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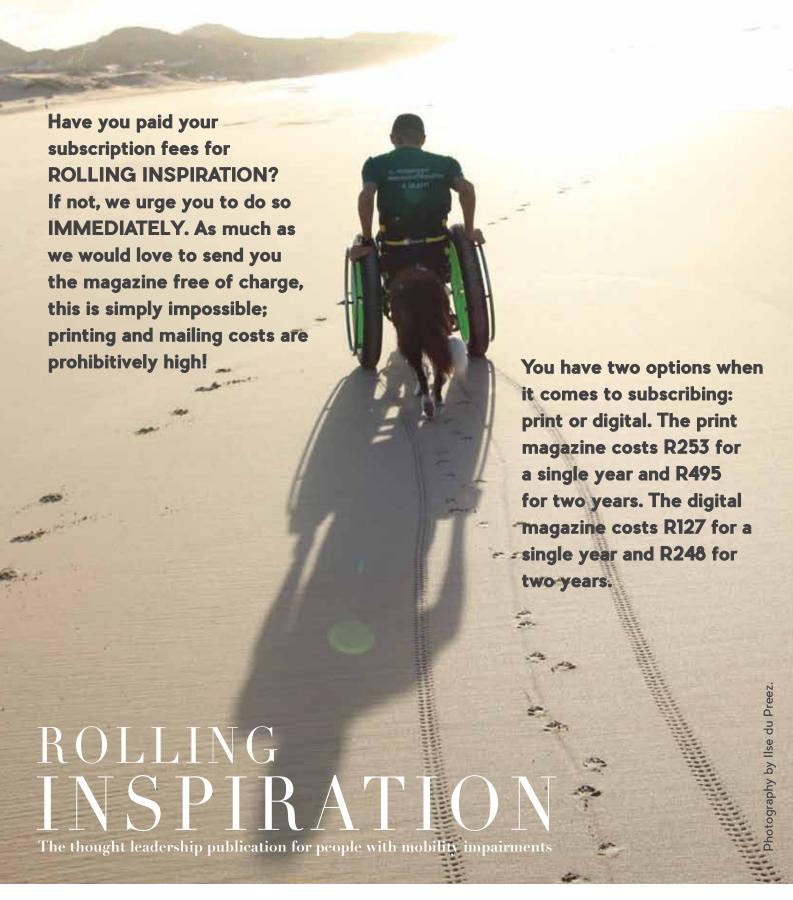
A necessary evil

"MY LIFE CHANGED DRASTICALLY, BUT FOR THE BETTER"

There is life after SCI

BUYING A
WHEELCHAIR FOR
THE FIRST TIME?
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ROLLING INSPIRATION

Published alternate monthly by Charmont Media Global Unit 17, Northcliff Office Park, 203 Beyers Naude Drive, Northcliff, 2195. P O Box 957, Fontainebleau, 2032, South Africa Tel: 011 782 1070 | Fax: 011 782 0360

MANAGING EDITOR

Ari Seirlis email: ceo@qasa.co.za

EDITOR

Charleen Clarke Cell: 083 601 0568 email: charleen@charmont.co.za

ASSISTANT EDITOR

Gavin Myers Cell: 072 877 1605 email: gavin@charmont.co.za

COPY EDITOR

Deborah Louw email: deborahlouw@telkomsa.net

JOURNALISTS

Anlerie de Wet Cell: 079 897 4338 email: anlerie@charmont.co.za

Mariska Morris Cell: 084 788 8399 email:mariska@charmont.co.za

PUBLISHER

Tina Monteiro Cell: 082 568 3181 email: tina@charmont.co.za

ADVERTISING SALES

Elsie van Wyk Cell: 072 827 2913 email: elsie@charmont.co.za

CIRCULATION MANAGER

Bev Rogers Cell: 078 230 5063 email: bev@charmont.co.za

DESIGN AND LAYOUT

Nelio da Silva email: nelio@charmont.co.za

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Cover Photo taken by Lee-Andra Schwagele.









BITTER TO SWEET

Despite an accident which left him with SCI, Ryan Madden's life has changed for the better. P4



ASSISTIVE DEVICES

The greatest minds in prosthetics and orthotics gathered in Cape Town for the ISPO World Congress.



NO INTEREST!

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Author Penny Metcalf explains how you can do it

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outh Africa's calendar is peppered with days of Religious commemoration. holidays and days with political significan<u>ce</u> usually are celebrated in the form of a public holiday. Freedom Day, April 27, marks the day on

which we had our first democratic elections 23 years

Does this make us a free country? Can we really talk about "freedom" while we're experiencing a pervasive sense of disquiet? I have difficulty in doing so. Don't get me wrong, I do not want to sound unpatriotic or suggest opposing the rule of law. But I want to point out that I do not feel free in my own country.

Why is this? People with disabilities are full citizens and therefore entitled to enjoy the rights and freedoms that everyone takes for granted. The rights of children with disabilities are guaranteed by international law and the South African Constitution, and the violation of these rights can therefore no longer be tolerated or defended.

The Constitution contains a number of rights that are relevant to children with disabilities. These rights to equality (section 9), to dignity (section 10) and to basic education (section 29) are very important. Section 28 also affirms the rights of children, including those with disabilities, to protection from maltreatment, neglect, abuse or degradation, and exploitative labour practices.

We (I include myself) should protect and nurture

our young in order for humankind to progress. When all possible laws have been passed and society has a workable consensus about issues such as the economy and climate, only then we will start really to feel freedom - the feeling that every member of society seeks, especially people with disability.

Full enjoyment by persons with disabilities of their human rights and fundamental freedoms will result in their enhanced sense of belonging and to their sense of contributing to significant advances in the human, social and economic development of society and the eradication of poverty. That is where we all want to be.

Now this is a very clear goal, but our frame of mind not only hampers us from reaching this goal, it terrifies us for our future. Because we cherish the notion of inclusion: remember nothing about us, without us. We need to be included in all spheres of society.

Inclusion is regarded as a universal human right and aims at embracing the diversity of all people irrespective of race, gender, disability or any other differences. It is about equal access and opportunities and eliminating discrimination and intolerance for all.

It is about a sense of belonging: feeling respected and valued for who you are; experiencing a level of supportive energy and commitment from others so that you can fully participate in society with no restrictions or limitations. Inclusion is the ultimate objective of mainstreaming. That will result in a genuine feeling of freedom. \mathbb{R}



Raven Benny is the vice chairperson of QASA. He has been a C5, 6 and 7 quadriplegic since 2000. He is married with five children, is mad about wheelchair rugby and represented South Africa in 2003 and 2005. He also plays for Maties. email: rbenny@pgwc.gov.za



MARCH #SOCIALROLLER

Samson Joseph is Rolling Inspiration's #SocialRoller of the Month for March. He got himself a nifty Smergos BBF wheelchair bag. "Thank you immensely for declaring me the March winner. It's a lovely bag indeed," says Joseph. YOU can become the next #SocialRoller and claim this amazing prize by simply clicking SHARE, LIKE, COMMENT or RETWEET on our Facebook (Rolling Inspiration Mag) and Twitter (@RollingMag) accounts!

QASA NAMED CHARITY FOR CONCOURS SA 2017

Concours South Africa, the national multibrand competition for classic cars, nominated the QuadPara Association of South Africa (QASA) as its beneficiary for the 2017 event, which will be hosted from August 3 at Sun City. The three-day event is expected to draw up to 150 of the country's finest classic cars.

Following the first competition last year, Chris Routledge, CEO of Coys of Kensington auction house, and Robert Coucher, editor of top classic car magazine *Octane*, will form part of the judging panel. Both are prominent figures in the world of classic cars.

"The Concours South Africa competition is a natural fit for our organisation. The partnership came about through our association with another motoring event, where we have enjoyed a lengthy and very rewarding association with some of the key Concours South Africa people," says QASA CEO Ari Seirlis.

During QASA's 14-year relationship with Ross Crichton as beneficiary of the Cannonball Run for Supercars, funds were used to invest in vehicles with hand controls to teach paraplegic and quadriplegic members to drive. Some of the funds were also used to promote road safety awareness through the campaign: Buckle Up, We Don't Want new Members.

"Our campaign encourages people to use their seat belts and not to use their mobile phones while driving," Seirlis notes. Concours South Africa's chief organiser Paul Kennard says QASA was a natural choice for the event.



Karen Key

on Radio

The DISABILITY REPORT

...tune in every first Tuesday of the month @ 21h05





Despite an accident which ended his career as civil engineer and dream of becoming a helicopter pilot, Ryan Madden tells MARISKA MORRIS that his life has changed for the better



yan rolls up to the step leading to the patio at Primi Piatti in Somerset West. Without a moment's hesitation, he swivels his chair back and hops down the large step to join his beautiful fiancée, Sune van Nieuwenhuyzen. Sune wasn't

kidding when she said Ryan was a very mobile person despite his impairment.

He joins the table, puts his leg on his knee, leans forward and explains that he can do most things without assistance. The only real challenge is going up a staircase, but even this challenge is no match for the power couple.

"I just pivot in my chair and she pulls me up," Ryan says. He demonstrates how easily he can manoeuvre his chair, tipping it backwards, holding the position for a few moments and then dropping back down. Sune jokingly comments that she needs to keep training so that she can pull him up a staircase.

Sune works as a personal trainer and spends most days at the gym. Ryan also practically lives in the gym. He trains for an hour and 40 minutes six days a week. Ryan has always had a love for sport, especially swimming. After his spinal cord injury, he decided to continue his participation in sport by training for triathlons. Since there are very few triathlon races for people with disabilities in South Africa, he raced against people without a mobility impairment.

"I've always participated against able-bodied

people and it's very different. The transitions are more difficult. When you get out of the dam somebody needs to assist you into your chair and push you to your bike, because of all the grass. I would cycle the same route, but the other contestants often run offroad. So, I am given another route," Ryan says.

It was during a series of training sessions that Ryan and Sune met in the pool of a local gym.

"She was racing to keep up with me," he says laughingly.

Now, however, the couple have taken up cycling. They are planning to participate in the Cape Town Cycle Tour in 2018. But before attempting that feat, they tied the knot with a small ceremony in May. There was, however, no dancing. While Ryan can do most things, he no longer feels comfortable dancing.

"Ryan used to love dancing and he misses it so much," Sune says. Ryan adds that he never goes onto a dance floor these days, because it looks "pathetic". Still, he remains positive and says that the only difference between him and a person without a mobility impairment is that he has wheels.

Eight years ago, Ryan was working in Ghana as a civil engineer. One Sunday, a motorist skipped a traffic light and collided with Ryan's motorcycle five minutes from his apartment. He was travelling 10 km/h.

"When driving that slowly, it is difficult to avoid a collision. I rolled over the roof and felt the aerial and I thought: 'What has she done? My bike is going to be buggered!""



Ryan hit the road, hips and legs first, which caused the damage to his spinal cord.

"Of course, you lie there in denial, thinking to yourself that the feeling will come back soon."

However, the feeling never came back. A private ambulance was arranged, which took Ryan to the military hospital – the best hospital in the country.

"The first time I realised it was serious, I was lying in the trauma centre and a nurse came and put a catheter in me. I couldn't feel the catheter."

The surgeon at the military hospital kept Ryan in Ghana because of the swelling in his legs. Finally, his company flew in two American surgeons, who operated on him. After a couple of weeks, he was flown to Cape Town. Ryan spent six months in rehabilitation and three month living with his parents, before he moved out on his own.

"Things happen for weird reasons. My wife and I were having problems. Then I had my accident and I decided I'd get divorced. I was still lying in the hospital and I said to my mother that I'll never find another girl, because I am in a wheelchair. My mom said: 'Ryan, you are going to learn that women aren't fickle.' And they are not," Ryan says. Five years later, he met Sune.

The accident meant that Ryan needed to give up a few of his dreams, including becoming a pilot. Yet he believes his life turned out for the better.

"Many people say ag shame. I appreciate that, but I could have been so much worse off. I don't have my legs. There are people who steer their wheelchair with their chins. My life has changed drastically, but for the better."

"I don't like to regard myself as disabled," Ryan notes. "I just kind of made my mind up when I came out of hospital that I was going to do the things I wanted to do." The couple often go on holiday with little thought about the accessibility of the destination.

"Often when you go to a new place and tell the owner, 'My other half is in a wheelchair,' they say, 'Oh no, it is not accessible.' But they don't understand. Not all wheelchair users are the same," Sune says.

"Some hotels have dedicated rooms for disabled people and I refuse to stay there. They have the worst view and they are just awful," Ryan adds.

Even Ryan and Sune's friends often forget he is a wheelchair user. Ryan always hoped that people would look beyond his chair, which seems to be the case

"Ryan's personality is bigger than life itself. You don't see his wheelchair. You feel inspired and admire him for the person he is and his positive outlook on life. He has a way of leaving footprints in every heart he meets, brightening and touching lives all around him," Sune says about her newly-wed husband.



Wheelchairs



Walkers



Scooters



and much more



The International Society for Prosthetics and Orthotics (ISPO) hosted its 16th World Congress in Cape Town in May, where professionals from the industry shared their knowledge on assistive devices

rofessionals and manufacturers from the world of prosthetics and orthotics gathered at the Town International Cape Convention Centre to showcase the best of the industry. ISPO South Africa chairperson Mike Barkley noted that it was the first time the ISPO World Congress had been held on

At the opening of the four-day event, Claude Tardif from the International Committee of the Red Cross emphasised the importance of improving access to mobility services and devices. He noted that "no-one is left behind" in an inclusive society, but that there were barriers to inclusivity.

the African continent.

"Not only the cost of the service, but also the cost of reaching the centre remains a challenge," Tardif commented. He noted that transport is often not provided by governments, despite their assistance with funding services. His address set the tone for much of the congress, as many workshops and presentations focused on inclusive services.

The World Health Organization (WHO) announced its new standards for prosthetics and orthotics, which included the Priority Assistive Device List. The list was inspired by the Essential Medicines List published by WHO in 1977 and is updated every two years.

The Essential Medicines List has served as a guideline for many countries on pricing essential medicines to ensure they are accessible. WHO hopes the Priority Assistive Device List will have a similar function. Both the list and the standards were introduced through the Global Cooperation Assistive Technology (GATE) initiative.

One new standard, for example, states that insurance companies in all countries need to make

provision for prosthetics and orthotics services. These services not only mean independence and inclusion for the patient, but also have economic benefits, as the patient is enabled to return to work or school. GATE also launched the Wheelchair Service Training of Trainers Package, which aims to educate professionals on what is considered an appropriate wheelchair.



Various prosthesis manufacturers used the opportunity to display their latest technology.

The Centre of Rehabilitation Studies at the University of Stellenbosch is working with the WHO to ensure the Priority Assistive Devices List is introduced into South Africa's healthcare system. Gubela Mji, its director, noted that only around 15 to 25 percent of people who require assistive devices receive the services.

She warned that old technology is often "dumped" in Africa, despite being ill-suited to the continent's environment. Her sentiment was echoed by Elsje Scheffler, researcher at the Centre. In her research on assistive devices in Zimbabwe, Scheffler found that 90 percent of wheelchairs in the country were donated. While some of the locally manufactured wheelchairs could withstand the rural terrain, donated wheelchairs often broke or were completely inappropriate to the needs of the user.

One type of commonly donated wheelchair consists of a plastic garden chair attached to a steel frame with wheels. These chairs offer no comfort and are available in only one size. Scheffler pointed out that any wheelchair is not necessarily better than no wheelchair.

"Only with an appropriate wheelchair can you participate in society," she said.

at the congress. Canadian Computer Assisted Design (CAD) or Manufacturing (CAM) company Vorum presented their Spectra Scanner and 3D technology at a workshop. The scanner replaces traditional plaster work and takes only 30 minutes compared to plaster, which takes most of the day.

This technology was used by the University of Toronto in partnership with Canadian non-profit organisation Christian Blind Mission (CBM) to provide 3D-printing technology to three countries, including Uganda and Cambodia. Through their non-profit organisation Nia Technology, the university and CBM are attempting to provide quality prosthetics in less time by printing prosthetics.

However, in the four years since the inception of the project, they have realised that the technology is susceptible to factors such as power cuts. When a 3D-printing session is interrupted, the process cannot



LEFT: Otto Bock personnel demonstrated their new technology at ISPO.
BELOW: Students and researchers were invited to display posters about their findings.

The Centre of Rehabilitation at the University of Stellenbosch plans to implement the Priority List into tertiary learning through providing short courses and revising undergraduate courses to include more content on assistive devices.

Other researchers also presented the findings of their projects. Ed Giesbrecht from the University of Manitoba, Canada showcased his EPIC programme, which allows wheelchair users to learn wheelchair skills through an app on their tablet. In Canada, he said, there is a lack of skills training for wheelchair

Krista Best, another Canadian researcher from the Centre for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRIS) in Québec, shared her findings on the advantage of peer-to-peer training when teaching wheelchair skills.

Emma Smith from the University of British Columbia, Canada, shared her team's research on wheelchair cushions. They recreated the Tuball cushion developed by Evandro Guimaraes and William Mann in 2003: it's made out of bike tyres and is said to offer similar seating to the ROHO air cushions. Smith found that with the correct material and detailed instructions, anyone can recreate the cushion. It costs US\$6 (about R80) to produce one cushion.

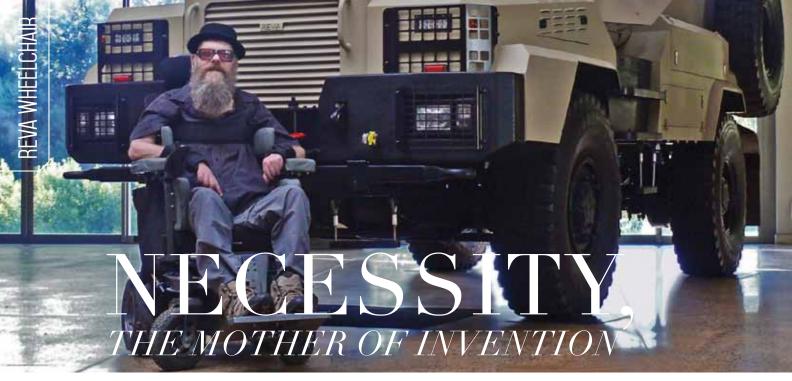
Along with accessible prosthetists and orthotic services, 3D-printing technology was a popular topic



continue where it left off; instead it needs to start again. In addition, the printed devices were prone to breakage due to the material used in the printing. The organisation is looking at creative solutions to resolve these issues.

Other companies, such as Otto Bock, Ossür and Shonaquip, displayed their latest technology at the exhibition hall.

At the closing ceremony on May 11, various researchers received awards for their outstanding research. Details of the next ISPO World Congress were also announced – it will be held in Kobe, Japan in October 2019.



After years of frustration with uncomfortable wheelchairs that broke, DIETER MARZINGER, with the assistance of his company Integrated Convoy Protection, designed the ultimate all-terrain wheelchair – the Reva Wheelchair

was at the end of my tether, endlessly negotiating with a local wheelchair manufacturer to get my wheelchair back from their workshop after it had been there for weeks. The workmanship was so poor that the wheelchair kept breaking at regular intervals.

The backrest was cheap and uncomfortable, and the centre of gravity was wrong.

It wasn't cheap and I could not afford it myself. I had organised a fundraiser among my friends and family to buy this vital piece of equipment. This made me feel worse: I wanted to be responsible with the cash raised for me, but I had bought a piece of rubbish.

I had been lying in my bed for a couple of weeks in a state of frustration when my boss paid me a visit. He asked me what was the matter. Why don't we build wheelchairs that don't break? I asked.

I work for Integrated Convoy Protection (ICP), which builds a range of armoured vehicles specifically for military applications. It's diversifying into the cashin-transit field. If it can build military vehicles that can withstand explosive devices and landmines, I had no doubt that ICP could build the toughest wheelchair around.

I received access to the company's engineering department, where we spent many hours designing the Reva wheelchair. We tested it for an entire year over the roughest terrain and obstacles to identify any weaknesses in the design, and we made various corrections until we were happy with our product.

The pre-production model had me focusing on the softer side of things. Never in my previous five electric wheelchairs had ergonomics played a factor. The backrests were always incorrectly angled, they were cheap and none ever gave lumbar support. I was determined to change this, adding torso and leg support to ensure good posture and body stability.

A ventilated backrest was added, which is a first, according to my knowledge – yet it's such a simple addition! The Reva wheelchair is able to elevate, which is helpful in a social setting, as you can converse with others at eye height. It can recline and "tilt" to shift your body weight and relieve pressure, which ensures a longer, more comfortable sit.

I have designed and manufactured the ideal wheelchair for me and I believe that it will be of benefit to others as well. Wheelchairs are such important assistive devices that we need them to be well-designed, ergonomic and robust. They are our legs and we cannot afford to have them break.



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ANOTHER FRUITFUL MONTH FOR DRIVING AMBITIONS

Both Jeannet Malapile from Rustenburg and Joseph Ketso from Zwartkop passed their driving test in April thanks to the help of Driving Ambitions. Malapile stayed at QASA's David Lewis Lodge for the duration of her driving lessons and test as she doesn't live locally. Her instructor, Des Harmse, scheduled her test to accommodate her during her stay at the lodge. Congratulations to both Malapile



QASA MAKES THE RURAL COMMUNITY ACCESSIBLE

British Airways has extended its partnership with QASA to fund its rural development programme aimed at providing opportunities for quadriplegics and paraplegics who do not have basic resources.

QASA provided rural farmers with water storage tanks, access ramps and grab rails in house and ablution facilities as well as new computer equipment for the Gauteng North Digital Village Computer training centre. The centre will help develop the skills of people with disabilities who do not have access to training.



ABOVE: Jabu Dlamini (right) with his new Commode chair and Busiswe Mbambo using the new ramp into her home.



QASA's "Eish" Campaign 2017 highlights key issues faced by people with physical disabilities.



Ari Seirlis is the CEO of the QuadPara Association of South Africa (QASA) and managing editor of Rolling Inspiration. email: ceo@gasa.co.za



People with mobility impairments have specific dietary needs that must be taken into consideration to ensure their wellbeing - and this involves more than just watching their weight and fluid intake

o find out more I chatted to Charlene Grimsehl, a dietitian at the Netcare Rehabilitation Hospital in Johannesburg, where she has been working for the past eight years after completing her studies and community service...

I asked her to describe how, from a dietary perspective, she would approach a person who was admitted as a patient with quadriplegia. She assesses a patient with quadriplegia by carrying out a clinical evaluation: to measure the patient's weight and hydration, and to check for pressure sores. Secondly, she looks at all the blood test results to see if the kidneys and liver still work well and if there are any nutritional or mineral deficiencies. The presence of lifestyle diseases such as diabetes, cholesterol and hypertension is also assessed. Where needed, food supplements must be incorporated into the diet.

I asked Charlene why all of this was necessary: at home we seldom really bother about being so finicky with what we eat. She explained that for persons with paralysis it is very important to establish and maintain what she calls "an ideal weight". If patients

are underweight, they do not have muscle support for their bones and this can cause bones to fracture more easily. Underweight persons develop pressure sores more easily because bones press directly against the skin, especially in areas such as the pelvis and heels. Low muscle strength also weakens those areas of the body that still function, so it is difficult for working areas to compensate for the losses experienced by paralysed limbs. For instance, to push a wheelchair requires upper body strength.

On the other hand, being overweight also presents problems. The additional weight makes moving around more difficult - for the paralysed person as well as for the caregiver. There are also potential complications such as heart attacks and strokes, and the additional weight on pressure points can lead to pressure sores.

For these reasons diet management is crucial: the paralysis prevents the patients from expending energy as well as blocking them from building strength. With the lack of exercise, diet becomes the mainstay of weight management.

Another important component of management is fluid intake, which helps the kidneys to work optimally. Kidney failure is one of the causes



of death in persons with paralysis, yet it is easy enough to monitor fluid intake and pre-empt failure - just look at the colour of the urine. If it is too dark, more fluids are needed. (Smelly urine is not a good indication of dehydration, because many medicines can cause urine to become smelly. Also, be aware that some medicines and supplements may change the colour of the urine. Don't confuse this with dark, concentrated urine.)

Water is the mainstay of fluid intake and at least 1,5 to 2 litres of pure water should be consumed each day, in addition to coffee or tea etc. Fizzy cool drinks, energy drinks and pure fruit juices are loaded with sugar, which can cause problems besides weight gain. We all know what happens to toddlers at kiddies' parties. The sugar rush makes them go crazy, like Duracell bunnies. Now imagine what a sugar rush does to a person who is unable to expend that energy. Could excessive sugar be the reason why persons with paralysis become aggressive? In addition, many energy drinks contain electrolytes that replace substances lost in sweating during heavy exercise. Drinking lots of these drinks without sweating can cause a build-up of electrolytes in the body, which places strain on the kidneys. So be very careful of high-energy and high-sugar drinks. The argument that fruit juices are healthier than fizzy drinks is true - but only up to a point. Excessive kilojoule intake causes weight gain and it does not

matter where the kilojules come from. Fruit juices are packed with kilojules...

If drinking pure water is unappealing, add a little sugar-free cordial, or slices of cucumber or strawberries for flavour. A good hydration formula is up to two litres of water per day, supplemented by tea or coffee in moderation and a small amount of fruit juice. Preferably stay away from energy drinks and the fizzy stuff.

Just a warning for those of us who have neurogenic bladders that we manage naturally. We have a tendency to "run dry" especially when travelling or finding ourselves in areas where toilet facilities are difficult to access. Dehydration has a very insidious onset. Before you know it, you are dehydrated and then you need to make a plan. Charlene's advice is to put out at least half your daily water needs (about one litre) in an easily accessible place and sip-sip it during the day so that you take it in small quantities frequently. (When I'm travelling, I make a point of stopping every two hours and I drink my water about 20 to 30 km before each pit-stop.)

Diet and bowel management are also closely linked. Persons with SCI (spinal cord injury) often have decreased or no awareness of the need to pass a stool because of a reduced or absent nerve communication between the bowel and the brain. Charlene explained that her team trains SCI patients to establish a "bowel programme" for themselves. This consists of three components: a manual stimulation method, laxative medication every second day and diet. A bowel-management diet consists of two focus areas: fluids and fibre. Without sufficient fluids stools turn into concrete and fibre provides bulk that stimulates the bowels to evacuate the stool. Fibre is found in fruits, vegetables and grain foods such as high-fibre breakfast cereals. The skins of vegetables and fruit are particularly high in fibre - so eat your potatoes, skin and all. Betweenmeal snacking choices are also important. Rather than chocolates, cookies or crisps, opt for nuts, dried fruits, Provita pieces, and so on.

Diet also plays a role in good skincare. Resilience against pressure sores and other skin afflictions can be enhanced with a good intake of protein and antioxidants. Animal protein from meat, dairy products, fish, chicken and eggs provide the best skin support in terms of skin integrity as well as improved skin healing. Vitamin C is the most important antioxidant; sources include all brightly coloured fruits and vegetables, such as paw paw, guavas, oranges, mango, broccoli, spinach and pumpkin.

I asked Charlene if there was a relationship between diet and mental wellbeing. Her response was insightful: don't use food as your go-to consoler when you are feeling down and equally don't use food as a reward for achieving something good. Rather find activities that lift your mood; music, audio books, games - whatever tickles your fancy.



But if you do like chocolate or cookies or whatever, don't punish yourself. By all means have some but in moderation. Learn to eat a block or two rather than a slab or two... Life is too short to miss out on those "nice-to-haves" that are still available to us.

I asked Charlene what caregivers should look out for when preparing meals for persons with spinal cord injuries or afflictions. She made the following astute observation: "We must understand that these injuries or afflictions have drastically changed the





lives of these people. We link food to socialising. So many persons with SCI/SCA become emotional eaters. If the person they are caring for is frustrated or depressed, caregivers should not say, 'Let's go find a nice big piece of cake.' Another pitfall is thinking, 'He is eating healthy food so it is OK for him to eat lots of yoghurt and nuts and fruits.' At the end of the day portion control is just as important, so one must look at portion size of main meals, the dietary content of pre-made meals and the type of in-between snacks. Steer clear of 'empty' snacks which have high sugar and high fat. Rather provide smoothies, vegetable sticks, sliced tomatoes and cottage cheese dips. Lean biltong - without fat - is also good but, again, in moderation. Look at the

fluid intake and steer clear of high-kilojoule and energy drinks."

Lastly, because people with paralysis do not expend a lot of energy, Charlene recommended that the focus should be to prepare foods that provide limited sustained energy. The GI Foundation (www. gifoundation.com) provides useful information on the glycaemic indexes of various types of food, indicating which types provide sustained energy.

Food that is treated with olive or canola oil and fried

presents two problems: the oils add kilojoules and the heat of the frying process converts the "good" fats into "bad" fats. Rather use cooking methods such as grilling, baking or steaming. Measure oil with a teaspoon - don't pour the whole bottle over the food. Finally, more frequent smaller meals "manage" weight better than larger, less frequent meals do.

Look at portion size: starch portions such as rice or pasta must not be larger than your fist; meat and fish portions should fit in the palm of your hand only; and half of the plate should contain vegetables, fruit or salad. The definition of a snack is something that fits into your cupped hand.

Food for thought for all of us indeed. \mathbb{R}



Ida's Corner is a regular column by George Louw, who qualified as a medical doctor, but, due to a progressing spastic paralysis, chose a career in health administration. The column is named after Ida Hlongwa, who worked as caregiver for Ari Seirlis for 20 years. Her charm, smile, commitment, quality care and sacrifice set the bar incredibly high for the caregiving fraternity. email: georgelou@medscheme.co.za



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Despite various grading systems and regulations, numerous establishments are still not accessible even though they claim otherwise. It might be time for change

am compelled to write this article to vent some of my frustration with accessibility within the hospitality industry. I have been involved with trying to get the concept of Universal Access into the Tourism industry for many years now.

After working with a team for four years to completely rework the entire manifesto of the Department of Tourism to remove the words "facilities for people with disabilities" to "facilities that are Universally Accessible", the Department signed its new manifesto in 2010 at the national tourism Indaba.

At about the same time the Tourism Grading Council was also instituting its Universal Access Grading Star system, which was to run alongside the standard star grading. On paper this looked great, with three categories being introduced so that if, for example, buildings were inaccessible for people with mobility impairments, they had the opportunity to try and be accessible for people with hearing or visual impairments.

I felt that we were finally moving forward with the tourism industry, which would now have to comply with the National Building Standards, which state that all establishments should have facilities for persons with disabilities, and would understand the concept better.

Boy, was I wrong...

Last year, I was invited to attend a wedding

at Easter this year at an upmarket game lodge in Northern KwaZulu-Natal called Zuzu Nyala Safari Lodge. I checked its website, which stated that they had facilities for the disabled.

I called the Lodge to ask if they had a step-free "roll-in" shower, and was told that they did. I paid my deposit and sent off the proof of payment together with the reiteration that I required the accessible room with the step-free roll-in shower. I received confirmation that I was indeed getting that room.

In February, members of the bridal party, including the parents, went up to check out the various facilities as the wedding ceremony was to be held on the lawns overlooking the reserve, with the reception in the quarry - a beautiful open area backed by large rock walls. My friend then asked to be shown the accessible room, as she wanted to make sure that I was going to manage on my own.

The reception staff informed her that the room was occupied, and that she would not be able to see it. She mentioned this to me, but we were not very concerned, as we had both been informed that the room and bathroom would be accessible. I was especially excited as I had earmarked this establishment for my next RI article, and had done some research on the history of the property.

So, after flying down to Durban and spending the night with our QASA CEO, I collected various family members who had flown in from overseas, and we all drove up to the lodge. There was one accessible parking bay, which was at the start of a rather steep paved ramp up to the entrance.

Unfortunately, the ramp stopped at a step, which meant that I had to have assistance entering the building. The staff was very welcoming and keen to show me my room, which was situated on the deck above the pool area. The room itself was very spacious and luxuriously appointed, but for me the most important thing is always the access in the bathroom to the loo and shower. The bathroom was huge and there was a bath and basin as well as an enormous shower. They had placed a grab rail in the shower area and also put in a plastic garden chair, but the step into the shower was nearly 20 cm high!

The staff had made two ramps, which they had joined together making a pitch-type structure that was far too steep and ended at the basin, which meant that there was no space to move onto the ramp even if I was able to get up it. I was deeply disappointed, as I had offered them

but, using my own travel tips and expertise, I was able to use this room for my stay.

Had I not been as able as I am, I would not have been able to make use of these facilities and would have and to return back to Durban and miss the entire wedding and weekend.

I am fed up with access regulations that are not adhered to. I'm also fed up with the attitude of most people that it is OK not to comply as they know that they will not be brought to book. It is time that we get the tourism industry in line, as we cannot offer services to guests, especially overseas tourists, and expect them to have to deal with issues like this.





I am ashamed to have to notify them that our services are not up to par, and so I will be investigating what steps I can take to have this matter addressed with the Tourism Grading Council, the Department of Tourism as well as the legal system (to combat false advertising). This lady is on the warpath! Enough is enough ... so, watch this space for further developments.

assistance to make their rooms accessible in my initial conversation, explaining that this was my area of expertise, and that we had lots of time to get it right.

My friend was devastated as she felt responsible and knew that I had spent quite a lot of money on the flights, accommodation, car hire, etc. Luckily her partner had checked their room, which was next door, and they had a much smaller shower with a smaller step. I was able to just fit into their shower (as I use a rigid chair with smaller turning circle).

The toilet seat height was very low and had a flimsy plastic seat, which I was sure wouldn't last for four days of a paraplegic having to launch themselves onto this low height and hoist themselves up again. The bed height was over 600 mm from the ground and the cupboard clothes rail at 1800 mm,

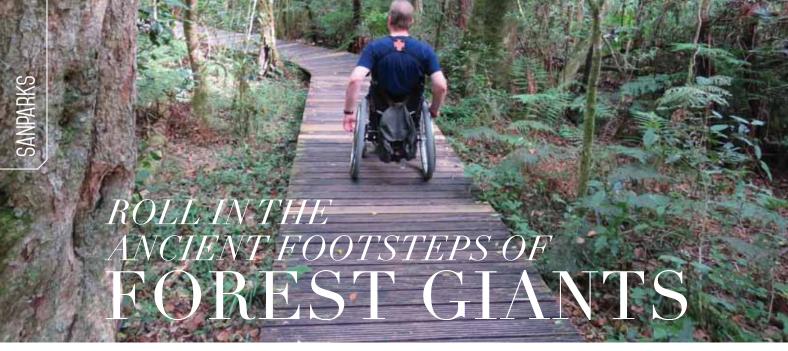
In the meantime, if you find yourself in a similar situation I suggest you do the following:

- Contact the establishment and discuss a refund of your accommodations costs.
- 2. If you want to take the issue further or if you do not get satisfaction, contact QASA and let them know of the incident and the facility.
- 3. There are additional channels for redress, such as the Consumer Protection Act and the Human Rights Commission. There is a free service at the Consumer Goods and Services Ombudsman at 0860 000 272 or info@cgso.org.za and the Human Rights Commission at 011 887 3600 or visit the website at www.sahrc.org.za, select the Disability tab and follow the prompts.

Happy travels for you all. 🛽



Mandy Latimore is a consultant in the disability sector in the fields of travel and access. email: mandy@noveltravel.co.za



The Garden of Eden forest boardwalk in Garden Route National Park is perhaps the most accessible forest trail in South Africa



hat could be a more accessible forest trail than one that is roadside to the N2, and a boardwalk running the entire distance of several hundred metres through pristine Afromontane forest? The last Knysna elephant still stalks a

lonely existence through the forest, along with a variety of other wildlife. Mature, moss-covered forest trees, many of which are labelled for identity, give an enchanted feel to this magical place.

ATTRACTIONS AND ACCESS **ADAPTATIONS:**

• The wheelchair-friendly boardwalk through indigenous forest has two loops (red and green) of about 500m each with a combined length of around 1km.

HOW TO GET THERE

The Garden of Eden is alongside the N2, midway between Knysna and Plettenberg Bay. There is a slip road off the N2 for parking. There is a small office at the entrance point and a nominal charge for non-Wild Card holders.

More information (including rates) about the Garden of Eden, Garden Route National Park or the other 18 national parks can be found on the





- There is a community market that offers locallymade crafts.
- There are ablutions with a separate universally accessible toilet at the start/end of a widened
- Several information boards are accessibly erected that tell about forest wildlife, history etc.
- · Ideal for school groups and individuals alike.

SANParks' website www.sanparks.org. Designated UA accommodation units are kept on reserve for those who need them and can only be booked directly with SANParks on special request. Unlike other units, they cannot be booked in advance on line until the reserve period has expired. Visitors to the parks pay a daily conservation fee to make use of the facilities and enjoy the natural heritage, but if you buy a Wild Card, the fee is waived. ${\Bbb R}$



www.sanparks.org reservations@sanparks.org +27 (0)12 428 9111



www.wildcard.co.za wildcard@sanparks.org +27 (0)861 GO WILD (46 9453)

ON HIS WAY TO

Meet Jarryd Solomons, a kind, soft-spoken, active individual. He is a student, an athlete and an amputee



mputees on the athletics field are not news any more. As Samkelo exemplified by Radebe, it's quite obvious that amputees are able to compete in the athletics arena with times of some of the world's best able-bodied runners. If it wasn't

for decades of research and development on the topic of blade running, I'm sure many amputees would never have achieved this type of performance.

But have you ever seen an amputee-athlete prancing around and going about normal daily life with their blades on? That's because those blades weren't made for walking. The human gait cycle is such a detailed process and it differs so immensely from a running cycle that developers have been unable to design a daily prosthetic foot that could take its user from walking to running in less than a second. That was until now...

Jarryd and the newly launched Otto Bock Challenger Foot are a match made in heaven. The name of the foot says it all - bring on the hurried lifestyles, flights of stairs and rough terrain - challenge accepted! The lightweight carbon spring foot offers the amputee the ease of use and flexibility to adapt to any of life's physical challenges in a split second.

Factors like socket comfort and volume control play in the user's favour now, because there is really no need to use different sockets or take off the prosthesis before taking part in more challenging activities, such as jogging, hiking or cycling. It also means that the standard prosthesis won't hinder the user from walking faster or doing a light jog when they choose to do so.

Jarryd says that the Challenger Foot gives him the ability to run comfortably and powerfully with marked forward propulsion while allowing him literally to jump back into normal daily life with no effort.



ABOVE: Jarryd Solomons shows off his Challenger Foot.

Jarryd is a kind, soft-spoken, active individual who lost his leg when he was involved in a motorcycle accident in 2013. Before his accident, he could run 100 m in 11 seconds. So we are very excited to follow his progress!

In our eyes he is quite the hero and we are sure he will make it to the next Paralympic games in Tokyo! 🛭



Heinrich Grimsehl is a prosthetist in private practice and a member of the South African Orthotic and Prosthetic Association (SAOPA), email: info@hgprosthetics.co.za



Universal design is a strategic approach to ensure that the 2030 agenda for sustainable development is realised. This is what you need to know about universal design



ersons with disabilities are often excluded from opportunities, services, and family and community life due to the design of an environment, services and equipment. This exclusion is not unique as children, older persons, pregnant women,

and religious or cultural minority groups often experience the same limitations in participating as equal citizens.

Universal access is a generally accepted principle in both the international and national arena. Through the 2030 Agenda for Sustainable Development, through the Sustainable Development Goal commitments, governments agree to 'LEAVE NO-ONE BEHIND'. The Universal Declaration of Human Rights and the African Charter on Human and People's Rights commit governments, which have ratified these treaties, to protect the rights of all persons, regardless of difference.

This includes the UN Convention on the Rights of Persons with Disabilities. The South African Constitution prohibits discrimination on the basis of disability, among others. The provision of universally accessible services therefore results in the independent living, participation in society and an increased choice and options for quality of life.

Universal Design, also referred to as lifespan design, is the most important tool to achieve universal access. It ensures that all residents, irrespective of age, size, ability, etc., benefit from accessible places and products. The fundamental premise of Universal Design is the recognition of human diversity as opposed to the concept of the 'average man'.

The benefits of widely implementing universal design and applying the seven principles are an important way of meeting the needs of as many people as possible. The principles are:

- Equitable use Useful and marketable design for persons with diverse access needs.
- Flexibility in use Accommodating design for various preferences and access needs.
- Simple and intuitive use Design that is easy to understand regardless of experience, knowledge, language, skills or concentration level.

- Perceptible information Design that effectively communicates necessary information, regardless of ambient conditions or the user's sensory access
- Tolerance for error Design that minimises hazards and adverse consequences of accidental or unintended actions.
- · Low physical effort Efficient and comfortable design, which doesn't cause fatigue.
- Size and space for approach and use Design that provides appropriate size and space regardless of body size, posture or mobility.

Universal design significantly reduces the need to provide accessible accommodation, as everyone is catered for as part of the expected provision of services. The White Paper on the Rights of Persons with Disabilities (WPRPD) commits duty bearers to realising the rights of persons with disabilities by, among others, ensuring universal design informs access and participation in the planning, budgeting and service delivery of all programmes.

The policy defines universal design as: "The design of products, environments, programmes and services to be usable by all persons to the greatest extent possible without the need for adaptation or specialised design. Assistive devices and technologies for particular groups of persons with disabilities, where these are needed, must also respond to the principles of universal design. Universal design is therefore the most important tool to achieve universal access."

The Department of Social Development, in its capacity as the National Disability Rights Coordinating Mechanism in government and as custodian of the WPRPD, will be releasing two National Frameworks on Universal Design and Access as well as on Reasonable Accommodation in November 2017 to provide further guidance for implementation of the WPRPD

Progress reports on the implementation of the WPRPD are submitted to Cabinet on an annual basis. A participatory rapid impact assessment on how implementation of the WPRPD has changed the lives of persons with disabilities and their families will be conducted towards 2020. R



Zain Bulbulia led the South African government delegation team to the United Nations (UN), New York, for the ratification and signing of the UN Convention of the Rights of Persons with Disabilities. He is currently the acting head for gender, youth and disability in the planning commission of the Premier of Gauteng. email: zain.bulbulia@gauteng.gov.za



- · Standing Wheelchair
- · Powered Wheelchair
- · Lightweight Wheelchair
- · Pediatric Wheelchair









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Wheelchair design can be technical and complex, which gives the customer a difficult choice! With CAROLINE RULE's list of pro and cons of the various frames, it might be a little easier to decide



hoosing a wheelchair can be a daunting task, especially when you don't know quite what to look for. You will be spending most of your time in the wheelchair and you want to be comfortable. But what does that mean? Do you need quick-

release wheels? What size do you need? Which frame is the best?

To help you understand some of the science (and comfort levels) behind the designs, I have done a comparison of the three types of wheelchair frames in the market: folding, rigid and folding-rigid frames.

FOLDING FRAME

A folding-frame wheelchair has an X-bar across the middle and folds by bringing the sides together. This design was first developed by Everest and Jennings in the 1930s and the basic design is still very similar. It has a cross-bar under the chair and flip-up footplates, which allow the wheelchair to be folded.

These chairs generally offer very few adjustments, except in the more expensive ranges where they are built of a lighter material and provide optional extras.

ADVANTAGES

It takes up less space for storage and transport. Generally, these are in the lower-cost range. They have high backrest with handles that are at a



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convenient position for a helper to assist with pushing the wheelchair. The footrests can be flipped up for people who want to do standing transfers or when they want to propel the chair with one foot.

It is also useful if a wheelchair user wants to do a forward transfer onto the toilet: it enables them to get the footrests out of the way in order to slide down each side of the toilet thus letting them get out the seat next to the toilet seat.

DISADVANTAGES

The wheelchair is heavy. It is not energy-efficient when pushed as the amount of movement in the frame absorbs much of the kinetic energy without it being converted into forward motion. The upholstery sags as the frame is not held rigid, which can lead to poor posture. Long-term users are prone to developing scoliosis, with a tilted pelvis, which increases the likelihood of pressure

They come with armrests, which give the user a sense of security; however, the armrests make it difficult to push. It also forces the users to open their arms very wide to get over the armrests. This is a very inefficient and a tiring position. The high backrest can

be a hindrance, too, when a user reaches back to push the wheels. The angle of the footrests makes the wheelchair

much longer and it therefore requires a larger turning circle or more space to turn. These chairs are very frequently too big for the user, which aggravates these disadvantages.

RIGID FRAME

These chairs have a rigid bar between the wheels as well as a rigid footplate. The wheelchair cannot be folded from side to side, but, normally, the backrest folds down. They also have quick-release wheels, which are easily removed. This leaves a frame that is fairly easy to lift and load into a vehicle. The frame design is naturally stronger, which makes it lighter than the folding-frame chairs.

The rigidity of the frame is far more efficient when pushing. It takes far less effort to manoeuvre the wheelchair. This design was first used in sports wheelchairs and was introduced into the SA market in the early 2000s by Rollability as a day chair after the improved sporting performance was recognised as a benefit for daily use.

ADVANTAGES

The chair is lightweight and is efficient for pushing. In the long term this helps to protect the shoulder girdle. The upholstery is held tight, which provides better postural support. These chairs frequently have Velcro strips built into the backrest, which enable the back upholstery to be tightened and loosened in different areas of the back to give specific postural support and follow the shape of the user's back.

The firmer upholstery of the seat provides a far more stable base and supports the pelvis in a better alignment than the folding-frame chairs. The risk of developing scoliosis, tilted pelvis and pressure sores is thus greatly reduced. The frame design allows for adjustments to be easily fitted according to the user's needs and pushing action.

It is easy to add adjustments for the centre of gravity. This is done by positioning the axle forwards or backwards in relation to the seat position. If the axle is moved backwards, it puts more weight onto the front castors. This makes the chair more stable but heavier to push. For more experienced wheelchair 🕑





our mission

The Health and Welfare Sector Education and Training Authority (HWSETA) endeavours to create an integrated approach to the development and provision of appropriately skilled health and social development workers, to render quality services comparable to world-class standards



users, the axle will be moved slightly forwards, putting more weight behind the axle and thus less on the front wheels (similar to the effect of a see-saw).

This makes the wheelchair lighter and easier to push, but also more prone to tipping. The user needs to know how to pivot and push without falling over backwards. The height of the seat in relation to the wheels can also be easily adjusted.

This affects the amount of push-rim that the user can reach and will influence the amount of strength they can apply through the push. It is particularly beneficial for a quadriplegic who has weaker arms, particularly if they have strong biceps and weak triceps (i.e. can bend their elbow with strength but cannot straighten their elbow with strength).

By positioning them deeper in the chair, it allows them to reach far back onto the wheels and use their pulling strength to pull the rear of the wheel upwards (since they do not have much strength to push the wheel forwards!). The smaller casters make the chair more efficient on smooth ground, but trickier to push on rough ground.

These wheelchairs are seldom sold with armrests. If they do, the armrests are small, narrow and lower than the folding-chair versions. They frequently gave a skirt guide, mudguard or protective flap between the wheel and the user to prevent clothing from

getting caught in the spokes.

The rigid-frame chairs usually have an adjustable backrest. The height of the backrest is positioned according to the level of injury and the user's balance. The paralysis usually starts from the level of injury downwards. Therefore, a person with an injury low in their back will have more balance than a person with a higher-placed injury.

The low backrest does not restrict the pushing action of the user's arms and therefore makes pushing more comfortable with less effort. The frame is lightweight, once the wheels are removed and the backrest folded down, which is generally easier to load into a car than the folding frame, as it does not fall open while loading. It also means fewer places that can pinch fingers when loading the chair!

The feet are positioned much closer and under the user, with the knees bent close to 90 degrees. This makes the overall length of the wheelchair far shorter compared with the folding frame. It has a smaller turning circle, which makes it better suited to smaller spaces.

DISADVANTAGES

Generally, it takes up more space when being stored or transported as it doesn't fully fold. The frame often does not fit into the boot of a sedan and needs to be





Contact us:

0800 864 478

hwseta@hwseta.org.za

www.hwseta.org.za

transported on the car seat, which takes up more space. It cannot be transported on the roof of a car with an Omnigo hoist (a popular hoist).

The rigid footplates cannot be moved out of the way for people who are able to do a standing transfer or push the chair with one foot. These chairs frequently have no pushing handles on the backrest, so are difficult to give the person assistance with pushing. When there are handles, they are generally too low and therefore the person assisting has to bend down to reach them.

This wheelchair can be more expensive, but this is usually because it is made of lighter materials. Any adjustments added to the frame also increase the overall weight.

FOLDING RIGID

This design includes most of the best features of both, but comes with the compromise of increased weight and often a hefty price tag! The folding mechanism chair has been redesigned to give the rigid stability of the rigid-frame chair. The footplates have a hinge on one side so when they are slotted into position they "close" the frame around the footplates.

Good luck with your choice! ${\Bbb R}$



FINDING A WHEELCHAIR

Thinking of buying a new wheelchair? There is a range of companies that sell a looking for something you can easily fold into your car or something with a bit more back support, these companies have you

CE Mobility

010 593 2903

Chairman Industries

011 624 1222

Medop CC

011 827 5893

Mr Wheelchair

031 701 4620 www.mrwheelchair.co.za

Primacare

0861 7746 222 73 www.primacare.co.za

Sheer Mobility

021 552 5563

Shonaquip

021 797 8239

Thokomala Services (Well Care Medical)

031 564 3330

our vision

The creation of a skilled workforce for the health and social development needs of all South Africans

our values

- Integrity Transparency Transformation Service Excellence





The sporting calendar is filling up and athletes are already preparing for the 2020 Tokyo Paralympic Games



reparations have begun for the 2020 Paralympic Games in Tokyo, Japan. The next few years will be interesting, as numerous athletes aim to qualify for and attend these games. Some of our top athletes won't be there, though: Ilse

Haves, Arnu Fourie and Kevin Paul have announced their retirement (although Ilse and Arnu will still complete this season before retiring).

The South African Sports Association for the Physically Disabled (SASAPD) held its National Championships sponsored by Nedbank in Port Elizabeth at the beginning of April. There is definitely new talent coming through, especially in athletics. Hopefully, these athletes will be ready for Tokyo.

Some great results were recorded in Port Elizabeth, where numerous national and African records and one world record were set. Congratulations go to ex-Paralympic medallist Moekie Grobelaar for being voted in as the President of SASAPD. Good luck Moekie. Knowing you, the organisation will be in safe hands.

So far, because it's still early in the season, only one athlete has started competing internationally and that is the veteran Ernst van Dyk. In April he came second in the Boston Marathon and fourth in the London Marathon, which doubled as the World

Championships. Well done Ernst! Ernst has been the most successful South African athlete ever and just keeps on performing at the highest level. I, for one, feel that he never gets the recognition he so rightly deserves, and I urge all South Africans to acknowledge his multiple achievements across two sporting codes, athletics and handcycling.

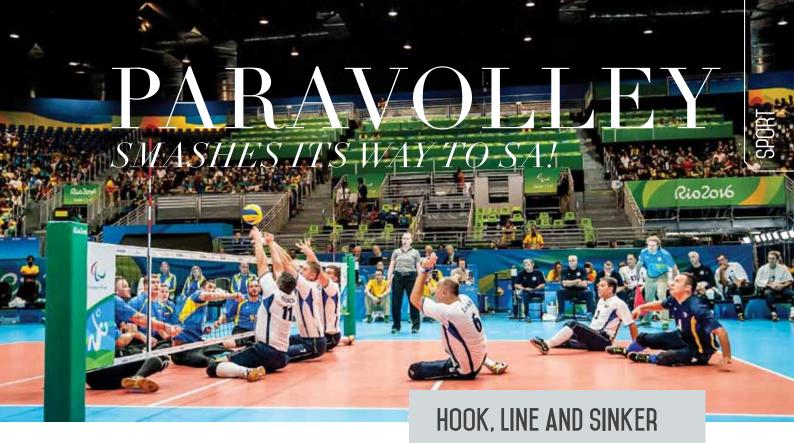


A number of our athletes will be attending a few World Para Athletics Grand Prix events over the coming months. Let's get behind them and give them

The Terence de Bruyn Wheelchair Basketball Cup took place at the Vodacom Mandeville Indoor Sports centre from April 27 to 30. Eight teams fought it out to qualify for the Supersport Series. Read our next issue to find out how they fared. \mathbb{R}



Leon Fleiser has been involved with sport in the disability sector since 1992, when he started playing wheelchair basketball. He captained the national team to the Sydney Paralympic Games and the 2002 World Championships. He started working for Disability Sport South Africa in 2001 as a Coordinator for High Performance. It merged into SASCOC in 2005 and he is now the Manager for Team Preparation and Academy Systems. He has delivered Team South Africa to numerous Olympic, Paralympic, Commonwealth and African Games.



Some people believe that the range of sports offered to people with disabilities is limited, but British Paralympic athlete Anton Raimondo is out to prove that notion wrong

n 2014, which offers men and women with a disability the opportunity to stay fit and social. Raimondo and his wife Tina introduced Sitting Volleyball to South Africa. The husband-and-wife power team hope to see South Africa

competing against the best teams in the world at future World Championships, or even the Paralympic Games.

Sitting volleyball is very popular in the rest of the world but is still relatively unknown in South Africa. People with and without disabilities can compete, making this sport a great platform to encourage open and free discussion, inclusivity and socialisation.

It is unique in that people with one leg have an advantage over people with two, as the reduced weight allows them to move around the court faster. Although it resembles volleyball, it has a different court and its own rules.

Players sit on the ground, but do not make use of any prosthetics or aids. They use their arms, sliding around the court to play the ball.

The sport has been welcomed by the sporting community in South Africa and is growing. Events and competitions are taking place across the country, as well as in neighbouring countries such as Zimbabwe, where a competition is set to be held soon.

In support of the competition, World Paravolley will be hosting training courses for all the coaches, referees and officials required for the tournament. $\overline{\mathbb{M}}$

The second freshwater South African Championship for Anglers with disability is set for October 2017. The first championship was hosted by the South African Freshwater Bank Angling Federation (SAFBAF) in partnership with Freshwater Fishing for the Disabled in October last year.

Piet de Witt won the first championship with a total of 103 fish weighing in at 126 kg. Riaan Bornman and HJ Kuhn shared a joint second. Bornman caught 81 fish weighing in at 106,4 kg, while Kuhn bagged 69 fish at 111,8 kg. Freshwater Fishing for the Disabled was established in November 2014.

"We found that there is no place where anglers with a disability can compete against each other," Bornman says. The social club dubbed "Rainbow Angling Club" encourages families to join in with the activities and gives people with various disabilities the opportunity to meet more of their peers.

"The beauty of this sport is that almost any person with a disability can enjoy it. As they say, a bad day's fishing is better than a good day's work," Bornman comments.

If you are interested in participating in freshwater fishing, contact Riaan Bornman on 071 889 5230 or email oerie30@hotmail.com.





Living with a disability is difficult enough for people with disabilities and their families. Making the situation tougher is having to deal with an uncooperative medical aid. ANLERIE DE WET does some research



oeye Swart has been fighting with medical aids for many years. Her 24-year-old son, Anton-Pierre Swart, was born with cerebral palsy. He is a dependant on Swart's medical aid; he is unable to afford his half of the total scheme, which

costs R6 000.

He has a job as an occupational health and safety officer in Port Elizabeth, but his condition allows him to work only part-time. "Although his income is too low to afford medical aid, he is still lucky enough to have parents who can take care of him - but I know there are others who aren't as lucky," says Swart.

Swart says that their medical aid has been refusing for years to pay for Attention-deficit/ hyperactivity disorder (ADHD) and the spasms that her son experiences as a result of his condition.

"My son wants to work, but for that he needs the medication to help him concentrate and drive safely - which costs us about R2 000 per month extra on top of the medical aid fees," she says.

"We have to constantly fight for something that's supposed to be a given."

Rodwill Beneckhe had and is still having the "worst experience" with his medical aid for his son.

"The amount given for equipment annually is a laughable R8 000. They even tried to send him to a rehab that was so far away that we would not have been able to see him. It wasn't until we opened a case with the ombudsman that they suddenly gave permission for the closer rehab," says Beneckhe.

He adds that his medical aid provider told him to make a co-payment for his son's medication even though it is medication that should be covered by the medical aid, according to its PMBs.

Swart says: "I admit, I have diabetes and it is covered in full under the PMBs. But my son is in a wheelchair through no fault of his own and his medication is not covered."

Simon Haifer of Medop says he ask medical aids and practitioners why the benefits for disabled products are low compared with other benefits. "I have never received a comprehensive answer. Medical aids will gladly pay for in-hospital scans that doctors request at the drop of a hat," he says. "However, they won't cover a decent spec product, such as a wheelchair, which could result in an early discharge; prevent the onset of pressure ulcers/ sores; reduce the physical stress on the immediate family member or caretaker; and encourage greater independence."

He says that earlier discharge would reduce longterm costs to the schemes directly, thus indirectly increasing their long-term profits.

"Some schemes have large external appliance benefits, although, in today's market, most of the high-end products are not covered due to increasing manufacturing costs and currency fluctuations," he adds.

Dr Elsabé Conradie, GM of stakeholder relations at the South African Council of Medical Schemes, says the PMB regulations are currently under review. "At this stage it is not possible to provide information on specific conditions and changes as the review process is still in the early phases," says Conradie.

However, as the PMB regulations currently stand, they include the following spinal cord and non-progressive neurological conditions:

effective or will cause adverse reactions or have already caused adverse reactions, the medical scheme must fund any drug as prescribed."

Many medical aids have a payback system where patients have to pay out of pocket for medicine and treatment and then the medical aid will pay back the money if the medicine or treatment is

accepted within the patient's benefits. Swart says this is a problem for people with low incomes (which is often the case for people with disabilities), who spend a lot of money on private medical aid and do not have the cash-in-hand to pay for the treatment when it is needed.

Conradie says the payback system is allowed under the Medical Schemes Act, 131 of 1998, which states that members are responsible to claim from the medical scheme and not the provider. "This statement was legally challenged and the final court ruling indicated that in cases where the provider has a specific contract with the medical scheme, direct payment must be made to the provider. In other cases the member may be asked to pay the doctor and then claim back from the scheme," explains Conradie.

Haifer says: "People should definitely speak to their therapists regarding internal procedures in the medical scheme, which may allow for increased benefits, such as PMB, ex-gratia payments (paying for treatment without being legally obliged), and trauma benefits."

CONDITION COVERAGE

Spina Bifida	Surgical management
Spinal cord compression, ischaemia or degenerative disease NOS	Medical and surgical management
Vertebral dislocations/fractures, open or closed with injury to spinal cord	Repair/reconstruction; medical management; inpatient rehabilitation up to 2 months
Stroke due to haemorrhage, or ischaemia	Medical management; surgery
Transient cerebral ischaemia; life-threatening cerebrovascular conditions NOS	Evaluation; medical management; surgery

Conradie says: "In cases where the treatment includes medical management, the medical schemes must fund chronic medicine. The only limitation will be that in order for the medicine to qualify for PMB level of care, the specific pain medicine must be available in the public sector. The medical schemes may have a medicine formulary as well and fund only the drugs on the formulary in full."

She adds: "Regulation 15I(c) determines if the formulary drugs were used, but if they are not

Another option is to politely express one's opinion in writing to the medical aid regarding the effect of the extremely low benefits on its patients. "This may be the only way to get the schemes to hear people's calls for help," concludes Haifer.

We at Rolling Inspiration urge people with disabilities and their families or caretakers to study and understand their healthcare benefits and legal rights. \square

NOT JUST FOR

FR() TINES

Don't confuse focal spasticity with general spasticity: the two are very different and require different treatment. Follow these tips to help you better deal with focal spasticity



pasticity is a condition that is commonly seen in patients who have suffered a neurological event. It is the uncontrolled contraction of muscle groups, and often occurs in patients living with spinal cord injury, traumatic brain injury, cerebral

palsy, stroke and other neurological disorders affecting the central nervous system.

Spasticity can not only inhibit function and thus lead to greater loss of independence, but can also cause local problems such as pain, contractures and difficulty with hygiene. Ideally it should be treated and managed adequately by a multidisciplinary team before complications set in.

Spasticity can be generalised - that is, affecting most or all muscle groups (usually seen in spinal cord injury) - or focal and limited to specific muscle groups such as a single limb. Generalised spasticity is managed with oral medications (muscle relaxants) or infusion pumps.

Focal spasticity, which is commonly seen in patients who have suffered a traumatic brain injury or a stroke, should not be treated with oral medications, which unselectively cause muscle relaxation. Instead, specific treatment of focal spasticity could include:

• Physical management, which includes good nursing care, physiotherapy and occupational therapy through the use of techniques to improve postural management, exercise, stretching and strengthening of limbs, splinting and pain relief. (These interventions are the basis of spasticity management, and are used as a first line of defence

for not only focal but also generalised spasticity.)

- Interventions using transcutaneous electrical stimulation, acupuncture and acupressure.
- If these are insufficient, a further possible intervention is the use of injectable drugs. These would include Phenol nerve blocks and the use of Botulinum Toxin (Botox) injections. Botox is better known as the wonder drug used to restore a youthful look, but both Phenol and Botox are useful to add to the physical management of patients with focal spasticity.

Phenol injections seem to be used less often today, as the potential for complications is high, the drug is potentially harmful with lasting neurological loss and the injections are not simple to give (and are potentially painful). Botox, on the other hand, although much more expensive, is easier to administer, the effects are not permanent (lasting up to four months) and it has been used very successfully to manage focal spasticity.

Many medical funders are now beginning to appreciate the value of Botox in the management of focal spasticity; although expensive, in the long run it can save money by preventing complications and improving quality of life. Not only can Botox be used in the management of focal limb spasticity, but it is now also widely used to treat overactive bladders.

Your therapist would normally recommend you visit your rehab doctor if Botox is being considered. Don't forget to ask your doctor to save a drop or two to inject those pesky forehead wrinkles! ${\mathbb R}$



Dr Ed Baalbergen is the medical officer at the Vincent Pallotti Rehabilitation Centre (Cape Town) and is a member of the International Spinal Cord Society and the Southern African Neurological Rehabilitation Association. email: ed.baalbergen@lifehealthcare.co.za

CREATIVE

HOME MODIFICATIONS HELP SAVE MONEY

One creative wheelchair user has found a way of making her home accessible without breaking the bank. MARISKA MORRIS asks Penny Metcalf about DIY home modifications especially for wheelchair users

P

enny Metcalf, author of *I Can Do It*, opens the glass door leading to the study. The door was formerly a window, and its new incarnation is one of many renovations made to the old house. The only other accessible entry point is the ramp leading into the kitchen, which was built by Penny's husband, Charles.

Penny closes the door behind her by pulling a tennis ball, which is dangling from a piece of string

next to the door frame. The string is attached to the open door and as Penny pulls down on the ball, the door shuts.

A pair of braai tongs is always with her to assist with picking up papers or to reach the sugar packet on a top shelf in the kitchen. With Charles's carpentry skills, they were able to make most of the kitchen accessible. Drawers have replaced the cupboard doors and shelves; the wall cupboards have been lowered and a special worktop has been built.



ABOVE LEFT: Strong towel rails can double as grab rails. **ABOVE RIGHT:** Penny Metcalf uses a pair of braai tongs to access difficult-to-reach areas in the kitchen.

The worktop, along with a gas stove top, are attached to wheels, which allow Penny to simply roll it out from underneath the counter. The couple cut costs in the bathroom by using strong, steel towel rails as grab rails.

"You just need to make sure the rail is very strong and that you have some good bolts in the wall," Penny says. She warns against plastic towel rails, which are not necessarily strong enough.

Penny's creativity comes from years of experience. In the 1980s, she helped renovate houses in Soweto to make them wheelchair accessible.

"We had to literally take the doors off their frames and hang a curtain to allow wheelchair users to pass through the doorway," she notes. She also worked at the Independent Living Centre, which is where she became even more active in renovating existing buildings by assisting church officials to make their facilities wheelchair accessible. The most important lesson that her years in home modification have taught her is the importance of space.

"If a wheelchair user is house-hunting, they should look at old homes, because the rooms are big. You can barely get into most new homes," she says

Penny also emphasises the importance of taking the correct measurements. "Measure the wheelchair from armrest to armrest, as they can also add some width," she notes. It is also important to include the width needed for the hands of a wheelchair user when pushing a manual wheelchair. With a bit of planning, anyone can do DIY home modifications.

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PUTTING CAREERS ON THE MAP

Hope School in Westcliff, Johannesburg, hosted its sixth Hope-Mandeville Disabilities Career Expo in April. Exhibitors were given the opportunity to present high- school students with disabilities with various possible job opportunities, learnerships and possible further opportunities. All the proceeds made during the two-day event are donated to Mandeville Disability Swimming.

The club is the official partner in the event, but also trains swimmers with disabilities up to Paralympian level. For this sixth instalment of the event, there were a variety of exhibitors including the University of Johannesburg, South African National Parks, the South African Police Service and eDEAF.

Students also attended a session on preparing for university, presented by the University of Witwatersrand and the University of Pretoria, a discussion on entrepreneurship, and a "fun session" with Zongi Mgcina, a representative from the SABC.

At the launch of the event on April 19, Nicholas Serra, an assistant teacher at Saint Stithians College, addressed the exhibitors.



At the age of 10, Serra was hit by a school bus, which left him in a coma and severely injured. After 20 years of perseverance, he made a near-full recovery, although partly paralysed throughout the right side of his body. Nevertheless, Serra is leading a fulfilling life, having climbed Mount Kilimanjaro and sailed on the Lord Nelson.

His message to the exhibitors: "Different does not mean less, it just means different and it is a privilege to be different."

ARE YOU FIT TO DRIVE?

In May, Rolling Rehab hosted a two-day workshop on assessing the fitness to drive of people with disabilities. Occupational therapists, doctors, psychologists and a few members of the Department of Transport gathered in Centurion to learn more about the relatively underdeveloped field.

"We can put lives at risk when we allow an unfit driver on the road, but we can also take away someone's independence," expert and organiser of the event Caroline Rule said. She argued the importance of having standardised guidelines and better legislation.

"Many wheelchair users drive with expired licenses and there are no learner licences for people with disabilities, so, unfortunately, we need to manipulate the system," she said. She shared some of her eight-year experience in assessing the fitness of people with disabilities.

Attorney Eugene Searle discussed the legal implications of assessing driver fitness. He spoke about his own challenges and confusion as a wheelchair user who wanted to drive after he didn't fully recover from Guillain-Barré syndrome more than a decade ago.

"I don't want to hear that I need to retake the test when I know I can drive," Searle noted. He cautioned medical practitioners against being negligent, as they may be targeted in case of an accident. Yet, he also urged the practitioners not to be deterred and, to avoid any legal action, he advised them to ask a fellow medical practitioner when they are unsure.



ABOVE: (From left) Jople Mbete from the Department of Transport, Caroline Rule from Rolling Rehab and speakers Eugene Searle and Dr Greg Kew.

"If you don't want to sign off a person as fit to drive, it is very likely that the person is not fit to drive," Searle said. Dr Greg Kew discussed the medical guidelines for testing a patient's fitness to drive. The workshop gave the medical practitioners the opportunity to share knowledge and network so that they would be able to refer their patient to the correct practitioner.





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DON'T MISS OUT!

Be sure to diarise these important upcoming events

2 - 4 JULY WCPT CONGRESS

Physical therapists from across the globe will gather at Cape Town for the World Confederation for Physical Therapy Congress.

The conference, hosted in Kimberley, will explore modern approaches to child and youth care practice, programmes and policies.

Concours South Africa will host its second classic car competition, with QASA as its beneficiary for 2017.

The African Network on Evidence-to-Action in Disability will host its fifth conference in Ghana on research into disabilities.

Support inclusivity and equity by purchasing a Casual Day sticker and celebrating diversity with persons with disabilities - this year's theme.

Spread awareness of SCI on September 5. SCI not only causes trauma, but can cost an affected individual up to R13 million in the first year.

THE LIMITED-EDITION GENERATION

In the times before video games, cellphones and Internet, there was a world of marbles, skipping ropes and bare feet

It is said that people born between 1950 and 1980 are the blessed ones. The awesome people. Their lives are proof of that. While playing and riding bicycles, they never bothered to wear helmets. They played marbles and hide-and-seek, and jumped over skipping ropes. After school, they played until dusk. They didn't watch the world on TV, shut away in a room. They played only with their real friends, not with website friends.

If they felt thirsty, they drank tap water or water from the stream. Bottled water didn't exist. They didn't fall ill by sharing the same juice or a drink with four other friends. On special days like Christmas and New Year, it was luxury to be served rice and chicken and it was okay. Nothing happened to their bare feet even after roaming and kicking balls made of rags or rubber.

They never used any health supplements to keep themselves healthy. They created their own toys, from cartons or tins. Their parents were not rich, and they never chased after money. They just searched for and gave only love, rather than worldly possessions. They never had mobile phones, DVDs,

PlayStations, video games or personal computers; they didn't post on Instagram or Facebook - but they had many good friends.

They used to visit their friends' homes unannounced. They didn't have to ask for their parents' permission to visit their friends. Loving people were all around them, so their hearts and souls were happy.

The ultimate is that they're a unique and understanding generation, because they're the last generation who listened to their parents and also the first that have to listen to their children. They're the last set of people to have walked kilometres barefoot to school, and now they take their children to school in cars. They're the last generation to enjoy free public school education but the first to pay to have their children to be taught in private schools.

They had less homework than today, so they could help their parents with household duties - but now they have to assist their own children with their homework. They're not special, but they do make up a limited-edition, endangered species and I am proud to belong to this noble generation. \mathbb{R}



Emilie Olifant is a disability activist, entrepreneur and motivational speaker. She is the director of the Emilie Olifant Foundation, an organisation that strives to address socio-economic issues experienced by people with disabilities. email: emilie.olifant@gmail.com

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