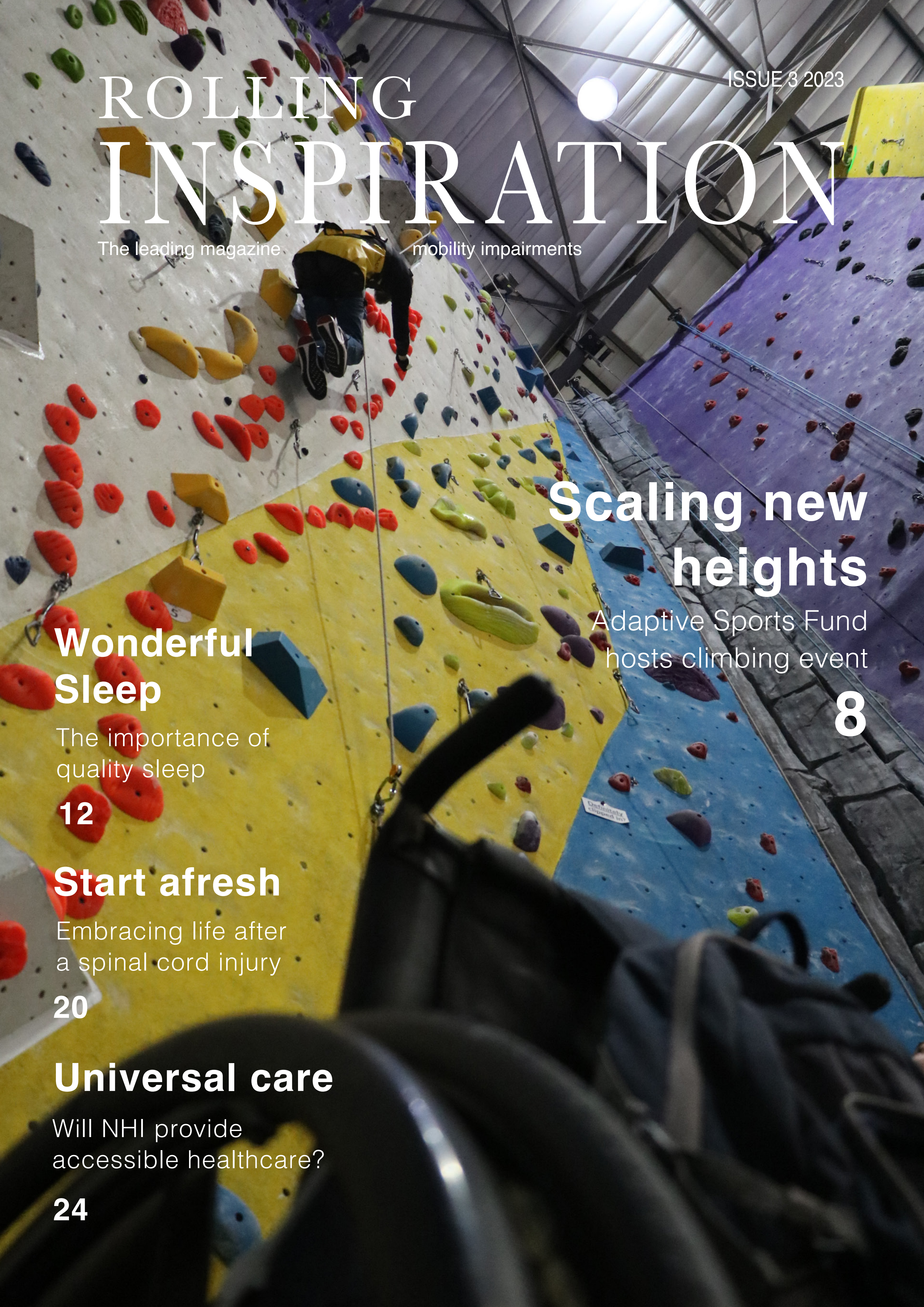

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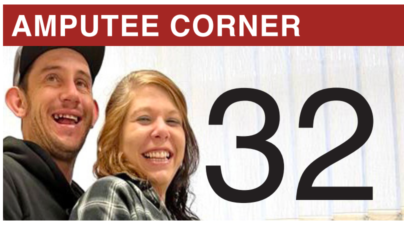

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NAVIGATING THROUGH UNINTENDED CONSEQUENCES OF SCI

Beware the unintended consequences of spinal cord injury. We must look after our mental health and well-being

We have some superb columnists writing for *Rolling Inspiration* and have covered many topics regarding health within spinal cord injury. Recently, a good friend of mine, a quadriplegic of almost 30 years, took his life.

No explanation given. Such a sad ending to his wonderful and active life. Nobody would have thought it possible that he wanted to end his life.

I lost another good friend, a paraplegic of almost 30 years, as a result of pressure sores and eventually septicaemia. Another a life ended far too soon, especially one so active. I tried to get my head around why? I do not have the answer, but I want to share this thinking and at the end of my column callout to all of us with spinal cord injuries to give attention to our mental health and well-being. They are our nemesis, not our broken spines.

Whether we have broken our backs or our necks, the result is that we are wheelchair users and people see us as such. We suffer the indignity of being stared at, our unacceptable terminology.

We are seen as a homogeneous group and people see us as confined and bound by our wheelchairs. Clearly, we are not. You need only read some of the inspirational stories in *Rolling Inspiration* to know that.

We are often defined by our hardware. Very few people see the unintended consequences of a spinal cord injury.

It is so important for everybody, including ourselves, to understand that our challenge is not the navigation of our wheelchair, but rather the navigation through the unintended consequences to make sure that these don't get us down, don't create risk, and don't affect our mental health and wellness.

> **Our challenge is not the navigation of our wheelchair, but rather the navigation through the unintended consequences.**

The list is long and in no particular order of inconveniences severity: bowel routine, bladder management, sexual function, temperature control, risk of pressure sores, autonomic dysreflexia, spasm, pain, breathing difficulties, societies judgement, prejudices and perception, financial devastation, loss of friendships and relationships, inaccessible home, inaccessible public infrastructure, inaccessible transport, caregiver management, disability discrimination, reduced or no chance of employment, wheelchair parking abuse and crime risk. I guess load shedding now too.

This list encompasses not only physical health risk, but mental health issue stimulants.

These are our nemesis of our coping or not, our frame of mind, our ability to integrate, our future, our lifestyle choices, our ability to get work or a career or return to work, to remain in relationships or get into relationships.

We are often complemented about how brave we are, how cheerful we seem to be, and how well we seem to manage, but sometimes behind the facade or the poker face are underlying issues that we need to face up to and ensure that we conquer.

I have often stated that walking is overrated, and I can say that with a bit of a smirk on my face as I have been using a wheelchair for 39 years. But it is the unintended consequences that are a daily grind and can get to your head and your wellness.

Explain this to your loved ones and allow people to dig deeper into our well-being. Sometimes we are too proud to expose this or talk about it ourselves.

Let's talk more freely and openly about these unintended consequences. This might be the secret to our longevity.

ABOUT THE AUTHOR

Ari Seirlis is the former CEO of the QuadPara Association of South Africa and, presently, a member of the Presidential Working Group on Disability. He is a wheelchair user and disability activist. Ari has recently published his biography, which can be found at www.wheelsoffire.co.za.

KNOW THE SIGNS
OF DEPRESSION

Depressive episodes last (mostly) every day for at least two weeks with feelings of:

- Deep sadness;
- Irritability; and/or
- Hopelessness.

Other signs include:

- Changes in appetite or weight.
- Excessive guilt or low self-worth.
- Thoughts about dying or suicide.
- Not enjoying hobbies.
- Disrupted sleep.
- Poor concentration.
- Feeling very tired.

If you or a loved one show signs of depression, contact a professional or reach out to the **South African Depression and Anxiety Group** (SADAG) on **0800 567 567**.

SUICIDE

Unbearable weight of being

Anyone can feel suicidal for a host of reasons. Offering support and understanding can help talk someone off a ledge

By Sandy Lewis, clinical social worker and Netcare Compassion Coach

Suicide is the final symptom of a brain that is no longer able to cope, just like any other type of organ failure, it is the result of an illness that has become terminal.

Some people die by suicide without necessarily showing their intentions. If you have an uneasy feeling that someone may be thinking about suicide, it is very likely that by this time, the person is already well advanced with their plans to die.

For a person to consider suicide, the distress and suffering they are experiencing seems inescapable and endless, exceeding their perceived capacity to cope. Suicide may seem like the only way to escape the pain when a person feels their heart is broken, their soul is shattered, and their body can no longer fight. A person's mind may beg for release, even at the expense of life itself.

The risk factors for suicide are a combination of biological, psychological and social factors, often all coming together at once in a potentially lethal mix that leaves a person buckling under the unbearable weight of their pain, worry, fear, grief, and despair.

Any one of us could find ourselves in a suicidal frame of mind if faced with a set of personally tragic and unfortunate circumstances that could threaten to break us. It is part of our shared humanity that we find ourselves in dark spaces at times. This is the time to offer compassion and kindness.

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>
> **Suicide may seem like the only way to escape the pain when a person feels their heart is broken, their soul is shattered, and their body can no longer fight.**

According to the Global Health Estimates Report 2019, South Africa has a suicide rate of 23,5 deaths per 100 000 population compared to a global average of nine per 100 000.

The local statistics for teenagers are deeply concerning, as the South African Depression and Anxiety Group (SADAG) reports that 17,6 percent of teens have considered suicide, and as many as one in five 18-year-olds have had one or more suicide attempts.

Suicide can result from factors like mental health concerns, grief, trauma, physical illness, bullying, abuse, serious relationship troubles, work and financial problems, loneliness, burnout, and a family history of suicide.

Men and boys are at higher risk of completing suicide, and it has been suggested that outdated notions of what it means to be a man, as in “cowboys don’t cry”, contribute to this as males may find it more difficult to talk about feelings of emotional distress and ask for help due of shame and stigma. Substance use and financial pressures are also believed to be significant factors driving male suicide globally.

Never dismiss, brush off, shame, minimise, invalidate, or turn away from a suicidal person when they are trying to communicate their distress and their intentions. It is a myth that talking about suicide will increase the chances of it happening. We should never avoid having a conversation that could save a life. It can be difficult to find the words to open these conversations, and a helpful start could be, “It must be so very hard for you to be feeling like this, I would really like to understand and offer my help to you”. Most importantly, let the person know they are not alone.

Always seek help from a mental or medical healthcare practitioner who is professionally trained to assess and treat this particular emergency. Be proactive, don’t wait. The suicide warning is always a powerful communication of desperation and seeking help.

Judgment simply alienates the person in their loneliest hour and cuts off sorely needed potential support. Please take notice and extend a hand to anyone who might be at risk. Treat the warning signs of suicide as a medical emergency, and do not leave the suicidal person alone.

We should never underestimate the power of a kind presence when a person is in despair. Loneliness often tips a person from holding on to life to the decision to die. R

Lived experience: A survivor’s insights

By Melissa Kemp

When I was in that really dark place, I would have thoughts that would scare me and find myself doing things without thinking, especially when alone. If you find yourself alone with the means to harm yourself, try to get out, even if just to the shops, as a temporary escape from that frame of mind.

When you are depressed, you don’t feel like socialising, but the situation can escalate quickly when you are isolated. It is hard to reach out to talk to people, but that really helped me. Nobody wants to air all their dark scary, intrusive thoughts, but when you do, you are surprised how many people struggle with something similar or can relate to how you feel, so you realise you are not entirely alone. Often, other people can share their coping strategies, too.

Family and parents can sometimes [miss] the signs of suicidal thoughts or mental health problems, which stems from a lack of understanding. Trying to open up to someone, and they respond by dismissing you with “you can’t be mentally ill because…” is not helpful – it only adds to the suffering because it makes you question yourself even more.

Writing down what you want to say is helpful. It gives you time to reflect on how you can frame your thoughts in a way that will be understandable for your parents or whomever you can talk to about what you are going through. This can take some of the pressure off.

Going into 21 days of inpatient therapy was the hardest and best thing I have ever done. It is a life-changing experience to realise mental health difficulties don’t make you defective, it is an illness. I feel like I’ve gone from seeing the world in black and white like an old TV to full-colour HD. R

IN MEMORY OF

PHILLIP THOMPSON

Memorialising 40 years of friendship

Phillip Thompson passed away in May. His life and work touched the lives of many. He was a trailblazer for universal design in South Africa, a beloved husband, father and friend. Ari Seirlis memorialises Phillip and their several decades-long of friendship.

Dear Phillip,
Thank you for 40 years of friendship …

I met Phillip before his accident when I was selling a product to architects in the Durban area. He gladly bought my product and our friendship began.

He was friends not only with myself, but had a great relationship with my mum, Joan, who was also an architect specialising in universal design principles. They worked well together and the two of them paved the way for the introduction of accessibility.

Arguably more important, they introduced the concept of universal design as a solution for all people and not only for people with disabilities and mobility impairments.

Phillip and I served on many South African Bureau of Standards (SABS) committees. He chaired most of the meetings as his leadership was invaluable and he had the ability to articulate the position on behalf of people with disabilities.

The Gautrain and most of the Bus Rapid Transit programmes in South Africa had his signature input. All commuters can be grateful for that. His signature in terms of universal access is also prevalent in most of Airports Company South Africa (ACSA)'s airport terminals as well as the 10 stadia used in the 2010 Soccer World Cup.

Through his leadership at the Federal Council on Disability, he also demonstrated his advocacy and lobby skills to ensure that legislation was applied for the benefit of people with disabilities.

> **[Phillip Thompson and Joan Seirlis] introduced the concept of universal design as a solution for all people and not only for people with disabilities.**

He led the concept of universal design in the Institute of Architects in South Africa and ran many workshops, influencing our thinking to ensure we would not compromise for anything less. For that, we are very grateful.

Phillip was also an advocate for the rights of people with disabilities and his services on the Presidential Working Group on Disabilities, advising several presidents (including former President Jacob Zuma and President Cyril Ramaphosa) was a huge influence.

The sad reality is that no one can replace the knowledge that he had and deployed in the disability sector to influence the public and private sector. He was one of the greatest and the disability sector will miss him dearly.

I enjoyed many an evening with Phillip over refreshments and good food. We had some memorable road trips together on our way to meetings.

ABOVE: Phillip Thompson passed away at the end of May.

MAIN PHOTO: (From the left) Phillip Thompson with former President Jacob Zuma and Ari Serilis.

We knew that, when the ignorant attending those meetings would see us arrive, they would silently mouth "OH F…" as they knew that there would be no compromise for the rights of people with disabilities with us in attendance.

Phillip and I worked in Sweden for a month. We were there on a learning excursion; however, it didn't take long for them to learn far more from him than he did from them. Such was his knowledge and influence.

In saying goodbye to Phillip, I must say that life with a spinal cord injury is not easy. It is difficult, very difficult. Yet, he pursued, persisted and persuaded with resilience, not complaining about much at all.

Phillip Thomson, you have left a huge legacy that has made the lives of people with disabilities easier in South Africa and I'm sure even globally. Thank you for that. You will be remembered for a long time.

Thank you for your friendship, your sense of humour, your resilience and your bravery. Although for most of your life you could not walk, you certainly walked your talk. R


Definitely clipped in?

Scaling new heights

The Adaptive Sports Fund enabled people with mobility impairments to scale new heights by hosting an adaptive rock climbing event

The Adaptive Sports Fund (ASF) uses adaptive sport and adventure activities to empower people with disabilities. In June, the non-profit invited people with various mobility impairments to join them in an adaptive rock climbing experience at the City Rock climbing gym in Johannesburg.

Speaking on behalf of the organisation, ASF director Jeff Yates says: "ASF was inspired to host the rock climbing day as part of our commitment to providing inclusive and empowering outdoor experiences for individuals with disabilities."

"Rock climbing was chosen specifically because it embodies the spirit of challenge, achievement, and camaraderie. It offers participants a unique opportunity to overcome physical and mental obstacles, building personal growth and self-confidence. It presents various challenges for participants with disabilities, including physical limitations and fear of heights," Jeff adds.

With the use of adaptive equipment, the experienced adaptive climbing instructors and team at City Rock were able to assist wheelchair users to scale the 16-metre tall indoor rock climbing walls. While the harness provides some stability and support, it is still up to the individual to pull themselves up with the use of their upper body strength – no small feat.

"ASF worked closely with experienced adaptive climbing instructors and provided specialised adaptive equipment to ensure that all participants could safely and confidently engage in the activity," Jeff says. "Our instructors tailored climbing routes and techniques to accommodate each individual's abilities, making sure everyone could progress at their own pace and find success in their climbs."

For some that might have meant a route with the holds (or grips) spaced closer together, while others were able to venture onto more difficult climbs with minimal assistance. For the participants, the feeling of accomplishment after completing the route was unmatched.

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> **Rock climbing embodies the spirit of challenge, achievement, and camaraderie. It offers a unique opportunity to overcome physical and mental obstacles.**

Jeff explains: "The participants were particularly enthusiastic about the sense of accomplishment and empowerment they gained from conquering the climbing walls. Many spoke about the exhilaration of reaching the top of a challenging route and the feeling of being part of a supportive community. The day was filled with moments of triumph, laughter, and shared experiences that left everyone with lasting memories."

"ASF hopes that the participants took away a sense of empowerment, increased self-confidence, and a deeper appreciation for their own capabilities. We also hope they left with new friendships and a sense of belonging to a community that understands and supports their goals and aspirations. Ultimately, we aim for this event to inspire participants to explore other adaptive sports and outdoor activities, further enhancing their quality of life," he continues.

Through these events, ASF hopes to promote inclusivity of people with disabilities, encourage physical fitness among people with disabilities, and promote personal growth.

"By showcasing the potential of adaptive sports and outdoor activities, we hope to break down barriers and challenge stereotypes. Our goal is to create a more inclusive society where everyone has equal access to recreational opportunities and can lead active, fulfilling lives," Jeff says.

ASF offers much more than just rock climbing with go-karting, scuba diving, wakeboarding, wheelchair rugby, golfing, rowing, skiing, hand-cycling, mountain biking and para gliding among the many sports it has opened up to people with disabilities. The organisation is continuously looking for more sports to add to its list.

"ASF is constantly working to expand its range of adaptive outdoor events," Jeff explains. "In the near future, we have plans for an adaptive go-karting event happening on the 30 September. Additionally, we are exploring partnerships with local organisations to offer more diverse and inclusive activities for our members."

So, how can people get involved? First, you can visit the ASF website and check the events calendar for upcoming events. You can reach out to the organisation through the contact form.

"ASF is always looking for dedicated volunteers, sponsors, and supporters who share our passion for making outdoor experiences accessible to all. Whether as a participant or a volunteer, there are countless opportunities to engage with ASF and contribute to our mission of empowerment through adaptive sports," Jeff concludes. R


PETZL
ASF
City ROCK

GEORGE LOUW • IDA'S CORNER

Sleep, wonderful sleep, wherefore art thou?

Sleep is crucial to our health, but is often a challenge for people with spinal cord injuries

In the previous edition of *Rolling Inspiration*, Diving Deep explored the hidden demons of spinal cord injuries (SCIs); those complications that no one sees but that probably trouble us more than our paralysis. But I left out sleep – a serious omission.

Poor and interrupted sleep has a number of consequences; physical as well as mental and psychological. In this article, I will explore the various causes of disturbed sleeping patterns in persons with SCI, and what can be done about it.

Sleep disorders are common in persons with SCI. Notable lesion-related causes include breathing disorders, abnormal body movements and spasms, a disturbed natural rhythm of sleep and simply being awakened periodically to be repositioned for the prevention of pressure sores.

This compromises daytime functionality, including general alertness, concentration, and physical energy. In many instances, it can also lead to anxiety and depression.

So, let's examine a few of the more common causes of sleep disorders in persons with SCI.

SLEEP DISORDERED BREATHING

Sleep apnoea is very common in persons with SCI. Causes include a disturbance in the breathing regulatory system, a reduced awareness of having stopped breathing and an increased collapsibility of the upper airways.

Obesity plays a significant role in sleep apnoea in that it compresses the upper airways, and it reduces lung volume. Muscle relaxants such as Baclofen as well as sedatives and narcotic analgesics also impact on breathing.

Sleep apnoea is managed by continuous positive airway pressure (CPAP) – a machine that uses mild air pressure during inspiratory (breathing) to keep breathing airways open while you sleep.

In severe cases, bilevel positive airway pressure (BiPAP) may be used. This is a machine that pushes air into your lungs maintaining a positive pressure while you breathe in and out. In so doing it keeps the lungs inflated.

A PERSPECTIVE ON OBESITY

We need to understand that a major reason for eating is to replenish used up energy. Persons with SCI are paralysed and as such have non-functional, therefore non-energy-using limbs.

Sticking to your pre-SCI eating habits could therefore lead to obesity because we eat more than we need. Visits to a dietician to assist with reorganising your intake of food is therefore a good idea.

PERIODIC LEG MOVEMENTS

This entails repeated flection of the hip and knee joints as well as an upward pulling of the ankle and big toe. This is very sleep-disturbing and often associated with painful muscle spasms.

Periodic leg movements are also often associated with Restless-Leg-Syndrome (uncomfortable leg sensations). While both conditions also affect able-bodied persons, the prevalence is much higher in persons with SCI, particularly in lesions above T10.

Once again, the result is daytime sleepiness and all the other consequences described above.

Treatment with medication appears to be somewhat haphazard. What works for one may not work for another. Trial-and-error seems to be the way to go if the movements and sensations severely impact on sleep.

SLEEP-WAKE DISORDERS

The Circadian Rhythm is a highly complex neurological process that is disrupted in cervical spine lesions. The outcome is a significant delay in the onset of rapid eye movement (REM) sleep, particularly so in complete lesions.

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> **Poor and interrupted sleep has a number of consequences: physical as well as mental and psychological.**

REM sleep is a very necessary part of a four-stage sleep cycle during which our emotions are processed restoring balance. New learnings and newly acquired skills are processed and committed to memory.

Finally, REM sleep takes the body out of deep sleep and prepares us for wakefulness, making waking up easier.

It is also thought that brain development occurs during REM sleep. It is postulated that this is why new-borns spend most of their sleep time in REM sleep.

The Circadian Rhythm also influences various bodily functions including eating habits, metabolism, hormone release, and body temperature.

Poor sleep quality may interfere with the alignment of your circadian rhythm and cause you to feel more extreme spikes of tiredness throughout the day.

Melatonin supplementation may assist in regulating the Circadian Rhythm, but this must be managed under medical supervision.

SCI and Insomnia

Insomnia is not lesion related but appears to occur more frequently in persons with SCI than in the general population.

Insomnia is defined as difficulty falling or staying asleep that persists for at least three months, occurs at least three nights per week and is accompanied by daytime consequences.

The go-to remedy for persons with insomnia is sedative hypnotics (sleeping tablets), but most prescription sleeping tablets are highly addictive and not recommended for long-term use. (A recommendation that is generally ignored.)

Alternative options include warm milk at bedtime, breathing routines and soft soothing background music. (I find listening to a news channel takes my mind off my own thoughts and puts me to sleep in no time.)

PRESSURE SORE AND BLADDER CARE

So, just when you have overcome your insomnia and having fallen into a comfortable, gentle slumber, the bedroom light goes on and a voice tells you that it is time to turn … I could use worse words but let's stick with "Bummer!"

Not only are you wide awake but your mind goes berserk, nuts, bananas; making nocturnal mountains out of daytime molehills and keeps you awake until just before having to catheterise…

There are no treatments or solutions for what is needed. We must just take it in our stride and find ways around it that work for us.

I know the words of about six or seven songs off by heart and sing myself to sleep in my mind. Out loud is scary. But if in your approaching sleepiness you forget the words, just hum the tune. Trying to remember words wakes you up again.

There are several other causes of sleep disturbance in persons with SCI, including:

- Body temperature dysregulation: Following an SCI, the body may struggle to regulate its body temperature. As a result, individuals may become too hot or cold during sleep and wake up.
- Impaired motor control: Inability to or difficulty shifting positions during sleep can cause discomfort.
- Chronic illness: Individuals with chronic illnesses such as hypertension, diabetes, and obstructive pulmonary disease are more likely to experience sleep problems.
- Pain due to secondary complications like spasticity and pressure sores can disrupt sleep.

> **Most prescription sleeping tablets are highly addictive and not recommended for long-term use.**

IN CONCLUSION

There are many factors to consider in the management of sleep disorders in persons with SCI, including lesion related, obesity, environment, and care routines, to name a few. Mostly a combination of factors is at work to disrupt sleep in affected individuals.

This makes management highly personalised and includes caregiver understanding, medical intervention and psychological support. Trial-and-error is the name of the game and hopefully this article provides some insight and will help to focus management on an acceptable sleep routine.

ABOUT THE AUTHOR

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: yorslo@icloud.com

Reimbursement Toolkit relaunch

QASA has updated and relaunched its Reimbursement Toolkit – a step-by-step guide to help individuals approach funders about medical reimbursements. It offers advice, information and template letters that can be used to approach, for example, a medical aid about necessary, appropriate medical devices, equipment and care. For the relaunch, QASA hosted a webinar during which contributors Mark Brand and lawyer Elsabé Klinck explained the various step to approaching funders, and discussed some of the expenses that should be funded in full. The toolkit is free to download from the QASA website and can be accessed here.

Get in touch

QASA will be introducing Whatsapp Groups as a way to communicate more directly with its members and share important information. There are several groups created for each region to allow the regions to communicate important region-specific information. Using the Whatsapp Community service, QASA will be able to distribute national news and information to all the regional groups.

To ensure that the group act as a messaging board only, the chat function in the groups will be turned off. This service will be on an opt-in (or voluntary) basis. Keep an eye on the QASA website for more information on the launch of the Whatsapp groups.

ABOVE: (From the left) Luyanda Khoza, QASA Office Administrator, and Louise Rode, QASA Office Manager, celebrate Casual Day on Friday, 1 September.

FOLLOW QASA ON SOCIAL MEDIA

My Bowel & My Bladder

YOUR QUESTIONS ANSWERED AS WE DISCUSS BEST PRACTICE

SPEAKER

DR VEE WILSON

Dr Virginia (Vee) Wilson is a medical practitioner with a special interest in physical & rehabilitation medicine, and in particular spinal cord injury. She is immediate past chair of the Southern African Spinal Cord Association and a member of the SASCA Clinical Advisory Panel (CAP).

DATE: Thursday, 28 September 2023

TIME: 11 AM

WHERE: Zoom

RSVP: HTTPS://FORMS.OFFICE.COM/R/IWHMNKPUD5

WEBINAR

QuadPara

QUINTIN VAN JAARSVELD • PLAYERS' FUND

From injury to glory

Through uplifting love, faith and exercise, Charles Oppelt overcame the challenges of a disabling rugby injury and the battle with drugs and alcohol to reach the pinnacle of South African bodybuilding

Transformation doesn't come much more powerful than Charles Oppelt who, over the last 21 years, has gone from a young man with a death wish to a champion of life.

Charles was 17 years old and playing hooker for Mamre Rugby Club against Rockland in the Western Cape on 23 March 2002. He dislocated his C7 vertebra when a scrum collapsed – a crushing injury that left the Grade 10 learner at Saxonsea Secondary School paralysed.

After a long, arduous year at Conradie Hospital, he was able to return to school and matriculated in 2005, a phenomenal feat for a teenager who'd endured such a devastating tragedy. However, like slow poison, depression quietly crept in. He hit rock bottom six years after his injury.

"I didn't realise I was going into depression and turned to drugs to comfort me," says Charles. "I was in a dark place, full of hate, and didn't know if I was coming or going. I gave up on life ... I wanted it to end, and I became an alcoholic."

The life-changing lift he desperately needed came from the very people who gave him life.

"I put my parents through so much pain, suffering and hardship and the realisation one day of how they stayed strong through it all and dedicated their lives to make mine the best it could be was the turning point for me," Charles recalls.

With that mental shift, he committed himself to going to a support group for drug addicts, completed rehabilitation and turned to the thing he loves most, sport.

"A friend of mine introduced me to wheelchair rugby in 2016 and I'll never forget the day I got into that sports chair for the first time. It felt like the weight of Table Mountain had been lifted off my shoulders," he notes.

A reinvigorated Charles started playing for Maties and went on to represent Western Province and form part of the South African squad. He says: "The best part of wheelchair rugby is being part of a team of people who understand the daily challenges you face and how, through the sport, we help each other become the best version of ourselves."

His new-found positivity and passion saw the once self-destructive Charles become health conscience and fall in love with exercising.

"I train with Rob Evans at the Enable Center, where I do strength and endurance training, transfers in and out of the chair, plus standing and walking," he explained.

He got into bodybuilding through Marco Pietrowski – a former professional bodybuilder who became a wheelchair user after a car accident. Charles put long hours into his training and saw it pay off when he won the wheelchair category at last year's national championships in Randburg, Johannesburg.

"That moment on stage when I was crowned champion was priceless. I was overcome with emotion as I thought back to everything I'd gone through, and I'd overcome."

Faith, he says, has been the driving force of his success: "Faith is my train to my next station. As you believe, so it shall be."

He adds that the Chris Burger Petro Jackson Players' Fund has been an invaluable part of his journey. "The Players' Fund has helped me tremendously over the last 21 years," Charles says. "They've provided me with a wheelchair and other equipment, made my day-to-day life easier by making my house wheelchair accessible and supply me with tickets to go watch live rugby matches. I'm forever thankful for their support."

LEFT: Charles Oppelt training with Rob Evans at the Enable Center. **MAIN PHOTO:** Sport allowed Charles to connect and build a community with other people facing the same struggles.

Going from strength to strength in his bodybuilding career, he proudly flew the South African flag at this year's Arnold Classic Africa in Roodepoort, where he secured a silver medal.

"It brought tears to my eyes," he says of his medal-winning moment. "I trained years to achieve it, giving my blood, sweat and tears. Before I got my car, I took four busses, two taxis and an Uber to get to practice and now, through perseverance and the grace of God, I'm the second-best wheelchair bodybuilder in Africa."

The 38-year-old is thriving in all aspects of life. He's a motivational speaker, busy writing a memoir that's set to be published in December, studying office administration at West Coast College and got engaged to the love of his life on the plane heading to the Arnold Classic, all of which, he says, sprouted from rediscovering a positive outlook on life.

"I'm a product of hard work and the belief that, against all odds, life is meant for all of us to enjoy and to do our best in. There's always hope. Always! For any person with or without a disability going through tough times. Don't give up and don't let anyone label you. You are worthy and wonderfully made in the image of God."

DONATE TO THE PLAYER'S FUND

If you would like to support the Chris Burger Petro Jackson Players' Fund, visit their website at www.playersfund.org.za and select any number of the giving options available, which include EFT, payfast, Snapscan and Zapper.

MANDY LATIMORE • TRAVEL

“Wheelchair Friendly” versus Universal Accessible

– the ongoing Saga

Not all accommodation advertised as wheelchair friendly is accessible according to universal accessible standards

In Issue 2 of 2017, I wrote an article on the term “Wheelchair Friendly” and how it should be abolished. I’m currently travelling literally every second week for business and therefore have to find accommodation that I can use in many centres (often not the usual cities).

So, taking my own advice, I’m calling the various establishments that offer “Wheelchair Friendly” accommodation and asking for pictures and videos of the accessible rooms and bathrooms.

This has been such a help as some establishments have responded with pictures of their “accessible step-free shower” that clearly show a step and a concertina glass door, which I know will mean an extremely small opening to enter the shower!

LEFT: A photograph of the “accessible step-free shower” at one establishment, which clearly has a step.

One establishment sent pics and a video of the room – which is accessible – but then sent a pic of the flight of steps to the main building and restaurant. When I stated that I would not be able to make the booking as I was travelling with other people in my party, they offered me room service with my meals sent to my room. Thanks, but no thanks! I don't want to feel like a banished child – sent to my room as punishment!

I had a very positive interaction with one establishment who immediately sent pics of the shower that had a tilt door opening (which I could see was too small).

I called them and asked if they could measure the opening. It was 60 cm and thus is too narrow. When I asked, they immediately agreed to remove the shower door for my stay (which was only two nights).

Obviously, I confirmed the booking as I was impressed by their attitude and I needed to be close to the venue I was assessing. It was done before I arrived and I was able to use the shower stall even though their grab rails and controls were not situated in the correct places.

ABOVE LEFT: One establishment had a step-free shower, but the shower door resulted in the opening to the shower being too narrow.
ABOVE MIDDLE: The establishment shared a photo of the measurements and it was too narrow.
ABOVE RIGHT: The same establishment, however, agreed to have the door of the shower removed so that it is accessible.

The attitude of the staff and management is always so important and it is refreshing to find an eagerness to want to assist and make changes in establishments that are not on the usual tourist routes and places.

However, we need to address the problem at the root, which I believe requires the people who design the environments and the Tourism Grading Council and Department of Tourism to be trained to ensure that universal access (UA) is included within the grading of establishments.

ABOVE LEFT: One establishment has an accessible step-free shower.
ABOVE RIGHT: Unfortunately, that same establishment has steps leading into the main building and restaurant.

There are a few new exciting projects that are being developed within the UA arena which should be a big boost to change perceptions within the built environment from the start – creating a UA attitude from the schools of architecture and interior design planning through to the grading of tourist attractions and establishments.

Various tools and apps are being developed and these should – once they have been marketed and distributed – start making it easier for those who want to make the changes to find solutions and products that will assist.

In the meantime … keep researching, happy travels and let me have feedback on your experiences! R

ABOUT THE AUTHOR

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Ready to start afresh

Tenacious mother of two embraces life after a spinal cord injury (SCI)

Written by Netcare Rehabilitation Hospital and Netcare Milpark Hospital.

When 34-year-old police officer Ntsako Mathebula set out for a routine patrol with her colleagues one quiet Spring morning in 2022, it felt like any other day. Little did this fit and active mother of three know that it would be the last day she would ever have use of her legs.

While on duty, Ntsako sustained a bullet wound to her back, resulting in severe abdominal injuries, a collapsed lung and, most devastatingly, irreversible damage to her spinal cord, leaving her paralysed from the midback downwards.

Ntsako recalls the moment her life changed when she and her colleagues pulled up to a garage in a residential area where, unbeknownst to them, a robbery was underway. They immediately came under fire. While Ntsako and her partner survived, tragically, their commander was critically wounded and died in hospital.

“All the while, I was praying to God, saying, ‘I am not ready to come to you yet’. After the incident I was in a lot of pain and could not feel my legs, but I was grateful to be alive,” Ntsako says.

She was taken to Netcare Milpark Hospital and once stabilised, the extent of her injuries was determined. The bullet had gone right through Ntsako’s spine to her small intestine and the damage to her spine was irreversible. After moving to Netcare Rehabilitation Hospital, the reality began to sink in.

“At first, I was in denial,” Ntsako recalls. “I kept thinking the feeling would return to my legs and life would go back to normal. But the first time I was pushed in a wheelchair, it felt real. I tried to keep my spirits up, smiling every day and encouraging myself, but it was very hard, knowing how easy it was before to do something as simple as sitting up. As a previously fit and active person, I now had to learn how to sit up.”

Dr Aneesa Khan, a general practitioner with special interest in rehabilitation at Netcare

Rehabilitation Hospital, explains that a primary concerns is sensory impairment, which prevents paraplegic patients from feeling pain or sensing limb position. This can lead to pressure sores.

“Pressure sores can become infected and be fatal if left untreated,” Dr Aneesa says. “After sustaining an injury like Ntsako’s, it is important to get the patient out of bed and moving as soon as possible to avoid this.”

Patients are also at risk of osteoporosis due to the lack of movement. Dr Aneesa explains: “[This] makes you far more susceptible to bone fractures if you have a fall – again, you may not be immediately aware of this since you cannot feel the pain.”

“Lack of sensation also affects bladder and bowel control, and it is essential for patients to get onto a scheduled plan so that they can manage this,” she adds.

“Nerve pain is another major concern and the medications for managing this pain are limited. Physical and psychological therapy are important in helping patients to manage their pain and the process of acceptance,” Dr Aneesa says.

“The SCI experience is multi-faceted, and we therefore work in a multidisciplinary team to give patients the strongest foundation for moving forward and having a full and happy life,” she concludes.

Trinesh Baroon, a physiotherapist at Netcare Rehabilitation Hospital, notes that the mental shift for SCI patients is an enormous challenge. Ntsako has shown herself to be a remarkably tenacious, highly motivated person.

“By the time I saw her, Ntsako had already made tremendous progress, but the move home can be challenging as it is a very different environment. You go from having round-the-clock care to being responsible for your daily needs,” Trinesh says.

“In fact, she went in person to her healthcare funder to motivate her case to receive outpatient care as she is so determined to recover to the best of her ability. Her bravery and determination will influence the lives of people she will never even meet because she has helped to pave the way for others in similar circumstances,” he adds.

ABOVE: Ntsako Mathebula with physiotherapist Trinesh Baroon.

MAIN PHOTO: Ntsako Mathebula sustained a spinal cord injury while on duty at the age of 34.

“We have worked a lot on strength and endurance, and have been doing therapeutic standing to try to build up her blood pressure,” Trinesh comments. This will prevent low blood pressure and vertigo. Trinesh continues: “It requires continued commitment, and Ntsako has fully embraced that, taking ownership of her rehabilitation – and this is when we see the most successful outcomes.”

Ntsako notes that while the adjustment to this new way of life is emotionally challenging, she feels a great sense of relief and comfort in being able to talk about it with her social worker and her loved ones.

“Talking openly about my experience is helping me to relate to my family in a new way. I feel that I have been able to process what has happened emotionally. My goal is now to master the physical aspects of living back at home so that I can care for myself and also my family,” Ntsako says.

“I have learned from this experience that there are some things you cannot change, but you can always change your mind. It is all about attitude. I am looking forward to going back to work in an administrative role. I am ready to start afresh, and am still inspired to do good and make a difference,” she concludes.

A NEW WEAPON
TO PROTECT THE KIDNEYS

By Dr. FJ van Wijk | Urologist

Spinal cord injuries lead to different types of neurogenic bladders. It is very important to manage bladder function, not only for social reasons, but to prevent incontinence and incomplete emptying.

Bladder dysfunction is the most common reason for kidney abnormalities that affects quality of life and life expectancy. High pressure in the bladder and infection will cause backward pressure. Stasis of urine increases risk of infection and the combination of high pressure and infection is devastating to the kidneys.

Contributing to the problem is recurrent use of antibiotics that increase the risk of resistant organisms. Therefore prevention and treatment of urinary tract infections are a constant focus for patient and physician.

This is where treatment with an antimicrobial solution like Microdox becomes an integral part of care. To create a safe environment for the kidneys we need a low pressure bladder to store urine and an effective way to empty normally or with indwelling or intermittent catheterization. Organisms can develop resistance to antibiotics or form a protective layer (Biofilm) where antibiotics are not effective.

Microdox is a potent antimicrobial hypochlorous acid solution developed for instillation into the bladder. This overcomes the resistance and biofilm problem. It is also a topical treatment without systemic side effects.

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The main component, hypochlorous acid (HOCl), is naturally produced as part of our immune system during phagocytosis. When neutrophils encounter bacteria or other pathogens, the neutrophils engulf it, generate HOCl and instantly destroys the microorganism. This process is called the “oxidative burst”.

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A gentle and natural ingredient solution that increases blood/oxygen flow to the wound, resulting in faster, more effective healing.

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Universal care
or universal despair

The National Health Insurance Bill aspires to provide accessible healthcare to all South Africans, but many question whether this will be the case in practice

In June, the Nation Health Insurance (NHI) Bill was adopted by the Parliamentary Portfolio Committee on Health and approved by National Assembly. The Bill aims to create better universal healthcare by grouping the public and private healthcare in one system that will service all South Africans.

Through the NHI Bill, a Fund will be established to purchase healthcare services and products from accredited healthcare service providers and health establishments (such as hospitals), including private service providers that contract with the Fund.

The goal is to provide affordable, quality healthcare for everyone. While this sounds wonderful in theory, the big question is whether government can deliver on its promise in practice. Many still have reservations about the Bill.

Prelisha Singh, head of public law at Webber Wentzel, comments: “The concept of universal healthcare or universal health coverage is generally supported, on the understanding that it will grant access to healthcare services by all who require access.”

“However, in the context of the realities facing our country and the significant lack of resources, the Bill will not be able to realistically provide quality healthcare to everyone,” she explains. “That is because, by removing the two-tier healthcare system, the already overburdened public healthcare system will simply be overloaded.”

“Unfortunately, public hospitals are already suffering from a lack of budget and there is little chance that the NHI will be able to provide adequate healthcare until such a time as the basic infrastructure is fixed first,” she adds.

The government has indicated plans to address the quality of the healthcare services and overcome budgeting issues, but whether these are realistic is another question.

QUALITY OF CARE

The goal is to roll-out the Fund over several stages. During the first stage (estimated to take up to five years), government aims to upgrade current public sector facilities while implementing the NHI infrastructure.

"Government will upgrade all facilities to ensure that there is no difference between a public and private facility – all NHI facilities have to be at the same standard because they will have to follow the rules of the Office of Health Standards Compliance to be part of NHI," the government NHI brochure reads.

> **The already overburdened public healthcare system will simply be overloaded.**

Part of the upgrades includes "refurbishing clinics and hospitals, train and employ more staff, improve the quality of healthcare, implement systems to ensure that medicines do not run out of stock [and ensuring] that maladministration and corruption is uprooted so that all facilities will be ready for NHI".

These upgrades are sure to be costly without the cost of implementing the NHI infrastructure and administration needed.

In a press release, partners at the law firm Webber Wentzel, Martin Versfeld, Prelisha Singh, Glenn Penfold and Robert Appelbaum write: "Many stakeholders and experts have raised concerns that the NHI scheme envisaged in the Bill is simply unaffordable, particularly as it would require an extensive administrative apparatus."

"Given the dire state of public healthcare in our country, it is surprising that the government persists with plans to spend vast resources on implementing the NHI. Those resources would greatly improve the delivery of quality healthcare – and universal access to that care – if they were deployed directly in the public health sector," they argue.

Why implement a new system instead of improving the system that already exists? Surely, that will be more affordable.

FOOTING THE BILL

Currently, the public healthcare system is funded by the taxpayers, while private healthcare is funded by medical schemes.

Experts estimate a ridiculous R660 billion will be needed to fund the NHI. In 2023, the public health budget was R60 billion, which government confirmed meant that the sector was underfunded by at least R11 billion.

By combining public and private healthcare funding, government can tap into the money paid to medical aids; however, this is unlikely to fill the massive gap in funding required.

At the end of 2021, there were 4,06 million main members with the various medical schemes. A further 8,94 million South Africans were beneficiaries, which includes non-working individuals such as pensioner or children. This 13 million medical aid members make up only 4,5 percent of the total population in South Africa, and three percent of employed South Africans.

Prelisha notes: "The current health budget and medical scheme tax credits won't be sufficient to cover the shortfall hence the need for an additional tax to be levied."

Government has stated that there won't be a tax for NHI "initially", but there might be some tax implemented at a later date.

"The government will pool the funds that already exist in the public sector to start the NHI. When the NHI is up and running, then Treasury may introduce a small tax to augment the money allocated through the public budget," it says.

The Bill doesn't specify how this tax will be collected, but this could be in the form of an income tax, increased VAT, corporate income tax or a combination.

Government refers to this tax as “mandatory prepayment”, which requires payment for healthcare services before it is needed according to income levels.

“NHI will eliminate out-of-pocket payments when the population needs to access healthcare services. In the long run, households will also benefit from increased disposable income as a result of a significantly lower mandatory prepayment,” the government states in its *White Paper on National Health Insurance*.

But with unemployment at 32,6 percent and 75 percent of employed South Africans earning below R5 800 per month, it is hard to imagine how these taxes will increase disposable income as well as fund the NHI.

FREEDOM TO CHOOSE

While the NHI does promise access to quality healthcare, it doesn’t allow for much freedom of choice. It requires individuals to register with the Fund at a registered facility near the individual’s home or work. This will be the individual’s main healthcare facility.

If the individual needs to see a specialist, or would like to access another facility (for example, a rehabilitation centre), they would need a referral from their main healthcare facility.

If the individual makes use of an unregistered facility, or bypasses the referral process, they won’t be reimbursed by the NHI. The individual thus doesn’t have a choice in the facility or specialist they see, but is dependent on the referral process of the facility with which they are registered.

Prelisha says: “Specific details around the referral process are still to be prescribed (by way of regulations) and it is difficult to say with certainty what the impact will be on individuals who require specialised treatment. Onerous referral pathways could severely impact on individuals’ ability to access specialised treatment.”

CONSTITUTIONAL CHALLENGES

The Webber Wentzel team also made a case for the infringements on various Constitutional rights. They write:

“This regime is likely to face constitutional challenge, including on the basis that it infringes: (a) the right to access healthcare services, by forcing many people who currently access private medical care via medical scheme funding to rely on what is currently a woefully inadequate public healthcare system; (b) the property rights of medical schemes and their administrators; and (c) the right to freedom of trade, occupation and profession.”

> **Onerous referral pathways could severely impact on individuals’ ability to access specialised treatments.**

While many of these rights impact the those in the medical field more directly, the right to access to healthcare is a key issue for all South Africans.

Prelisha explains: “If the NHI Fund is fully submitted, medical aid schemes may only offer complimentary cover to services not reimbursable by the NHI Fund.

“The Bill will therefore increase the burden on the state, even if one assumes that the contributions which would have been paid over to medical aid schemes, is now contributed to the NHI Fund in the form of imposed tax.”

“There is a real possibility that instead of improving the right of access to efficient healthcare services, the existing right to access to healthcare, which members of private medical aids currently hold and pay for, may be diminished by the very Bill which aims to achieve the realisation of the right,” she explains.

It is not only medical aid members who might not get access to healthcare, but anyone who is not registered with the Fund.

"It is further submitted that some of the provisions contained in the Bill will have the additional likely effect of preventing access to healthcare services, especially if a person who is eligible to receive healthcare services has not registered with the NHI Fund," Prelisha notes.

UNCERTAINTIES

One of the big concerns with the Bill in its current form is that many key issues are left to be determined later – for example how the process of referrals will work, or the type of medical equipment, devices and supplies will be provided. This makes it difficult to determine whether the NHI will be able to provide adequate healthcare.

WHERE TO NEXT?

The Bill is currently before the National Council of Provinces (NCOP) where the Select Committee will conduct its set of public participation processes.

Thereafter, the Bill will be debated with one of three outcomes:

1. The NCOP passes the Bill without amendments after which it is submitted to the President;
2. The NCOP passes an amended form of the Bill, which must first be referred back to the National Assembly (NA) to be approved before it is submitted to the President; or
3. The NCOP rejects the Bill, or the NA refuses the amendments, at which point it is referred to the Mediation Committee for further deliberations.

"The precise date of implementation of the Bill (if approved) is difficult to pre-empt as it depends on how the legislative process unfolds," Prelisha says.

"For example, if the President has reservations about the constitutionality of the Bill, he may wish to refer it to the Constitutional Court or back to Parliament for their reconsideration," she continues.

If the President approves the Bill, it becomes an Act. It can only take effect when it is published in the government gazette or on a date determined in terms of the act.

A rough timeline, based on a study by the Parliamentary Monitoring Group, estimates it would take 153 days for the introduction to adoption, 96 days for the President to assent, and another 161 days for the commencement.

"The first of these processes is yet to be complete, meaning the implementation of the Bill is at the very least some 250 days away," Prelisha notes. "This is assuming that the legislative process runs smoothly – that the NCOP approves the Bill without amendments and/or that the President does not refer the Bill back to Parliament or to the Constitutional Court."

> **"There is a real possibility that instead of improving the right of access to efficient healthcare services, the existing right to access to healthcare may be diminished.**

"It is important to note that the Bill might also not be brought into full implementation at the same time and certain provisions might be introduced incrementally or in a staggered fashion," she adds.

While the implementation of the NHI is some ways away – if at all – it is worthwhile to rethink the approach to universal healthcare. Should government perhaps consider allocating more existing tax funds to healthcare to upgrade facilities? Or is a combined revenue pool for healthcare the true solution to affordable, quality healthcare in South Africa? R

Disability Employment Equity targets a travesty

With the introduction of the Employment Equity Amendment Act, Rustim Ariefdien discusses the disability targets set for businesses

The Employment Equity Amendment Act was signed into law. This Act prioritises Employment Equity by introducing targets. The published disability targets was deeply disappointing.

When the Employment Equity Act was first promulgated in 1998, there was hope that disability would feature in the world of work.

The 2011 Census confirmed that disability represented 7,5 percent of the population. In certain quarters it was believed that this would be the disability employment equity target.

This notion was supported by the Code of Good Practice on Employment Equity that indicated that demographic statistics would guide target setting for disability employment equity.

In the public sector the disability employment equity target was set to two percent and notably certain government organs actively sought to surpass this target.

The Skills Development Act set a target spend of four percent as a guideline, but even the SETAs were challenged to achieve this target.

The introduction of B-BBEE provided a hard target of two percent black disability employment equity. From the various targets stated above, how could we achieve disability employment equity parity?

The Commission on Employment Equity has reported disability employment equity only achieving between one and 1,3 percent, which confirmed that the disability community remains hugely marginalised.

The incentives provided by B-BBEE are significant for disability, but we have not seen its impact in terms of disability employment equity data reported. Similarly, Skills Development greatly incentivises employers with the implementation of learnerships, but its impact has proven to be miniscule as well.

Then came the Employment Equity Amendment Act target setting disability employment equity at two percent! How will this target increase the economic empowerment of people with disabilities?

It does not make a dent into the 7,5 percent of the working population that should be made provision for in terms of employment.

If employers are going align this disability employment equity target of two percent with the black disability employment target of two percent in the B-BBEE scorecard what happens to white people with disabilities?

It is sad that all the hard work that disability activists have done to bring disability awareness to the limelight is greatly diminished through this target. It is a travesty indeed.

However, as disability activists we must not give up the fight. Our strategy must be to ensure that these targets are achieved:

- Two percent disability employment equity as per Employment Equity Amendment Act.
- Two percent disability employment equity in the Public Service.
- Two percent black disability employment equity as per B-BBEE Scorecard.
- Four percent disability skills spend as per the Skills Development Act.

To achieve this strategy, we need to use the following tools:

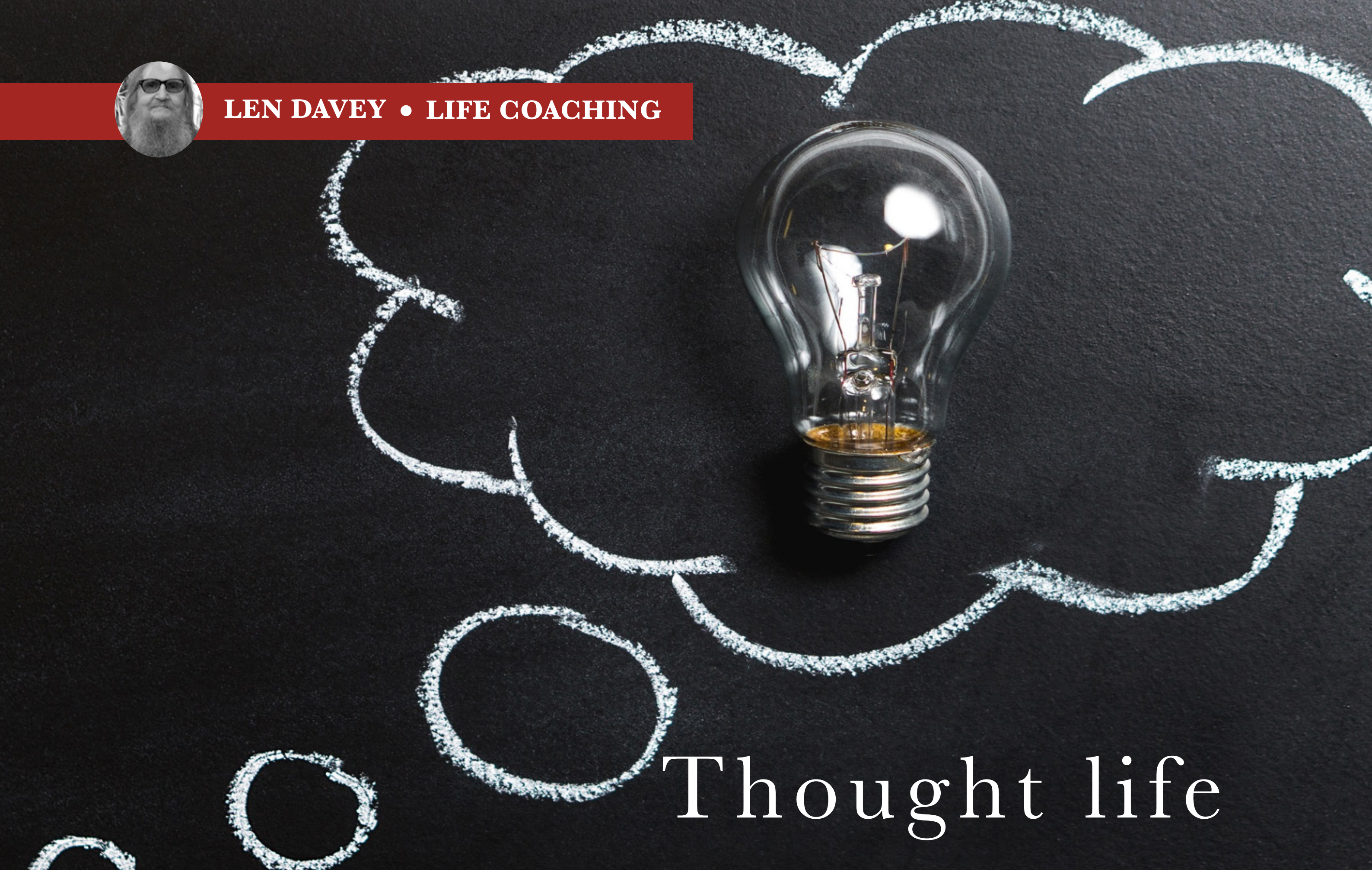
- Employers need to achieve the two percent Disability Employment Equity Target or face huge penalties.
- Businesses are encouraged to engage disability to earn them extra B-BBEE Scorecard points.
- Businesses have higher Tax Allowances when doing learnerships with people with disabilities.

The above list is certainly not exhaustive, but provides direction in terms of the economic empowerment of the disability community in South Africa.

ABOUT THE AUTHOR

Rustim Ariefdien is a disability expert extraordinaire who assists businesses to "let the Ability of disAbility enAble their profitAbility" through BBBEE, skills development, employment equity and socio-economic development. His purpose is the economic empowerment of persons with disability in Africa. As a person with a disability himself, he has extensive experience in the development and empowerment of persons with disability.

LEN DAVEY • LIFE COACHING



Thought life

Our thoughts about our lives play an important role in shaping it

What has our thought life got to do with our happiness and ultimate success I hear you ask? Everything! I would like to refer to a quote by James Allen from his book, *As a Man Thinketh*:

"Man is made or unmade by himself; in the armoury of thought he forges the weapons by which he destroys himself; he also fashions the tools with which he builds for himself, heavenly mansions of joy and strength and peace."

This quote is all over my website for a very good reason, because our happiness and success as human beings depend on it. It was relevant then and will be for evermore.

Unfortunately, as I mentioned in my previous article, we are not taught this extremely important lesson while we are growing up.

This makes way for so many limiting beliefs that contribute to self-sabotage, a low self-image, and a host of other negative feelings and behaviours contrary to our authentic nature.

Before we consider how life coaching can bring about change in one's life, let's have a look at the correlation between the brain and the mind.

There is debate in science between whether the mind is what the brain does or if the brain does the bidding of the mind. The position you adopt will impact how you view free will and choice.

The first argument proposes that thoughts come from our brain as though our brain is generating all aspects of our mental experience. Up until a few decades ago, this was the *de facto* teachings. However, this theory is scientifically flawed and incorrect.

Let's look at the second argument, we are thinking being. We think all day long and, at night as we sleep, we sort out our thinking. As we think, we choose.

As we choose, we cause genetic expression in our brain. This means we make proteins that then form our thoughts. Thoughts are real physical things that take up real estate in our brains.

> **Thoughts are real physical things that take up real estate in our brains.**

Each morning when we wake up, we have new baby nerve cells born inside our brain ready to use to wire out old bad thoughts and wire in new positive and happy thoughts. This is called neurogenesis.

This is such a fascinating subject. I could go on and on, but time and space dictates. (The scientific facts come compliments from Dr Caroline Leaf.)

You see our happiness comes from within (the world within, creates our world without) and success follows, not the other way around.

This is where a good life coach with a good programme, coupled with your willingness to learn, can assist in revealing you to yourself in unique ways seldom explored. We help to discover and correct your negative beliefs and behaviours in order to achieve your goals and live your authentic life.

This life is so beautiful, and investing in your happiness, is the best investment you will ever make. The benefits far outweigh the cost. Next time we have a look at beliefs and values and how they impact on our lives. Look forward to seeing you there! R

ABOUT THE AUTHOR

Len Davey is a qualified life coach. To book a session, contact him via his website: www.theworldwithin.co.za. A free "goal setting" session is offered without any obligation so that you can experience life coaching first hand.


NYC
STATEWIDE

Carrying Mommy and Baby
on the same prosthesis

The perfectly fitted prosthetic breathed new life into a new mommy after battling discomfort

When one thinks of a woman in her 20s, the term “bright-eyed and bushy-tailed” usually comes to mind. Unfortunately, initially, this was not the case for Marissa.

For years she struggled with a prosthesis that fitted uncomfortably, was difficult to walk with and normally took forever to put on – Marissa was unenthusiastic about her prosthetic journey and physical abilities. This young lady thought her life was reduced to walking slowly and focussing on every single step not to fall.

In life we all need people who believe in us despite the dark and gloomy situations we might find ourselves in. We believed in Marissa’s ability to walk with a prosthesis without difficulty. Her husband also believed that she could live life as the healthy young woman.

So, it was all up to Marissa. She had to make the choice. Stay stuck in the situation she’s currently in, or shift her thoughts to positive prosthetic fitting and commit to a new journey that will change her life and her mindset for ever.

Boy did she deliver! And by deliver, we mean actually deliver – a baby! After taking the first few steps with her new prosthesis she broke the news: “I am pregnant!”.

A pregnancy poses very specific challenges, not only to Marissa, but to her treating Prosthetist as well. Constant changes in centre of gravity, volume fluctuations and increased load placed on the stump. Marissa took every single one of these challenges in her stride.

As a baby shower gift we bought her a new dynamic foot. We are all parents and thought that this was the very best way to contribute. Following a detailed prosthetic fitting protocol was the key to ensuring her mobility during the pregnancy period.

LEFT: (From the left) Marissa and her husband while Marissa was pregnant. **MAIN PHOTO:** Marissa, her husband with their new-born.

The stakes were high and our responsibility towards Marissa unquestionable. An extended test socket period carried Marissa to motherhood.

Her little girl was born – healthy and well – and this proud mommy is now beaming with pride. But she should also be very proud of herself and the journey she successfully travelled.

Marissa’s picture has changed from gloomy, lack of energy and demotivation to the ultimate feel-good outcome. Marissa, we can now comfortably refer to you as “bright-eyed and bushy-tailed” while pushing your baby stroller and carrying the nappy bag over your shoulder! R

ABOUT THE AUTHOR

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

Seeing the future

A new future is finally insight for former optometrist, Gavin Klevansky, after he sustained a traumatic brain injury. Vanessa Klevansky shares

No one can ever accurately foretell our future. My brother Gavin seemed to be on track to what seemed to be the perfect life.

He was an optometrist with a very successful practice, a serious long-term relationship, a beautiful home and a close-kit family including myself and his two doting parents. He was surrounded by friends and had an active life racing cars, cycling and travelling.

This idyllic picture got derailed one seemingly run-of-the-mill morning as Gavin was travelling on his motorbike from home to work.

One. Split. Second.

Gavin was hit by a woman in a car who didn't see him when changing lanes. Gavin and the motorbike were flung up a hill. The bike stayed put, and he rolled down, landing with his head sideways, lifeless across the busy road.

He was resuscitated once. Then again. Then taken to the intensive care unit, where the neurologist told myself and my parents that he had sustained a severe axonal injury [shearing (tearing) of the long connecting nerve fibres in the brain] of the brain stem [the section that connects the brain to the spinal cord] plus multiple brain bleeds. The prognosis was bleak.

Gavin's coma lasted a week, which become a month, then two, then three. Yet, as a family, we just couldn't give up hope, despite the specialists telling us he would be vegetative for the rest of his life.

It's just not possible to give up on someone you love. So, when, after three months, he finally began to open his eyes, I believed that our prayers had been answered.

It wasn't until he returned home, completely reliant on caregivers to move, to eat, to do anything, that reality finally set it.

Every time he was lifted into the standing frame, Gavin would scream in pain. He was unresponsive when spoken to, unable to interact. It was brutally painful to watch.

But, somewhere in this man who had once had such a passion for life, the same spark existed. Very slowly, the determination and the drive to overcome began to deliver change. He regained more movement. Began to feed himself, tried to talk.

Gavin began to emerge from a cloud, coming into focus – with an incredible team of caregivers and therapists coaxing him along the journey, willing him to succeed. It can be in the most challenging moments that the most profound change can happen.

Gavin fell and cracked a rib. His therapies came to a halt as his new found mobility was severely limited by the pain caused by the fracture. He would be homebound, and a dark cloud of fear that he would regress enveloped all who cared for him.

We needed to find a physiotherapist who could come to Gavin's home to treat him, in the absence of him being able to continue his usual out of home therapies.

Gavin's new physiotherapist, rather than seeing the victim of terrible circumstances, saw something in Gavin that was still there, deep inside: an irrepressible ability to challenge the expected, to do things his own way, to break the rules.

So, the broken rib would be the instigator of a new chapter for Gavin, as he was challenged to move more, to stand with a walker and then walk. Later, he would be challenged to walk only with a walking cane, to walk unaided, to dance, play guitar, talk, write … to live.

MAIN PHOTO: Gavin Klevansky is slowly recovering after suffering a traumatic brain injury that doctors said would leave him unable to care for himself.
ABOVE: Gavin greets all his hobbies and activities with an unique enthusiasm and determination.

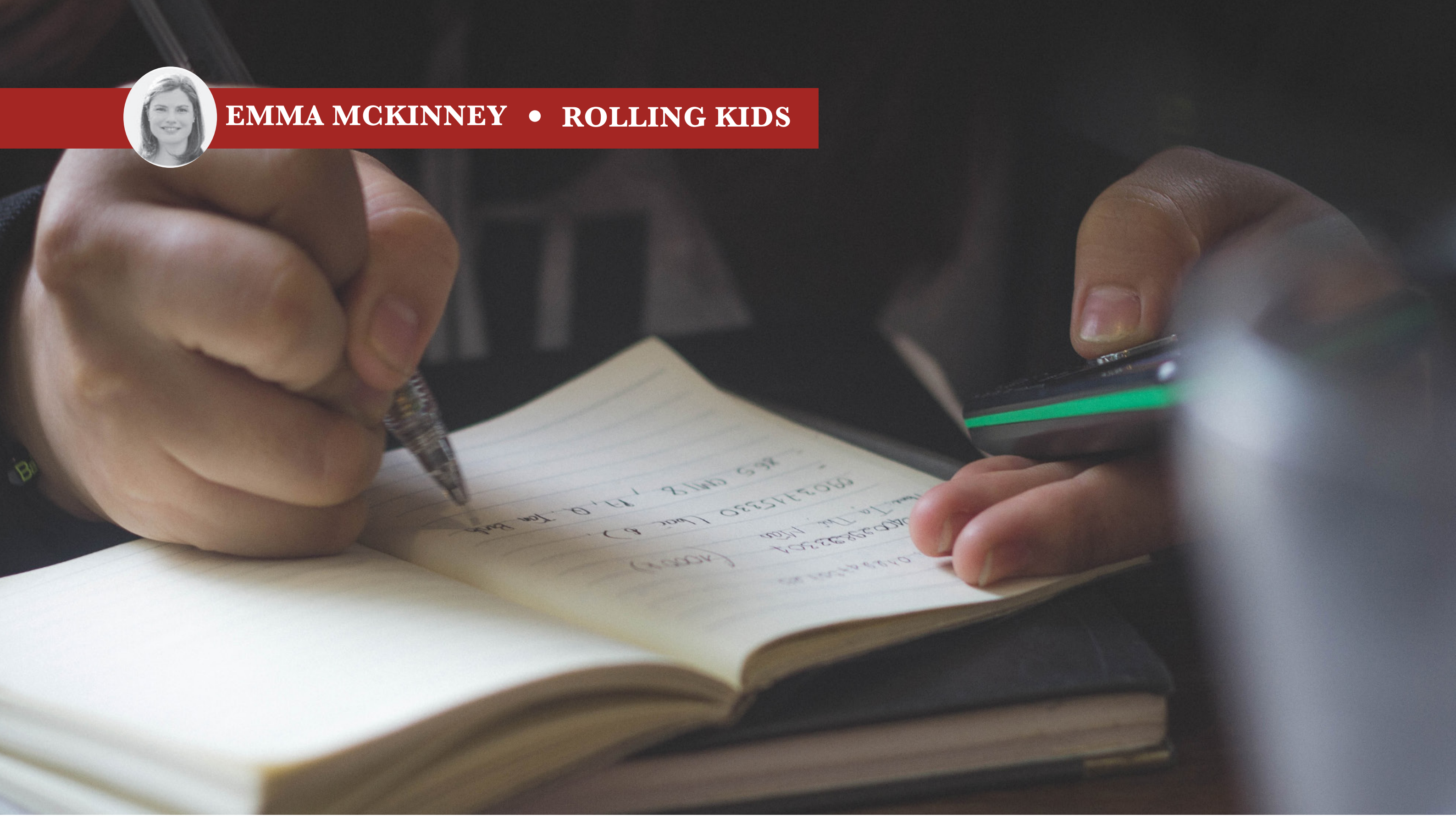
All photographs by Carolyn Gregorowski.

Today, despite both our parents passing, Gavin is supported by the most incredible team. Each day shows a new spark. When you ask, "What night is Friday night?", Gavin responds, "It's pizza night!".

He painstakingly writes beautiful cards and creates a variety of art. He always wants the music louder. He follows a very busy routine, with a huge variety of activities, all of which Gavin greets with his unique enthusiasm and determination.

So, while we may not be able to see the future, with love, and dedication, constant input, laughter, and tears, we see an opportunity for Gavin to live a rich and fulfilling life, as an inspiration not just to us, but to all who those who need a little reminder that in their future too, anything is possible.

EMMA MCKINNEY • ROLLING KIDS



Pursuing Tertiary education

Despite your level of schooling or job experience, there are ways to still pursue an education at a university or college

Previously, many children with disabilities never considered studying further because of inaccessible campuses, policies that discriminated against them, or because there were no support services available.

Over the years, there have been big drives to include students with disabilities in higher education institutions (HEIs) like universities and colleges. This month, we look at some tips you might want to use if you are considering studying further after school:

FIND WHAT INTERESTS YOU

While it is important to work out what subjects you enjoy and are good at, it is also important to find out what you are interested in outside of school.

You might really love working with children, maybe you could consider studying to be a teacher in a school or early childhood development (ECD) centre? When you are selecting your subjects for school, start thinking about which you might need for studying further.

FIND OUT MORE

Some schools have job-shadowing programmes where learners visit a place of work for a week to really see what employees do on a daily basis. If your school does not have this, you might want to make this happen yourself.

For example, if you love animals, you might want to call, write an e-mail, or visit an animal shelter or dog groomer and ask if you could volunteer during your school holidays.

This will give you a practical experience and you can see if this is really something you want to learn more about.

While there, try to see as many different parts of the job, ask questions and give it your best. Who knows, maybe you will be offered a part-time job that will help you gain experience!

WHAT COURSES ARE OFFERED

If you have a Life Orientation teacher who offers support in career guidance, tell her what you are interested in and ask for help.

If not, google search, or ask teachers, friends and family for advice on possible courses that you could take. After that, see which universities, colleges or training providers offer courses.

> **Try to see as many different parts of the job, ask questions and give it your best.**

Find out what subjects your need and what grades you must have in order to meet their entrance requirements. Make sure that the institution and courses are accredited.

There are many people who offer courses, take your money, but do not provide you with qualifications that are accredited, which may prevent you from getting a job.

RECOGNITION OF PRIOR LEARNING (RPL)

For some of us, studying after school was never an option because of the level of education or subjects that were offered when we were at school, having healthcare needs, having to get a job to support our families, or having children.

Some HEIs offer people who have never had the opportunity to study a chance to apply.

Some will offer an Recognition of Prior Learning (RPL) programme where you can prove that you will be able to take the course because of your workplace experiences, what you have done in your community, or how passionate you are about your area of interest.

In this programme you may be required to create a portfolio of evidence that will help those selecting applicants for the courses see what you have done and may consider overlooking your previous marks for example.

You may need to attend a bridging programme and put in a great deal of work. Have a look at the HEI's website and search for RPL requirements.

DISABILITY AND SUPPORT

As a prospective student with a disability the choice to disclose your disability is a choice only you can make. Previously, many people were discriminated against because of their disabilities.

The benefit of disclosing your disability is that you will be entitled to receive reasonable accommodations if the HEI has the funds available.

These could be additional time, a note taker, separate venues for writing exams. HEI's are also needing to meet their equity targets, which includes students with disabilities. Many HEI's now have disability services or units. Do a google search and see if your one has, and if so, make contact.

If you need financial support they may be able to guide you on what bursaries are available. They may also be able to assist you with your application forms.

The most important thing is that you need to be proactive and take responsibility for getting the advice and support you may need.

Ask for help, do your research, find out when the deadlines are, what documents your need, ask questions and find out more. R

ABOUT AUTHOR

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Delicate journey of rediscovery

It takes delicate and intentional actions to rediscover intimacy and sexuality after a spinal cord injury

Intimacy and sexuality are integral aspects of human relationships, serving as vehicles for emotional connection and physical expression.

However, the aftermath of a spinal cord injury (SCI) often casts a complex shadow over these dimensions, necessitating a delicate and intentional journey of rediscovery for both the individual with the injury and their partner.

CHALLENGES AND EMOTIONAL RESONANCE

The changes in physical function and sensation resulting from a SCI can trigger a myriad of emotions, ranging from frustration and anger to sadness and insecurity.

These emotional responses may be mirrored by partners, who might also grapple with their feelings of loss, confusion, and concern for their loved one.

In the realm of intimacy and sexuality, these emotions can create a substantial barrier, impeding the natural flow of connection and leaving both individuals feeling vulnerable and disconnected.

The injured individual may encounter altered sensations, loss of bodily autonomy, and changes in sexual function that challenge their self-perception and body image.

Partners, in turn, may find it difficult to balance their roles as caregiver and lover, navigating a landscape filled with ambiguity and uncertainty.

Thus, addressing the emotional impact of these challenges is paramount, requiring empathetic communication and a safe space for sharing thoughts and fears.

> “
> **Addressing the emotional impact of these challenges is paramount, requiring empathetic communication and a safe space for sharing thoughts and fears.**

EDUCATION AND EXPLORATION

An essential aspect of post-SCI intimacy is education, both for the individuals directly affected and for their partners.

Many couples may be unfamiliar with the potential physical changes and adaptations that come with a SCI, which can exacerbate anxiety and misconceptions.

It is vital to seek reliable information and professional guidance to dispel myths and misconceptions surrounding intimacy and sexuality after SCI.

By understanding the intricacies of the injury and its effects on physical sensations and sexual function, couples can embark on a journey of exploration.

This journey involves a willingness to experiment with various techniques and approaches that cater to the new circumstances.

Communication, once again, plays a central role, enabling partners to express their desires, preferences, and concerns.

Attending workshops or counselling sessions led by experienced sex therapists can provide practical tools and techniques for maintaining a fulfilling intimate life.

These sessions create a space for individuals and couples to ask questions, share experiences, and learn from others who have successfully navigated similar challenges.

RECONNECTING THROUGH EMOTIONAL AND PHYSICAL INTIMACY

Reconnecting on an emotional and physical level post-SCI requires patience, trust, and a commitment to mutual growth.

The journey of rediscovery entails a shift in focus from traditional notions of sexual performance to a broader understanding of intimacy – one that encompasses emotional closeness, affection, and shared experiences.

Engaging in activities that foster emotional closeness, such as open communication, shared hobbies, and quality time together, can help partners forge deeper connections.

Physical touch, affectionate gestures, and non-sexual forms of intimacy also play a vital role in rebuilding trust and intimacy.

Moreover, couples can explore alternative methods of physical pleasure that align with the individual’s capabilities and preferences.

This process of exploration can not only reignite physical intimacy but also strengthen the emotional bond, promoting a sense of unity and shared growth. R

ABOUT THE AUTHOR

Dr Danie Breedt is a passionate scholar-practitioner in the field of psychology. He divides his time between training, research and clinical practice. Danie works from an integrative interactional approach in psychotherapy, dealing with a wide range of emotional difficulties and sexual rehabilitation for patients with disabilities. He is the co-owner of Charis Psychological Services, a psychology practice that specialises in physical rehabilitation across South Africa.

True Christian Hearts

Written by Leon Mouton

My brother, Paul and his wife are permanent caravanners in the Dibiki Holiday Resort in Hartenbos owned by Oosie and Martie Pretorius. Paul suffers from Facioscapulohumeral Muscular Dystrophy, a debilitating neuro muscular disease that causes deterioration of the muscles in the entire body. Deterioration differs from person to person. Paul was still able to walk with the assistance of a cane, three months ago.

After contracting shingles, his nerve endings deteriorated to the extent that he has no feeling in his hands and all his limbs collapsed in a very short time, leaving him at the mercy of others. His dear wife Jeannie bearing much of the load.

Caravan life became difficult to impossible without the assistance of expensive equipment. The ablution facilities became out of reach as Paul could not even get upright in his bed.

He lost dignity in a very short space of time, due to his dependence on others for the most basic tasks that includes basic hygiene.

In came the contribution of two beautiful Christian people in the owners of the resort, Oosie and Martie. Where permanent caravanners such as Paul and Jeanne would normally move out of the resort over Christmas as it is a high income period, they were given a permanent space that would not necessitate them moving out.

Oosie and Martie built, at their own expense, ablution facilities for people with disabilities, that can only be described as magnificent. With the necessary assistance, Paul can now attend to his ablution duties in a much more dignified way, opening the door for him and Jeannie to continue living in the resort.

TOP: (From the left) Oosie and Martie Pretorius, owners of the Dibiki Holiday Resort.
LEFT: The new accessible bathroom.
RIGHT: Permanent resident Paul Mouton will greatly benefit from the new ablutions.

Oosie, Martie and the community around them clearly portray the principles and example set by Jesus. The whole community have contributed to making circumstances for Paul and Jeanne, live-able.

AfriNEAD Conference returns

The AfriNEAD Conference will be held at the Artscape in Cape Town from 29 November to 3 December 2023. The annual conference brings together researchers from around the world to discuss disability. Click here to read more about the event.

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