often pulled into dancing a cha cha



cha and even the *Tumba Francesa*, a dance tradition influenced by Franco-Haitian immigrants in the 19th century. Cuba's Spanish colonial architecture, much of it crumbling but slowly being restored, is unique and listed among UNESCO's World heritage sites. Cuba's 1959 revolution remains an unapologetic theme, with Cubans citing its achievements in universal health and education while acknowledging its abiding economic challenges. Representations of Che Guevara on T-shirts and billboards stand alongside those of Fidel Castro and are found everywhere, celebrating their contributions to the fall of the Juan Batista dictatorial regime and the implementation of new revolutionary principles.

Seeking to understand limb loss among Cubans proved to be challenging. Armed with Amputee Coalition materials in Spanish, I visited the major state-run rehabilitation center in Havana, where I received varying

quotes as to the number of amputees in Cuba, ranging from 2,000 to 3,500. I was initially led to believe that all services were free, but later learned that some clients did indeed pay a small fee. In chance meetings with amputees on the street, it appeared that obtaining a prosthetic device did involve a cost. In Cuba's current economy of scarcity, where one month's salary in the public sector is the equivalent of \$20, acquiring prostheses seems to be a healthcare choice, not a right.

Peer visitor programs, or support groups, as we know them in the United States are not yet part of the limb loss scene in Cuba. Rehab centers in each of the 16 provinces, in principle, have a psychologist to deal with emotional issues; however, there proved to be no one filling that role in the Havana Rehab Center. Government officials proudly affirmed that the use of Heberprot-P, a Cuban-generated drug in use over the past decade, has reduced the risk of amputation among

diabetics by 75 percent. Because of the U.S.-imposed blockade with Cuba, the drug is not yet available in America but is in wide use in other Latin American countries and Europe.

Despite the Cuban-American standoff over the past five decades, Cubans like Americans. Their enthusiasm over the opening of the American Embassy in Havana and the March visit of President Obama was palpable. They were welcoming, hospitable and ever-attentive to lending a helping hand, be it in climbing stairs without a handrail or stepping off a high curb. As with any trip, the most lingering memories are more about people than about places, and the warmth and enthusiasm of my new Cuban friends will not be forgotten. As the end of my visit approached, Cubans frequently asked me if I would return. My answer was always *quizás, quizás, quizás*, the title to one of Cuba's most popular 1930s songs: "perhaps, perhaps, perhaps." 🌍

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Check out Aimee and Ali's videos at [www.youtube.com/biodesignsvideos](http://www.youtube.com/biodesignsvideos)

# It's Time to RALLY!

by Leif Nelson, DPT, ATP, CSCS

**S**ergeant Nick Kimmel, U.S. Marine Corps (Retired), is a difficult man to track down. He lives in Fallbrook, California, but when I finally caught up with him, he had just stepped out of his Jeep in Moab, Utah. Kimmel was a combat engineer in the Marines, a job he describes as being “a jack of all trades.” He built roads and bases, constructed vertical and horizontal domains, and swept for improvised explosive devices (IEDs).

On December 1, 2011, during his second deployment to Afghanistan, Kimmel’s squad was building a patrol base in Northern Sangin, just three miles south of the Kajaki Dam. After assessing a roof on the newly built guard post, Kimmel jumped down from the forklift on which he was standing and landed on a 40-pound IED. He woke up in Bethesda, Maryland three days later. He is now living with a left above-elbow and bilateral above-knee amputations.

After inpatient care, Kimmel transferred to Naval Medical Center San Diego for his outpatient rehab. Since he was still active duty, his job continued as it had for the past two years to include high and tight haircuts and morning formations.

He also regularly attended medical appointments in the 30,000-square-foot Comprehensive Combat and Complex Casualty Care (C5) facility. Kimmel describes C5 as a streamlined program in a fully automated facility, where it’s easy to get to all his daily appointments. He was aided by facility design, as well as the ability to just hit his cell phone to receive reminders about his appointments.

Physical therapist Jacqueline Moore, MPT, DSc, OCS, ATC, CSCS, describes C5 as a “comprehensive, multidisciplinary care for service members, veterans, family members and other beneficiaries with polytraumatic injuries, including amputations.” A veteran herself, having served in the U.S.

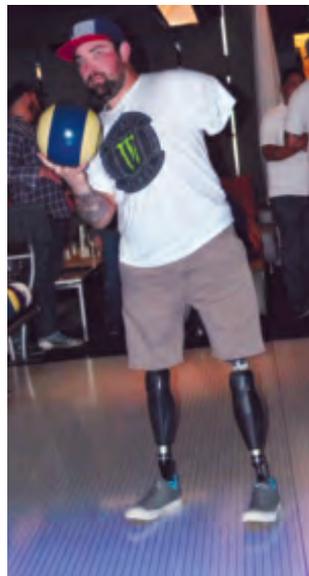
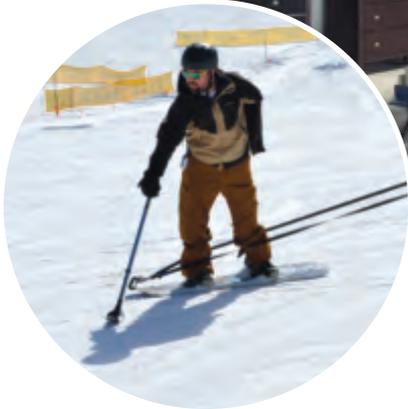
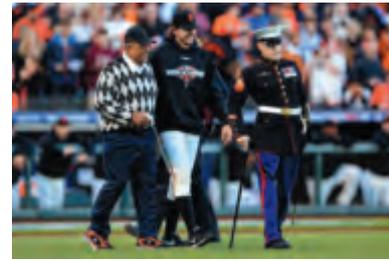
Army as a physical therapist from 1995-2007, she adds, “Our patients are the best part of C5, and it’s a privilege to serve them. We are able to work closely with other specialty care providers to deliver the best care possible.” Moore commends Kimmel for his focus and motivation. “He knows what he wants to do and will work diligently to accomplish those tasks, from snowboarding, to off-roading, to restoring old Corvettes with his dad.”

Having spent so many hours with the rehabilitation team, Kimmel is happy to continue to have a close relationship with Moore, who was watching his dog while we spoke. He still sees the same rehabilitation specialist, Jay Pyo, DO. Dr. Pyo is the medical director for the polytrauma amputation network site at VA San Diego Healthcare System, and has worked with Kimmel since 2012.

Dr. Pyo transitioned to VA in 2013 from his own military career as director of rehabilitation at C5. He sees his current role is to “establish a lifelong care plan” for his patient with traumatic amputations he saw at C5, as well as for veterans of all generations with various pathologies. When describing his experience in working with Kimmel, he fondly shares, “He is a really sharp guy. He has always had a lofty yet proven realistic outlook on what he could achieve, and continues to push our rehabilitation team to progress our team goals at the accelerated rate. He was walking in a couple of months, and back into sports and life at an exceptional pace.”

Completing a driver training course was a requirement for graduation from rehabilitation at C5. For a self-described “gear-head” and “adrenaline junkie,” driving was a primary recovery goal for Kimmel. When asked what adaptations he had on his Jeep, I was surprised when he said “A five-inch lift, 37-inch tires, a wrench, bumpers, rock sliders, it’s all decked out!” Clarifying that I was asking about disability-specific adaptations, he said, “Nothing injury-specific, really.”





I have a second mode programmed in my X3 [microprocessor-controlled] knees, and I drive using my hips and both feet while gearing with my good hand.” This is how he negotiated the world-class terrain that makes up the courses at the 50th Annual Easter Jeep Safari in Utah. “Warfighter Made helped build my Jeep and sent me to Utah. This is my version of rec therapy.”

Kimmel is now in school working toward a career as a mechanical engineer. He wants to impact the off-road industry, which has its mecca in Southern California. A certified welder since he was 16, he built a 26-foot metal fishing boat while still in high school. Now, he is using his “mechanical mind” working in technical and smaller scale product design in the world of shocks and sprockets. “I think it would be cool to design a suspension system, and then see a professional truck racer using it. A piece of equipment I made up in my head, drew on a piece of paper, and then it went into production.” Clearly, Kimmel is excited by this opportunity to be “an architect for moving machinery.”

For a guy who will wear his prostheses for the straight 22-hour drive to visit his family up in Washington for the holidays, Kimmel is driven by what he loves. He continues to engineer ways to stay on the road, and sometimes off it. 🌀





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# Financial Planning:

## *The Basics... and Beyond*

by Lee Zimmerman

There's no doubt about it. Planning for the future is one of the most essential – and intimidating – propositions that we as individuals ever undertake. It's mired in uncertainty and unpredictability, its reliability dependent on shifting trends and circumstances that are far beyond our ability to control. It can be easily undermined by events in the global marketplace, the possibility of war and conflict, shifting energy prices, unemployment data, political undercurrents and a host of other scenarios that can trigger a monetary reaction one way or another.

That's the bad news. The good news is that you don't have to sit idly by and allow the shifting winds of fortune to steer your fate. There are plenty of things you can do to ensure a future free of financial stress and a comfortable lifestyle in retirement.



## Create a financial plan

It always makes sense to begin at the beginning. Know what you want and where you want to be down the road. Sadly, too many people are content to simply wing their way through life, living from year to year, month to month and oftentimes, week to week. In a way, that's understandable. While job growth is up, there are still many people who are either unemployed or under-employed. Many of those individuals fall under the category of those with physical challenges. However, a financial plan doesn't deal with the here and now. It's a long-range view that should gauge your progress going forward.

A financial plan should be twofold. For starters, it should take into account your physical and financial assets, your earnings and any other factors that might contribute to your overall ability to pay your bills, buy the house of your dreams, or relocate to the place where you want to retire. Do you expect to come into an inheritance? Are you invested in stocks, bonds or commodities? How much cash do you have on hand? How is your health? Do you own your home, or do you rent? Do you have cash reserves?

Of course, the more assets you've accumulated, the better the chances are that you can see your financial plan through to success. But first you need a goal. The most common question a prospective employer will ask you at a job interview is, "Where do you see yourself in five or 10 years?" Many people respond by saying they hope they've advanced their career. However, far fewer are willing to answer that question for themselves, or to be bold about their individual goals for the future. After all, looking ahead isn't simply about your job. That's only one piece of the puzzle. It's also about where you want to live, what you want to do, what activities you want to enjoy and how you intend to finance those goals once you achieve them.

That's why it's important to look ahead, not five years into the future, not 10, but, depending on your age, 20, 30, 40, or maybe even 50 years from now. People are living longer these days, so your finances need to sustain you far longer than ever before. It can be a scary prospect and more than a bit worrisome. And again, those shifting winds of geo-political turmoil can disrupt even the best prepared strategy.

Fortunately, there's no need to tackle the situation alone. A good financial planner can take into account your current holdings, your present occupation, your job skills, your health, and your financial prospects, and then weave all these factors into a viable financial plan flexible enough



Of course, finding a good, reliable and credible financial planner isn't as easy as simply googling a choice online. There are different areas of expertise and a wide array of skill sets that have to be taken into account. Does your employer offer financial planning services? Seek recommendations from people you trust, especially those who seem to have their finances in order. Some folks will tell you that asking a friend or colleague about their assets is rude or inappropriate. However, there's nothing wrong with asking, "You seem to have managed your money well. Can you tell me what resources you use and who helps with your financial planning?" Most people will take that question as a compliment and will be only too happy to pass on a recommendation of someone who has done a good job on their behalf.

Once you've homed in on some possible candidates, investigate further. Look online for comments from their clients, either good or bad. Check their reports with the Better Business Bureau. Ask for a prospectus with a listing of their funds, and rates of return since inception. The one axiom engraved in stone is the one that states: "Past results are not an indication of future returns," but a portfolio that generally weighs heavily with winners can indicate their track record regardless. Has their fund manager fared well? Have they had any complaints or legal actions taken against them? What is the total amount of assets that they currently manage?

A good financial advisor will take into account your own tolerance for risk, your age and, of course, your goals. In many cases, that involves answering a series of questions that offer insights into how comfortable you are with certain types of investments and what you would or wouldn't sacrifice to get a desired rate of return. If you're older – say, in your 50s or 60s and nearing retirement – your investments ought to be more conservative because you will have less time to make up for any losses you might suffer during a downturn. On the other hand, those of a younger age and just starting out – people in their 20s, 30s and even into their 40s – can afford to take more chances for the sake of making more of a profit, because (A) that's the time to lay a financial foundation and (B) if things do go awry, there will be more time to make up for it in the future.

to deal with any unforeseen changes in the financial landscape while accommodating your own dreams and desires. We all know that nothing ever goes as planned, but a good financial advisor has the tools to factor those choices and considerations into a sound strategy for the future.

***Then there's this  
other rule of thumb:***

## **DIVERSIFY**

Don't put all of your assets in one basket. Distribute your portfolio between stocks, bonds, cash, real estate, precious metals, commodities or other holdings you and your advisor feel comfortable with. This ensures balance and protects you in case one asset should suddenly falter. Precious metals tend to rise in value when the economic outlook is dimmer. Stocks and bonds work counter to one another – when one goes up, the other is likely to go down. Having cash on hand for emergencies or to sustain you for three to six months due to a sudden job loss is equally important. Granted, most banks offer insignificant rates of return, a fraction of a percentage point in most cases, but the ability to pull out cash at a moment's notice goes a long way toward sustaining peace of mind.

While we're on the subject of financial advisors, there's this to consider as well: Does the firm take commissions on their trades, or do they set their fees based on your total holdings? An unscrupulous agent that's on commission might make a trade simply to add to his earnings. That's called "churning" and it's highly unethical. If your advisor takes a percentage of your holdings on an annual, semi-annual or quarterly basis, then you'll be better assured that his or her priority is to see your assets grow, not only because they want to do well by you, but because the more you have in your funds, the larger their own return. While their interests should always be in sync with your own, this is one way to give them a vested interest in your success. Check the fee structure and then ask around. Is it in line with what other companies charge?



## **Think for yourself**

Never leave your investments entirely in the hands of others. Study your statements and see if your goals are being accomplished. Know exactly which funds you are invested in. If you don't understand, ask questions. And then ask more questions. You can never be too informed.

Take steps on your own. When you get your pay check, pay yourself first, before you pay your bills. You may not be able to afford a lot, especially after the normal deductions and withholding, but give yourself something you can bank and build from there. Use a portion of your annual raise or cost of living increase to steadily increase the amount of money you put away. Even putting away a small sum, say \$100 a month, will give you a feeling of satisfaction that you're being proactive when it comes to saving. Better yet, if your company matches any money that you set aside, say, as an example, 50 percent of the first \$100 you automatically deduct from your pay check, that's a free \$50 you earn even on top of any rate of return. Maximize it to reap the greatest rewards.

## **Insurance and looking out for your needs**

Nobody looks forward to paying their insurance premiums. After all, you're essentially paying for something you hope you never have to use, be it death, disability or long-term care. Unfortunately, some of these things are inevitable and it's best to be prepared. Spending money now on disability or long-term care coverage can save thousands of dollars when the time comes. The cost of a stay in a hospital or nursing home can otherwise be prohibitive. Life insurance coverage can help provide for your family once you're gone. Choosing the amount of coverage and figuring out the costs involved can be complicated and frustrating. That's where a good insurance agent can help. Take the time to investigate the options and listen carefully as your agent goes over the details with you. That little extra time you spend now on finding a plan that's affordable and practical can make things much more manageable in the future.

## Social Security isn't going away any time soon

Despite the political bantering back and forth about the dangers of Social Security not being able to sustain itself, the fact remains that no one *wants* Social Security to go away. That would be political suicide. Those within reach of retirement – anyone 55 or older – needn't worry, although annual increases due to inflation might decrease as the years go by. Still, for most people, Social Security remains a major source of income for many individuals during their retirement years.

If you apply for disability benefits, you're likely entitled to receive the same monthly stipend that you would receive at the usual retirement age of 66. However, if that's not the case, and you are trying to decide when to take your benefits, the choice becomes more complicated. A person is first eligible for Social Security at age 62. For most baby boomers, full retirement occurs at age 66. However, you can wait until a maximum age of 70 to get a larger monthly benefit. Just how much you will receive at any given age depends on your employment history and what you've contributed over the years. Generally, though, you can think about it like this: For every year you wait, you can expect an additional 8 percent increase in your annual benefit. That's a return far greater than a typical investment will bring you these days. And since it's backed by the government, that's a pretty good prospect for building your wealth safely and securely. As an example, someone who earns \$2,200 a month at age 66 will likely receive a monthly check of nearly \$2,900 at age 70, before Medicare deductions.

But what if you can't wait until age 70 to begin taking benefits? What if you can't even wait until full retirement age at 66, and you need to begin drawing at age 62? Your benefit will be substantially less, of course, and unless you suspend it and pay back what you've received, you will be stuck at that payout rate for life. So does that mean you should try to hold out, even at the risk of not being able to pay your monthly bills? Not necessarily. Factor in the amount of money

you'll forfeit between the ages of 62 and 66 alone. It can amount to tens of thousands of dollars. For most people, the break-even point between the amount you would have gotten early on and the additional amount you'll receive at full retirement age isn't reached until you're in your late 70s. If you wait until age 70 to collect, your break-even point comes even later, not until your early 80s. Go to [socialsecurity.gov](http://socialsecurity.gov) and use the calculator to help find your best options.

The decision often boils down to your health and your family's medical history. It may be sobering to think about, but if your parents died young, or if you have some recurring health issue that indicates you will not live until a ripe old age, it may be best to take your benefits sooner rather than later. It's money you can use now that you won't have any need for later on.

## Don't do it alone

If you're struggling with a financial burden now, seek help. No matter where you live, there are state agencies that can help you with your needs, either due a physical impairment or a lack of financial resources. Ask about food stamps, job placement services, transportation assistance and daycare possibilities. If you're having trouble paying the mortgage or making the rent, talk to your bank or landlord and explain the situation. In most cases, they'll appreciate your honest assessment of the situation and will show a willingness to work with you. Take the time needed to investigate, because as with most efforts we make, the results are generally worth the time spent pursuing them.

## Finally...

Think positive and don't allow yourself to be overwhelmed. These are important decisions that need to be made, and they literally affect your entire life. The choices that you make now will make your future more secure and give you that feeling that your destiny is in your hands. And that's exactly where it should be. Take control, and good luck! 🍀

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# Calculating the Lifetime Cost of Prosthetics

by Tony Phillips

**A**dvancement in prosthetic technology, as in all fields, comes at a price. A modern prosthetic limb is more than a peg or a hook. The research, design, testing and refinement of the most advanced limbs is something approaching the boundary of science fiction. Yes, there are “basic” model arms, legs, hands and feet in use around the world, even in advanced countries. But more and more, one sees images of amputees functioning with the most high-tech devices; one might assume that the state-of-the-art is available to anyone, but it isn’t – and cost is a major reason.

Figuring the real cost of amputation (or limb difference) is a tricky thing, for several reasons. First, it’s not just the cost of the prosthesis that has to be calculated – there is also the cost of service, maintenance and repair. There is the cost of prosthetic supplies (liners, socks, etc.). Then there is, of course, the cost for the prosthetist, whose expertise makes all the difference between a good prosthesis and a bad one. These things add up and change the true cost projection of anyone living with limb loss.

Perhaps the most significant obstacle to calculating the real cost of a prosthetic limb is the fact that virtually no manufacturer openly discloses its prices. If you want to buy a BMW, you can check the sticker price. If you want a new myoelectric hand, you’ll probably never know for certain exactly how much your transaction cost. Cash buyers in the advanced prosthetics market are scarce, extremely so. The overwhelming majority of prosthetic limb expenses are borne by public or private medical insurers. Those insurers negotiate rates with prosthetists and prosthetic manufacturers and whatever the sticker price of a new limb might be, it’s far different than what actually gets spent.

That being said, there are some generally accepted figures that are at least in the ballpark for calculating prosthetic cost. Perhaps the most accurate numbers



come from a 2010 study published in the *Journal of Rehabilitation Research & Development*. The study found that, for veterans of post-9/11 conflicts returning with limb loss, the average cost of an upper-limb prosthesis and related supplies and services exceeds \$23,000 per year, and the lifetime cost for the average veteran surveyed will reach a projected \$823,239. For lower-limb prosthetics, the average annual cost is nearly \$46,000 and projected lifetime cost is a staggering \$1.46 million.

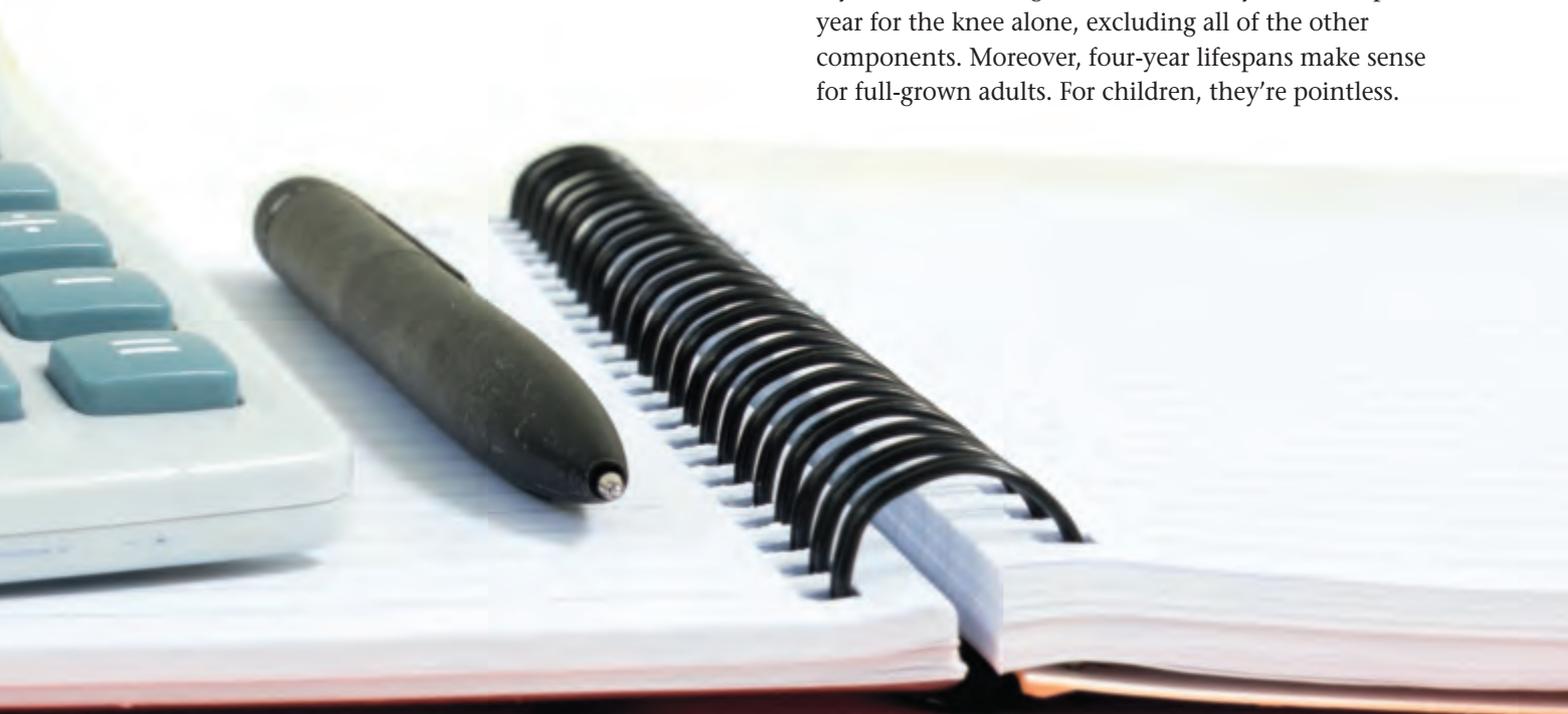
However, the VA provides its patients with a higher standard of care than most other insurers. So to calculate what things cost for the non-veteran, the best self-declared authorities on the subject report the following round numbers for different amputation levels:

- Below-Elbow \$5,000 to \$8,000
- Above-Elbow \$12,000 to \$15,000
- Below-Knee \$8,000 to \$15,000
- Above-Knee \$20,000 to \$40,000

These are averages. They reflect the cost of widely accepted contemporary components from major manufacturers. They do not reflect the cost of the most newfangled gear. A single high-end hand can cost more than \$20,000 from the factory and a top-of-the-line microprocessor knee ranges from \$30,000 to \$100,000. Using a mid-range of the more conservative numbers is probably the best way to calculate typical costs.

Thus, if you're wearing the latest microprocessor knee from an industry-leading manufacturer, plus an energy return foot, plus a suction suspension socket, plus a gel liner – then you're wearing a new BMW. If you're wearing two, you're wearing a condominium in Boca Raton. If you're wearing those plus a myoelectric hand and an above-elbow socket, you're wearing a veritable yacht.

Sadly, the string of big numbers doesn't end there. Even the best prosthetic components have no more than a three-to-five-year lifespan – let's call it four. So that \$30,000 knee will need to be replaced soon and, if you are the average user, it will cost you \$7,500 per year for the knee alone, excluding all of the other components. Moreover, four-year lifespans make sense for full-grown adults. For children, they're pointless.



## Lifetime Cost of Prosthetics | continued from previous page

A toddler fitted with her first prosthetic leg before her second birthday will change legs more than a dozen times before she reaches maturity. Sockets will be re-cast and rebuilt. Feet and knees will be replaced. Pylons will be lengthened.

Also contributing to the turnover cost of a prosthetic limb is the wearer's activity level. An active child might nearly destroy his or her leg by the time it's replaced. Likewise, athletic adults will find that the lifespan guidelines are overly optimistic.

In general, the consensus seems to be that the real lifetime cost of prosthetic replacement for an amputated or congenitally absent limb is equal to one-fourth the cost of the complete prosthesis times the number of years the individual will live. If you have a \$30,000 prosthesis, you're 50 years old and expect to see 80, that means the cost of your prosthetic care, maintenance, replacement, etc., will total roughly  $\$7,500 \times 30$ , or \$225,000. For a newborn, the cost will be at least double that and likely much more.

That sounds like horrible news for insurers, who ultimately bear most of the cost, even at negotiated rates.



But it turns out that, despite the astronomical expense of prosthetic technology, the cost of fitting patients with technology suitable to their functionality and lifestyle is actually lower than the cost of doing nothing at all. Prior to implementation of the Affordable Care Act, the California Health Benefits Review Program determined that every dollar spent on rehabilitation saves the economy \$11 dollars in various welfare and disability benefits.

Cost, of course, does not determine either necessity or medical appropriateness. Just because BMWs exist, there is nothing wrong with a Chevy. The most salient consideration for patients, insurers, prosthetists and policy makers should always be what is best indicated for a given patient to maximize the likelihood of his or her return to the most active, functional life possible. That may come at a high price but it's a price worth paying. 🔄

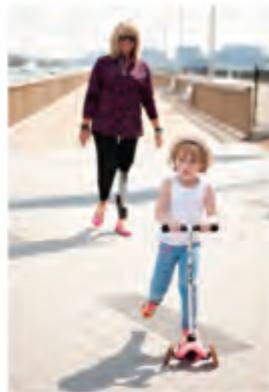
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# Do You Have Phantom Limb Pain?

If so, you might be eligible for a research study that aims to decrease and/or resolve phantom limb pain in people with an upper- or lower-limb amputation.

The purpose of this research study is to determine if putting local anesthetic (numbing medication) through one or two tiny tube(s) placed next to the nerve(s) that go to an amputated limb will decrease and/or resolve phantom limb and residual limb pain. The procedure, device and infusion are all FDA approved and have been used for over 20 years to decrease pain immediately after surgery.

Participants will receive \$100 following each catheter insertion plus \$50/day during the 6-day infusion(s), up to a maximum of \$800/subject.

This study is being conducted at the University of California (San Diego, California); Cleveland Clinic (Cleveland, Ohio); Walter Reed National Military Medical Center (Bethesda, Maryland); Veterans Affairs Palo Alto Medical Center (Palo Alto, California); and Naval Medical Center (San Diego, California).

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- Only a single 2-4 hour visit to the treatment center (2nd visit optional)



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# Applying for **Disability Benefits After an**

**Whether from an illness or an accident,** having to amputate a limb is a serious and life-changing event. One of the last things on your mind should be finances. If you have found that you are no longer able to work after an amputation, there could still be resources available. The Social Security Administration (SSA) offers financial resources for people who are unable to earn income due to an illness or injury.

## **Medically Qualifying for Benefits**

To keep the approval process as straightforward as possible, the SSA has a medical guide called the “Blue Book” that it uses to determine whether or not an applicant is eligible for benefits. Amputations are listed in Section 1.05 of the Blue Book. There are four ways to medically qualify if you have received an amputation.



# Amputation

by Deanna Power

## one:

### You have lost both of your hands.

This is the first and most straightforward way to qualify. If you have lost both of your hands, you will automatically medically qualify for disability benefits.

## two:

### You have lost both of your legs from the ankle above, and you cannot walk effectively.

This is the second listing, and it is a little more complicated to prove in some cases. Not only will you need to have both feet (or higher) amputated, but you must be unable to use prosthetic devices. The way the SSA defines walking effectively is being “capable of sustaining a reasonable walking pace over a sufficient distance to be able to carry out activities of daily living.” Activities of daily living include preparing food, using the restroom, using public transportation or driving, grocery shopping and daily grooming.

If you must use a wheelchair after your amputations, you will likely qualify for disability benefits under this second listing. If you are able to wear prosthetic limbs, you may not qualify.

## three:

### You have lost one hand and one leg above the ankle, and you cannot walk effectively.

This listing is very similar to the one above. Qualifying after losing a hand and a leg will depend on whether or not you are able to use prosthetic devices.

## four:

### You have had a hip disarticulation.

Regardless of any ability to wear prosthetic devices, the SSA understands that losing three weight-bearing joints is exceptionally challenging. You will automatically qualify if you had a leg removed from the hip.

## Applying for Social Security Benefits

If you are ready to apply for Social Security disability benefits, you can apply for benefits in one of two ways.

The first would be to apply online on the SSA's Web site. This is the easiest way to apply for benefits, as you only need to list the doctors or surgeons who have treated you. You can also start the application, save it, and come back to finish it at any time. Applying online is only available for adults who have been a part of the workforce.

You can also schedule an appointment at your local SSA office. This is the only option available for parents applying on behalf of a child who has received an amputation. There are SSA offices in every state. To schedule an appointment, you can call the SSA toll-free at 800/772-1213. 

## Related Resources

**Amputation Blue Book listing:**  
[ss.gov/disability/professionals/bluebook/1.00-Musculoskeletal-Adult.htm#1\\_05](https://www.ssa.gov/disability/professionals/bluebook/1.00-Musculoskeletal-Adult.htm#1_05)

**Apply for disability benefits online:**  
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**List of Social Security locations:**  
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**Checklist of necessary material for adults:**  
[ssa.gov/hlp/radr/10/ovw001-checklist.pdf](https://www.ssa.gov/hlp/radr/10/ovw001-checklist.pdf)

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[ssa.gov/disability/disability\\_starter\\_kits\\_child\\_eng.htm](https://www.ssa.gov/disability/disability_starter_kits_child_eng.htm)

## The Difference Between Myoelectric and Body-Powered Upper-Limb Prostheses:

# What Does the Science Say?

by Jason T. Kahle, MSMS, CPO, FAAOP, and M. Jason Highsmith, PhD, DPT, CP, FAAOP

**W**hile there are an estimated 2 million amputees in the U.S., it's reported that only 14 percent are upper-limb amputees, and 10 percent of these are multiple amputation. The Amputee Coalition reported in 2004 that nearly one-third of people with limb loss are dissatisfied with the comfort of their device. However, dissatisfaction among upper-limb users is much higher. Some reports suggest up to 50 percent of people with upper-limb loss choose not to wear a prosthesis, often stating that the functional



Body-powered prosthesis with HiFi socket, TRS Sure-Lok and Grip 3 terminal device.

advantage or appearance (cosmesis) did not outweigh the discomfort or inconvenience of the device. Reasons why users rejected a prosthesis include: not getting enough benefit from the prosthesis, prosthetic weight and socket discomfort, and higher rejection rates correlate with higher amputation levels, congenital limb loss, females and students. Ultimately, the role of the user making an educated choice of whether to use a prosthesis or not will determine the success.

When considering the design of an upper-limb

prosthesis, there are two categories: body-powered and externally powered, or myoelectric (myo). Factors that affect prosthetic prescription and recommendation of a body-powered or myo prosthesis depend on patient input, the prosthetist's experience with available components, evidence supporting the effectiveness of a component's function, manufacturer's claims, and whether an insurance company will pay for the device. The choice of a myo or body-powered upper-limb prosthesis should always be made by the user (amputee). Factors that might help the user decide include control of the prosthesis, function of the specific components, like the hand, usefulness of the device, or cosmetic appearance. Any or all of these factors can lead to the user accepting or rejecting an upper-limb prosthesis. The amount of use and overall acceptance is considerably



HiFi socket, Boston Elbow and Touch Bionics' i-limb myoelectric hand.

more complex than the decision of a lower-limb amputee. Choosing between body-powered or myo is one of the biggest decisions the user can make.

## The science

If we examine the scientific reports of the differences between body-powered and myo over the last 25 years, there are around 500 articles. From these articles, we find evidence-based statements that help guide prosthetists regarding prescription of these devices and training of users. The statements we can make, based on the best evidence, are outlined in the table on the right. Sometimes these statements agree; sometimes they don't. In science, the same experiment and device might be used and there might be a different result or conclusion. The reason is, there are different subjects, different researchers and differences in the experiment. These small differences can produce an entirely different result.

Body-powered prostheses have been shown to have advantages in durability, training time, require less adjustments and maintenance, and give better feedback. Generally, when considering a specific task like kayaking, golfing, or lifting weights, a body-powered prosthesis with a hand (terminal device) specifically made for that task is more practical and will be preferred by the user. Task-specific hands can be used for very high-impact sports as well as low-impact, allowing users to return to their preferred activities. Externally powered (myo) upper-limb prostheses cost substantially more than body-

### Evidence-Based Statements Regarding Body-Powered (BP) and Myo Prostheses

Activity-specific prostheses provide functional advantage for the user.

Depending on functional needs, control scheme familiarity and user preference, either BP prostheses with conventional hooks or myo are advantageous compared with each other or other alternatives.

Compared with myo prostheses, BP prostheses are more durable, require less training time and adjustments, are easier to clean, and function with less sensitivity to fit.

BP prostheses provide more sensory feedback than myo prostheses.

Improvements in BP prosthetic operation may be made within harness and cabling systems.

Intuitive prosthetic control may require use of multiple control strategies, such as BP, myo, or hybrid, that require less visual attention and ability to make coordinated motions of two joints but should be evaluated for each individual upper-limb prosthesis user.

Cosmesis is improved with myo prosthesis over BP prostheses.

Prosthetic rehabilitation plan addressing critical factors such as EMG site selection, controls and task training, and comfort by cohesive team will improve function and long-term success of electrically powered prosthesis users.

Roll-on sleeve improves suspension and increases range of motion compared with self-suspending sockets.

Regular myo prosthetic use supports reduced cortical reorganization and phantom-limb pain intensity.

Proportion of rejections are not different between BP or myo prostheses.

Carey SL, Lura DJ, Highsmith MJ. Differences in Myoelectric and Body-Powered Upper-Limb Prostheses: Systematic Literature Review. 2015, *JRRD*, 52 (3)

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powered prostheses when considering fitting, training and maintenance. However, myo prostheses have been reported to improve phantom-limb pain and are more accepted for light-intensity work. Myo prostheses with hands reportedly improve cosmetic appearance compared with body-powered prostheses with a hook. Users concerned with appearance prefer a myo prosthesis. The highest percentage of people using a prosthesis in social situations were users of a myo system and reportedly have improved psychosocial and social adaptation. This is most likely because of the aesthetic design of myo prostheses. Myos have greater resemblance to an anatomical arm. Additionally, from a cosmetic perspective, a myo does not have harness suspension systems and cables that are seen or wear out clothing. The combination of these factors may influence prosthetic choice for users concerned with appearance. Prosthetic selection should be based on a patient's individual needs and include personal preferences, prosthetic experience and functional needs.

### Why do 50 percent of users reject an upper-limb prosthesis?

Rejection of upper-limb prostheses is a complex issue; users reject a prosthesis for a multitude of reasons. Overall, the reported average rejection rate for myo was 23 percent and 26 percent for the body-powered prosthesis. Not only is the rejection rate similar but the reasons for rejection are also similar: weight, heat-skin temperature, durability, reliability, and a reliance on using visual cues for the myo. For body-powered, the rejection reasons included weight, heat-skin temperature, durability, reliability, difficulty with operation, clothing damage, poor appearance, and weak grasp. There is still a lot of work to be done to address unacceptable rejection rates. In short, the designs of the prosthetics need to better address the needs of the users.

### Does either a myo or body-powered prosthesis help phantom limb?

Phantom limb is any sensation in the amputated part of the arm that makes the arm feel like it is still present. Sometimes this can be painful, but more often it is merely a sensation. Phantom-limb sensation may begin immediately post-amputation and is higher and causes more problems in the upper limb compared to the lower limb. There is an estimated 50 percent prevalence in people with upper-limb amputation. There is some evidence that active use of a myo prosthesis may reduce phantom sensation and phantom pain.

### Optimizing your upper-limb prosthetic control

In order to improve prosthetic control, multiple factors and control strategies may need to be implemented. When the use of the prosthesis becomes automatic and you don't have to think about it, it is known as intuitive control. Intuitive control of a prosthesis usually requires less visual attention and will better allow for coordination between all of your joints. The ability to use a prosthesis intuitively will depend on

you and your prosthetist working together to find the right prosthesis and combination of components. A key factor for intuitive use of the prosthesis is proprioception, or your ability to know where your prosthesis is in space without looking at it. The better your proprioception, the better you will be able to intuitively control it. There are reported proprioceptive and intuitive feedback advantages of both myoelectric and body-powered prostheses. One is not recognized as being better than the other.

## Healthcare Costs

Often, insurance may dictate whether myo is even an option – even more often, insurance will rarely pay for both, even though a myo may be better in some circumstances and the body-powered in others. Recent changes in healthcare (Obamacare) have forced an emphasis on healthcare cost and the return in function for that cost. To highlight the cost difference, in a report on veterans who lost their upper limb in service, prosthetic costs over the lifespan for Vietnam veterans with unilateral upper-limb loss who owned and used a prosthesis were \$131,900. In contrast, veterans from the more recent wars (OIF/OEF) had projected lifetime costs of \$823,239 for prosthetic care. In general, myoelectric prostheses range in cost from \$25,000 to \$75,000, while body-powered prostheses range from \$4,000 to \$10,000. We need to better understand if the higher cost is worth the extra usefulness a user may get from a myo prosthesis. When healthcare costs are a factor, a body-powered system requires less training and is more durable than myo, while there is no clear difference in function between myo and body-powered. In short, body-powered and myo prostheses have the same reported function, with potentially less healthcare financial resources with body-powered.

## Conclusions

There is still room for functional improvement in both systems, as 50 percent of upper-limb amputees still choose to use neither. Comfort, weight and not enough function, including taking too long to complete a task, have been identified as the main problems in UL prosthetic users.

There is insufficient scientific evidence regarding both body-powered and myo upper-limb prostheses. The limited reports address control, function, cosmesis, and acceptance. There is still no agreement on which is superior. Body-powered and activity-specific hands cost significantly less and provide more advantages than myos. Body-powered prostheses have been shown to have advantages in durability, and require less training time, adjustment and maintenance. Myo prostheses have some advantages over body-powered. They have been shown to provide a cosmetic advantage, are more accepted for light-intensity work, and may positively affect phantom-limb pain when used on a regular basis. Scientists need to do a better job in designing standardized tests to allow for better comparisons. For now, there is limited scientific evidence of one over the other, so rely on your instincts and demand that your prosthetist allow you to try many different types of prostheses, hands and components prior to committing to a certain device. 



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# Navigating Life's River of Choice and Chance

by Harriet Kay

**I**n 1968, there was nothing to prepare my mother for what she would discover upon awakening from delivering her baby. There was no ultrasound available to answer the questions in her mind about why her baby didn't move the way her last one had during pregnancy. It was also the time when husbands paced in the waiting room and women were sedated just before delivery. Nothing could prepare my dad for the news he would need to give my mother – that their little baby had been born with some kind of defects and that doctors and nurses were still trying to figure out what was wrong.

No matter that first day into the world, I came in not just surviving but thriving. And from those first years grew a young girl with a heart that would find a way to make whatever she wanted to do happen. It wasn't always easy. I had a deformity that caused entrapment of my lower limbs, feet and ankles and my right hand in tissue. There was clubbing, fatty parts and webbing where healthy ankles, feet and fingers should have been. But I was fortunate that my family found the help for me that would make a difference in my life.

We lived in rural southwest Georgia. Finding the right help meant hours of driving for my family back and forth to Atlanta for surgical consultations, hospitalizations, clinic appointments, prosthetic appointments and therapy. At one point, it meant my mother and I living in a duplex in Atlanta so that I could learn to walk while my father worked and provided for all of us. It meant years of hardship in the form of untreated pain and frightening surgeries and treatment. Pediatric medicine is practiced

very differently today. Thankfully, there is greater attention to the physical and emotional suffering that can occur to small patients. Mornings sometimes meant getting up hours earlier before school because new sockets were painful and adjustment took time. Tears and the knowledge that I just had to do it were the precursor to morning classes.

Despite all of this hardship, there was incredible joy and laughter. My parents believed in integrating all of this into our lives. Moving forward and having a "normal" life in very abnormal circumstances were the order of the day. I learned to ride a bicycle, run and swim. I played kickball at recess, climbed the ropes and the monkey bars, and jumped off the swings. I pushed through pain and adversity along with my family to create an awesome and full life.

Today, I am 48 years old and am continuing to fulfill my dreams and goals. I recently completed my Masters in nursing as a nurse practitioner, specializing in psychiatry and behavioral health. I work with clients from children to seniors in assisting them with a variety of behavioral health needs to improve their quality of life. I own a home and work too many hours to pay a mortgage and support a lazy dog and a diva-like kitty. I have survived divorce, loss and the disappointment that living almost half a century will bring to a person. And just as I did in my youth, I have found incredible happiness and accomplishment. I appreciate the smallest gift of the day. And I still love to play, but now it is in a whitewater kayak or on a rock wall.

It is all this that makes the reply to the fact that "I was just born this way" so much



harder to take sometimes. I am proud of my body and am never shy about the fact that I have carbon fiber and shine in a dress or skirt. I am often asked the question of what happened to me that I have bilateral below-knee amputations. It isn't the question that makes me cringe, but the statements that burn, diminishing not only my sacrifice but my parents.' They seem innocent enough: "Oh, so you never knew anything different," or "Well, you just learned all of this so much easier," or "No wonder you do so well – it was a lot easier for you being a kid and growing up this way." The bottom line is, I *did* have an instinct to adapt. However, I certainly knew that there was a difference. Growing up with any kind of difference can be extremely challenging on an emotional level. There are foundational ideas about one's identity that are formed in childhood. Unfortunately, these ideas can be in the form of lies that you tell yourself about your very existence. It can take a lifetime to dispel the demons inside your head.

Those of us who have experienced limb loss all have a story and challenges. Not a single one of us is better off than another. Just as all of us in life have our own struggles, we all have an individual experience. We are all on a river that changes every single day, bringing with it beauty, peace, fear and challenge. It is just that each of us has a different run. 🌀

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