

**AMPUTEES FEDERATION OF
NEW ZEALAND INCORPORATED**

PURPOSE

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



MARCH 2009

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GUEST EDITORIAL

No. 86 – March 2009

It is now about 3½ years since I assumed the role of Acting President which was subsequently changed to President when I was elected in 2006. As I will complete my term at the coming conference I find myself reflecting on the role of the Federation in the welfare and rehabilitation of amputees.

In 2006 the Federation published “An Ongoing Challenge” which follows from the initial shock of learning that amputation is necessary through to maximising the quality of life; providing up to date information on support and services available. The Federation also provides information via its website, www.af.org.nz, which has proved very successful with over 2,000 hits per month.

One of the concerns of the Executive has been problems that sometimes arise when an amputee is discharged from hospital. During 2008 progress has started to be made to ensure that in the future all amputees will have the essential services and facilities provided so that they can have a lifestyle commensurate with their abilities and circumstances. The Ministry of Health has agreed to fund the Federation to conduct training sessions/workshops. All District Health Boards have responded enthusiastically and sessions with them will commence early in 2009.

Another area of great interest to me is the development of prostheses. Until recently most of the hi tech prostheses were lower limb but recently an article in New Scientist (3 January 2009, p36) outlines the amazing advances with bionic arms. At present these hi-tech prostheses are very expensive and have high maintenance costs. However I am sure that, in the future, they will become available via the New Zealand Artificial Limb Board, which does a great service in providing prostheses pertinent to the requirements and ability of the amputee.

Finally, let me say I have enjoyed my term as President. I would like to express my sincere thanks to members of the Executive, and especially to Lorraine Peacock, for the support and guidance that they have given me during this time.

Bob Smith
President

NEWS FROM THE REGIONS

Auckland & Northland - The retirement function for Mr Geoff Lamb, Orthopaedic Surgeon, on 22 November was a huge success. The plaque presented to Mr Lamb was made from a handrail demolished at the old Limb Centre. More photos will be on display at their AGM and barbecue to be held on 8 March.



Waikato, Bay of Plenty & Districts - A Fun Day at the Hamilton Zoo will take place on 8 March. The day is organised by the Dinsdale Lions for those with disabilities, their families and caregivers.

Hawke's Bay/East Coast - No recent news from the Bay but we look forward to catching up with their representatives at the National Conference.

Taranaki - A well attended clinic was held early in November and a Christmas function at the Cobb & Co in New Plymouth was an enjoyable occasion, especially for the Hon. Pres. who managed to “snaffle the raffle”. They are on the lookout for a new Secretary as Lynnette will be taking on more volunteer work for another organisation.

Manawatu - They also had a successful Christmas lunch at Cobb & Co. and their AGM was to take place on 22 February.

Wellington Regions & Wairarapa - 22 February was also the date scheduled for their AGM. A warm welcome to their new Secretary, Sue Collins.

Nelson & Marlborough - Guest speaker at their AGM was member Amy Hindley (see page 4). Their Society will be one of more than 80 which will be having a display at the Blenheim Seniors Expo on 25 March. And a reminder to members that they have mobility scooters available for loan.

Canterbury & Westland - The Christmas function was well attended and enjoyed by all. The sessions at Burwood Pool have a regular attendance of enthusiastic members. And a mid-winter Christmas function is planned for July.

Otago & Southland – A large turnout of members was expected for a function on 28 February for George Mitchell who retired last year as Manager of the Dunedin Limb Centre and General Manager of the NZ Artificial Limb Board. George will be greatly missed by amputees in the south. Their AGM and dinner was to follow.

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

SUPPORT YOUR DISTRICT AMPUTEE SOCIETY
IT SUPPORTS YOU

ATTITUDE IS EVERYTHING (Reprinted with permission from the Taranaki News 1 January 2009)



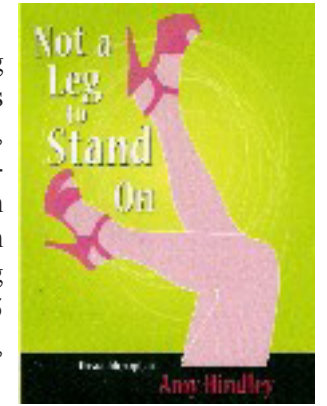
Double amputee Ben Hekenui is the first Taranaki Daily News Person of the Year because of his courage, tenacity and humour following an horrific life-changing accident. But the man himself says these qualities come from his family and gifts to them the honour of the award. "It's all part of you guys. If it wasn't part of you I wouldn't be here," he says to a group of 40 or so family staying with him at the Onaero campground where he was presented with the trophy yesterday. As the award is accepted, a group of men, including Mr Hekenui's two teenage sons, performed an impromptu haka in his honour. Despite the sweltering early morning heat, the performance clearly sent shivers of pride through the bare chested Mr Hekenui.

In April last year the 37-year-old's legs were amputated in a terrifying industrial accident at Taranaki Recyclers in New Plymouth. As a measure of his strength and temperament he was able to tell his colleagues to call an ambulance seconds after his legs were gone. In another testament to his positive nature, he began joking about his condition from his hospital bed less than 12 hours after his accident, asking his son Isaac to bring his shoes from home next time he visited. His partner of 20 years, Chrissy Brown, days later recalled the strength of her partner with tears in her eyes, laughing gently about the humour the man she loves has never lost. It is this attitude that has enabled Mr Hekenui to make such an incredible physical and psychological recovery. Released from hospital four weeks after the accident and fitted with prosthetic legs in October, there is no bitterness at the twist his life has taken, only desire to make the most of his new journey. "I'm just lucky, lucky to be here. And all the support I've been getting from my family is making me strive to do really good. " I get a lot of people coming up to me on the street too and saying 'Good one, mate. You're doing great' and that makes me want to do all I can for them too," he says.

At this stage he is striving for the 2012 Paralympics in London. Though as yet undecided on what sport he wants to represent his country in, his natural athleticism means he could choose almost any. A keen rugby league and rugby player, he was playing just two weeks before his accident. Though he never made it into the Kiwis team as he once hoped, in the early stages of his career he looked a certainty. At 16 he was playing premiere grade league for Kia Ora in Palmerston North. He also spent time with the Manawatu Mustangs and the Central Falcons playing in 12 grand finals over his 20-

year playing career. Four times he was in the winning team, the memory of which he clearly treasures. "I guess I could play rugby or anything on the track once I've got used to using my legs. Maybe I could do weightlifting but there are some really big guys out there." Not that he is small. And with all the arm strength his wheelchair requires, his muscles are only likely to grow. Just as his ability to cope will grow. "It gets me down sometimes when I need someone to take me somewhere but for most things I can sit there and think about how to do something and generally come up with three ways for doing it. Then I pick the easiest way," he laughs. With a long way to go on the road to recovery, the presence of his two sons Isaac, 15, and Anthony, 19, his beloved partner Chrissy and being part of the 2009 Marist Dragons coaching team are likely to keep him on track. "You know you can't give in, mate. You don't chuck it in that easily because there is always light at the end of the tunnel."

NOT A LEG TO STAND ON by Amy Hindley
Born with spina bifida, Amy has been a double leg amputee since the age of 18. Her childhood experiences - being abandoned by her parents, deprived of education, and the subject of ongoing medical "experiments" - could well have made her bitter, but she proves what can be achieved by force of character and the determination to lead a full life. The book is an engrossing, inspiring and surprisingly humorous read. It costs \$40 plus \$5 p&p and can be ordered from Amy at 47 Bisley Avenue, Tahunanui, Nelson 7011.



LETTERS TO THE EDITOR and any other contributions to *Purpose* are very welcome. If you have anything to share with readers, please send it to the Editor at 213A Bay View Road, St Clair, Dunedin, fax to (03) 455-9547 or email to lorrstan@xtra.co.nz. Personal profiles in particular are always appreciated - as a guide, these should consist of approximately 400-500 words and include a photo.

VISIT the Federation's website at www.af.org.nz It contains a wealth of useful information and "visitors" to the site number around 3,000 every month.

NATIONAL CONFERENCE - This will be held at the Brentwood Hotel in Wellington, on 20-22 March. The National Council meeting will be held on the Saturday morning and the remainder of the weekend will be taken up with a variety of interesting speakers, including Paralympians Kate Horan and Paula Tesoriero. If you would like to join in, further information and registration forms are available from your District Society Secretary or the National Coordinator.

TRAVEL TO LIMB CENTRES

As a result of a meeting last year between members of the National Executive and Ruth Dyson, the previous Minister of Disability Issues, Work & Income has made policy changes which enable amputees attending Limb Centres from out-of-town to claim expenses prior to the Limb Centre appointment. The following notes cover the types of assistance available.

What you can claim

You can claim for travel in a **private car** either by mileage or petrol costs if a receipt is produced (but this should not be more than mileage). The amount paid per kilometre depends on the cc rating of the vehicle. You can claim for travel by **public transport** to and from the Limb Centre. You can claim for the cost of travelling by **taxi** to a Limb Centre where a receipt is produced and you are not physically able to use public transport. Note that when a mobility taxi is used and you have received a 50% reduction in fare, only the remaining 50% is reimbursed. You may claim for the cost of **air travel** where there is written evidence that this is the most appropriate form of travel (such as a letter from an orthopaedic surgeon or Manager of the Limb Centre).

You can claim for **accommodation** costs if your appointment time or the distance travelled means that an overnight stay is necessary. The actual cost of accommodation or \$100, whichever is the lower, may be paid. Accommodation and meal costs incurred will not be paid for more than ten days per assessment. You can be paid for the cost of each meal required during travel times and overnight stays when attending a Limb Centre. The actual cost of the meal or \$13.05, whichever is the lower, may be paid. If applying for assistance in advance, you must provide confirmation of the accommodation booking and details of the cost.

Assistance can be granted to cover the costs of one **attendant** if the person travelling to the Limb Centre is a child aged under 15 years or medical evidence is provided stating that the person cannot travel by themselves. The loss of earnings of an attendant cannot be reimbursed.

Payment for **loss of earnings** may be made only where you do not have any sick leave available. You must provide a letter from your employer confirming you have no sick leave available and stating the wages (net) lost. Reimbursement must not be more than the current rate paid for ordinary time weekly wage. Overtime or penal rates cannot be reimbursed.

How to apply

For payment before your appointment, you must provide:

- confirmation of your appointment date and time at the Limb Centre; and
- quotes or estimates, and

- confirmation of any loss of earnings from your employer if you don't have sick leave available.

Work & Income can grant you the financial assistance you're entitled to from the date you first contact them if you complete your application within 20 working days of that date.

You can apply to have your costs reimbursed if the amount you were paid in advance did not meet all your costs, or you chose not to be paid before your appointment. You need to

- claim your costs within six months of attendance at the Limb Centre; and provide proof of your attendance at the Limb Centre; and
- provide receipts of your costs; and
- provide confirmation of any loss of earnings from your employer if you don't have sick leave available.

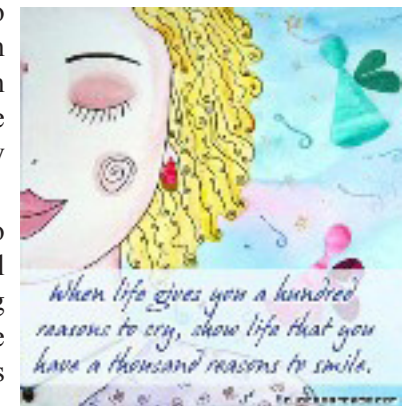
CAREGIVERS NEED HELP TOO!

(A contribution from Michelle Simpson, Nelson & Marlborough Society)

When someone in your family becomes an amputee they and their family will have feelings of loss. Those with an amputation not only have to adjust to the loss of a part of their bodies, but also the loss of abilities that were a normal part of daily living. New ways to do things have to be learned, and the process of rehabilitation may be long and difficult. There are many health care professionals - surgeons, physios, limb centre staff - focused on assisting the amputee, but the caregiver (who suffers along with their loved one) is often neglected.

You are firstly still a wife, husband or partner, son or daughter, brother or sister, to your family member, but you are now also an amputee caregiver. You too suffer your own sense of loss and may have trouble coping with the changes in your life due to the stress and the added responsibilities of caring for your family member.

The Amputee Society in your area is there to assist those who care for an amputee. You will have an opportunity to talk to others going through similar experiences to you. You will be able to express your feelings, share experiences and receive much needed emotional support.



OVERCOMING BACK PAIN by Jordan Ritter-Soronen, PT, DPT *Reprinted with permission from The Amputee Coalition of America*

Back pain can come in many forms, and its severity can vary greatly as well, but even the most minor back pain can slow you down and alter your normal functioning. The causes and treatment of back pain also vary greatly, but these are things that you can try, to start taking control of your pain. This article will explain ways you may be able to reduce your back pain. If your back doesn't hurt, some of these suggestions should help keep it that way.

First and most important, back pain can be a sign of a more serious medical condition. If any of the following symptoms are associated with your back pain, speak with your doctor right away:

- Pain that is not getting better or is getting worse
- Pain that wakes you up at night
- Unexplained changes in weight
- Changes in your bowel or bladder control
- New, significant weakness in your legs

Prosthesis Fixes - Some treatments for back pain are prosthesis related. First, work with a therapist and/or prosthetist to make sure that your prosthesis fits and is adjusted correctly, especially if you have not worked with a therapist for a while. A lower-extremity prosthesis that fits incorrectly may cause you to walk incorrectly, which may contribute to your back pain. If your prosthesis is adjusted correctly, make sure to work on your gait. Working with a therapist or prosthetist to analyze your walk can help you to detect and change any abnormal patterns that may cause your back pain. This is especially important if you are new to using a prosthesis. Bad habits are easy to develop, but sometimes very hard to break, so it's best to develop good habits and work to prevent problems before they start. These suggestions also apply if you use an upper-extremity prosthesis. A properly fitted, working prosthesis may help reduce upper-back or shoulder pain.

Weight Loss - Excess weight increases strain on your lower back and legs. Although it may not be easy, losing weight may help to decrease your back pain. Losing weight may also help to control other conditions, such as diabetes.

Adjusting Your Posture - Another cause or aggravating factor of lower-back pain may be incorrect posture. Make an effort to be aware of your normal posture. When you are sitting, especially for a long time, if you notice your shoulders are rounded, try to sit up taller by bringing your shoulders slightly back and tucking your chin slightly. A good way to find your best posture is to sit up as tall as you possibly can and then relax just slightly. The position that you relax into is the position you should try to sustain.

At first, you may find that this adjusted posture is hard to maintain for long, but don't worry; your muscles will get stronger. Begin by maintaining this position for short periods, then slowly increase how long you hold this posture. This exercise may be particularly important if you wear an upper-extremity prosthesis, because its weight may alter your posture and increase the strain on your lower back. You can also ask a therapist and trainer to analyze your sitting and standing postures to identify specific muscles to focus on.

Stretching and Strengthening - Stretching and strengthening exercises that target specific muscles may help with your back pain. Before starting any new exercise programme, consult your doctor or other medical professional. Also, if any of the following exercises increase your pain, stop immediately and talk to your healthcare professional. Ease into these exercises slowly; your body needs time to adjust to a new routine.

Stretching your muscles can help to keep your body balanced and flexible, which may also help to decrease and prevent back pain. When doing these exercises, slowly move into the position until you feel a gentle, tolerable pull in the muscle you are stretching. Hold the pose for about 30 seconds and repeat on each side three times. Don't move into the stretching positions too quickly; this could damage your muscles. First, stretch your upper trapezius muscle. This is one of the muscles that runs up the side of your neck. For this stretch, you may stand or sit. If you are sitting, make sure that you are sitting with a straight posture. Then, bend your neck to one side as though you were trying to touch your ear



to your shoulder. Keep looking forward, and do not turn your neck. Once you feel a pull along the side of your neck, hold that position. Next, stretch your pectoral (chest) muscles. While not part of your back, these muscles may be tight and contributing to a slouched posture. Using an upper-extremity prosthesis, an assistive walking device or a wheelchair could cause tightness in these muscles. For this exercise, stand or sit next to a doorframe. Place one forearm flat against the doorframe slightly below shoulder level. Turn your body away from your arm until you feel a gentle pull in your chest. Next comes a stretch for the lower-back muscles. Lie on your back and slowly bring your bent knee up to your chest. You should feel a gentle pull in your lower back. As you do this, do not allow your hips to rise as your leg moves. You can also bend your knees up toward your chest and let your legs drop slowly to one side, keeping your back as flat as possible. Again, you should feel a slight stretch in your lower back and hip muscles.

Your hamstring muscles are the large group of muscles that run along the back of your thighs. There are several ways to stretch these muscles, so choose whichever feels most comfortable.

- Lie on your back and bring your knee up toward your chest, then slowly straighten your knee until you feel a pull along the back of your thigh.
- Sit with your legs straight out in front of you; then, slowly lean your body forward until you feel your hamstrings stretching.
- Stand near something sturdy that you can lean on for balance. Place your leg on a raised surface (a step stool, a chair, a step on a staircase or a similar surface), then lean your upper body forward slowly until you feel your hamstrings stretching.

To strengthen specific back, shoulder and abdominal muscles, you can also do some exercises with the following points in mind:

- Start with two or three sets of 10 repetitions. As you get stronger and feel more comfortable with the exercise, increase the repetitions up to three sets of 15.
- Take breaks when you need them. This will help to ensure that your repetitions will be close to the best they can be.
- Do not hold your breath while exercising. To avoid holding your breath, breathe out during the hardest part of an exercise.
- Do all of these exercises slowly; completing the exercises quickly will not work your muscles as hard.

The first exercise is for some muscles between your shoulder blades in your upper back. These muscles are important for keeping proper posture and are often under-exercised. To do this exercise, sit with good posture and your feet flat on the floor. Then, squeeze your shoulder blades together and down; your chest should stick up and out. Do not let your shoulders hunch up toward your ears. Once you have achieved this position, hold for 5 seconds, then relax.

An easy exercise for your lower back and abdominal muscles is called a pelvic tilt. Start by lying on your back with your knees bent up and your feet flat on the surface you are on. In this position, you may notice a slight curve in your lower back; you are going to work to flatten this curve. Tuck in your stomach muscles, and pull in your bellybutton. This movement should gently rock your pelvis backward and flatten the curve in your back. By doing this, you are working your core muscles, the layers of muscles that run around your back and abdomen. Hold this position for 5 seconds, then gently release. Once you have achieved your pelvic tilt, you can add movements, such as raising one or both arms above your head or sliding your heel up and down the surface you are on.



Maintain your pelvic tilt when you move your arms or legs. As you begin to understand how your core muscles work, start working them into your daily activities. Try tensing those same muscles when you are sitting in the car, at the dinner table, or standing in line at the grocery store. The more you use them, the better. A stronger core may help with back pain and also helps the rest of your body work more efficiently.

Once you get stronger, you can choose many more exercises to work on your core muscles. Work with your therapist or a trainer to take your exercise to the next level, so you can keep getting stronger.

10 STEPS TO REDUCE THE RISK OF INJURY

1. Be sure that your prosthesis fits comfortably at all times.
2. Be sure that your prosthesis and sound limb are of equal height; avoid having your prosthesis shortened.
3. Walk with an equal width of walking base and don't favour your sound leg.
4. Avoid hopping excessively on your sound limb when not using your prosthesis. Use crutches around the house when not wearing your prosthesis.
5. Stand with equal weight distributed between limbs; avoid favouring your sound limb.
6. Maintain good posture while sitting or standing.
7. If pain is present, use a walking stick to reduce excessive stress to the knee or back.
8. Maintain a nutritious diet and retain your appropriate body weight.
9. Exercise regularly, incorporating a strengthening, stretching and cardiovascular endurance programme, with your doctor's permission.
10. Maintain a regular appointment schedule with your doctor, prosthetist and physiotherapist.

(Reprinted from Amputee Journal, Spring 2008)

PUBLICATIONS available (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)

Note: The histories are free, even though they are advertised on Trade Me for varying amounts!

THE HEALTHY WHO THINK THEY SHOULD LOSE LIMBS

by Ruth Hill (*Reprinted with permission from the Dominion Post*)

Surgeons may have a duty to amputate healthy limbs if that is what patients want, an Australian psychiatrist says. Christopher Ryan, a senior lecturer at Sydney University's School of Medicine, says people with the rare Body Integrity Identity Disorder (BHD) could be cured by getting rid of unwanted body parts. Though able-bodied, sufferers believe they should be amputees and often resort to maiming themselves.

"I am not saying we should unthinkingly cut off people's legs," Dr Ryan said. "However, there are a small number of people who see themselves, and have always seen themselves, as amputees."

The origins of the condition were not known, he said, but it was probably due to a congenital brain abnormality. "We do know, though, that they are often miserable their whole lives because of their 'extra' limb, and we know that at least some of them feel much better if it is removed."

His paper, published in the international philosophy journal *Neuroethics*, suggests that after exhausting all other treatment options (such as psychotherapy and antidepressants), doctors could be duty-bound to offer "elective amputation" to stop patients taking matters into their own hands.

"A 30-year-old patient of mine eventually took the only step he thought he had open to him, and placed his leg in a bucket of dry ice until it died and had to be removed. Now, a year later, he is living happily as an amputee and getting on with his life."

Dr Ryan likened elective amputation to plastic surgery and cited the importance of patient choice. BHD sufferers could even be allowed to donate their unwanted limbs, he wrote.

In 2000 it was revealed that Scottish surgeon, Robert Smith, had amputated healthy legs from two patients with the disorder. At the time, Dr Smith said he operated to end his patients' suffering. "They may lie on a railroad line and get run over by a train. They use shotguns and shoot their limbs off. They really are a desperate bunch".

The head of orthopaedics at Otago University's Wellington School of Medicine, Geoffrey Horne, said he did not believe any New Zealand surgeons would consider elective amputation for a psychiatric problem. "It would present serious ethical issues for a surgeon because you are destroying a healthy limb and wrecking the patient's life. And what happens when the patient attains a 'normal' state of mind, whatever that is, and wants to know "Why did you cut my leg off?"

(UNBELIEVABLE!)

PHANTOM LIMB PAIN: THE INVISIBLE THIEF

by Brenda Murdough (*Reprinted from Amputee Journal Summer 2008*)

It varies in severity from mild to sharp, from an occasional stabbing pain to a severe burning, aching, excruciating pain, as though your body is being crushed in a vice or set on fire. It has confounded researchers and practitioners, and drained the emotional resources of individuals who have suffered this all-too-common occurrence. It is the experience of phantom limb pain.

Different from phantom limb sensation, in which an individual may experience the feeling that the amputated limb is still present, phantom limb pain can be perceived as a real, relentless pain experience involving the limb that is no longer there. It is estimated that between 50% and 80% of those who have had a limb amputated will also have phantom limb pain.

The actual cause of phantom pain is not fully understood, but most authorities agree that both phantom pain and other phantom sensations are generated from the central nervous system, which includes the spinal cord and brain. Nerve endings at the amputation site may continue to send signals to the brain, which are perceived as pain, so the mind continues to think the missing body part still exists. If the person suffered limb pain prior to amputation, the brain may "remember" the sensation. It is not an imagined pain. It is also possible that when a body part is amputated, the area of the brain responsible for perceiving sensation is affected by the trauma and, therefore, begins to function abnormally.

Phantom limb pain is not the same as residual limb pain, which can be caused by many factors, such as infection, a poorly fitted prosthesis, a bony growth or other problems at the amputation site. Persistent phantom limb pain often interferes with every aspect of people's lives, silently robbing them of their quality of life.

CONGRATULATIONS TO
PAULA TESORIERO
SOPHIE PASCOE
CAMERON LESLIE
ON THEIR AWARDS OF MNZM
IN THE NEW YEAR HONOURS
THOROUGHLY DESERVED!

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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.**