

**AMPUTEES FEDERATION OF
NEW ZEALAND INCORPORATED**

PURPOSE

**Newsletter of the
Amputees Federation of New Zealand Incorporated**



MARCH 2012

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GUEST EDITORIAL

No. 95 – March 2012

When I was being fitted for a replacement prosthesis at the Wellington Artificial Limb Centre back in November last year, I met a young man in his early twenties. He had recently lost his leg above the knee due to an accident involving a portable sawmill and was at the Limb Centre for his first assessment and obviously an introduction to a new way of life going forward. I was impressed with the way in which he was informed by a staff member of what he was going to be doing that day at the Limb Centre, the order in which it was going to happen, and who he was going to be seeing. I am sure he and his family would have really appreciated the information and the opportunity for any queries.

This approach by the staff today is a far cry from the “good old days” where new amputees were pretty much left to fend for themselves and it was left to the individual to find out these things for themselves. By and large we now live in a more caring society and there is a lot more thought put into the overall welfare of new amputees as they face their new challenges.

This same young man, who coincidentally comes from Taranaki like myself, seemed to me to have a really positive attitude towards his new circumstances. While he was waiting, he had the opportunity to have a really good discussion with another two AK amputees who were a little older than him. I was really impressed with the “can do” attitude of these two older guys and I’m sure that the young man would have taken on board an awful lot of information that will be of great benefit to him in the long run.

To sum up, the point I am making is that there is nothing like peer support from people who are in a very similar position to yourself. These people can relate to your issues. After all, the problems to overcome for an AK amputee are far more complex than those for a BK amputee. Therefore, talking to another person who has the same type of amputation should be more beneficial. That is one of the really great attributes of our various district Amputee Societies where you will be sure to find someone who can offer meaningful advice.

Wally Garrett
President

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and click on our name to LIKE us!**

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NEWS FROM THE REGIONS

Auckland & Northland - About 30 amputees and supporters turned up to their 66th AGM on Sunday 12 February, including a large number of first-timers. The Auckland Limb Centre played a valuable part in this influx as they sent out 848 letters advertising the meeting to amputees in the Auckland region. As a result, the Society now has some new Committee members.

Waikato, Bay of Plenty & Districts - Their membership continues to grow, although they would love to see more members at their luncheons. Field Officer Kerry continues to support the amputees in the wide area they cover and they had a good response to their request for volunteers to provide assistance with this visiting.

Hawke's Bay/East Coast - An enthusiastic committee is busy with preparations for hosting the large number of attendees expected at the conference in Napier on 23-25 March.

Taranaki - President Chris is representing the Society on the Taranaki DHB Disability Action Group, a current task of which is the provision of disability parking at the new hospital.

Manawatu - A good sized committee was elected at their AGM on 19 February and they are all looking forward to catching up with friends at the Napier conference.

Greater Wellington Region - Everything's ticking along smoothly with our newest Society and we look forward to some of them joining us in Napier.

Nelson & Marlborough - The new support group for amputees is proving successful, with the last meeting having a psychologist as guest speaker. The focus at present is on establishing a positive link with Blenheim and Picton members.

Canterbury & Westland - Ava advises that she will be resigning from her position as Secretary at their AGM but will carry on as Treasurer and Total Mobility assessor. The shaking continues in Christchurch and some members have had to relocate.

Otago & Southland - An optometrist was guest speaker at their 68th AGM and gave an interesting talk on “Fred Hollows and his Foundation”. As with other Societies, a large contingent was expected to attend the Napier conference.

Newsletters of District Societies are available to readers on the Federation's website (www.af.org.nz), along with plenty of other useful information.

**SUPPORT YOUR DISTRICT AMPUTEE SOCIETY
IT SUPPORTS YOU!**

LETTER TO THE EDITOR

LThe article on “Finding Your Pathway” in the November issue of Purpose has prompted this response from a reader:

I lost both legs in an accident 55 years ago. At the time I was serving in the armed forces, was married and had a 3 year old daughter. I won't go into the recovery details etc, as every person goes through similar things. However, I was fortunate enough to meet Douglas Bader whilst I was recovering and before I received prosthetics. A sound piece of advice he gave me was “learn to walk without using supports of any nature” so I did. I served a further 10 years in the military during which I returned to night school and obtained a degree. When I left the military I obtained first of all a position in education, then changed to trade and industry, and ended up as executive managing director of a NZ wide company. This necessitated travel overseas and believe me I was glad that I had taken the advice to learn to walk without aids. I could travel with a briefcase in one hand and a suitcase in the other. Those amputees who are prepared to adapt can do anything that other people are capable of. If they can no longer play football okay, take up golf or bowls. I have played them both. I have also selected and coached representative teams in one of my former pursuits (after receiving prosthetics.) Losing a limb/s is perhaps a setback in one direction but there are lots of directions to take in this world. Just choose one and follow your new dream.

Sgd. Anon

(Any responses to this? Ed.)

PUBLICATIONS - These are available (at no cost) from the National Coordinator or District Society Secretaries

A New Challenge - Advice for New Amputees (a 32 page booklet)

An Ongoing Challenge - A 60 page publication which covers a wide range of topics and includes personal profiles of 10 amputees.

A Challenge with Purpose – A History of the first 50 years of the Amputees Federation of NZ Incorporated (275 pages)

The Amputee Society of Otago & Southland Inc. –The first 60 years (146 pages)

*A hole in the sole of your boot is a better sign of industry
than a shiny patch on the seat of your pants*

MOTIVATION by Kim McNamara

MHi, my name is Kim McNamara and I am a Motivation/Life coach. My late father was an amputee for 23 years, losing his lower leg due to diabetes complications and later becoming a double leg amputee a week before his death. I was very close to my dad, and although not an amputee myself, I can understand the challenges mentally and physically you can face when losing a limb. My dad was an inspiration in himself, his theory was “that's life, lets make the best of what we have now”.

I am delighted to write a motivational piece for the Amputees Federation and thought I might share a goal setting technique that was taught to me many years ago. Firstly when we have something in front of us that we need to achieve, we think what actually is the GOAL? What is it I am wanting to achieve? It might be getting out for the first time after becoming an amputee. The second part is, what is the REALITY of the situation we are facing? So if it is the first outing, what do I need to achieve this? Who do I need to help me out? Remember when asking for help, be specific; communication easily breaks down when we think people automatically know what we need. What material things might I need to make this outing easier? The third part is OPTIONS. Brainstorm as many options as you can think of to make this goal achievable. The last part of the technique is WAY FORWARD. Which one of those options is the best to move towards my goal? There might be several, but one might stick out more than others. Then go for it.

Being an amputee must be hard, but you are still the same person you were before. Try to find a positive out of a negative. If you wake up and think it's raining, it's cold and I feel awful, it's going to be an awful day, then that is more than likely what will happen. Sometimes reframing the situation we are in can be helpful. So try taking a positive approach. It's cold and raining but I am going to make an effort and go out; who knows what pleasure you might have.

I am happy to offer any amputee a free coaching session. This session can be around the trauma of losing a limb, moving forward, motivation, dealing with feelings, dealing with families or any issues that come about. Email me at kim.motv8ncoach@ihug.co.nz or 0274 249-956.

Take care, be positive and keep smiling.

AT the time of preparing this issue of Purpose the Federation's website is in the process of being upgraded and rebuilt.

Check it out on www.af.org.nz and tell us what you think!

ISPO 2011

In November last year, the Annual Scientific Meeting of the International Society for Prosthetics and Orthotics (ISPO) was held in Sydney, Australia. This year's theme was the Psychosocial Impact of Disability and Limb Loss. The following two articles are reprinted from Amputee Journal Vol.24 No.4. The first is by amputee Deb Roach.

To kick proceedings off, there was a brief address from 13 year old Jake Widjaya, who, like myself, was born with limb difference. He started campaigning for limb difference awareness at age 9 and released a DVD called my special hand that focuses both on his childhood experiences as well as advice for parents and peers of children experiencing limb difference. As someone who has shared in Jake's experiences, I think his courage is remarkable and I'm both extremely proud of him as well as grateful for his accomplishments in generating awareness and of his chosen direction and attitude. Then it was over to Pamela Gallagher for her keynote address. Pamela travelled all the way from Dublin Ireland to share with us her insight into the world of the Psychosocial Impact of Disability and Limb Loss - right after talking to us about the rugby! Pam's address focused on the issues we experience as amputees, especially our psychological wellbeing, body image and goal engagement, and how the clinicians who care for us can do a better job by understanding what the issues are and how to better respond to them. The study she is involved with is centred around improving our quality of life and breeding resilience and positive outcomes. She presented us with some alarming statistics - her studies indicate that between 20 and 40% of amputees have indicators for depression. She then outlined the complex challenges an amputee faces and which impact our adjustment. The most positive and profound insights Pam shared with us were about self-worth and acceptance. Our self-worth, not just as amputees but as human beings, is established by overcoming the challenges that life presents to us. This is how we achieve psychological growth. Days come and days go, regardless of whether they are "good" or "bad", and resilience is the ability to forge ahead with that very fact in mind. She asked if acceptance was always appropriate. It isn't! There are situations in which we are entitled to be angry. There are situations in which anger will spark action and this action will result in a positive outcome. Just look back at how segregation came to an end, how women won the right to vote, etc. We don't have to accept disability as a sentence to misery or a limited life. It is what we choose to make it. Pam talked about the importance of goals and how necessary they are to enable us to experience purpose, fulfilment and ultimately happiness. I was interested to learn of two different variations of goal setting - one being Tenacious Goal Pursuit, where we modify our own behaviour and lifestyle to fit our goals, and the other being Flexible Goal Adjustment, where we adjust our goals to suit the situation. Both methods were shown to reduce depressive symptoms and improve perceived quality of life. It beckons the question: What are you working towards??

After morning tea, it was over to Sydney based Psychologist Chris Basten to talk to us about Responding to the Emotional Needs of Amputees. His focus was on how occupational therapists, physios and other therapists including psychologists and psychiatrists, can best assist amputees cope with the task of adaptation. He talked about the emotional problems commonly experienced by amputees, such as depression, anxiety and PTSD, and ways to both identify and address these issues. He explained the importance of a positive attitude, optimism and accepting responsibility for ensuring your own positive outcome - as well as accepting that it's perfectly OK to need help, to do so and reach out to your support network, which could be friends and family, a psychologist, or the Amputee Society's peer support network. He talked about how important it is for amputees to focus on your strengths and find ways to increase your confidence, as well as the tremendously important role of goal setting and achievement in leading fulfilling and rewarding lives. I can definitely vouch for that being true!

Right after Chris, I was delighted to hear the findings of the lovely Sarah Eskandari's PHD, which examines Body Image as an Important Factor for Adjustment to Amputation. Sarah's study surveyed 218 amputees and supported an alarming statistic: that while 5-8% of the general population experience depression, the condition affects between 20-30% of amputees. Those who viewed their bodies negatively subsequent to amputation reported more symptoms of depression and anxiety, as well as a poorer perceived quality of life. We then heard from Andrew Steele of Body Care Solutions (Melbourne), who outlined to us a case study in which elective amputation resulted in exceptionally positive outcomes. The goal of his message was to prompt the medical faculty to consider amputation as a valid treatment option which is not limited to negative psychosocial impacts. Weighing up the pros and cons of amputation versus reconstruction was enlightening.

Lastly, Carla Negri from Ossur Asia-Pacific (Sydney) presented a review of the Psychological Benefits Associated with Physical Activity for Persons with Lower Limb Amputation. Like Sarah's presentation, the topic discussed by Carla was of special interest to me as an athlete and personal trainer focussed on wellness. My favourite article that Carla brought to our attention focused on investigating the relationship between participation in physical activity and body image in 56 lower limb amputees. The study highlighted a significant difference between the inactive group and the active group (who participated in a minimum of 2 hours aerobic activity weekly, in sessions no shorter than 20 minutes) and a positive relationship between physical activity level and body image - it's another good reason for us all to get out there and get moving! In a 1985 study, Valliant et al. found that physical activity for the disabled population can be an incentive to reshape their lives in a positive direction. Our focus needs not to be returning to our previous activity level: it should be achieving a

healthy activity level and a balanced lifestyle that accommodates our physical condition, whatever it may be. There's ALWAYS a way to work up a sweat - and improve proprioception, confidence and coordination which are just a few of the reasons we should want to.

I loved sitting in on the ISPO conference and wish I could have been at the symposium the day before. There is always next year though! It was such a valuable experience, which I hope I have been able to pass on and share with you in some small way.

Summary of the Symposium on Phantom Limb Pain

by Dr Lee Laycock BMed DCCH FAFRM (RACP)

The organisers of the ISPO congress were very supportive of the phantom limb pain meeting, which had a great deal of relevance to amputees and to health professions involved in their care. It was a very interested audience of 70 people. This was split fairly evenly between amputees and health professionals. The make-up of the audience signified the importance of the topic to many amputees. A number of amputees present were actually representing a larger group of amputees in their role within some of the smaller and more regional amputee groups.

Prof Phil Siddall was the first speaker and he provided a background to this issue and spoke of definitions and terminology. He also introduced the concept of amputee pain, which involves phantom limb pain, but also involves a number of the other pains that an amputee may experience. He also spoke of the relationship that phantom limb pain has with other known pain processes which have a neuropathic ("nerve problem") origin. The critical role of the brain in our perception of pain was emphasized.

Prof Lorimer Moseley (Professor of Clinical Neurosciences and Chair in Physiotherapy at the University of South Australia) was the second speaker. He has a fairly unique experience with physiotherapy at an academic and professional level, but also neural research. He is an acknowledged and successful researcher in this area. He introduced the concepts of neural networks and neuromodulation, functional neuroplasticity, facilitation, disinhibition and brain training (including the Pinocchio Effect and graded motor imagery) and where they fit into the pain picture.

Dr Chris Hayes (Director of Hunter Integrated Pain Service) was the third speaker. In his years working as an anaesthetist and a pain specialist, he has become more convinced of the need for a holistic approach to the management of chronic pain. He has an interest in neuropathic pain and was able to talk about specific strategies that can assist people with generic chronic pain problems, but also with specific neuropathic pain, not unlike that which people with phantom limb pain may experience. The limited role that medications and surgery have in chronic pain management was mentioned. The panel discussion provided a good opportunity for interaction between the three invited speakers and the audience.

There were no simple answers that came from the meeting for particular problems that people had. It was my feeling that the majority of people were not expecting those, but were pleased with being presented with an update of where research has brought pain specialists and a direction into future research may assist people with phantom limb pain. It is always likely that a tailored and composite approach to the management of people with phantom limb pain will be needed. A referral by an amputee's GP (or specialist) to a chronic pain service may assist in the management of phantom limb pain that remains a problem after first line treatment strategies.

(Wouldn't it be great if we had the opportunity in NZ to attend a similar meeting with such interesting speakers? Food for thought! Ed.)

KEEPING IT IN THE FAMILY

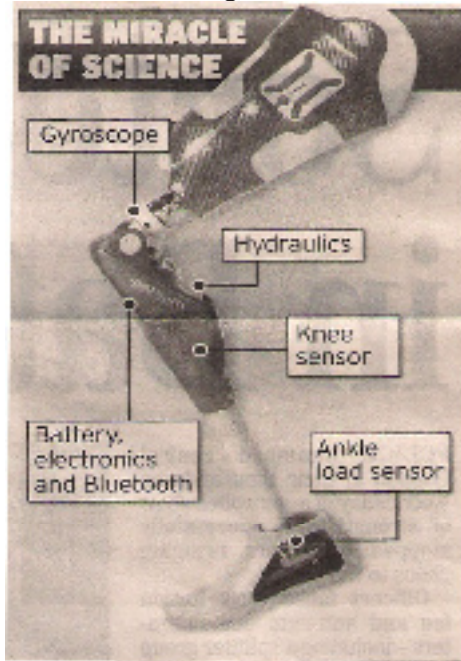


Kerry Wilfred-Riley
(Bilateral amputee, NZALB Board Member and Field Officer for Waikato Society)
with amputee family members, Charlie and Leo

A GIANT LEAP: THE FIRST BRITON TO GET A BIONIC LEG

Reprinted from International Express November 15, 2011

A property developer left unable to walk after a road crash has become the first Briton to be fitted with the world's most advanced bionic leg. Amputee Matthew Newbury can now climb scaffolding and cycle thanks to revolutionary medical technology. He has been fitted with a Genium prosthetic leg, the first in a new generation of "intelligent" bionic limbs that allows amputees to move with "greater precision and response". Makers Otto Bock Healthcare claim that the micro-processor operated system, which launched last week in the UK, can transform patients' quality of life. Mr Newbury's left leg was amputated after a motorbike he was a passenger on was hit by a Land Rover when he was aged 15. The 30-year-old from London spent more than 18 months in hospitals and rehabilitation centres and needed 11 skin grafts as doctors battled to save his right leg. He claims his life



has been changed thanks to his new limb, which allows him to walk backwards, tackle rough terrain and stand for long periods with his knee locked, which was previously impossible. A trained pilot, it also allows him to enjoy his hobby flying a Beechcraft Baron twin-engine aircraft. But it has not come cheap at a cost of £50,000, including fitting and six years warranty and servicing. Mr Newbury said: "The new Genium has completely changed the way I live my life and has provided me with the confidence to attempt things that I had thought were beyond me. "With previous prosthetics, I was constantly aware and cautious of their limitations - you need to think about every step. With Genium, it does all the thinking for me.

HOLIDAYING IN AUSTRALIA and needing a modified and/or wheelchair accessible vehicle for touring around? Check out *Disability Hire Vehicles* on their website www.disabilityhire.com.au

HELP US TO HELP OTHERS

Just one paragraph in your Will can help us to assist other amputees:

*"I give and bequeath to the
Amputees Federation of New Zealand Incorporated
the sum of"*

Thank you for your support. We are dependent on your goodwill and donations.

LATEST NEWS FROM PARALYMPICS NZ

Amputee Achievements

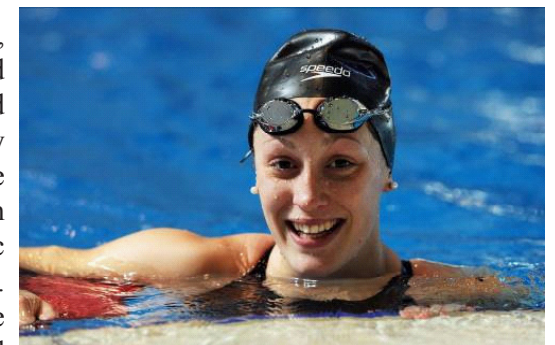
Paracycling Track World Championships, Los Angeles, Feb 2012



Riding in the men's C5 kilo, Chris Ross, who has been cycling for only 2.5 years, was looking to improve on his 12th placing at last year's world championships. Chris was the 9th of 19 riders to race and posted a time of 1.10.555. From there, Chris had to watch the following 10 riders to know what his final placing would be. With many of the world's top riders to come, expectations were

that a top 10 finish would be a credible performance, however Chris's time was too superior for some and the young kiwi finished fifth overall, a superb performance considering his time in the sport.

In this year's **Halberg Awards**, swimmer Sophie Pascoe was named the inaugural winner of the disabled sportsperson of the year. In the newly introduced category, Pascoe won the award for winning two gold medals in world record time at the Pan Pacific Para Swimming Championships. Pascoe said she was honoured to be the first ever recipient of the disabled



award, emphasising its importance to New Zealanders' outlook on sport. "I'm very humbled but this award means more than just my achievements, it's about recognising Paralympic sport," Pascoe said.

(Photos by Paralympics NZ)

SELF ESTEEM ISSUES: Isolation, Alienation and Loneliness

Excerpts from "Coping with Limb Loss," a practical guide to living with amputation for you and your family, by Ellen Winchell, PhD.

No-one could have gone through my surgeries or the gruelling physical therapy sessions for me. No one could have relearned to walk for me, or make the emotional adjustments that I needed to get on with my life. Despite the fact that I was blessed with a loving family and friends who rooted for me and encouraged me, I felt isolated, burdened, and very much alone. These feelings of isolation cause you to feel cut off from fellow human beings and those who care for you. Help yourself through this period of isolation by doing the following:

- Recognize destructive self-talk. What are you telling yourself about the "way things are" that is causing you to feel alienated from others? You may, for example, be distorting reality – making things worse than they really are. Correct yourself, then replace the negative self-talk with more positive thoughts and encouragement.
- Recognize destructive self-talk. What are you telling yourself about the "way things are" that is causing you to feel alienated from others? You may, for example, be distorting reality – making things worse than they really are. Correct yourself, then replace the negative self-talk with more positive thoughts.
- Recognize your human need for connection with others and reach out. Examine what you feel you are lacking – friendship, someone to care about you, intimacy, etc. Let your friends and family know what it is you need. Spend time with loved ones and those who care for you. Even if they do not know exactly what you are experiencing, their love and caring should nurture your spirit.

- Do what nurtures you. You know what best soothes your soul. Stay active. Laugh. Play. Get plenty of rest. Do something to contribute to others.

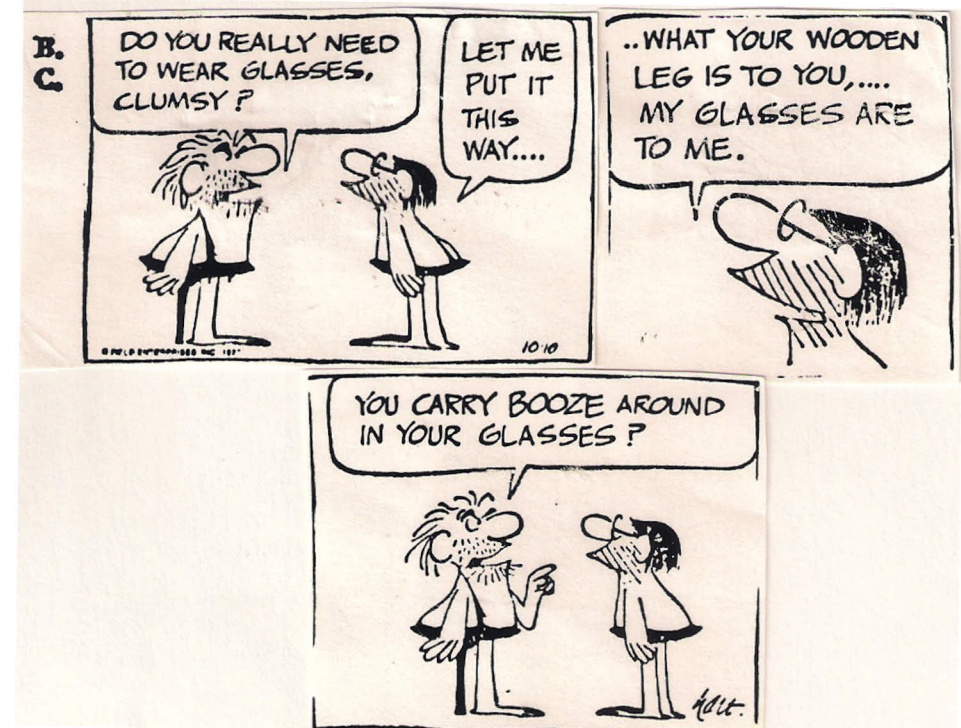
While it is true that no one can step inside you and experience exactly what you are going through following the trauma of amputation, you need not feel alone. By opening yourself to the empathy and compassion of others, you will feel nurtured during this difficult time. So reach out to others, and allow them to reach out to you.

The question: How can the well-meaning people in your life help you if they do not know how? The answer: You have to help guide them. Remember, this is a new experience for them as well as it is for you. Let them know that their loving presence can, in itself, be a comfort and support. Offering advice or trying to "fix" your situation is not necessary. What they can do is offer an empathetic ear when you wish to express yourself. This will help you validate your feelings. Their acceptance of your amputation can be tremendously reaffirming when you discover that they treat you as the same person you were before your limb loss.

You must be vocal in letting others know what they can do to be supportive. Perhaps you would like more quiet time for yourself, or a hand with some household responsibilities. Whatever your desires – and they will be different for each individual – be sure to express them. Your friends and family will welcome your guidance in telling them how they can help.

THE WAY OF THE SEA

A sailor met a pirate in the bar and they took turns recounting their adventures at sea. Noting the pirate's peg-leg, hook, and eye patch, the sailor asked "So, how did you end up with the peg leg?" The pirate replied, "We was caught in a monster storm off the cape and a giant wave swept me overboard. Just as they was pullin' me out, a school of sharks appeared and one of 'em bit me leg off." "Blimey!" said the sailor. "What about the hook?" "Aahhh...." mused the pirate, "we were boardin' a trader ship, pistols blastin' and swords swingin' this way and that. In the fracas me hand got chopped off." "Zounds," remarked the sailor. "And how came ye by the eye patch?" "A seagull droppin' fell into me eye," answered the pirate. "You lost your eye to a seagull dropping?" the sailor asked incredulously. "Well...." said the pirate, ".... it was me first day with the hook!"



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**REMEMBER THAT YOU'RE NOT THE
FIRST PERSON TO HAVE LOST A LIMB -
MANY OTHERS HAVE PASSED ALONG
THE SAME ROUTE AND ACHIEVED
CONSPICUOUS SUCCESS.
IF YOU WISH TO DO THE SAME,
YOU ARE MORE THAN HALF-WAY THERE -
THE REMAINDER IS AS EASY OR AS
DIFFICULT AS YOU MAKE IT.**