

ROLLING INSPIRATION

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The thought leadership publication for people with mobility impairments



SAB FOUNDATION AWARDS

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The following acronyms are used:

QASA = QuadPara Association of South Africa
SCI = spinal cord injury / spinal cord injured



EMPOWERING COMMUNITIES

Through its Social
Innovation and Disability
Empowerment Awards,
the SAB Foundation is
empowering communities!
P4



A FAREWELL

Former QASA CEO Ari
Seirlis takes a graceful bow
in his farewell letter, and
our community shows its
appreciation.
P14



ENERGY: LESS IS MORE

Guy Crankshaw provides
some valuable insights
into calculating how much
energy our bodies really
need.
P22



THE ATTRIBUTES OF A GOOD CAREGIVER

George Louw learns what
makes a good caregiver -
some results might surprise
you!
P6



GAUTRAIN GIVES BACK

Mariska Morris visits
Pillsbury Childcare Centre
to learn about Gautrain's
invaluable contribution to
this facility.
P18



EYE ON THE BALL

Mariska Morris interviews
top South African boccia
champion Brett Dakin and
learns about this sport.
P25



DEPRESSION AND SCI

Dr Ed Baalbergen discusses
depression and provides a
self-test to help determine
whether you're at risk.
P20



GET UP, DRESS UP AND SHOW UP

Wanda Boshoff shares how
making an effort with self-
care sets a great example
for her children.
P28



REGULARS

Upfront	2	Sport	24
Ida's corner	6	Employment	26
QASA news	9	Rolling kids	27
Travel	10	Parents on wheels	28
Amputee corner	12	Hotspot news	30
Medically speaking	20	Backchat	31
Sexuality	23	Calendar of events	32

CONTENTS

FIGHTING FOR EQUALITY

WHILE BIG STRIDES HAVE BEEN MADE TO IMPROVE THE ACCESSIBILITY OF PUBLIC TRANSPORT, MANY PEOPLE WITH DISABILITIES ARE BEING LEFT BEHIND. IS IT TIME FOR THE DISABILITY COMMUNITY TO TAKE MATTERS INTO THEIR OWN HANDS?

As we exit transport month and enter Disability Rights Awareness Month, I want to share my opinion on both these vital issues. Huge strides have been made in the rollout and delivery of accessible public transport. I acknowledge the role players who made this possible, but public transport still is inadequate and not inclusive.

There are still too many people left stranded on the pavement and at home while the economy moves on without them. People with disabilities require safe, secure, accessible, integrated and affordable public transport. The provision of accessible public transport is a mandate in various legislations, including the Constitution of South Africa, the United Nations' Convention on the Rights of Persons with Disabilities, the White Paper on the Rights of Persons with Disabilities and the National Land Transport Act.

People with disabilities – young and old – have been unable to integrate into society because this basic need for accessible transport has not been met. Without transport, public space and an inclusive built environment, people with disabilities cannot access jobs, generate an income or participate equality in society, as the Constitution requires.

Inaccessible transport denies us our right to access goods and services. We are discriminated against and treated


unequally. Equality ensures that individuals or groups of individuals are treated fairly and no less favourably than another group. It is the right of all people to have their social position respected and to be treated equally.

Maybe it is time to rethink how things have been done up until now. Maybe the disability sector should unite, rise and claim this one right. Let us use the focus on the awareness of our rights and make it count. There are numerous opportunities waiting if this one right is realised – but if it is not, what steps can be taken?

The Promotion of Equality and Prevention of Unfair Discrimination Act, also referred to as the Equality Act, could be used to ensure that this right is realised.

Proceedings under the Equality Act may be instituted by any person acting in their own interest, in the interest of someone unable to act on their own behalf, in the interest of a group or in public interest. Associations acting in the interests of its members or even the South African Human Rights Commission can institute proceedings.

And there is more ... It is the duty of the state and constitutional institutions to assist any person who wishes to institute proceedings in terms of or under the Equality Act. Hopefully we don't have to go this far and those in power will relook plans to ensure everyone is included.

I trust you all will have a safe and inclusive festive season. All the best for 2020! 



Raven Benny has been a C5, 6 and 7 quadriplegic since 2000. He is married and has five children, is mad about wheelchair rugby and represented South Africa in 2003 and 2005. He relocated from Cape Town to Durban, where he was appointed the Chief Operating Officer (COO) of QASA from August 1, 2019. email: coo@qasa.co.za



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BUSINESSES EMPOWERED BY SAB FOUNDATION AWARDS

AT THE ANNUAL SAB FOUNDATION SOCIAL INNOVATION AND DISABILITY EMPOWERMENT AWARDS, DR DAEMON MCCLUNAN, INVENTOR OF THE OPTISHUNT, WON THE 2019 DISABILITY EMPOWERMENT AWARD. MARISKA MORRIS REPORTS

Each year, the SAB Foundation identifies small businesses or entrepreneurs who are empowering their communities and people with disabilities through their unique innovations. These exceptional businesses are awarded prize money and gain access to expert business consultants for a year to support their growth.

After a vigorous vetting process, the 2019 Social Innovation and Disability Empowerment Award winners were announced in October at an event at the Polo Room at Inanda Club, Sandton.

Dr Daemon McClunan, CEO at LIQID Medical, was awarded joint first place in the Disability Empowerment category for his invention, The OptiShunt. This implantable device offers the world's first definitive treatment for glaucoma, a disease that is the leading cause of disability due to irreversible blindness globally. McClunan shared his win with Specialised Seating for Disabled Children.

The OptiShunt drains excessive fluid from the eyes of a glaucoma patient using a naturally occurring fluid reservoir

behind the eye ball to equalise the pressure between the eye and the optic nerve.

"I heard about the SAB Foundation Social Innovation and Disability Empowerment Awards through a friend and previous winner Will Mapham," Dr McClunan explained. Mapham won the SAB Foundation Social Innovation Award in 2013 for his Vula app, which allows primary healthcare workers in rural areas to make quick and simple referrals to on-call specialists.

"It was clear that the SAB Foundation was perfectly aligned with our mission to make a big impact in the fight against the leading cause of disability in South Africa: visual loss and blindness," said Dr McClunan. "Winning the award is a major achievement that has made us feel vindicated in all the hard work we've put into The OptiShunt project."

"It has emboldened us in our belief that we are on the right track in our fight against blindness. It has also humbled us to learn about all the other inspiring innovators fighting to improve the lives of people facing various disabilities across South Africa."

The R1,3 million in prize money will finance the first-in-man clinical trial of The OptiShunt at Groote Schuur Hospital in Cape Town later this year. It will also enable the company to employ its first full-time employee and prepare the OptiShunt for its international disclosure at the World Ophthalmology Congress in June 2020.

Second place was awarded to Lucy Slaviero and Little Eden CEO Xelda Rohrbeck, who developed the ShowerBath. This raised, heated concrete bath-shower allows caregivers

LEFT: (From the left) Mpho Mohlolo, William Rowland, external trustee of SAB Foundation, Dr Daemon McClunan, winner of the Disability Empowerment Award, and Ntandokazi Nodada, social innovation project manager at SAB Foundation.

BELOW: Little Eden CEO Xelda Rohrbeck (centre) accepts second place at the 2019 SAB Foundation Disability Empowerment Awards for the organisation's innovative ShowerBath.

RIGHT: The ShowerBath provides a heated, elevated surface to allow caregivers to comfortably bath residents with severe disabilities.



at Little Eden to bath residents with severe disabilities comfortably. Traditional bathtubs are strenuous on the backs of caregivers.

The SAB Foundation's vision of improving the lives of people with disabilities resonated with their mission, said Rohrbeck: "The Disability Empowerment Award is aimed at promoting social innovations that improve quality of life for people with disabilities through assistive devices, training or employment opportunities.

"This resonated with the reason why the ShowerBath was invented. It enables the easy bathing of individuals with profound intellectual and physical disabilities who are unable to bath themselves and depend on caregivers, while easing back strain put on the caregiver."

Winning second place and R900 000 in prize money will make it possible for Little Eden to roll out the initiative into all their homes and then throughout South Africa at organisations, care facilities, hospitals and institutions caring for people who are unable to bath themselves.

"The prize money will enable Little Eden to enhance the prototype and develop a business plan to roll out the product. The potential revenue earnings from the sale of the Little Eden ShowerBath would contribute towards Little

Eden's sustainability to reduce the organisation's reliance on donor funding," Rohrbeck said.

A planned total of 14 ShowerBaths – seven per home – will be rolled out at Little Eden initially. Commenting on the importance of these baths, Rohrbeck said: "Lucy Slaviero designed the ShowerBath when she saw how caregivers struggled with bathing, in particular the elderly with profound intellectual disabilities and limited mobility.

"Traditional baths put strain on the caregiver's back, inhibits a hygienic bathing process and restricts movement by the caregiver. Since the prototype was implemented, it has received many positive reviews from the caregivers.


"It solves a social and health problem relating to effective personal hygiene care for the person being bathed while



"The SAB Foundation was perfectly aligned with our mission to make a big impact in the fight against the leading cause of disability in South Africa."

contributing to the wellbeing of the caregiver. In addition, it is a viable low-cost solution for Little Eden that is not based on electromechanical hoists, which are expensive and prone to breakdowns," Rohrbeck concludes.

Since 2010, the SAB Foundation has been identifying, supporting and helping to scale social innovations that demonstrate a sustainable business model while solving a social problem. A total of R13,65 million was awarded to the 20 finalists for the 2019 Social Innovation and Disability Empowerment Awards, with Regenize – a free recycling service with reward systems – snapping up first place in the Social Innovation category.

"To date, we have committed more than R77 million towards promoting social innovation and supported 162 businesses that solve social issues and provide solutions to people with disabilities. Over and above this, we are proud that these businesses have also created 614 jobs," concluded Bridgit Evans, director of the SAB Foundation. 



ATTRIBUTES OF A GOOD CAREGIVER

WHEN WE ASKED READERS TO LIST THE MOST IMPORTANT ATTRIBUTES OF A GOOD CAREGIVER, THE RESULTS PROVIDED INCREDIBLE INSIGHTS AND RAISED CONCERNS ABOUT SOME SIGNIFICANT BUT UNDER-APPRECIATED CHARACTERISTICS

In a recent survey by QASA on the attributes of a good caregiver that attracted 48 responses, we listed six attributes with five characteristics per attribute. Some of the characteristics pertained to more than one attribute. For example, the importance of pressure sore prevention was covered in two attributes: "Competence with techniques"; and "Knowledge of dangerous complications".

The questionnaire requested respondents to grade the importance of each characteristic on a scale of one to five and the importance of each attribute on a scale of one to six. Based on the collective results, a score out of five was calculated for each characteristic per attribute. A similar score was calculated for each attribute to illustrate the importance of each attribute in relation to one another.

Lastly, the free text comments were grouped into the underlying attributes deducted from the comments. The scores of each characteristic was multiplied by the respective attribute scores. This provided an attribute-weighted overall ranking of the 30 characteristics as displayed in Table 1.

The results illustrate very interesting and positive findings but also raise several red flags. In this article we reflect on the positive findings as well as the red flags. Where relevant, reference will be made to previous ROLLING INSPIRATION articles, which can be found on the website by clicking on the "Ida's Corner" tab in the "Regulars" drop-down menu.

THE POSITIVES

The characteristics of the attribute "Commitment to caring" dominated the top 10, including top scoring "Work ethic", "Willingness to go the extra mile" and "Anticipation of needs". Personal hygiene, bowel care and pressure sore prevention also featured strongly.

It is evident that the respondents were united in their regard for the importance of a positive and constructive caregiver attitude as well as competence in the execution of their duties. Characteristics such as compassion, gentleness and empathy were all at the lower. The free text questions on positive and negative caregiver characteristics also focussed mainly on caregiver attitude and hygiene.

I consider this very positive, but I must point out that

all of the above cuts both ways. Constructive and caring attitudes as well as excellence in the execution of duties must be appreciated and nurtured by the person who is being cared for.

All too often I hear of and experience that people being cared for consider caregivers as a right that they pay for. They become overly critical and abusive of caregivers, at times even accusing them of being incompetent or stupid. Very often such abuse stems from the person's frustration with their own situation and is more based in emotion than fact. Service excellence and positive attitudes become eroded by constant criticism, accusations and abuse.

At best, caregivers develop thick skins, toss the abuse over their shoulders and carry on for the sake of the income. At worst, the middle finger is raised as they walk away. Neither reaction is in the interest of the person that is being cared for.

For this reason, the contract between the caregiver and the person with an SCI must not only contain a service level agreement (SLA), but also explicit ground rules agreed upon between both parties. Competence and attitude must be measured against the SLA and the ground rules.

Articles that could assist include "Neurogenic Bowel" (Issue 1, 2019); "Pressure Sores" (Issue 2, 2016), "Fruits of Frustration" (Issue 2, 2018); and "Proactive Patience" (Issue 6, 2016).

THE CONCERNS

The low scores given to certain characteristics raised concern that respondents did not appreciate their importance. The most significant concerns are listed below:

- 58,5 percent of respondents considered passive movement exercises as not being part of the duties of a caregiver and 35 percent felt that exercises for the relief of muscle spasms in spasticity need not be included in the functions of a caregiver;
- 58,5 percent of respondents rejected management of fluid intake as an important attribute of a good caregiver;
- 41 percent believed it is not important for caregivers to understand the importance of dressing according to the prevailing climate;
- 32,6 percent of respondents did not believe that knowledge of autonomic dysreflexia is important in a caregiver, whereas 28 percent considered it to be vital for caregivers to know about it; and
- 56,4 percent of respondents rejected assertiveness as a positive characteristic of a caregiver.

References to articles in previous editions of ROLLING INSPIRATION are listed below each summary of the importance of the listed concerns.

• Passive movements

This is a daily routine of gently moving the paralysed joints through their range of movements. This prevents contractures from shortening the range of movement of the joints, which can complicate getting dressed and impact on your posture in your wheelchair. Passive movements are easy to do and well within the capabilities of a caregiver.

However, passive movements are very individual according to the needs of the individual. There are dos

and don'ts involved, as well as potential dangers. It is recommended that your biokineticist or physiotherapist draws up a passive movement routine for you.

Learn more in "Move It" (Issue 2, 2016).

• Muscle spasms in spasticity

Apart from an increased muscle tone, spastic muscles can also cause uncontrolled rapid shaking movements known as clonus and more pronounced myoclonic jerks that can propel the person out of their wheelchair or send their duvet flying. These spasms can usually be relieved by gently shifting, repositioning or lightly stroking the limb.

Often spasms are a sign of discomfort such as a full bladder, a pressure sore, an ingrown toenail or an injury of some kind. There is also a close correlation between the causes of myoclonic jerks and autonomic dysreflexia. It is imperative that your caregiver knows how to relieve spasms and to look for underlying causes of discomfort – especially if the spasms are ongoing.

Learn more in "Managing Spasticity" (Issue 4, 2016).

• Fluid intake

A focus on appropriate fluid intake is extremely important. Low or inappropriate fluid intake can cause dehydration and, eventually, kidney failure. Appropriate fluid intake as a rule of thumb means at least three litres per day, of which at least 50 percent must be water.

Fizzy drinks, fruit juices and beer are packed with sugar, which, apart from not being great sources of fluids, causes

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sugar rushes and obesity. A further concern is that persons with neurogenic bladders tend to "run dry" to reduce the frustration and anxieties related to bladder management.

All of the above requires caregivers to have knowledge on fluid intake in order to support (and keep tabs on) the people they care for.

Learn more in "Food for Thought" (Issue 3, 2017).

• Weather-conscious dressing

Many people with an SCI, especially those with higher-level injuries, lack awareness about temperature or may even have adjusted temperature regulators that cause discomfort, such as feeling cold when it is hot. You know who you are ... It is vital that your caregivers know how to accommodate your needs and preferences.

Learn more in "Body Temperature Management" (Issue 5, 2018).

• Autonomic dysreflexia (AD)

This is a complication of higher-level SCIs that is very debilitating and can be fatal. An added complication is

that many (most) doctors don't know about it or deny its existence. The triggers of AD are similar to those listed for myoclonic jerks under spasticity. Preventative management by a caregiver requires that they know about the condition.

A brief information document could be kept in the caregiver's wallet or purse to give to the attending doctor if the person with SCI is incapacitated.

Learn more in "Autonomic dysreflexia" (Issue 6, 2018).

• Assertiveness

It's a given fact that using a wheelchair doesn't automatically turn us into angels. Caregivers need a good degree of assertiveness to deflect the poo we tend to fling at them. Compassion and gentleness are all good and well, but without a good dollop of assertiveness they will fold and walk away.

In conclusion, a good caregiver is not merely an employee – they become valuable partners in our challenging lives. We need to nurture them and entrust them with our challenges so that in times when we find it difficult to carry on, their support can help us face life again. [\[7\]](#)

Table 1. Weighted Scores of Importance per Characteristic

Attribute	Characteristic	Attribute Score (AS)	Characteristic Score (CS)	AS X CS
Commitment to Caring	Work ethic	4.43	3.64	16.13
Understanding of my Needs	Importance of personal hygiene	3.98	3.81	15.16
Understanding of my Needs	Importance of a bowel care cycle	3.98	3.75	14.93
Commitment to Caring	Commitment to Caring	4.43	3.36	14.88
Knowledge of Dangerous Complications	Knowledge of pressure sore prevention	3.16	4.34	13.71
Physical Abilities	Bathing/showering/general cleanliness & hygiene	3.59	3.67	13.18
Commitment to Caring	Willing to go the "extra mile"	4.43	2.92	12.94
Commitment to Caring	Anticipation of needs	4.43	2.89	12.80
Disposition	Honesty	3.00	4.13	12.39
Commitment to Caring	Willingness to learn	4.43	2.78	12.32
Physical Abilities	Transfer technique into and from wheelchair	3.59	3.43	12.31
Understanding of my Needs	Importance of a bladder care routine	3.98	2.97	11.82
Competence with Techniques	Examination for potential pressure sores	3.10	3.81	11.81
Understanding of my Needs	Importance of body positioning	3.98	2.92	11.62
Disposition	Compassion	3.00	3.55	10.65
Competence with Techniques	Bowel care techniques	3.10	3.35	10.39
Physical Abilities	Ability to turn and position me in bed	3.59	2.84	10.20
Knowledge of Dangerous Complications	Dangers of urinary tract infections	3.16	3.19	10.08
Competence with Techniques	Body positioning in bed and in chair	3.10	3.19	9.89
Physical Abilities	Assistance with dressing and undressing	3.59	2.75	9.87
Knowledge of Dangerous Complications	Importance of a good bowel routine	3.16	3.05	9.64
Physical Abilities	movement exercises	3.59	2.65	9.51
Knowledge of Dangerous Complications	Potential triggers of Autonomic Dysreflexia	3.16	2.91	9.20
Competence with Techniques	Bladder care techniques	3.10	2.92	9.05
Disposition	Gentleness	3.00	3.00	9.00
Disposition	Empathy	3.00	2.76	8.28
Understanding of my Needs	Importance of appropriate fluid intake	3.98	2.02	8.04
Competence with Techniques	Passive movement exercises	3.10	2.15	6.67
Knowledge of Dangerous Complications	Ensure appropriately dressed for prevailing climate	3.16	2.10	6.64
Disposition	Assertiveness	3.00	1.97	5.91



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

WORK READINESS PROGRAMME SUPPORTS HOLISTIC DEVELOPMENT

In 2016, Katleho Moeketsi was excitedly preparing to work as a qualified teacher. But instead, his journey as a C4/C5 quadriplegic started when he was hit by a car while waiting to cross the road. During his recovery, the economic and risk management graduate made a plan.



ABOVE: (from the left) Johannes Sithole and Katleho Moeketsi.

Moeketsi joined the QASA Work Readiness Programme, where he is readying himself for permanent employment. The programme encourages holistic development, which, for Moeketsi, included obtaining his driver's licence.

He says getting his licence has brought hope and courage back into his life. Now he plans to secure permanent employment through the programme that has changed many lives in the mere six months of its existence. Moeketsi thanked the QASA team for their professionalism and willingness to assist.

Moeketsi was not the only participant in the programme to benefit from its holistic approach. Johannes Sithole suffered an SCI when he sustained a gunshot. The 28-year-old was thrilled to learn that he would be able to drive again after his injury. He passed his driver's licence test on the first try! His struggle to find accessible transport is over.

Sithole encourages all wheelchair users to make use of the services offered by QASA. He thanked the QASA staff for their ongoing support and dedication to helping paraplegics and quadriplegics realise their full potential. QASA would like to wish Sithole and Moeketsi all the best in this new chapter of their lives!

FIRST PASS IN DRIVE-FROM- WHEELCHAIR RENAULT

Tinyiko Gwambe was born with a physical disability called tetra-amelia congenital syndrome. The 23-year-old graduated with a distinction from the University of Pretoria to obtain her bachelor's degree in social work with a dream to drive regardless of her disability.

Unfortunately she was not a suitable candidate for the Driving Ambitions project when she initially applied. But after acquiring the Renault Kangoo, the Driving Ambitions programme could finally welcome Gwambe.

The new vehicle allows the driver to be seated in their wheelchair and offers various automations to assist people with more severe mobility impairments. Gwambe was assessed by Caroline Rule and passed her test on her first try!

Gwambe says getting her licence will give her more opportunities. She would like to thank Rule, Des Harmse, the QASA team, and friends and family for all the support. QASA wishes this tenacious lady well for the future.



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GETTING YOUR HOLIDAY ON

SOME ACCOMMODATION SUGGESTIONS FOR THOSE PLANNING TO SPEND THE DECEMBER HOLIDAY SEASON IN CAPE TOWN OR DURBAN



As we hurtle towards the end of another year, we are all looking forward to some rest and relaxation. Here are some accessible accommodation establishments you may find useful if you have not made holiday plans yet.

HEIDI'S B&B - TABLEVIEW, CAPE TOWN

While in Cape Town, I usually try to stay at Heidi and Russell Vollmer's bed and breakfast in Tableview. Two blocks from the Bayside Mall and a block from the M14 and a MyCiTi bus route, this converted suite, which is listed on Airbnb, is situated above the garage and accessed through a private entrance in the covered courtyard and up a paved ramp.

The suite consists of a bedroom and a bathroom with a roll-in shower and grabrails at the toilet. There is ample cupboard space. The unit is equipped with all the necessities (and a few extras) required for a bed and breakfast.

The property is not marketed as an accessible accommodation option, as the owners feel it doesn't meet all the universal accessible standards yet. However, if you can manage in smaller space, this is the place for you!

Breakfast is served in the main house and residents have access to the beautiful garden, which includes wheelchair access to the pool. There is a ramp along the side that allows level transfer to the paving around the pool.

You must love dogs if you'd like to stay here, as there are two service animals who are very keen to assist if you



arrive in a wheelchair, as well as the boisterous and loving Kimmi. They are one of the reasons why I absolutely love visiting here, as I'm unable to keep pets in my apartment. I get my dose of unconditional love from the furry Vollmer trio. For more information, visit the Airbnb website and select the Heidi's@home property, or contact the owners at heidivollmer@iafrica.com.

ONOMO HOTEL - DURBAN

I've found a gem in this upmarket hotel, which is part of a chain that offers great facilities at a reasonable price within the business districts of many cities on the African continent. The name was chosen as a tribute to the mythology of the Dogon culture found in Mali, West Africa: the son of the



sky goddess Ama, Onomo is responsible for creating harmony on earth.


The Onomo Hotel Durban is situated near the Durban International Convention Centre, behind the North Beach hotels. It offers a 24-hour reception desk within an relaxed, open-plan entrance space, which also includes a bar, a lounge and dining facilities.

The hotel has 160 rooms in total, of which seven are accessible. The rooms are all well appointed and spacious, and include a workspace and a small couch each.

There are conference rooms, and Wi-Fi is available throughout the property. The underground parking



garage includes two accessible parking bays. An airport shuttle service completes the offering. Visit the website for more information on this hotel and others within the group: www.onomohotel.com.

Whatever your plans for the festive season – whether you'll be chilling at one destination or travelling to many – please travel safely! 



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

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A FIGHTING SPIRIT


AFTER A HORRIFIC ACCIDENT AT HIS PLACE OF WORK, CLIVE ISAKS HAD TO ADJUST TO LIFE WITH TWO PROSTHETIC HANDS – AND HE HAS DONE SO WITH COURAGE

If you are working with an industrial electronic metal guillotine and, while trying to remove a metal plate stuck in the mechanism, the jaws accidentally close, instantly amputating both your hands, your life as you knew it changes immediately. This was the reality for Clive Isaks at the time of his transfer to the Netcare Rehabilitation Hospital to start his four-month rehabilitation process.

The human hand is far more than just a sensitive and highly functional physiological design for grasping and manipulating. It is precise, strong and versatile. It plays a vital role in communication and other social interactions. Your hands start working in the morning when you switch off the alarm clock and stop when you switch of the bedside

light at night. They preform all day long and are involved in most if not all of your tasks.

With eagerness and drive, Isaks dived right into the rehabilitation process. He quickly mastered most of his challenges, including the difficult rehabilitation exercises. He had to learn how to do all activities in his daily routine with his new prostheses.

Isaks has a fighting spirit that absolutely astonished his rehabilitation team. He kept at every single task he was given with determination and courage until he was successful, without ever giving up. We are all faced with challenges in our daily lives, challenges that might seem severe and overwhelming. Maybe we should take a step back and learn something about determination and courage from this remarkable person! 



ABOVE: With the help of his prostheses and rehabilitation exercises, Clive Isaks is still able to do activities that require fine motor skills, including beading and painting.



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

SABAT® WISHES YOU ALL THE BEST!



Thank you, Ari for the great relationship **QASA** and **SABAT® Batteries** have enjoyed over many years. They have been happy years which we will always remember fondly. Best wishes for a very happy retirement.



A FAREWELL FROM ARI SEIRLIS

FORMER QASA CEO ARI SEIRLIS TAKES A LAST GRACEFUL BOW IN HIS FAREWELL LETTER, WITH THE DISABILITY COMMUNITY SHOWING ITS APPRECIATION FOR THIS INCREDIBLE MAN WHO HAS DEDICATED HIS LIFE SO FAR TO SERVING PEOPLE WITH DISABILITIES

It's unusual for an NGO to have a CEO for overly long, yet I've held the title at QASA for 18 years. The career has been cut shorter than I would have liked because of the incessant pain and discomfort caused by ankylosing spondylitis, with which I was diagnosed in 2018.

Now I would like to share with you some parts of this unusual journey as I say farewell to the readers of ROLLING INSPIRATION and the wider QASA fraternity.

I broke my neck in a diving accident in 1985 at the age of 23, and my life changed dramatically. I was discharged from rehabilitation six months later as a C5 quadriplegic. Fortunately (in a way), I had led a full and physically active life up until that point. I had been to university (although for just a short time); had served my two years in the military;

fought in the war in Angola with the Bushman trackers; run the Comrades Marathon; and I was studying marketing when my accident happened.

I say "fortunately" because these experiences gave me all the skills and foundation for a mind-set that allowed me to face my future with its special challenges. I had a daunting mobility impairment and was learning how to be a wheelchair user.

I was "disabled" (the political definition), incontinent and facing uncertainty about employment, opportunity and sexuality. I was trying to work out how I was going to gather my dreams and face my future.

With limited space in this "farewell chapter", I would like to focus on my career at QASA. I joined an SCI support group very soon after my accident. This group turned into the Quadriplegic Association of KwaZulu-Natal, where I

cut my teeth in the complexities and challenges of NGO leadership, strategy and sustainability.

Many years later, I was elected chairperson of the QASA Board, on which I served for five years. Then, after a fair process, I was offered the position of CEO. I gave up my business after realising that the challenge and opportunity to lead QASA was far greater than the benefit of a successful small business.

In 2001, QASA's balance sheet was R70 000 and I can proudly say that I have handed the organisation to the 2019 Management Board and the new COO with the balance sheet of a sustainable R17 million made up of infrastructure, investments and cash reserves, as well as the peace of mind that QASA received unqualified financial audits for 18 consecutive years.

It has been a long and hard 18 years that involved travelling around the country at least 15 to 20 days a month, working six days a week and at least 10 hours a day. Honestly, it was my crutch to coping with quadriplegia. So I am especially grateful for that appointment in 2001.

It kept me out of trouble, positive and thinking ahead rather than looking backwards. Most importantly, it gave me the opportunity to create my legacy in the disability sector and change people's lives for the better.

I found I had to grasp the challenge of being innovative, sometimes even visionary, while ensuring and practically securing the right resources, then deploying them with

more than R7 million in unrestricted funding for QASA. It also gave me the opportunity to drive my adapted off-road quad bike for 16 years in a row from Johannesburg to Durban – each an adventure I'll never forget and made possible by the incredible support of friends in the team.

– The opportunity to spend time with Christopher Reeve on a visit to the United States was another highlight. Our deep conversations and debates about the necessity to walk were very thought-provoking and ended with me sticking to my guns and concluding that "walking is overrated"!



ABOVE: The annual Quads4Quads event raised R7 million for QASA, but also gave Ari Seirlis the opportunity to drive his adapted off-road quad bike.

LEFT: Seirlis dedicated nearly two decades of his life to bettering the lives of QASA members.



adequate monitoring and evaluation, all of which became part of the implementation of a theory of change. Some of the highlights of this period included:

– When charitable programmes and campaigns were still new, QASA founded TakkieTax, an incredible brand that, unfortunately, we had to abandon in the interests of good governance as the campaign agents decided to take more than QASA.

– The Quad Squad Day campaign that followed was a very creative offering to the public too, with Christopher Reeve (also known as Superman) giving us his support.

– The Quads4Quads event originated from a meeting I had with "Glenn and Corinne". We have since become close friends and this unique off-road motorbike epic has raised

– A working assignment of three weeks in Stockholm, Sweden, was life-changing. It gave me insight into equitable environments and an understanding of the socialist model of opportunity for people with disabilities.

– I was privileged to be the keynote speaker in Melbourne, Australia, at the World Spinal Cord Injury Conference, and to work on an assignment in San Francisco on behalf of SABS to ensure South Africa was well represented in the development of global standards for wheelchair manufacturing.

Other memorable projects that have enabled QASA to provide its members, the broader disability sector and general public with a full spectrum of services include:

- Driving Ambitions – a project that gives people with disabilities the opportunity of learning to drive;
- Buckle Up ("We don't want new members") – a unique road safety awareness campaign that became a brand on its own and gave QASA incredible exposure and credibility;
- Recently launched and already a gem, the Work Readiness Programme provides training for promising QASA members and includes three Digital Village computer training centres;
- The founding of and involvement in the rehabilitation centre Nurture Aurora Port Elizabeth;
- Bags of Hope, a unique database development project; and

- The founding of the ROLLING INSPIRATION magazine, which has published more than 90 editions and is a world-class publication.


QASA has become well known for its advocacy and lobbying initiatives with sometimes some unexpected outcomes. For instance, we joined OUTA to stop e-tolls and ensured exemption for people with disabilities through this illegitimate programme. (This was one of my toughest lobby assignments and included a death threat.)

We also led a campaign to ensure accessibility for people with disabilities to the 2010 Soccer World Cup stadia. We disrupted the World Architects Conference in Durban to have a memorandum of understanding signed that ensures the principles of universal access are taught in all schools of architecture and design (a world first by an NGO).

Throughout, I have been grateful for the strong relationships we have developed with Southern African Spinal Cord Association (SASCA), and to the Chris Burger Petro Jackson Players' Fund, for the nomination to serve on the Presidential Working Group on Disability and as executive of the South African Disability Alliance (SADA) for more than a decade.

I can't possibly list all the people who have been part of my journey within the limited space I have, but I must single out the late Neville Cohen for inspiring me and driving me till his last day; Wayne Duvenage, who got me to understand and engage in social and civil courage; my late mother, Joan, and my sister Angela, who made big contributions to QASA in many ways while always supporting me unconditionally; and Louise Rode, my PA and friend for the past 12 years. She has always been so efficient in all her tasks and made it easier for me to be effective logistically.

Finally, what has driven me? It has always been the sad witnessing of the terrible conditions (especially in rural areas) that quadriplegics and paraplegics have had to survive in, and the shocking lack of service delivery in health and social development, as well as the lack of or meagre job offerings available to them.

These were drivers to overwork and overperform in an attempt to find and implement some meaningful solutions. I have enjoyed being part of some of them. 

TRIBUTES TO A GREAT MAN

Ari Seirlis, what an inspirational human being! Selfless, compassionate and a fighter for a noble cause. Your legacy for championing those with mobility issues will live on. Thank you for fighting for an improved standard of care. Coloplast salutes you, a legend, for making life easier.

Coloplast South Africa

On behalf all our staff and customers we wish you, Ari, all the best while you recharge your batteries and prepare yourself for your next innings! Your integrity, commitment and grit have been and will continue to be an inspiration to all of us. All the very best.

CE Mobility

We would like to thank Ari Seirlis for the great relationship QASA and SABAT Batteries have enjoyed over many years. Your role was pivotal in setting up a partnership that has lasted close on 15 years and has contributed positively to the many QASA members involved.

SABAT Batteries

Farewell to Ari Seirlis! You were very supportive of the work done within Life Rehabilitation facilities and the disability community. You have touched many lives in immeasurable ways. You will be missed. May your legacy live on.

Life Healthcare

Thank you, Ari, for being a huge support to our organisation over many years. Your professional advice, expertise, encouragement and understanding have enabled us to provide the best possible care to our rugby players, whose lives have been changed.

Chris Burger Petro Jackson Players' Fund

If I had to dream up an acronym that described what my friend, Ari, brought to QASA, it would be PPPR: Passion, Productivity, Perseverance and Resilience. Ari radiates an aura of can-do capability and authority that earned him the respect of leaders and persons of influence in government, private enterprise and in the NGO environment.

He has a way of enthusing audiences, but also of rapping-over-the-knuckles that left you with the knowledge: "Ari has spoken". Ari also doesn't suffer incompetence, laziness or dishonesty, and this has left behind people who don't exactly consider him their favourite person – but "if you never made any enemies, you did not try hard enough".

The one thing that no one can say about Ari is that he did not try hard enough. So farewell and rest well, Ari, my friend. You've earned it.

George Louw

I have known Ari too long to mention – it might give both our ages away! Ari, you really are an inspiration. Despite the daily challenges that SCI has brought to your life, you have accepted the challenge head-on and have not only been an inspiration to the disability community but to all who have been privileged to be part of your journey.

You have been a beacon of hope for people with disabilities, driven so many projects to assist the disability community, and made a lifelong commitment to fight for disability rights. May you deservedly enjoy your retirement. But I somehow don't think we will see you sit back and watch!

Ed Baalbergen

FLYING THE COOP

FOR WHEELCHAIR USERS WHO WANT TO LEAVE THEIR FAMILY HOME BUT ARE NOT QUITE READY TO LIVE ON THEIR OWN, THERE ARE SOME ALTERNATIVE HOUSING OPTIONS

There are various reasons to consider assisted living or self-help centres, whether it is to gain better access to education or the formal labour market, because the family home can't be adapted or to access 24-hour care. Fortunately, there are numerous options.

Once you've made the decision to look for alternative options, carefully consider what you hope to get out of the living arrangement. Do you simply want to move out of your family home? Do you require full-time assistance? This will determine the kind of housing you can look at.

INDEPENDENT LIVING

Ann Harding Cheshire Home in Northwold, Johannesburg, is introducing independent living cottages that function in a similar way as a retirement village. A wheelchair user purchases a two-bedroom, two-bathroom cottage for R1,79 million that can be used as the buyer wants. The second bedroom, for example, can be rented out or could house a caregiver.

The houses are fully wheelchair accessible and encourages



completely independent living. When the wheelchair user moves, the property is sold, with the original investment and 25 percent of any profit returned to the seller. While it is an opportunity to invest in property, you are not required to purchase it in cash. For more information contact LPB Projects on 082 338 3416 or robbielpb@gmail.com.

SELF-HELP CENTRES

QASA established various self-help centres that essentially offer communal living for wheelchair users, with accommodation, meals, transport and care attendants provided. The residents are responsible for funding and managing the centre, including hiring staff, as a collective.

These centres are meant to give people with disabilities a stepping stone to purchasing their own homes. There is a total of 15 centres across South Africa. For more information, visit www.qasa.co.za/self-help-centres/.

ASSISTED LIVING

For individuals who require a more intensive level of care, there are several assisted living facilities to consider. Below are some of the options. ^[1]

Assisted living centre	Province	Phone number
Cluny Farm Centre	Gauteng	011 702 1690
Cresset House	Gauteng	011 314 1148
Huis Cornelius - Siyabonga	Western Cape	022 713 5730
Lake Farm Centre	Eastern Cape	041 379 1555
Leonard Cheshire Homes	Gauteng	011 792 3510
Nazareth Care	Countrywide	011 648 1002
Robertson House	Western Cape	021 551 3780/6
Woodside Special Care Centre	Western Cape	021 696 2811



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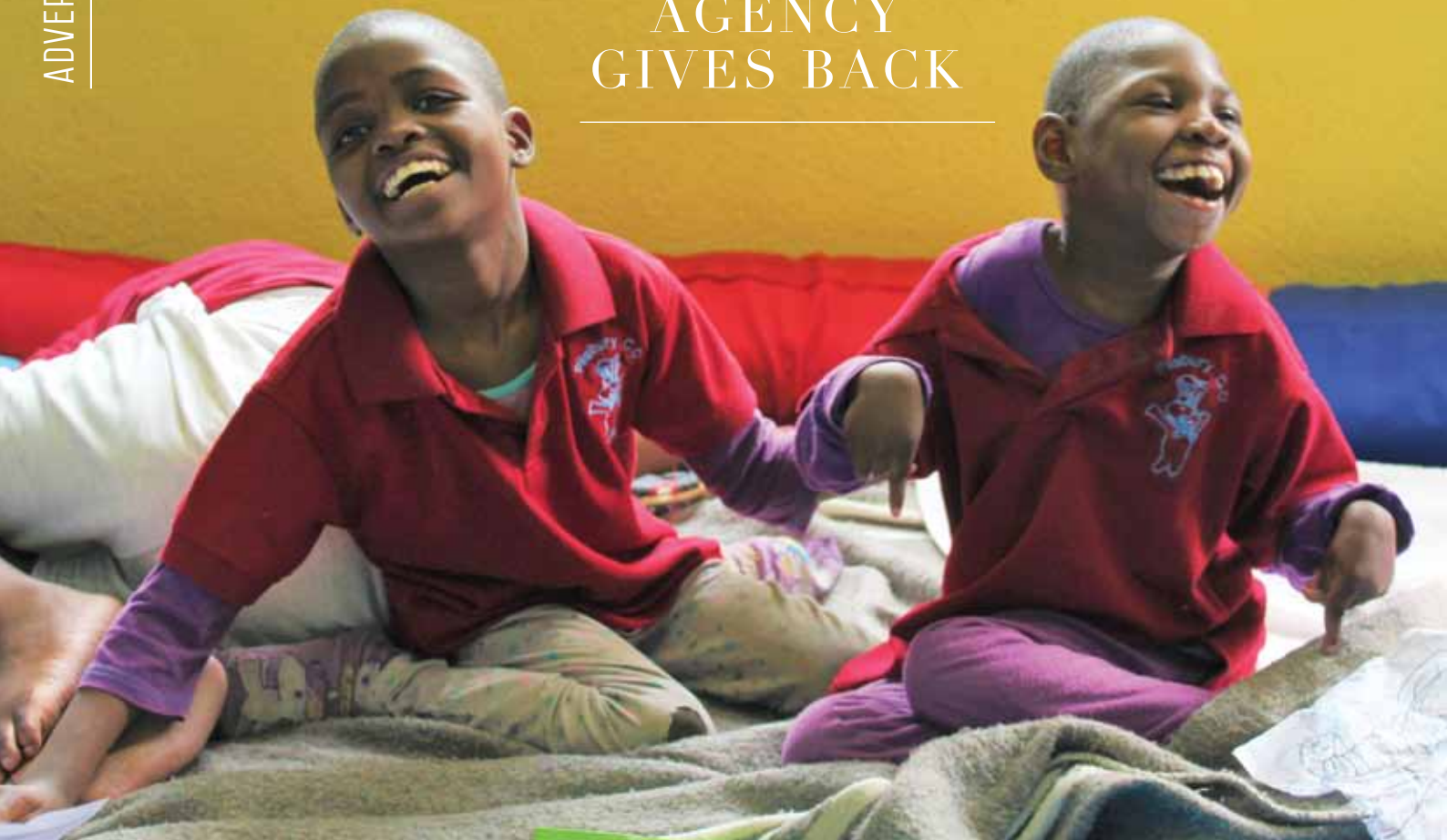
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GAUTRAIN MANAGEMENT AGENCY GIVES BACK



WHILE EMPOWERING PASSENGERS WITH ACCESSIBLE AND RELIABLE SERVICES, GAUTRAIN ALSO AIMS TO EMPOWER COMMUNITIES BY SUPPORTING CARE PROGRAMMES AND PEOPLE WITH DISABILITIES. MARISKA MORRIS VISITS A GAUTRAIN MANAGEMENT AGENCY BENEFICIARY TO LEARN MORE

In the unassuming Alexandra Disability Movement compound, bordering Johannesburg's Alexandra township, sits the Pillsbury Childcare Centre, a beneficiary of Gautrain that provides an invaluable service to parents in need in this area. The centre houses 22 children with severe disabilities and offers day-care services for an addition 10 children.

In spite of numerous struggles, the centre has become an institution servicing the community for two decades already. It all started at a meeting of the Alexandra Disability Movement to learn about the needs of the community. One mother expressed the need for a day-care centre.

Because of her child's severe disabilities that required 24-hour care, the mother unfortunately was unable to look for employment.

The organisation stepped in by employing some mothers to take care of the children on its grounds. Soon afterwards, however, the programme was halted because of a lack of funding and because some children were being neglected.

A year later Alexandra Disability Movement founder Jerry Ntimbane received funding from the United States company Pillsbury to reintroduce the programme with independent caregivers to ensure the health and safety of the children. Within a few years the centre started accepting permanent residents.

"Through the day-care centre, we realised that the children were cared for mostly by their grandmothers. When the grandmother passes away, there is a problem with caring for the child," Ntimbane explains. After nearly 20 years, Pillsbury withdrew its business from South Africa and, with that, its funding to the centre. Fortunately, the Gautrain Management Agency (GMA) stepped in.

Ntimbane recalls his first encounter with GMA. "It was a shock, because when they visited the centre, they didn't even stay for 10 minutes," he says. "They asked me to explain and as I was speaking, they said they understood and left for another meeting." For Gautrain, however, there was no need for a lengthy meeting.

On arrival, the organisation's representatives knew that the centre met the requirements set out in the GMA's social investment programme (SIP): providing community care and assisting people with disabilities. In fact, says GMA CEO Jack van der Merwe, "there was no way we can't help".

"We realised that if we could make the centre sustainable and keep it running, it would free up the parents to look for jobs and help an even wider audience," she says.

In 2017, GMA started donating to the centre. "With the little bit that we gave, they were able to upgrade the facility and its security as well as acquire new wheelchairs. We wanted to do our bit as Alexandra is very close to our hearts and near our offices in Midrand," Van der Merwe says.



Because of its location, the Pillsbury Childcare Centre was prone to burglaries. That is why, with the GMA's help, it was a priority to install security cameras and electric fences were installed to prevent crime. The funding has also made it possible to subsidise the stipend paid to the 16 caregivers working at the centre.

Some of the caregivers are unemployed women from the community, while others are teachers in training. Five of them are qualified physiotherapists. This means the children can participate in various age- and disability-appropriate activities.

evidence and the funding approved. This might result in bulk purchases, with some of the perishables expiring.

GMA assisted the centre in creating an account with Makro, which has allowed Ntimbane and his team to purchase food on a more regular basis with clear evidence of how the money is being spent. "Now, we can ensure that the children receive a healthy, balanced meal every time," he says.

Although located within an old building, the Pillsbury Childcare Centre is spotless and offers an invaluable service as is evident in the high demand among parents. "We have a



ABOVE RIGHT: (From the left) Tiisetso Mantu, senior social investment programme manager at the Gautrain Management Agency, with Jerry Ntimbane, founder of the Alexandra Disability Movement – the home of the Pillsbury Childcare Centre.

ABOVE LEFT: Children in the care of the Pillsbury Childcare Centre participate in a range of age- and disability-related activities whether it is listening to stories, playing with blocks or learning skills in a more formal classroom setting.

LEFT: When founder Jerry Ntimbane started the childcare centre, it was only a single room in the building that houses the Alexandra Disability Movement. Today, the majority of the building has been adapted to provide the children with bedrooms, bathrooms, classrooms, a dining hall and a kitchen.

Some children participate in more structured activities in a classroom-like setting, while those with more severe disabilities are entertained with books and toys in a more informal environment. It is evident that all the children are happy and healthy, the latter being an equally important aspect made possible by the GMA contribution.

Ntimbane explains that the government subsidies received by the centre are often unreliable, with a challenging number of requirements. When food is purchased, for example, the receipts need to be kept as

waiting list, with some applicants waiting up to three years," Ntimbane explains. Even with assistance from Gautrain, the centre lacks the funding needed to take on more children.

The centre is eternally grateful for the GMA's contribution. "We would just like to show our appreciation to GMA. They came at the right time," Ntimbane says. "The work relationship has been great, with clear communication channels and flexibility to shift funding where it is most needed. We've truly experienced ubuntu with Gautrain."

In turn, GMA only has high praise for the centre. "We are very happy with how they run the centre and handle the finances," Van der Merwe says. "The programme is only part of GMA's vision to give back.

"We believe we are part of the community; thus we have to be sensitive to their needs and help where we can to reinvest. It is the right thing to do, which is why it is part of our policy," he concludes. ^[4]

DEPRESSION AND SCI

MENTAL HEALTH CONDITIONS SUCH AS DEPRESSION AND ANXIETY ARE VERY COMMON, PARTICULARLY AMONG PEOPLE WHO HAVE SUFFERED A SPINAL CORD INJURY. IT IS ESTIMATED THAT THEY AFFECT UP TO 37 PERCENT OF THIS COMMUNITY



Depression is common and can affect anyone at any point in their lives. As many as one in six South Africans suffer from anxiety, depression or substance-use problems according to statistics released by the South African Depression and Anxiety Group (SADAG). Depression is even more common among people with an SCI – estimated rates range from 11 to 37 percent.

WHAT IS DEPRESSION?

There are unfortunately still serious stigmas attached to persons who suffer from mental health conditions such as depression and anxiety. Therefore, those who suffer from depression often are reluctant to see their healthcare practitioner. Everybody has days when they “feel blue” or “down in the dumps”. This is not depression. These are normal human emotions.

Depression, on the other hand, is a serious medical disorder that requires treatment. It affects both men and women. It can cause some or all of the following physical and psychological symptoms:

- Changes in sleep (too much or too little);
- Feeling down or hopeless;
- Loss of interest or pleasure in activities;
- Changes in appetite;
- Diminished energy or activity;
- Difficulty concentrating or making decisions;
- Feelings of worthlessness or self-blame; and
- Thoughts of death or suicide.

In the acute stages after SCI, periods of sadness are common and a normal part of the adjustment period. However, there is cause for concern when feeling depressed

or losing interest in usual activities occurs almost daily and lasts for more than two weeks.

CAUSES OF DEPRESSION

Chemicals produced in the brain called neurotransmitters are responsible for maintaining stable mental health. Certain internal and external stressors can upset this balance, resulting in clinical depression. The imbalance is linked to changes in mood, enjoyment, sleep, energy, appetite and ability to concentrate.

It is important to diagnose and treat symptoms of depression early. Left untreated, they can last for six months or more, and the risk of suicide is higher while someone is depressed. The mainstay of treatment is usually medication, counselling, psychotherapy or a combination of these.

Increasingly, research suggests that these treatments may normalise brain changes associated with depression. Regular exercise or physical activity can also improve mood, especially when used together with counselling or medications.

Antidepressant medications seem to work by restoring a normal balance of important brain chemicals such as norepinephrine and serotonin. Rebalancing these chemicals leads to feeling better both emotionally and physically. Treating depression helps you function better at home and at work. Antidepressants are not addictive. Some people do experience side effects, but these tend to lessen over time.

If you suspect you might be depressed, take the simple depression self-test opposite. It's important to be 100 percent honest when taking the test. When you're done, add up your score: if it is 10 or higher and you have felt this way for some time, it's important to contact your healthcare provider and seek treatment as a matter of urgency. [\[R\]](#)

Depression Self-Test

Over the past two weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or no pleasure in doing things.	0	1	2	3
2. Feeling down, depressed or hopeless.	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much.	0	1	2	3
4. Feeling tired or having little energy.	0	1	2	3
5. Poor appetite or overeating.	0	1	2	3
6. Feeling bad about yourself or that you are a failure or have let yourself or your family down.	0	1	2	3
7. Trouble concentrating on activities such as reading the newspaper or watching television.	0	1	2	3
8. Moving or speaking so slowly that other people have noticed, the opposite: being so fidgety or restless that people have commented on it.	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way.	0	1	2	3



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

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"We've made the process of placing orders quick and easy. Anyone with access to these methods of communication can make use of our services, which includes free delivery for chronic medication to any address within South Africa," Rentia Myburgh, director of sales and marketing at Medipost Pharmacy.

"Once an individual has been to their doctor and obtained a prescription, they place the order for delivery via our website, email, WhatsApp or fax - whichever is most convenient."

Medipost Pharmacy works with most medical schemes and claims directly on behalf of the patients. If the medical scheme doesn't fund a product, customers can choose from various payment methods such as Snapscan, EasyPay, debit order, credit card or direct deposit.

"Beneficiaries of the compensation fund will be aware that Medipost Pharmacy is now contracted to take care of their medicine needs, including the delivery of medicine

parcels," Myburgh says. "The size of our national pharmacy means that we have been able to scale our operations to save money for healthcare funders and the patients who make use of our service.

"For instance, Medipost Pharmacy's dispensing fees are considerably lower than the market average, and our customers are not billed for the administrative or courier delivery fee aspects of our service."

Orders for self-medication products - health items sold without a prescription - can be placed with a simple telephone call or a WhatsApp message. Medipost Pharmacy customers also benefit from access to telephonic clinical advice from pharmacists and pharmacist's assistants in their preferred official South African language.

"This excellent resource enables customers to discuss issues such as the potential side effects of medicine and directions for use with a properly qualified, registered professional in their language of choice," Myburgh says.

"Most South Africans now carry a cellphone in their pocket and, through this simple technology, we can provide you with all the benefits of a professional pharmacy service in the comfort of your own home," she concludes. ^[1]





THE BODY NEEDS LESS THAN WE MIGHT THINK

MEASURING YOUR REQUIRED KILOJOULE INTAKE ACCURATELY IS CRUCIAL TO MAINTAINING A HEALTHY WEIGHT. GUY CRANKSHAW, FOUNDER OF ACCESS A MEAL, PROVIDES SOME INSIGHT

The latest statistics show that South Africa has one of the highest rates of obesity and Type 2 diabetes in the world! People with mobility impairments in particular are at risk for obesity and resultant late-onset insulin resistance or Type 2 diabetes. In my nutrition consultations with people with mobility impairments, I see a common issue contributing to this risk.

In addition to poor dietary choice, the impact of nutritional value on weight management is a concept people generally don't understand. We need to look at the relationship between two factors. The first we call "energy in" – this is the total amount of energy we receive from the food we consume on a daily basis.

Then there is "energy out", which is the energy the body uses to function on a daily basis. This is also called the total daily energy expenditure (TDEE). A simple starting point in understanding personal weight management is to understand how your "energy in" values versus your "energy out" values affect weight loss, weight gain and the increased risk of lifestyle diseases.

Each person's TDEE is different and based on a variety of metrics. It is vital then to find the correct values for each person. Why is this so important? It has been calculated that a daily excess of only 10 percent in kilojoule intake can lead to a weight gain of up to nine kilograms a year. The concept of "energy in" vs "energy out" will be familiar to many people.

What is not understood by many in the disability community is that another factor needs to be considered – one that is critical in terms of calculating your actual "energy in" requirement in order to manage weight. To

illustrate this, let us use the example of an above-the-knee amputee.


The amputee's body systems may present similar to those of an able-bodied person. However, as one of his legs is missing, the body mass is lower. Thus we need to reduce the required "energy in" by about 20 percent versus the TDEE to maintain a healthy weight. This applies even though an above-the-knee amputee uses 50 percent more energy to walk compared to an able-bodied person.

Wheelchair users might have all their limbs but no mobility. As such, the same principle applies: a reduced daily kilojoule intake is required to lose weight or maintain a healthy weight. On average, we look at reducing the "energy in" by a further 15 percent per immobile limb. So a 30 percent reduction of "energy in" is required after a typical SCI.

A healthy diet is vital. Of critical importance to people with limited mobility is to ensure correct protein intake as this helps ensure skin integrity, which is an important factor in preventing pressure sores. Remember, meat is not the only source of protein and simply contains it.

It is recommended that an individual consumes a minimum of 0,8 grams of protein per kilogram of body weight per day. This applies to actual body weight, not desired body weight.

Each person is different; not one person's physiology is the same as another's. The key for people with mobility impairments is to balance quality nutrition with a significantly reduced daily kilojoule allowance. This can be quite challenging to set up and maintain on your own.

I specialise in creating customised nutritional programmes for people with mobility impairments. Contact me with any queries at guy@accessameal.com or on 079 228 5608. 

WOMEN WITH SCI: REBUILDING INTIMACY

WHILE IT MIGHT REQUIRE SOME TIME AND A FEW ADAPTATIONS, WOMEN WITH AN SCI CAN STILL ENJOY THEIR SEXUALITY. IT ALL STARTS WITH KNOWING HOW YOUR BODY HAS CHANGED

For women with SCIs, sexuality remains an important part of daily life. It often takes time for a newly injured woman to become comfortable with her body and resume natural feelings of sexuality. Healthy adjustment begins with knowing the facts around the impact of SCI on sexual issues.

There are not many physiological changes after an injury that prevent women from engaging in sex. The most common challenge is decreased vaginal lubrication, likely the result of an interruption in normal nerve signals from the brain to the genital area.

Lubrication generally results in easier penetration and more pleasurable sexual activity. A possible inexpensive solution to the problem is to use a water-based lubricant such as K-Y Jelly. An oil-based lubrication is not recommended as it can cause infections.

Depending on the completeness and level of injury, there may be changes in surface sensation and the ability to contract muscles. If that is the case, try different sexual positions or activities than those favoured prior to the injury. Talking to your partner about your needs and your interest in trying new things can go a long way towards improving intimacy in a relationship.

Because of possible changes in sensation, it could take longer for an orgasm to occur, or sex might just feel different. The majority of women with SCIs are still able to experience orgasms but they may require more stimulation to do so. Using a vibrator may help with stimulation for women with an injury below the T6 level.

Certain medication could also hinder the process. It may be helpful to speak with your doctor about adjusting medication to minimise the potential impact.

When it comes to sexuality, the difficulties faced by women with SCIs tend to be more emotional and relational than physical. Regardless of SCI, everyone wants to have meaningful relationships and feel desired by their partners. Being comfortable in your own skin and coming to terms with how your body has changed after the SCI will influence your desire to engage in sexual activity.

When the emotional aspects are addressed, you will likely feel more comfortable to explore, express and enjoy all aspects of sexuality regardless of the level of injury. All relationships take hard work, dedication and commitment from both partners. This implies that the solution to overcoming emotional difficulties is a team effort.

Women with SCIs need to help their partners understand the effects of an injury on all aspects relating to sexuality, as well as their personal concerns. This is a great way to build physical and emotional intimacy while simultaneously overcoming barriers to meaningful relationships.

A proactive approach is recommended to prevent potential relational problems resulting from intimacy challenges and manage areas of concern effectively. Sometimes professional assistance can be helpful when it feels as if you're not making progress in resolving issues related to sexuality. Sexologists, urologists and gynaecologists who are knowledgeable on issues related to sexual and reproductive health for women with an SCI could offer the necessary information and assistance. [\[1\]](#)



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.



HAPPY BIRTHDAY, IPC!

AMONG THE VARIOUS SPORTING EVENTS ENDING 2019, WE ARE ALSO CELEBRATING THE INTERNATIONAL PARALYMPIC COMMITTEE'S 30TH ANNIVERSARY

Time flies when you're having fun. What a year it has been! I have been living out of suitcases for the past few months, attending the African Games in Morocco, the Tokyo 2020 Paralympic Games Chef de Mission meeting and, last week, the International Paralympic Committee (IPC)'s general assembly and 30th anniversary at its headquarters in Bonn, Germany.

What a privilege to be part of this amazing organisation that has not only transformed my life as a person with a disability, but those of millions of people with disabilities. Happy 30th birthday, IPC, and here's to the next 30 years!

The IPC is in the process of producing a movie that will showcase the birth of the paralympic movement and its progression till now to show the growth and acceptance of sport for people with disabilities. We saw a small teaser while we were there and ... Wow! It promises to be a real tear-jerker.

As I'm writing this, we're getting ready to attend the 2019 World Para Athletics Championships in Dubai, which will take place from November 7 to 15. A team of 25 athletes and one guide has been selected to represent South Africa.


We are expecting great things from them.

This event is a key opportunity to qualify for the 2020 Tokyo Paralympic Games and only the best of the best have been selected to go.

Last weekend saw the finals of the 2019 SuperSport Wheelchair Basketball Series at the Vodacom Mandeville Indoor Centre. A very exciting final game took place between the Diesel Electric Services Eagles and Kiloskar Lions, with the Kiloskar Lions taking the win in the last quarter.

To Diesel Electric Services and Kiloskar, a massive thank you for your sponsorship of these two teams. Without sponsors, teams really struggle. Also, a huge thank you to SuperSport for its continued support of wheelchair basketball. This will hopefully assist our national teams in their bid to qualify for the 2020 Tokyo Paralympic Games.

Yes, 2020 is almost here and it feels like yesterday when we were in Rio de Janeiro, Brazil, for the previous Paralympic Games. Next year is going to be epic in the lead-up to the games, with some exceptional sporting events happening and culminating at the Paralympic Games. I have been lucky enough to have visited Tokyo several times.

Let me tell you once again ... If you can make it to the games, please do so! They are going to be amazing. 



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.



AN EYE ON THE BALL

THE SLOW AND STEADY SPORT OF BOCCIA REQUIRES ACCURACY AND STRATEGY, AS TOP SOUTH AFRICAN PLAYER BRETT DAKIN EXPLAINS. MARISKA MORRIS LEARNS MORE

Silence falls over the hall at Coetzenburg Stadium in Stellenbosch. Brett Dakin eyes the cluster of balls on the floor, raises his arm, angles it and throw his red ball towards the cluster. A small crowd gives a short and quiet cheer. While boccia might not seem like the most exciting sport to the untrained eye, Dakin knows how quickly the game can change.

"It is very enticing and difficult, and can be unpredictable. Everything can change in a minute. I have to perform at 100 percent, be accurate and make no mistakes," explained this top South African boccia player at the 2019 SASAPD National Championships, which was sponsored by Toyota South Africa Motors (TSAM).

Although boccia has been around for decades, it was only introduced in South Africa in the early 2000s. Dakin started playing in 2007 and soon found his rhythm. By 2011 he was securing medals in both the single and team competitions. While he enjoys the team aspect of the sport, the singles game appeals to him more.

"Singles are great, as I control all six balls. In a team event, I only have two balls," Dakin explained. The object of boccia is to get as many balls as close to the Jack (the white ball) as possible. Players may attempt to knock the opponent's ball out of the way. Strategising and controlling the path of the ball goes require skill.

As boccia is still quite new in the country, there is no Paralympian team, with every few players attending international events. "We are a little behind, but we are getting there slowly," Dakin said. "The SASAPD Nation Championships, for example, is getting close to the international level."



In 2018, however, Dakin was the first South African player to compete at the Dubai Boccia World Open. Along with a host of news skills, the event also gave him the opportunity to be ranked internationally. He played the world number 10 and 11 players.

"I did well at the event. I'm happy with my performance. I couldn't have done any better. It was a tough tournament," Dakin recalled. After the event, he was ranked 97 out of 186.

He aims to improve his ranking further by attending the Boccia International Sports Federation (BISFED) 2019 Boccia America Regional Championships, to be held in Sao Paulo, Brazil, from September 29 to October 6.

Ultimately, Dakin's goal is to get a South African team to the Paralympic Games.

With this kind of dedication from players and TSAM's three-year partnership with the SASAPD, aimed at promoting the sporting codes offered at Paralympic level for athletes with disabilities, boccia will likely continue to grow in popularity in South Africa. [\[7\]](#)



MORE SKILLS EQUAL MORE OPPORTUNITIES

WHILE THE ECONOMY IS STRUGGLING AND THE UNEMPLOYMENT RATE IS HIGH, THERE ARE INDEED OPPORTUNITIES FOR PEOPLE WITH DISABILITIES. IT STARTS WITH ACQUIRING THE RIGHT SKILLS

According to the annual Commission for Employment Equity (CEE) report, the percentage of people with disabilities employed in the formal workforce is still about one percent, despite the 7,5-percent target for Disability Employment Equity.

Expecting the percentage to increase is probably wishful thinking considering the state of the economy, with 29-percent unemployment and gross domestic product (GDP) growth below a percent. So how do unemployed people with disabilities address this issue?

ADEQUATE SCHOOLING

The education system has done people with disabilities an injustice, as many find a big educational gap when they leave school. Most companies are looking for matriculants or, if you lucky, a Grade 9. How do people with disabilities complete when unemployment is so high?

Learners who are still in the education system need guidance to ensure they take advantage of their schooling to best equip themselves for the formal workforce. This must be supported by the appropriate career counselling. Students should be encouraged to pursue life-long learning to equip themselves with as many skills as possible.

LIFE-LONG LEARNING

Opportunities for learning have increased over the past couple of years. Most of these opportunities are funded through organisations such as National Student Financial Aid Scheme (NSFAS) and the various Sector Education and Training Authorities (SETAs). Companies also take advantage of BBBEE programmes by supporting skills development.


What then are the options for an older person with a disability who hasn't worked for a few years? Generally, employers request proof of education and experience. Such older individuals should consider learning as much as possible to acquire the skills needed for the position. This can be done through online learning platforms or even YouTube videos if the skill is something basic.

With the help of these teachings, a person can volunteer at a local community organisation or a school in their field to acquire the necessary experience. As their experience develops, they should start looking for internship opportunities.

GETTING SOME WORK EXPERIENCE

The minimum wage for most learnerships is roughly R2 500, which would not affect the person's disability grant – naturally this is a concern for many people with disabilities. Various organisations offer learnerships, including community organisations, Technical and Vocational Education and Training (TVET) colleges, skills development providers, government and private companies. An internet search is a good way to start looking for opportunities.

It is also possible for a person with a disability to enlist on the Department of Labour's Employment Services South Africa database, which is used by employers seeking employees or learners with disabilities.

Don't be afraid to disclose a disability. When an opportunity arises, be sure to state clearly the requirements for the disability, including reasonable accommodation in the workplace. The plight of employment need not be as grave as it appears. There are opportunities out there. There is hope. 



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. He ensures that businesses are able to maximise their points on the BBBEE scorecard and become compliant with legislative requirements as stipulated in the Employment Equity and Skills Development Acts. 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.

WHAT IS SIAS?



THE SIXTH ARTICLE ON INTEGRATING CHILDREN WITH DISABILITIES INTO INCLUSIVE CLASSROOMS FOCUSES ON THE SCREENING, IDENTIFICATION, ASSESSMENT AND SUPPORT POLICY

The Screening, Identification, Assessment and Support (SIAS) policy applied in South Africa standardises the procedures of identifying, assessing and providing programmes for all learners who require additional support to enhance their participation and inclusion in school. It is important that teachers are familiar with the Individual Support Action Plan (Individualised Education Plan).

The rationale of the policy has three areas: Determining the support needs of all learners, addressing barriers to learning and development, and implementing the policy.

DETERMINING SUPPORT NEEDS

Teachers and schools need to understand the individual support needs of all learners in their classrooms. This allows them to assess the level and extent of the support required, and to ensure the learners can participate. Key to this is identifying individual needs in relation to the home and the school context.

ADDRESSING BARRIERS

The process of enabling access and providing support requires the completion of various forms by both the teacher and other stakeholders. These forms assist in identifying and addressing the barriers to learning, and determine the roles and responsibilities of teachers, managers, district-based support teams and parents or caregivers.

The barriers to learning are the result of a broad range of experiences in the classroom and at home, and/or health conditions. They might include:

- Socio-economic aspects (for example, if a learner doesn't have breakfast, it will impact their ability to learn);
- Factors that place learners at risk (for example, witnessing domestic abuse at home);
- Attitudes (stigma attached to certain conditions);
- Inflexible curriculum implementation;
- Language and communication;
- Inaccessible and unsafe structural environments (for example, lack of wheelchair ramps or accessible toilets);
- Inappropriate or inadequate provision of support services;
- Lack of parental recognition and involvement;
- Disability;
- Lack of human resource development strategies; and
- Unavailability of support materials and assistive technology.

In order to address such barriers, more equitable practices for school admission, support and funding are needed.

IMPLEMENTATION

To implement this policy, the Department of Education acknowledges that teachers, managers, and provincial and district officials require training in the use of the policy, and that collaboration between government departments is critical in ensuring that services and support are aligned and integrated. ^[1]



Dr Emma McKinney is a lecturer at the University of the Western Cape. She is also the owner of Disability Included, a company specialising in disability research, children, and employment of adults with disabilities. email: emma@disabilityincluded.co.za

GET UP, DRESS UP AND SHOW UP



WHY IT IS IMPORTANT TO BE AN EXAMPLE TO YOUR CHILDREN BY TAKING CARE IN HOW YOU DRESS AND PRESENT YOURSELF TO THE WORLD

The legendary bodybuilding champion Lee Haney says: "Parents must lead by example. Don't use the cliché 'do as I say and not as I do'. We are our children's first and most important role models."

I couldn't agree more. No matter what kind of parent you are, you will forever be one of your children's first and most important role models – with or without a wheelchair.

SO YOU'RE HAVING A BAD DAY ...

Most parents want their children to grow up to become independent, capable adults who display healthy behavioural patterns, including appropriate self-care and soft skills. An important question to answer is: How do children learn these skills?

The answer is relatively straightforward: They learn by example. Kids learn from the people around them – most importantly, from their parental figures. It's physically impossible for any human being to have a good day every

day of the week, month or year. We all have a bad day from time to time. It's normal and no different for a person – or parent – in a wheelchair. But it is important to consider how we deal with these bad days.

I vividly recall many of my bad days following my return home from the hospital. My kids were aged seven and four respectively. In line with a child's needs, they wanted my time and attention. They looked to me for guidance.

On my bad days, however, the only thing I wanted to do was to stay in bed with the duvet covers pulled firmly over my head. I didn't feel like talking to anyone, playing with the kids or dealing with homework – let alone getting up and dressing up! Perhaps I need to explain the dressing up part...

IMPORTANCE OF GETTING AND DRESSING UP

If there's anything I've learnt over the past two decades, it's that self-care starts slipping when a depressive episode sets in. The antidote, therefore, lies in combating the symptoms. Get up and dress up to combat depression and to elevate

self-esteem and self-confidence. I'm not saying it's easy, not by a long shot.

At first, it takes a fair amount of will and stacks of courage to get out of bed and into the shower. But once it's done and you're wearing a fresh change of clothes, it's so much easier to face the day. Don't think for a minute the kids don't notice the effort, because if that's the case, you would be completely wrong.

They notice. They know it's incredibly challenging to fight the urge to stay in bed, and they know it takes effort to get up and dress up.

By dressing up, I'm not referring to a fashion-forward outfit, layers of makeup or salon-styled hair. No, I mean simple self-care, self-respect and soft skills kids can learn from, model on and take with them into adulthood.

“Whether we chose to accept the responsibility or not, they look at how we deal with our challenges as an example of how to approach theirs.”

DON'T LIVE UP TO STEREOTYPES

Over the past 20 years, I've had countless people, particularly random members of the public, commenting that I "don't look like someone in a wheelchair". Apparently, there's a "wheelchair look" that doesn't include fashionable outfits aside from a warm blanket over the knees. There are not many other comments that cause my daughter more frustration!

Our kids see us as parents first and foremost – not as wheelchair parents. Whether we chose to accept the responsibility or not, they look at how we deal with our challenges, including unwelcome and offensive comments and stereotypes.

Admittedly, my style has inevitably changed and my shoe fetish had to take a back seat. But I realise the importance of taking care of myself while maintaining my authentic sense of style, regardless of stereotypes. When I'm cold, like any other person, I may choose to snuggle under a tasselled blanket, but not because people expect someone in a wheelchair to do so.

CLAIM YOUR POWER


Like it or not, your clothes, appearance and presentation speak volumes about you as a person. The question is not whether you care about fashion and style, it's more about

what you're communicating intentionally or unconsciously through your choices.

Do you want to be seen, and for that matter, be treated like an invalid or do you want people, including your kids, to take you seriously as a person? If it's the latter, choose your personal presentation with care – regardless of your chair.



Your presentation includes your clothes, but also your accessories, hairstyle, fragrance, posture, body language, tone of voice and the level of energy with which you move and speak – even in your wheelchair!

Decide what kind of person – not physically challenged person – you want to be and how you want to be treated. Then get up, dress up and show up in a way that helps you to assume that position. It will be one of the most valuable gifts you will ever share with your kids. 



Wanda Boshoff is a wife, mother and qualified occupational therapist who also happens to be a paraplegic. Thanks to her experience in these fields she is able to assist others in similar situations. Before her accident in 1998, she ran a successful private practice specialising in children – particularly those with childhood-development and school-related issues. Over the past 20 years she has been running her own businesses, and has become a blogger and the owner of a guest house.

CBD OIL FOR PAIN RELIEF

Patricia Taylor, owner of Life Retreat, shares some advice on managing neck pain and the benefits of CBD oil in pain management:

There is mounting evidence suggesting that cannabis oil helps alleviate symptoms of muscular dystrophy, multiple sclerosis, autism, insomnia and depression among others. Made from the calming cannabidiol (CBD) found in the marijuana plant, CBD oil influences the release and uptake of neurotransmitters, including dopamine and serotonin.

This leads to many therapeutic uses. Its calming effect can reduce acidity and muscle spasms as well as enable you to get a better night's sleep. It eases the throat and stomach muscles, allowing you to eat and digest your food more efficiently. Sleep and nutrition are two of the essential things in our journey to living pain free.

There are several ways to use CBD oil. You can use a drop of tincture twice a day or rub cramp cream onto painful and stiff areas twice a day. The healing benefits of both are enhanced by rolling the pain-ease or stress-ease roll-ease onto your temples.

It is important to remember that CBD oil is not a miracle

in a bottle. It really will help ease pain, but it is important also to address the cause of the pain (namely, posture and positioning) and adjust lifestyle habits.

Focus on sitting up upright as possible and regularly do exercises approved by your physio to strengthen your core. Ensure your seat cushion is suited for you by consulting a seat specialist. Try to avoid bumpy terrain. Alterations to your diet and ensuring you get enough sleep can also help prevent pain. Avoid cutting down on any prescribed medication without the consent of your doctor.

Visit the [ROLLING INSPIRATION](#) website to learn more.



INAUGURAL ROAD HEROES AWARD

The Road Ethics Project (REP), in partnership with the Occupational Therapy Association of South Africa, announced that former QASA CEO Ari Seirlis is its inaugural Road Heroes Award winner. This award celebrates an individual dedicated to improving road safety.

"While we had many worthy nominees, Seirlis was head and shoulders above the others because of the sheer scale of his impact over many, many years," says founder of REP Lee Randall. In addition to receiving a certificate from REP, Seirlis will also receive a cash prize of R5 000 sponsored by MasterDrive.

"I am honoured and humbled to receive the 2019 Road Heroes Award," Seirlis says about his win. "In my tenure as CEO of QASA, I ensured that the organisation invested in the prevention of spinal cord injuries and disability – as should all NGOs in the disability sector."

"We came up with some innovative prevention programmes, of which the most significant was our 'Buckle up, we don't want new members' campaign. It



created awareness among South African road users of the importance of using a seatbelt, but also formed a strong partnership for QASA with the Department of Transport and the Road Accident Fund."

The award is only one of the ways in which REP plans to address road safety in South Africa.

Essentially, the organisation aims to get society talking about responsible and ethical road use. "This will be done in a variety of ways, including public speaking, hosting think-tanks and workshops as well as producing fact sheets, articles and reports," Randall explains. The initiative will also assist in determining the road safety measures that will be the most beneficial for saving lives and preventing injuries.

"Road safety is a shared responsibility that involves not only blame responsibility (like the finger-pointing to which minibus taxi drivers are often subjected) but also causal responsibility and forward-looking responsibility," Randall concludes.

Visit the [ROLLING INSPIRATION](#) website to learn more about the award and REP.

LOVE EVEN THY ANNOYING NEIGHBOUR

BEING KIND TO PEOPLE WHO ARE RUDE OR INCONSIDERATE CAN BE A HUGE CHALLENGE, BUT WITH STRENGTH AND PATIENCE IT'S POSSIBLE TO BUILD A BETTER WORLD FILLED WITH LOVE



Doing everything with love can be hard. Sometimes I don't respond with love towards my siblings or that friend who drives me crazy. Being surrounded by unhappy and often demanding people makes it all too easy to snap back rudely. Responding with kindness and love can be the last thing on anyone's mind when their buttons are being pushed.


Yet it builds better communities and ensures a peaceful mind. This doesn't make it any easier to achieve, though, but it can be taught.

As you go through your day, there will always be that certain thing that sets you off and sends you into the deep end. Do you know what sort of things make you mad? It could be a friend forgetting your birthday or something as

small as finding out that another family member ate the last scoop of your favourite ice cream!

You may not be able to avoid these situations, but if you know your tendency to overreact when these buttons are pushed, you can prepare yourself to respond in a calm manner. Be aware of your triggers and plan a response. See this encounter as an opportunity to practise patience.

The world is full of temptations and obstacles ready to tear us down. Sometimes those challenges hit us out of the blue. Other times they are predictable. By being strong and courageous, we can face these difficult circumstances and people who cross our paths. We don't need to hide or run away. Nor do we need to be aggressive and rude.

We simply need to summon all our courage, strength and patience to help us respond with love. End the year and go into the future with nothing but love! 



Emilie E Olifant is a disability champion, an entrepreneur, an author and an inspirational speaker. She is accredited by the Education, Training and Development Practices (ETDP) SETA and is the founder of the Emilie Olifant Foundation, an organisation that strives to integrate persons with disabilities in the workplace and/or society. email: emilie.olifant@gmail.com

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COMING SOON!

YOU HAVE LOTS TO LOOK FORWARD TO! DON'T MISS THESE UPCOMING EVENTS OR THE AMAZING FEATURES IN THE NEXT ISSUE OF ROLLING INSPIRATION. OUR FIRST EDITION IN 2020 WILL BE PACKED WITH FABULOUS ARTICLES. HERE'S WHAT TO EXPECT:



HOME ADAPTATIONS

From grab rails to ramps, we look at what is required to make a home accessible.



LIGHT WHEELCHAIRS

With a little expert advice, it is easy to pick the best light-weight wheelchair for you!



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These pharmacies use innovative technologies and systems to improve service delivery.



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Check out our selection of the products that can help you manage bladder and bowel care.

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CALENDAR OF EVENTS

THERE ARE PLENTY OF EXCITING EVENTS HAPPENING NEXT YEAR. HERE ARE SOME OF THE HIGHLIGHTS:

3 MAY: WINGS FOR LIFE

The Wings for Life Foundation will once again host its annual Wings for Life World Run in Centurion on May 3. Join participants from across the globe in running for those who can't and raising funds for research to find a cure for SCI. How far would you be able to run before the Catcher Car passes you? Find out more and enter on Wings for Life World Run website www.wingsforlifeworldrun.com/za/en/.

30 MAY: WORLD MULTIPLE SCLEROSIS DAY

World Multiple Sclerosis Day aims to raise awareness about multiple sclerosis (MS). For information about events taking place globally, visit <https://worldmsday.org/>, and to find out more about local events, call Fanie Swanepoel from the National Centre for Persons with Disabilities (NCPD) on 011 452 2774.

25 AUGUST - 6 SEPTEMBER: 2020 SUMMER PARALYMPIC GAMES

The 16th Summer Paralympic Games will take place in Tokyo, Japan, from August 25 to September 6 and will include a total of 22 sports, with badminton and taekwondo making their debut. Governed by the International Paralympic Committee, this event will see the top para-athletes from around the world compete for glory. Visit <https://tokyo2020.org/en/> to learn more.

SEPTEMBER: MUSCULAR DYSTROPHY AWARENESS MONTH

Muscular dystrophy (MD) is a genetic disease that causes progressive weakness and loss of muscle mass. Most people with MD rely on a wheelchair as the disease progresses. The most common adult form of MD affects one in 8 000 people worldwide. For more information, visit the Muscular Dystrophy Association website at www.mda.org.

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