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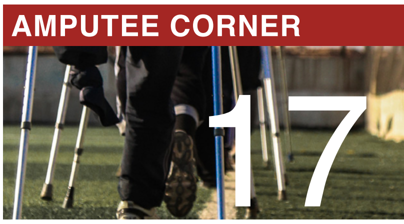

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ARI SEIRLIS • UPFRONT

DISABILITY ACT IS THE WAY TO GO

While there are guidelines in place to support people with disabilities, these do not have a legal standing; thus there is a call for a Disability Act

The documentary *Crip Cramp*, available on Netflix, tells the true story of how a summer camp for teenagers with physical and mental disabilities laid the groundwork for a civil rights victory. It is a beautiful story and a wonderful movie well worth watching. It was nominated for an Academy award in 2020.

The end result of the work of disability activists over many years was the Americans with Disabilities Act (1990), which is a piece of legislation that gives power and human rights for all people with disabilities in the United States. Civil society knows the power of this Act.

Some background to the disability rights documents developed in South Africa: The Integrated National Disability Strategy (INDS) was developed in 1997 through a collaboration of Disabled People South Africa (DPSA) and the South Africa Federal Council on Disability.

> “
>
> **The end result of the work of disability activists over many years was the Americans with Disability Act.**

Thereafter, the government ratified the United Nations (UN) Convention on the Rights of Persons with Disabilities (2007) and, finally, we have the White Paper on the Rights of Persons with Disabilities (WPRPD) which was ratified in December 2015.

The vision of the WPRPD is the "creation of a free and just society inclusive of all persons with disabilities as equal citizens". It commits duty bearers to realising the rights of persons with disabilities by:

- Accelerating implementation of existing legislation that advocates equality for persons with disabilities.
- Taking calculated action to ensure that their rights as equal persons are upheld;
- Removing discriminatory barriers to access and participation.
- Ensuring that universal design informs access and participation in the planning, budgeting and service delivery value chain of all programmes.
- Recognising the right to self-representation.
- Acknowledging that not all persons with disabilities are alike, and that personal circumstances such as gender, age, sexuality, religious and cultural backgrounds, geographical location, requires different responses.
- Embedding the obligations contained in the UN Convention on the Rights of Persons with Disabilities in legislation, policy and service delivery.

For this to all happen, it is the unanimous view of the disability sector that a Disability Act must be promulgated. The UN Convention and the WPRPD are but instruments influencing policy and legislation and have no legal status or standing.

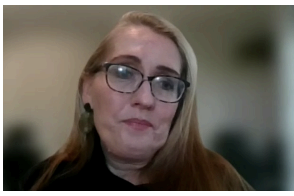
We, as people with disabilities, must ensure that our focus now is channelled towards a Disability Act and nothing less.

President Ramaphosa has committed to this taking place, but we must ensure that it happens. It might be a five-year process, so, let's set our sights to ensure we keep to this timeline and not a day longer. R

ABOUT THE AUTHOR

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

Advocating for the employment of people with disabilities



ABOVE: Lesa Bradshaw.

In June, employers joined QASA for a virtual Employment Workshop, which allows the organisation to educate employers on disability, advocate for the employment of people with disabilities, and identify businesses that can partner with QASA on its Work Readiness Programme.

Speakers included QASA general manager, Richard Barron, who spoke about his personal journey and the planned future for the NGO. Lesa Bradshaw, disability inclusion specialists, discussed reasonable accommodation. QAWC general manager Anthony Ghillino. Sandile Mthembu, an alumni from the programme, shared his personal journey with the programme. To read more about the event, click here. R

Highlights from Master Class

QASA held a Master Class for its Work Readiness Programme alumni in June. The session provided a summary of some of the content that is covered in depth during the programme. It served as a valuable opportunity for our alumni to reflect on their training and refresh their knowledge.

A range of topics were covered, including communication, conduct in the workplace, and interview and job search skills. QASA aims to journey with its members through their life. The Master Class allows QASA to continue assisting QASA members. To read more about the event, click here. R

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FILM REVIEW

A CAMP THAT INSPIRED CHANGE

A camp for people with disabilities in the 70s inspired many to fight for change which would ultimately lead to the American Disability Act

Image sourced from the documentary on Netflix.

The 2020 documentary *Crip Camp: A Disability Revolution* offers a wonderful insight into how the freedom offered at a summer camp shaped the future of disability access – especially in the United States.

The documentary was nominated for an Academy Award for best documentary and won the Independent Spirit Award for Best Documentary and a Peabody Award for Documentary.

SPOILERS

The documentary follows the lives of several people with disabilities who attended Camp Jened in the 1970s. The camp, started in the 50s, offered people with disabilities a breakaway with a sense of freedom that was novel at the time.

Campers could be themselves, share their experience, participate in activities, play sports, pursue romance and enjoy their youth.

At the time, there were little to no resources for people with disabilities to participate in the greater society. They were often ignored, isolated or institutionalised.

James LeBrecht, a Camp Jened alumni, shares at the start of the documentary how he was encouraged to be outgoing as a child. His father said that he would need to approach others as no one would approach him.

Another alumni, Steven Hofmann, notes in the documentary (footage taken from his time at the camp in the 70s): “If you’re a handicapped person and you happen to have a passive nature about you, you’re really screwed.”

For many, the camp opened their eyes to what their lives might look like. James says: “What we saw at that camp was that out lives could be better. The fact of the matter is that you don’t have anything to strive for if you don’t know it exists.”

The camp shaped the lives of the people who attended with many seeking a similar freedom in their lives thereafter. Of course, societal attitudes and physical barriers remained a big obstacle.

Alumni Judith Heumann took lead in a big way by starting Disable In Action and spearheading the 504 sit-in protest, which called for the signing of Section 504 of the Rehabilitation Act of 1973 – the most important disability rights legislation at the time.

> **The fact of the matter is that you don’t have anything to strive for if you don’t know it exists.**

The protest lasted 24 days. It was horrifying to see the apathy with which the protesters were met by some. However, many came to the aid of the protestors by providing whatever assistance they could.

Even more inspiring was how the group of people with all different disabilities supported each other to help solve the problems they faced during the protest. The group’s strengths and weaknesses complimented each other.

While success was achieved, the legislation was signed and later the Americans with Disability Act (ADA) was passed, it was a hard and continuous battle.

One that continues today. As alumni Denise Jacobson shares: “You can pass a law, but until you change society’s attitudes, that law won’t mean much.”

TRIGGER WARNING
Sensitive viewers might want to take note of the unsettling footage of the Willowbrook State School exposé shared in the documentary.

The school was mismanaged, overpopulated and understaffed. In the short clip screened, children with severe disabilities are seen in a state of horrible neglect. This can be upsetting to viewers.

THOUGHTS
The documentary is a must watch. It takes an honest and open look at the lives of people with disabilities, the challenges that exist and the hard work it took for progress to take place. It is heart breaking to see the discrimination and apathy many face.

However, the documentary is also sure to inspire as viewers get insight into what is possible through passion, drive and unity. The stories shared are sure to stay with you.

DISABILITY LEGISLATION IN SOUTH AFRICA

Currently, there is no disability act in South Africa. Various disability rights are protected within other pieces of legislation. For example, physical access to buildings for people with disabilities is included in the National Buildings Regulations while employment equity is built into the Employment Equity Act. Unfortunately, there is little reinforcement on these clauses, which means that discrimination and exclusion is still prevalent.

In 2015, the **White Paper on the Rights of People with Disabilities** (WPRPD) was approved by government. A white paper is not enforceable law, but rather a policy framework that guides the introduction and implementation of any new policies and legislation. Thus, while the WPRPD is a step in the right direction, it is still very limiting.

Ari Seirlis, a member of the Presidential Working Group on Disability, **writes**: “South Africa is seen as gold standard in human rights; however, people with disabilities do not enjoy the same experience. Discrimination still exists for people with disabilities.”

Member to manager

Richard Barron shares his journey from being a QASA member to becoming the General Manager of the organisation

In April Richard Barron officially started as the General Manager for the QuadPara Association of South Africa (QASA). While he has been involved with the organisation for many years, the new role will require more dedication and commitment – something Richard is more than happy to offer.

"I am thrilled about the chance and fully cognisant of the enormous responsibility that comes with realising the organisation's vision," Richard notes of his appointment. "I firmly believe that this role will offer both gratification and a sense of purpose as it involves positively impacting people's lives, especially those who are most vulnerable."

After nearly two decades in the corporate world, Richard wanted a change that would more directly impact the community and be meaningful to him. He shares: "I had plans in place to 'retire' from the corporate world within the next five years. The aim was to get involved in community projects."

So, when the opportunity arose to apply for the General Manager position, Richard didn't hesitate. A vigorous selection process was followed with many qualified candidates applying. However, Richard had an edge. He had benefitted from many of the QASA programmes and projects himself.

"I originate from a community where resources and opportunities were limited, especially for individuals with disabilities," he recalls. "However, with the aid of QASA, I connected with appropriate networks and joined forces with people who shared my interests, motivated and supported me."

"I utilised QASA's assistive devices and Educational Fund; and even learned how to drive [through the Driving Ambitions Programme] with the aid of an adapted vehicle provided by them. All of these efforts contributed significantly to my development as a self-sufficient and productive member of society."

Richard has an intimate understanding of the needs of the QASA members, as well as how the services and programmes on offer can impact on the lives of the members. Additionally, Richard has served on the QASA board for many years. Thus, he understands the challenges facing the organisation and its management.

As he takes on this new responsibility, Richard has a clear vision of what he would like the organisation's future to include.

"I want to extend QASA's reach, particularly in rural regions, to provide world-class service to our members with utmost efficiency; to uphold our outstanding governance standards and to become a sustainable organisation that holistically benefits future generations, in terms of humanistic, economic, social, and environmental aspects. I also want to create a pipeline of future leaders for QASA," he says.

"I strongly believe that in order to bring a vision to life, you must first experience it. My personal experience has shown me the incredible potential that can be unlocked through QASA. With our well-organised structures and support systems, it is possible to reach your full potential and achieve your vision. I want to pay it forward and realise the potential of many others," Richard adds.

Part of this vision includes encouraging QASA members to view the organisation as more than just a solution to a challenge, but as a community from which to benefit and give back; a place to grow, network and inspire others. QASA hopes to journey with its members through their lives.

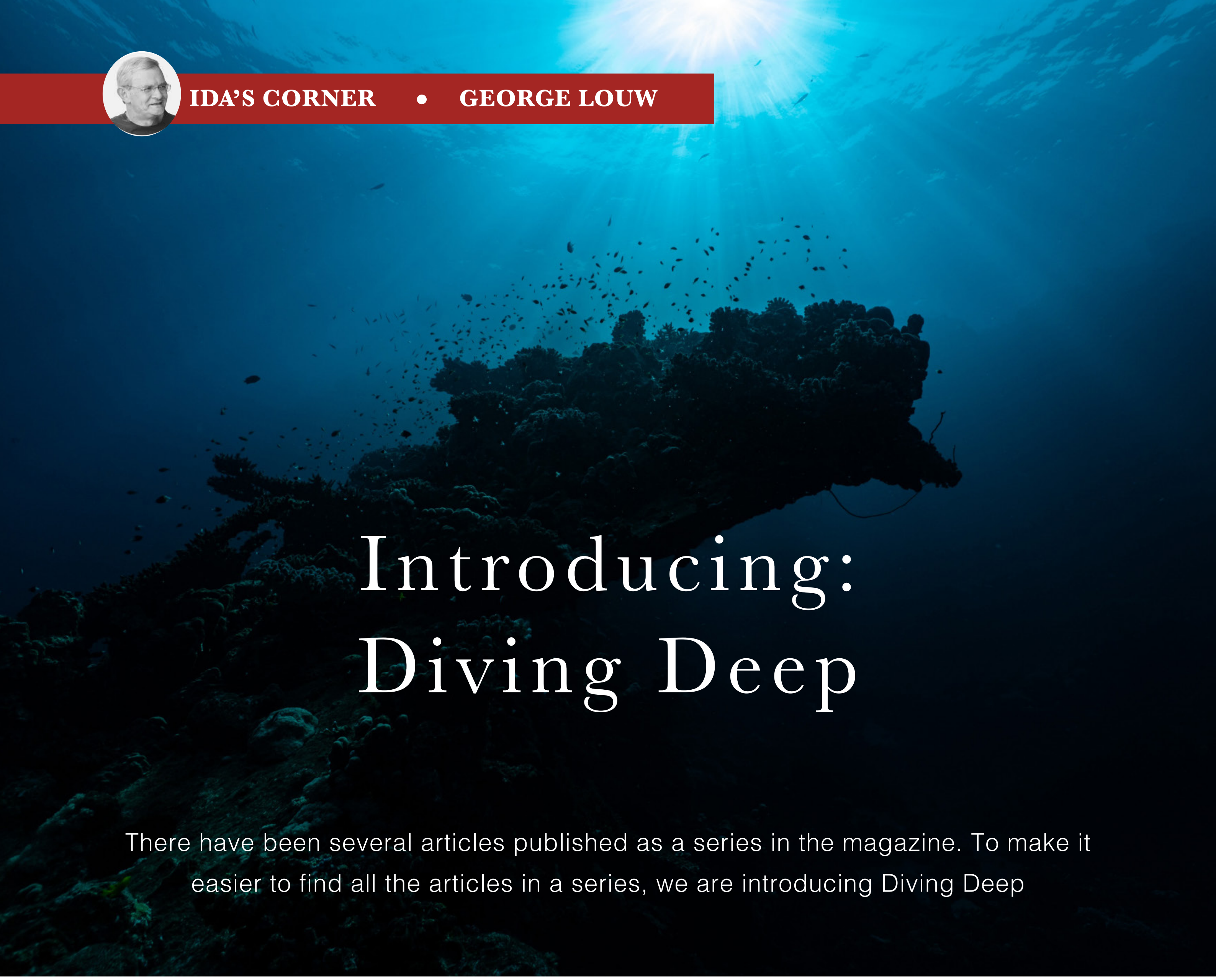
Richard is proof of how such a journey can be greatly beneficial to the members. His advice to members: "Do not settle for the status quo and accept the norms of a society that views disabilities as a reason for pity and dependence on others. We, as individuals with unique gifts, talents and untapped potential, can contribute to making a positive difference in the world.

"To our members, don't ever let your mind stop you from having a good time. Empower yourself to become the best version of who you can be. QASA will be there to assist you on the journey." R

ABOVE: Richard Barron on his last day in the corporate world before he took on the responsibility of managing QASA.

Become a member

Benefit from the QASA community by becoming a member. Members have access to all the QASA services and programmes. The membership fee is R20 per year. To apply, download the application form **here**.



IDA'S CORNER • GEORGE LOUW

Introducing: Diving Deep

There have been several articles published as a series in the magazine. To make it easier to find all the articles in a series, we are introducing Diving Deep

Over the years *Rolling Inspiration* published many articles on topics noteworthy to persons with mobility impairment. Often, when a topic is too broad or diverse to cover in a single article, aspects of the topic were published in a series of articles. Spinal cord injury (SCI) and sexuality is an example. Therefore, in order to get a comprehensive understanding of the topic, back copies of *Rolling Inspiration* need to be researched.

Diving Deep will do this for you. The authors of topics such as employment, travel, amputations, sexuality and parenting will be requested to do compilations of previous *Rolling Inspiration* articles. These compilations will be published in editions of *Rolling Inspiration* in a manner that will allow you to download it in PDF format for your records.

The first compilation, published in this edition of *Rolling Inspiration*, is from a series of articles published in Ida's Corner a few years ago under the heading, "The hidden demons of spinal cord injuries". These articles cover the impact of a damaged autonomic nervous system (ANS) on persons that sustained SCIs.

It summarises the function and anatomy of the ANS and explores the various and diverse impacts of a damaged ANS on the bladder and bowel as well as on body temperature regulation.

The impact of Autonomic Dysreflexia on persons with high level SCI is covered and the compilation concludes with a brief review of the impact of a damaged ANS on sexual function. All the articles follow on with ways and means to manage these difficulties in a manner that allows you to take control of your life again.

The snag with a damaged ANS is that its effects are experienced, but not visible. If a person is a paraplegic in a manual chair or a quadriplegic in a power chair, it is visible to others. I have a mobility impairment.

But my bladder and bowel continence issues, the fact that I am always out of sync with the ambient temperature around me (either too hot or too cold), that incidences of discomfort can trigger pounding headaches and massive fluctuations in my blood pressure, and that my sexual functionality is down the drain; all these scourges are invisible and mine alone to deal with.

> **The first compilation is from a series of articles published under the heading, ‘The hidden demons of spinal cord injuries.’**

And to add insult to injury, the rub is that the ANS is also a major trigger of anxiety, fear and panic attacks. This tends to draw us into ourselves and into our “safe spaces”. We fear going to visit friends because their homes and toilets are not accessible.

We fear going on holiday because we struggle with accessibility; not just physical accessibility but also with safe spaces to deal with our bladder and bowel needs. The showers are promoted as “roll in”, but the grab rails are cock-eyed and the shower seat is built to accommodate a five-year old…

We steer clear of sexual relations because we believe we cannot perform…

All of this manifests in ANS-triggered anxiety, fear and stress, that cause us to become recluses, outsiders, loners.

That is unless we learn to manage the effects of our broken autonomic nervous systems; understand what is happening and why. We can learn how to anticipate, manage and overcome the bladder, bowel and Autonomic Dysreflexia challenges that face us.

We can prepare and dress in a way that help us manage our out-of-sync-ness with the ambient temperature around us. And if need be, see a doctor or psychologist to help us manage our anxiety and panic attacks.

Diving deep on the hidden demons of spinal cord injuries strives to help us understand why we are saddled with these horrible afflictions and how to manage them in order to take charge of our lives again and break out of our self-imposed cocoons. To become social beings again, as we were created to be.

An empty bladder gives us three hours of freedom. An empty bowel, a day or two. Dressing in layers and a mist spray helps with temperature regulation and responding to signs of impending autonomic dysreflexia can prevent its onset.

As for sex, the good news is that sexual expression and even orgasms are not merely physical; loving intimacy and the exploration of other non-genital triggers can result in very satisfying psychologically induced orgasms.

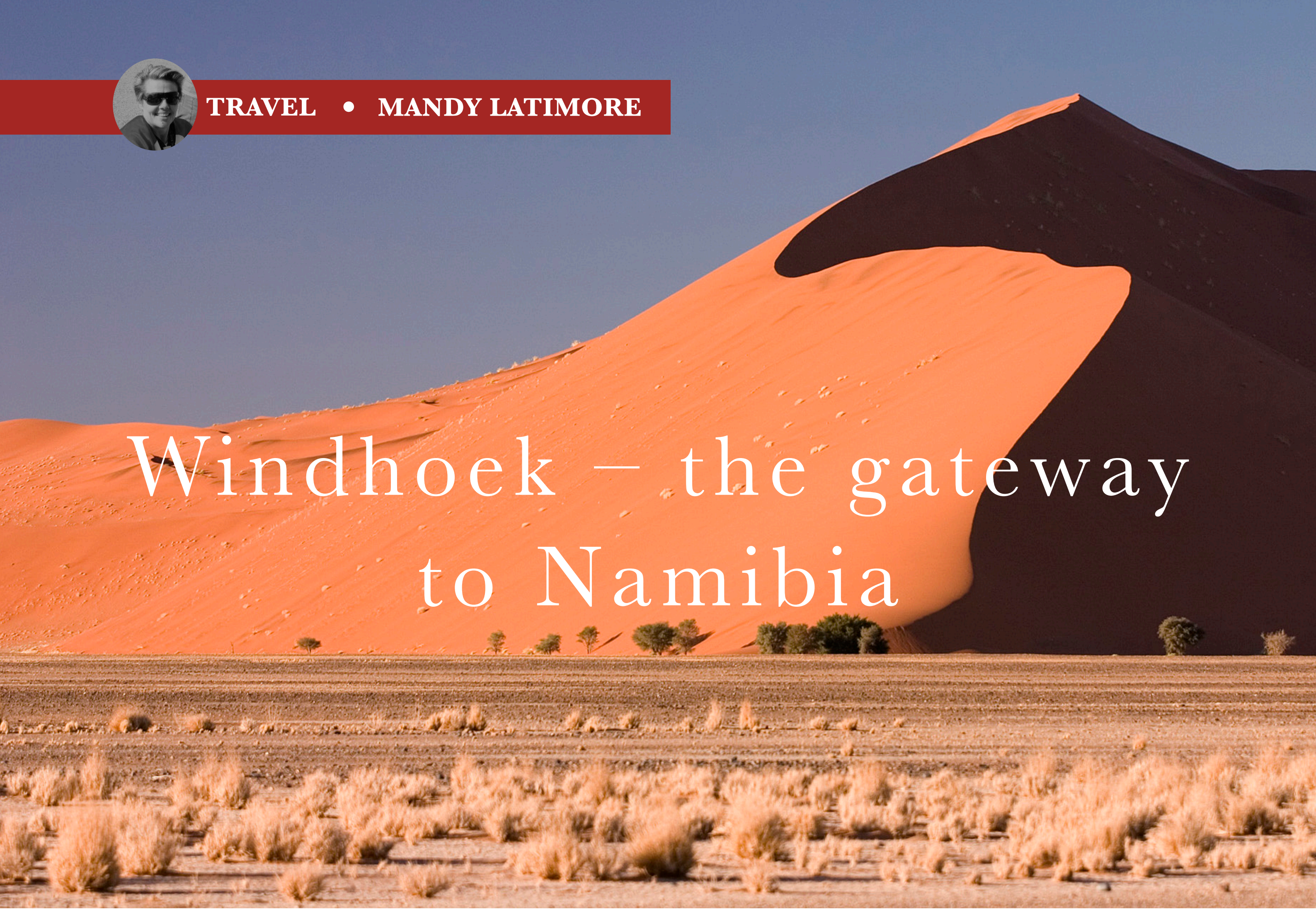
So, enjoy the first edition of “Diving Deep”, toss your disability out of the window and embrace “otherwise enabled”. R

CLICK HERE TO READ OR DOWNLOAD DEEP DIVE

ABOUT THE AUTHOR

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

TRAVEL • MANDY LATIMORE



Windhoek – the gateway to Namibia

A return to Windhoek allowed Mandy to reflect on what she loves about Namibia, and discover what the city has to offer in terms of accessibility

On a recent business trip, I had to visit Windhoek. As I had not been to Namibia for many years, I decided to look into what is currently available for persons with disabilities.

The city of Windhoek has a number of cultural and historical places. Katutura Cultural Township is an interesting cultural experience and tours usually last three hours with visits to grass roots social projects.

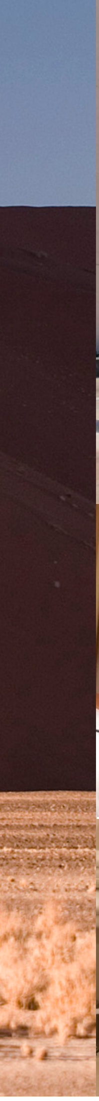
You meet locals and relax in a local restaurant and/or bar. You need to try the Namibian speciality Kapana – which is Namibian beef cooked by the local vendors.

The pavements are generally wide and they have regular curb cuts so access is reasonable; however, when you get to the individual projects, they are not always that accessible. The locals are really friendly and helpful. If you are happy for them to help, they are happy to take you wherever you may want to go!

There are many of the South African well-known branded shops like Spar, Checkers and KFC throughout the city, so it is like a home away from home.

Where to stay? There is a variety from basic accommodation through to five star hotels. I stayed at the Town Lodge Windhoek, which is a three-star hotel next to the big Virgin Active. This hotel has three accessible rooms available, each with a spacious step-free shower cubicle.

There is a large fixed bench within the shower, but there is a grab rail along the wall which protrudes into your back if you



MAIN PHOTO: Dune 45 at Sossusvlei in the Namibia Desert. Photo taken by Luca Galuzzi.
TOP: Town Lodge Windhoek is a three-star hotel that offers three accessible rooms.
MIDDLE: Mandy particulalry enjoyed the backdrop of the Namibia desert landscape above her bed.
BOTTOM LEFT: The bathroom is fitted with grab rails.
BOTTOM RIGHT: The bathroom includes a roll-in shower with a bench.

> **The locals are really friendly and helpful. If you are happy for them to help, they are happy to take you wherever you may want to go!**

don't sit sideways. The cupboard has a rail that is at a good height, however there are no coat hangers – so take your own. The coat hook and peep hole are currently too high; however, the manager was open to making the changes to more accessible heights.

The best thing about my room was the wonderful backdrop behind the bed of the desert landscape that I love so much about Namibia.

The breakfast buffets are comprehensive and all the staff are attentive and keen to assist you with anything that you may need.

There are meeting rooms on the ground floor so that you have a space should need to conduct any business at the hotel. There is secure parking should you be driving a vehicle. The hotel will also assist with airport transfers if you don't have a car.

Remember that Windhoek is just the gateway to the rest of Namibia. There is the famous Fish River Canyon and Etosha Pan in the North.

The costal playground of Swakopmund offers kayaking, dunes and quad biking if you are adventurous. And, of course, my favourite is the spectacular Sossusvlei with its coloured sands and desert landscape.

Should you hire a car to travel around the country, it is advisable that you go for a 4x4 vehicle as the roads are usually gravel out of the towns and cities. It is safer to have the 4x4 capability.

So, if you are thinking of taking a trip to a country on your doorstep, think of Namibia … You won't be disappointed.
Happy travels!

ABOUT THE AUTHOR

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

Addressing design that excludes

The Inclusive Africa Conference brought together design and disability experts to explore the ways in which design can still exclude people with disabilities

Technology, design and disability professionals from around the globe gathered in Nairobi, Kenya, or virtually, for the 2023 Inclusive Africa Conference. The annual event explores the ways in which technology and design can be more inclusive and accessible. The three-day conference, hosted by InAble from 29 to 31 May, welcomed a total of 2 500 attendees of which 118 were speakers at the event.

While the topics discussed during the conference varied greatly, a common theme that emerged was the need for better collaborations between people with disabilities and designers to ensure that the technology and design was accessible and useable.

ACCESSIBILITY ≠ USABILITY

Speaking on youth with disabilities and platform livelihoods, Irene Mbari-Kirika, Executive Director at InABLE, said: “Something can be fully accessible, but not useable. You need both.”

Software, for example, could include all the design elements needed to make it accessible, but have too many steps or be complicated to use. People with disabilities might thus avoid using the software. Similarly, something might be easy to use, but not accessible to people with disabilities. To ensure the design includes both, designers need to consult people with disabilities.

INVOLVED FROM THE START

Including accessibility as an afterthought can be expensive or time consuming compared to including it from the start. Installing a ramp after a building is completed can be challenging and costly. Designing a building with a ramp is more cost effective.

“Including people with disabilities or organisations during project preparation is important as it informs the project design,” said Charlotte McClain-Nhlapo, Global Disability Advisor of the World Bank Group, during her keynote address at the event.

Designers can benefit from including disability specialists in the design process and consulting people with disabilities throughout the project. This ensures that accessibility is at the foundation of the design.

WHO YOU CONSULT

It is important to consider who and how people are consulted during the design process. Ideally, designers will consult people of diverse race, background and disability as each individual, their life experience and disability will impact on how they engage with the design.

During a session that looked at consumer research, Bruce Walker from the Georgia Institute of Technology said: "There is great diversity in Africa. Designing for that is a big challenge." Especially as designers aren't always familiar with the challenges the individuals might face.

He shares the example of design students not from Africa who might never imagine a school without electricity. Their design might heavily rely on electricity, which then won't work for schools in Africa with little or no electricity. He urged for a knowledge and experience transfer between designers and users.

During the same session, Christine Hemphill from Open Inclusion said: "Design needs to come from Africa so that it can work for Africa." Similarly, design needs to come from disability so that it can work for disability – something the bigger technology companies understand well.

Discussing Big Tech, Sunday Parker from Microsoft shared: "Co-creation is important. We create for people with disabilities with people with disabilities." This includes consulting people with disabilities from within the organisation and externally through the Microsoft Inclusive Tech Lab.

Once a diverse group of people are selected, they need to be consulted in an accessible way so that they can fully participate in providing feedback on the design.

DON'T MAKE ASSUMPTIONS

Discussing consumer research, Christine shared an example of how the intended use can differ from the user's need. To accommodate the blind community, a theatre offered accessible screenings. One woman didn't enjoy the experience.

She had always gone to the theatre to spend time with her friends more so than for the film. With the accessible screenings, she was separated from her friend group. Thus, the design didn't meet her particular need. Christine added: "Don't assume you know why the person is there."

By consulting people with disabilities throughout the project, designers can get a range of perspectives on their product, ensure it is useable and accessible so that everyone can enjoy it.

DESIGN FOR EVERYONE

"Sometimes it is the simple innovation that leads to change," Charlotte said during her keynote address. This change can often benefit more than just the disability community.

"Not designing for accessibility is failing our families and our future selves," said Colette Fransolet, Global Leadership Council Member of the International Association of Accessibility Professionals (IAAP).

It is very possible to develop a disability later in life through illness, an accident or old age. A more accessible environment will benefit the disability community today, and everyone tomorrow. Colette adds: "We need to share skills of accessibility so that it can be applied everywhere."

INCLUSIVE AFRICA CONFERENCE AWARD

The conference also showcased innovative design. This year, the top accolade went to Kochi – a digital manufacturing technology from Kenya that specialises in producing comfortable, portable, and safe wheelchairs. Kochi received a generous US$10 000 (R184 620) grant that will significantly contribute to enhancing the usability of their product.

"It is overwhelming that we won even though we were unable to make it to the conference," said Kenneth Gichohi, Co-Founder and Chief Design Officer at Kochi.

"Someone saw the potential and believed in our product which will make it possible for people to get affordable assistive technology solutions after proper assessment has been done."

The first runners-up was Deaftronics from Botswana with the world's first rechargeable solar-powered hearing aid designed explicitly for individuals with hearing loss. R

RUSTIM ARIEFDIEN • EMPLOYMENT

Fundraising with learnership for NPOs

NPOs working in the disability field are at an advantage when applying for Discretionary Grant funding from SETAs

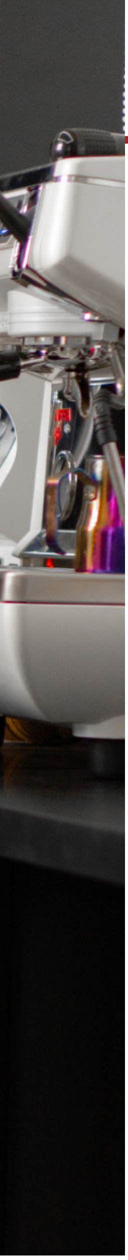
Only about a percent of the workforce are persons with disabilities. A very high rate of unemployment and jobs generally difficult to come by exacerbates the chances of persons with disabilities finding employment. Furthermore, the training and skills gap is larger for persons with disabilities, which makes it even more difficult to find employment.

Learnerships are thus a good pathway to get a qualification in a field of choice for the person with a disability. Additionally, the learners are able to earn a stipend in the process and gain valuable work experience. Many learnership fields have further learning pathways that learners with disabilities can follow if they choose.

Non-profit organisations (NPOs) are struggling to raise funds to execute their valuable work for people with disabilities.

Sector Education and Training Authorities (SETAs), of which there are 21 in South Africa, have a disability target which they struggle to achieve. This presents an opportunity for NPOs to apply.

SETAs regularly invite applications for Discretionary Grant funding from stakeholders.



The SETA pays the stakeholder the cost of delivering the learnership. This includes a learner stipend and training grant – the latter can be used to source an accredited training provider. The Discretionary Grant ranges from about R6 000 to R12 000 per learnership.

NPOs are in the best position to apply. They have good databases of learner candidates with disability, and they understand the concept of reasonable accommodation. They are able to identify and offer the necessary support to the learner with a disability in training and in the workplace.

> **Learnerships are thus a good pathway to get a qualification in a field of choice for the person with a disability.**

The funding equation could be lucrative for the NPO. The training grant can be negotiated in such a way as to where the NPO is able to keep a surplus, which could be about R2 000 to R5 000 per learnership.

Furthermore, as the Lead Employer on SETA Discretionary Grant allocations, the NPO is able to claim the Employee Tax Incentive (ETI) which amounts to R18 000 for the 12-month duration of the learnership project.

The NPO could thus easily earn about R26 000 to R35 000 per learnership as net income on a learnership project. An allocation of about 20 learnerships would thus have a net worth to the NPO of R700 000.

The role of the NPO covers the following:

- Making an application for funding.
- On allocation source a Skills Development Provider.
- Ensure the hosting of the learner.
- Adequately support the learner.
- Project manage the project.
- Financially manage the project.

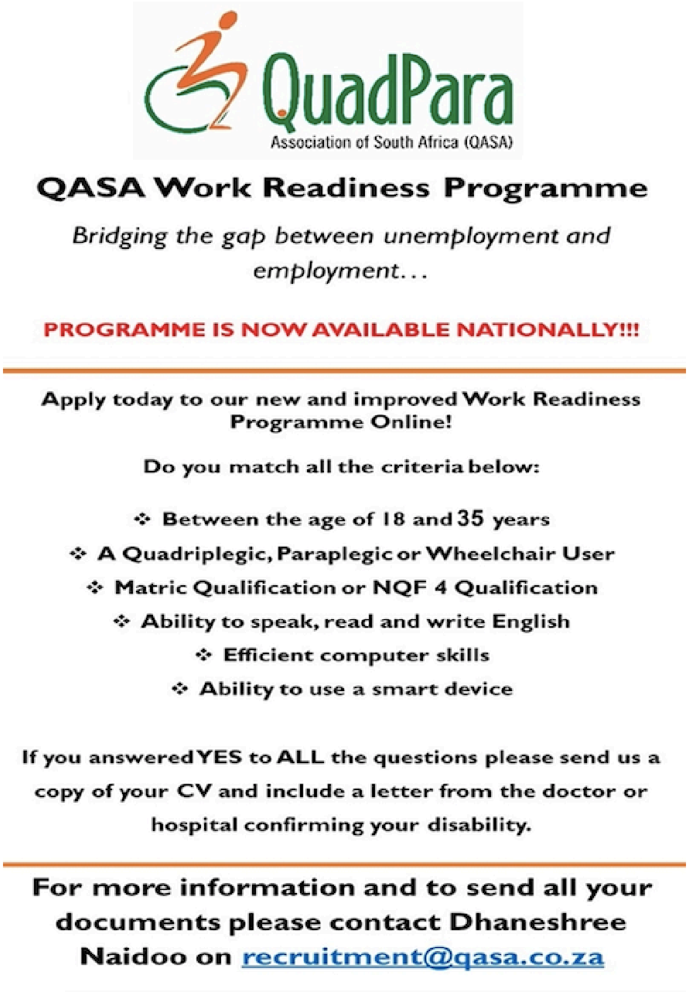
The learner with a disability benefits in the following ways:

- They get a monthly stipend.
- They get a qualification.
- They get valuable work experience.
- They are able to enhance their CV.

There are opportunities for persons with disability out there. Through access to knowledge, collaboration and cooperation we can empower people with disabilities.

ABOUT THE AUTHOR

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



Coaching for a fulfilling life

In a new series, Len Davey takes us through the process of life coaching

Life coaching speaks to us firstly as human beings. Our human needs are not wants; they are ontological (stemming from the condition of being human). Our needs, among other things, are fundamental to our happiness. Unfortunately, these topics are not taught or discussed in our upbringing. Life coaching bridges these waters of uncertainty, and teaches us to fulfil these needs and conditions of happiness and success.

Let me explain. Life coaching is not counselling nor a branch of psychology. It is a solution-focused approach to personal development that can assist with making lasting changes in all areas of your life by empowering you with specific tools and scientifically tested techniques that work for everyone.

It is such an awesome journey of "self-discovery" that we undertake together by establishing your unique purpose in life and then living into that purpose. It is so important to understand, clearly, what makes a person tick. It is important to realise the extent to which your actions and behaviours have been influenced, not by your true passion, but by the seemingly chaotic, demanding and largely ambivalent external world.

The above is termed "Transformational Life Coaching". If we looked at your goal in isolation, and only focused on attaining that specific goal, it would be called "Transactional LC". The latter may require only two or three sessions.

This field of coaching has a place in society if one is stuck, overwhelmed, or if one just needs inspiration. We can work out a course of action designed to provide intermittent coaching for a specific solution. However, it is actually not what we recommend.

Life is a journey and life coaching is not just focused on the destination. It is about "the journey" and assists you to create your own specific road map, as each person's journey is unique.

Life coaching also helps you to identify and eliminate your "limiting beliefs and behaviours" in order to create the life of your choosing. We explore the two main protagonists in life, namely, the pursuit of pleasure and the avoidance of pain. We explore how these protagonists influence our behaviour and, ultimately, our life. R

ABOUT THE AUTHOR

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

Nkosi Sikilel iAfrika

It seems as if amputees in South Africa are outliving their international peers

Yes, our national Anthem! Nkosi Sikelel' iAfrika is a Christian hymn originally composed in 1897 by Enoch Sontonga, a Xhosa clergyman at a Methodist mission school near Johannesburg.

"The Call of South Africa" is now the national anthem of South Africa. It is the only neo-modal national anthem in the world, by virtue of being the only one that starts in one key and finishes in another. And we sing it in three languages. Quite significant and the opening line literally means "God Bless Africa".

If we look at South Africa today it is sometimes quite difficult to see where the blessing is. Newspaper headlines of the last few years paint a different picture. State capture, stealing politicians, looting, loadshedding, potholes, crime and corruption, rhino poaching and water supply issues to name but a few. "Nothing works in Africa" might be true.

But the flip side of the coin is that American and European research and statistics doesn't work in South Africa as well. For example, take mortality rates in amputees.

Well researched "overseas" stats tell us that 44 percent, 66 percent and 85 percent of all amputees pass away in year one, three and five respectively after amputation. This is their averages. But, honestly and quite frankly, we do not see these figures on our side.

We see more amputees of all ages living fully integrated fulfilling lives than the stats from abroad might suggest. A truly phenomenal and strange occurrence for a third-world country. So, what brings this about is the next logical question.

Could it be our social structures and family support? Could it be our resilience and fighting spirit in the face of adversity? Could it be our humorous outlook towards problems? Could it be our tougher-than-tough attitude? Could it be the African sun shining in our hearts every day? Or the diversity in our population?

Our awesome rehabilitation protocol's and level of prosthetics? Or is it something in the water? Or could it simply be God Blessing Africa and its people?

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

QUINTIN VAN JAARSVELD • PLAYERS' FUND

Dogged determination forges new future

Arthur Cullinan's dogged determination has enabled him to deal with the heartache of a catastrophic rugby injury

Arthur Cullinan was 22 and playing hooker for University of Pretoria (UP) Onderstepoort's first team when he suffered a dislocation between his C5 and C6 vertebrae as he tackled one of Vividus's props on 5 May 2013. In the fourth year of his veterinary science degree, the tragedy left him a quadriplegic and robbed him of his dream profession, and the lifestyle he'd envisioned for himself since childhood.

"I immediately went down and it felt like electricity was running through my entire body with severe muscle weakness, but I never lost consciousness during the ordeal," Vryburg-based Arthur recalls 10 years on. It's a double blow that would break the will of most, but not that of the courageous Arthur.

"Faith, hope and ignorance saved me in the early stages. It helped me to not have to deal with all the losses at the same time, but in smaller portions as I went along. The downside is that it took me a lot longer to let go and start living again," he says.

"I've always been hard on myself, so it's been a learning process to realise you're running your own race and that your situation differs from others, even if there are similarities.

You can't compare your timeline to other people's timelines."

Seven months of gruelling rehabilitation followed at Life Riverfield Lodge and Mediclinic Muelmed, while the mental healing remains a work in progress. "To a certain degree, I'm still fighting that [mental] battle daily, because the veterinarian dream is more alive now than it was before my injury," he admits.

> **The veterinarian dream is more alive now than it was before my injury.**

It's indeed a lifelong journey, however, he turned a vital corner on his psychological road to recovery and found a new way forward roughly a year after his injury when he started teaching physical sciences and mathematics to high school students, which graduated into a stint as a math teacher at Kismet Secondary School from 2016 to 2018 before he branched out into tutoring again.

"The opportunity to teach as Kismet showed me that it's still possible to make something out of myself and made me curious to see how far I can push things and what I can still achieve. The tutoring started from home in the afternoons, but when Covid came around, it forced me to do the classes online.

This turned out to be a blessing in disguise as it has expanded my classes tremendously. Currently, it's a mixture of online classes and personal sessions from my home," Arthur shares.

"I have a passion for the youth, so that's part of the reason why I went into tutoring and also to go beyond the academics and impart in them some life lessons like not to take anything for granted, but to be grateful for what you have. In that regard, I've also learned to make the most of the life I have and hopefully be an example for someone."

Arthur, too, is still studying. The 32-year-old's finishing up a BSc degree in genetics and physiology through UNISA and is also doing an Animal Pharmaceuticals course through the South African Animal Health Association. As for what the future holds after his studies, Arthur says: "I'm not much of an entrepreneur because I'm not motivated by money.

"My main drive is to be able to help people or to join the farming and livestock industry in some capacity, where I feel I can play a role if I let myself. Mainly, I want to feel that I'm making a contribution to society and do something that makes me excited to get out of bed in the morning."

There for Arthur since that fateful day is the Chris Burger Petro Jackson Players' Fund. He notes: "The Players' Fund paid for all my initial equipment and was there from day one with advice, guidance and support, especially in the beginning when things were hectic and I was entering unknown territory with very little information. Knowing that they are there if I need them gives me a lot of comfort."

"The rest of my support structure is my family and friends, mainly my parents whom I still live with and who help me with the few small things I still can't do for myself," Arthur adds.

His story is one of raw resolve, starting over and continuously coping with loss. "We have very little control over the cards we're dealt, but we can control how we respond and what we do with what we've been given. So to anyone in a similar position or who's going through other hardships, stop complaining about things being unfair and start living your life to the best of your ability," Arthur concludes. R

DONATE TO THE PLAYER'S FUND

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

EMMA MCKINNEY • ROLLING KIDS

Parenting tips

from parents of children with disabilities

Parents of children with a range of, and multiple, disabilities share some advice on how to best care for your child

Chatting to parents of children with a range of physical and multiple disabilities, I asked them to share some tips on parenting. Here are some of their responses:

THE MORE INDEPENDENT YOU CAN MAKE YOUR CHILD, THE BETTER

The world is a tough place. If we bubble wrap our kids, it will just make coping in the “real world” more difficult later. We are not going to be around forever. We need to give them coping skills and strategies.

BE KIND TO YOURSELF

So often all of our focus and energy are on our children, and we have very little time or energy left for ourselves.

I always think about the flight attendant’s speech about first putting on the oxygen mask before helping our kids. If we don’t look after ourselves, we are going to burn out and not be the best parents for our kids.

INCLUDE YOUR CHILD IN EVERYTHING

Many parents hide their child, or leave them at home rather than taking them out in public. So often we want to protect our kids from people staring, and inappropriate comments and questions, but we have to get our kids out there.

The public needs to see that they are part of society and have the right to be out and about. If my kid makes you uncomfortable, that is your problem. Not ours.

I went to a moms and babies group, and was amazed to see a mom with a son with severe multiple disabilities. She was so confident and seeing how she was bonding with her boy just holding, singing and rocking him brought me to tears.

She wasn't hiding him. The other moms were so kind and non-judgemental. I learned a big lesson that I should just get out there with my kid.

> **If we don't look after ourselves, we are going to burn out and not be the best parents for our kids.**

BE YOUR CHILD'S ADVOCATE

We have to fight for our children. The world is not going to. While we have come so far in terms of creating awareness and fighting for disability rights, we still have a long way to go.

LET YOUR CHILD HAVE A VOICE

So often we want to speak on behalf of our children. When they are small that is our job. When they get older, we need to give them tools and confidence to fight their own fights. I am talking about equipping them to ask for help when they need it. Not when we think they do.

They need to be able to speak to their teachers and share what they need in the classroom, what helps them, what works and what doesn't. If we don't, what will happen when they are adults?

PUSH YOUR CHILD TO THEIR LIMITS

Our children have additional challenges, including getting sick more easily, tiring more quickly, and needing more support.

Sometimes we try to overcompensate for all their struggles and try make things easier by giving in and not pushing them academically.

For many of our kids, it is just their physical bodies that might be affected. They need a push and be challenged. We have to encourage them to persevere and not give up. But, I know this is tough in reality. I don't always get this right.

THINK OUT OF THE BOX

You can have 30 kids all with cerebral palsy in one room and you will have 30 different kids needing 30 different things! Our kids are all unique and while we can get ideas from what other parents are doing, at the end of the day, our kids are all different.

That is okay! If you look at our kids without disabilities, they are also not all the same. So, why do we expect our kids with disabilities all to fit into one box?

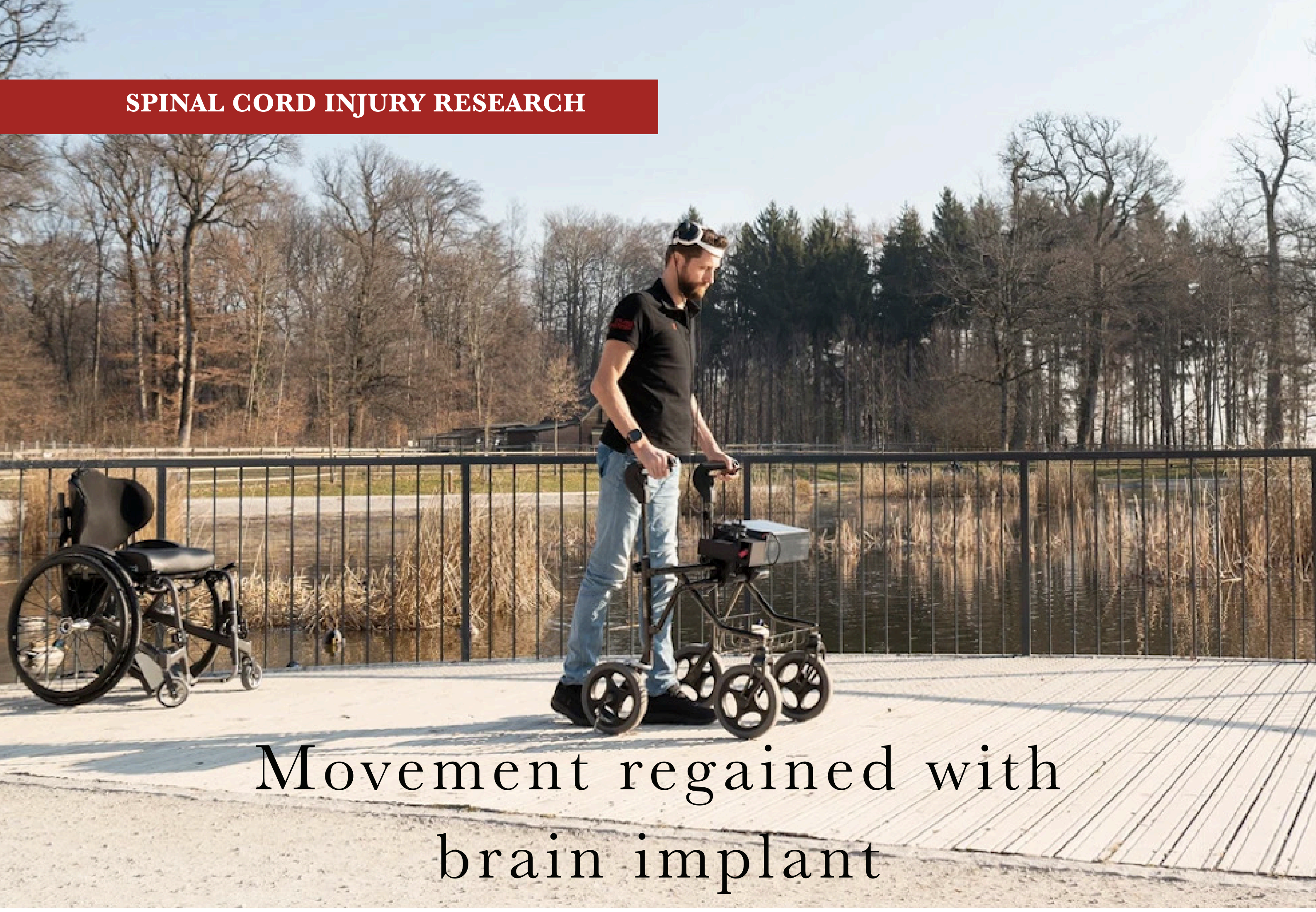
WORK WITH THEIR STRENGTHS

Find out what fuels, motivates and drives our kids. Know your child's strengths, interests and abilities and use these. So often we focus on what they can't do. What they find difficult and struggle with.

This is normal, but can make us feel down and negative. It can be exhausting. Focus on what they can do. Keep a diary so you can go back in dark times and see how far your child has come. Sometimes you can't see it as you are so in it! R

ABOUT AUTHOR

Dr Emma McKinney is a Senior Research Officer at the University of Cape Town, and owner of Disability Included, a company providing disability employment and educational research, training, support, and resources. email: emma@disabilityincluded.co.za



Movement regained with brain implant

Digital implants in the brain and spine has allowed Gert-Jan Oskam to regain control of his legs – a breakthrough that could lead to a cure for spinal cord injuries

Gert-Jan Oskam was in a motorbike accident in his 20s, which left him a paraplegic. Now, at 40 years old, he is walking again thanks to ground breaking scientific research.

In order to walk, the brain needs to send a command to the neurons located at the lumbosacral part (or very bottom) of the spine. A spinal cord injury disrupts the connect between the brain and lumbosacral; thus, the command never reaches the lumbosacral spine.

Often, the neurons remain undamaged during a spinal cord injury. Thus, they can still act on the command if it was received.

Many researchers are trying to find a way to restore the connection. This would allow someone with a spinal cord injury to walk again.

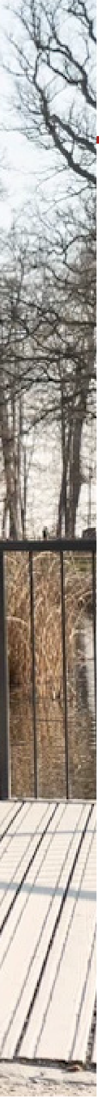
A group of neuroscientists in Switzerland, led by Grégoire Courtine and Jocelyne Bloch, have now managed to "bridge" this paralysis with a brain-spine interface.

WHERE IT STARTED

In 2018, the researchers introduced the Stimulation Movement Overground (STIMO) clinical study, which combines two different treatments: precise epidural electrical stimulation of the spinal cord, and robot-assisted locomotion (walking) training.

The epidural electrical stimulation sends electrical currents to the spine with the help of a little electrode chip implanted in the spine. This is controlled wirelessly with voice control.

Stimulation is then applied during rehabilitation to encourage movement and the reorganising of the nerve circuits in the



brain. The aim is to "awaken" the dormant spinal tissue below the level of injury.

Participants of the study had the challenge of coordinating their intention to walk with the electrical stimulation.

The robot-assisted locomotion training allowed them to move freely while preventing falls by supporting their bodyweight as needed.

The success achieved thus far has been incredible with participants walking with their bodyweight supported after only a week.

By the end of the study, the participants could walk more than a kilometre on a treadmill without using their hands for support.

While STIMO seems to be successful and safe, it does have its limitation. The control of walking was not perceived as completely natural, and walking was possible only on flat and obstacle free ground.

The clinical study is still ongoing with final results only expected within another year or two.

> "
> **The team designed a digital bridge between the brain and spinal cord by implanting two devices.**

WHERE IT'S HEADING

Recently, the team designed a digital bridge between the brain and spinal cord by implanting two devices that work together to record brain activity and stimulate in the spine.

A special headset detects the brain activity (or thought) and processes it to a computer carried on a backpack. The computer analyses the signals and controls the epidural stimulator.

MAIN PHOTO: Gert-Jan Oskam making use of the brain implant device.
ABOVE: Neuroscientist Grégoire Courtine assisting a patient on the robot-assisted locomotion during the STIMO study.

In simple terms, it means that the person thinks about moving and this stimulates the corresponding muscles immediately.

NOT THERE YET

While this new technology could empower the patient to achieve better mobility, there are still many limitations.

The device needs to be regularly re-calibrated. There are delays in message transmission, operation complications and more.

However, the research remains crucial to getting us closer to finding a cure for spinal cord injuries.

Both studies were funded by the Wings for Life Foundation – a benefactor of various research projects aimed at finding a cure for spinal cord injuries.

In May, the Foundation raised €5,8 million (R120 million) through its Wings for Life World Run. All entries and donations from the global event goes towards funding research in search of a cure.

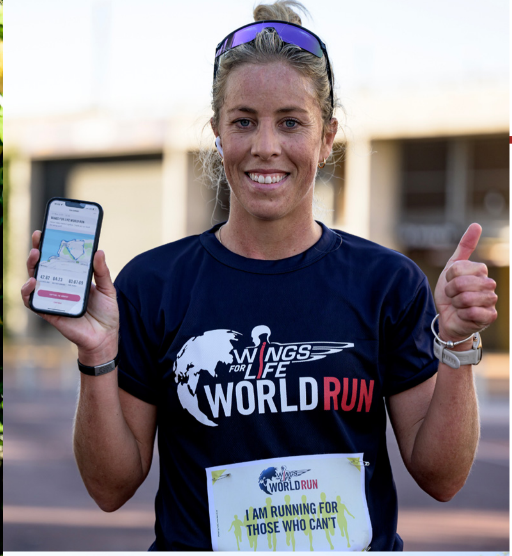
Millions raised with run

The 2023 Wings for Life World Run saw €5,8 million (R120 million) raised for the Wings for Life Foundation, which is searching for a cure for spinal cord injuries

The annual Wings for Life World Run returned in 2023 with participants from across the globe “running for those who can’t”. The event aims to raise funds for the Wings for Life Foundation, which provides funding to several research projects that are searching for a cure for spinal cord injuries.

All entry fees and donations go toward the fund. Through the Wings for Life World Run app, participants can join from anywhere in the world.

This year, Red Bull South Africa hosted two app events to encourage participants to come together for the run. These were



MAIN PHOTO: Participants of the 2023 Wings for Life World Run gather at the start of the App Run held at the Green Point Urban Park stadium in Cape Town on 7 May 2023.

TOP: By downloading the Wings for Life World Run app on a smartphone, participants could join the event from anywhere in the world.

BOTTOM: (From the left) Jenna Spooner and Melikhaya Jandick were the top racers at the Cape Town event.

at the Roodepoort Ruimsig Stadium in Johannesburg, and the Green Point Urban Park in Cape Town. *Rolling Inspiration* attended the app event in Cape Town.

Participants gathered on a field at the East Gate of the Green Point Urban Park. The atmosphere was lively with music, food stalls and a big screen to showcase the runners from across the globe. The event even boasted a Kaapse Klopse band.

In the build-up to the run, the Red Bull South Africa team took participants through a quick warm up. Thereafter, everyone gathered on the walkway facing the East Gate for the countdown. Participants took off down Vlei Road, up Fritz Sonnenberg Road towards Beach Road before turning onto the Sea Point Promenade, and finally coming back through the Green Point Urban Park through the West Gate.

They would repeat the route, which was close to five kilometres, until they were caught by the virtual Catcher Car. Once caught, participants made their way back to the start to collect their medals, handed over by QASA members, and a complimentary Red Bull.

Riaan Barnard was the overall winner of the South African leg of the race with 47.08 kms. Jenna Spooner was first among the woman participants with 42.62 kms. An estimated 4 700 people participated in South Africa.

Globally, there were 206 728 participants who raised an estimated €5,8 million (R120 million). Anita Gerhardter, CEO of Wings for Life, said: “The Wings for Life World Run acts like a turbo for spinal cord research. With the money raised, we have already been able to help several projects make the leap into the clinics to be tested with patients who have sustained spinal cord injuries. This in itself is a great success, and we’ll see even greater progress in the future.”

Scientific Director of Wings for Life, Dr Jan Schwab, shared: “I like running and this run is of particular concern to me. It creates awareness for people who have to live with a spinal cord injury.”

Research is expensive, Dr Schwab explained. The millions raised by the Wings for Life World Run every year is “important money and enables Wings for Life not only to fund a larger number of projects, but also to conduct clinical studies that are more expensive. The run is good news for research.”

He added: “On behalf of the many scientists who have received funding and on behalf of the entire field of research: I’d like to say a big thank you to all participants.”

The global event will return on May 5, 2024. Entries will open later this year.

PHOTO GALLERY • WINGS FOR LIFE WORLD RUN

Participants at the App Run held at the Roodepoort Ruimsig Stadium in Johannesburg for the 2023 Wings for Life World Run.
Photo by Red Bull South Africa

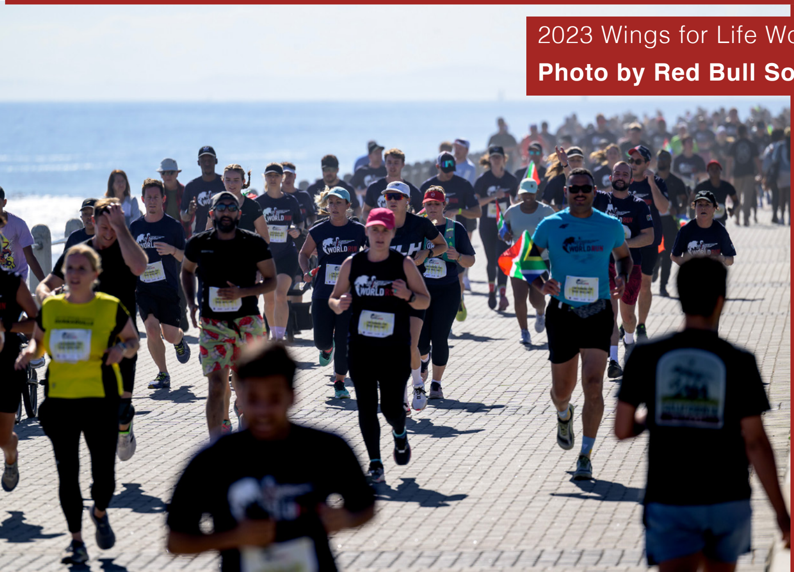
2023 Wings for Life World Run in Johannesburg.
Photo by Red Bull South Africa

A little helping hand offered at the 2023 Wings for Life World Run in Johannesburg.
Photo by Red Bull South Africa

2023 Wings for Life World Run in Cape Town.
Photo by Red Bull South Africa

Participants of the 2023 Wings for Life World Run could join the App Run held at the Green Point Urban Park in Cape Town.
Photo by Red Bull South Africa

2023 Wings for Life World Run in Cape Town.
Photo by Red Bull South Africa



Road to Paris has started

As we get closer to the 2024 Paralympic Games, Leon discusses the important events for athletes with disabilities who want to qualify for the Games

April 16 marked 500 days to go to the Paris 2024 Paralympic Games. The qualification process has started in earnest for this sporting spectacle for athletes with disabilities.

Various sporting codes have had their 2023 National Championships already and the athletes are trying to qualify for this year's World Championships (8 – 17 July 2023), which for some sports are major qualifications for the Paris Games.

The two standout Para Sports events this year are the World Para Athletics Championships being held in Paris, France, in July, the World Para Swimming Championships being held in Manchester, England, in August and the inaugural Africa Para Games being held in Accra, Ghana, in September this year.

Wheelchair Basketball hosted the men's zonal qualifications for the African Para Games at the Vodacom Mandeville Indoor Sport Centre in early April with South Africa and Angola men's teams qualifying for Ghana where the winner of the African Para Games will be the Africa representative at next year's Paralympic Games. Good luck to our boys!

I recently visited Paris to see the village and some venues and I must say that Paris is going to be a special games with a legacy of making Paris a lot more accessible to people with disabilities.

The year is young and we will be seeing our athletes participating more over the coming months so let's start getting ready to get behind our heroes and upcoming heroes as they strive to be excellent ambassadors and inspire the world through their achievements!

ABOUT AUTHOR

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.

DANIE BREEDT • SEXUALITY

Under pressure

The pressure to perform can remove the pleasure for some individuals

Although sex, for many people, is an enjoyable and satisfying experience, that is not always the case for everyone. For some people, sexual activity can feel pressured or even stressful. In such cases, sex loses its playfulness and tends to feel like an obligation or a job to be accomplished.

Instead of sharing an intimate experience with a partner, the focus shifts to achieving a satisfying erection or insuring that one's partner reaches an orgasm. Function then becomes the goal of sex rather than pleasure.

It is quite common to have certain standards by which we "measure" our sexual experiences. This is called a performance model of sex. In order to change this pressure to pleasure, we need to make a mental shift. A traditional individual performance model needs to give way to a more realistic shared experience model of sex where the focus is on pleasure and connection.

An SCI is often accompanied by emotional distress and frustration in relation to sexual performance and enjoyment. This often becomes an issue in relationships and can damage sexual confidence. If a couple cannot communicate about the problem, it can quickly grow into an even bigger issue. Sex then becomes something that is avoided or a source of conflict and insecurity.

An SCI makes achieving the traditional performance measures (like erections and orgasms) for how "successful" a sexual encounter is more difficult. In my work as a psychologist, a large portion of the discussions that we have about sexuality after an SCI focus on relational aspects and our brain as a source of arousal and enjoyment instead of relying solely on physical experiences.

When people are willing to engage with this alternative way of viewing sexuality, the experiences of intimacy and enjoyment has been overwhelmingly positive. Ironically, when the pressure has been removed, physical enjoyment also seems to happen more naturally as a by-product.

This takes time, patience and acceptance of one another. It requires a realisation that, on our journey to more satisfying sexual encounters we will experience disappointment or frustration. What is important however is that we not view sex as a pass or fail experience.

Your SCI is an opportunity to discover alternatives that make sex personal and enriching. In the months after injury, the goal for the individual or couple is to explore and discover a unique satisfying experience that promotes sexual enjoyment in spite of age, disability, gender or other potential barriers to pleasure.

This journey could be a wonderful opportunity for self-discovery and deeper connection with your partner if you are willing to take up the challenge. You might even be surprised about something positive coming from an experience that's mostly viewed as negative.

ABOUT THE AUTHOR

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

Recognition of an incredible teacher

Qaphela Dlamini graduated from the University of Zululand in 2012. In 2020, he was promoted to the department head for intermediate phase at KwaZamokuhle Special School. In 2022, he won the National Teaching Award for excellence in special needs teaching in both KwaZulu-Natal and Nationally. He was invited to speak at the 2023 Basic Education Sector Lekgotla, held by the Department of Basic Education.

“The reason I enjoy being an educator is that I want to motivate pupils with special needs to focus more on education and not to lose hope,” Qaphela shares. “Persons with disabilities must prioritise education so that we will be able to overcome the challenges that we are currently facing.”

ABOVE: (From the left) Minister Angie Motshekga with Qaphela Dlamini.

He continues: “I wanted to express my thanks for the success in 2022 National Teaching Awards. I would like to sincerely thank Mr Esoup uThukela District Teacher support, Miss WB Ndima, our Loskop circuit manager, the principal of Kwa Zamokuhle Special School, Mrs TV Mazibuko from Amahlubi High School and my fellow colleagues at Kwa Zamokuhle Special School.”

“Their proper guidance and support has led me to get first position in excellence in special needs teaching. I would really like to honour other people with disabilities with this award,” Qaphela concludes.

Congratulations to Qaphela for these prestigious awards. We look forward to see what he does next. R

In case you missed it

Catch up on all the news and information you might have missed

Highlights from SASCA Congress

The biennial Congress of the South African Spinal Cord Association (SASCA) was held in Cape Town from 18 to 20 May. The informative, three-day conference included several international speakers and an exhibition.

Click here to read more about the event.

AfriNEAD Conference returns

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

Click here to read more about the event.

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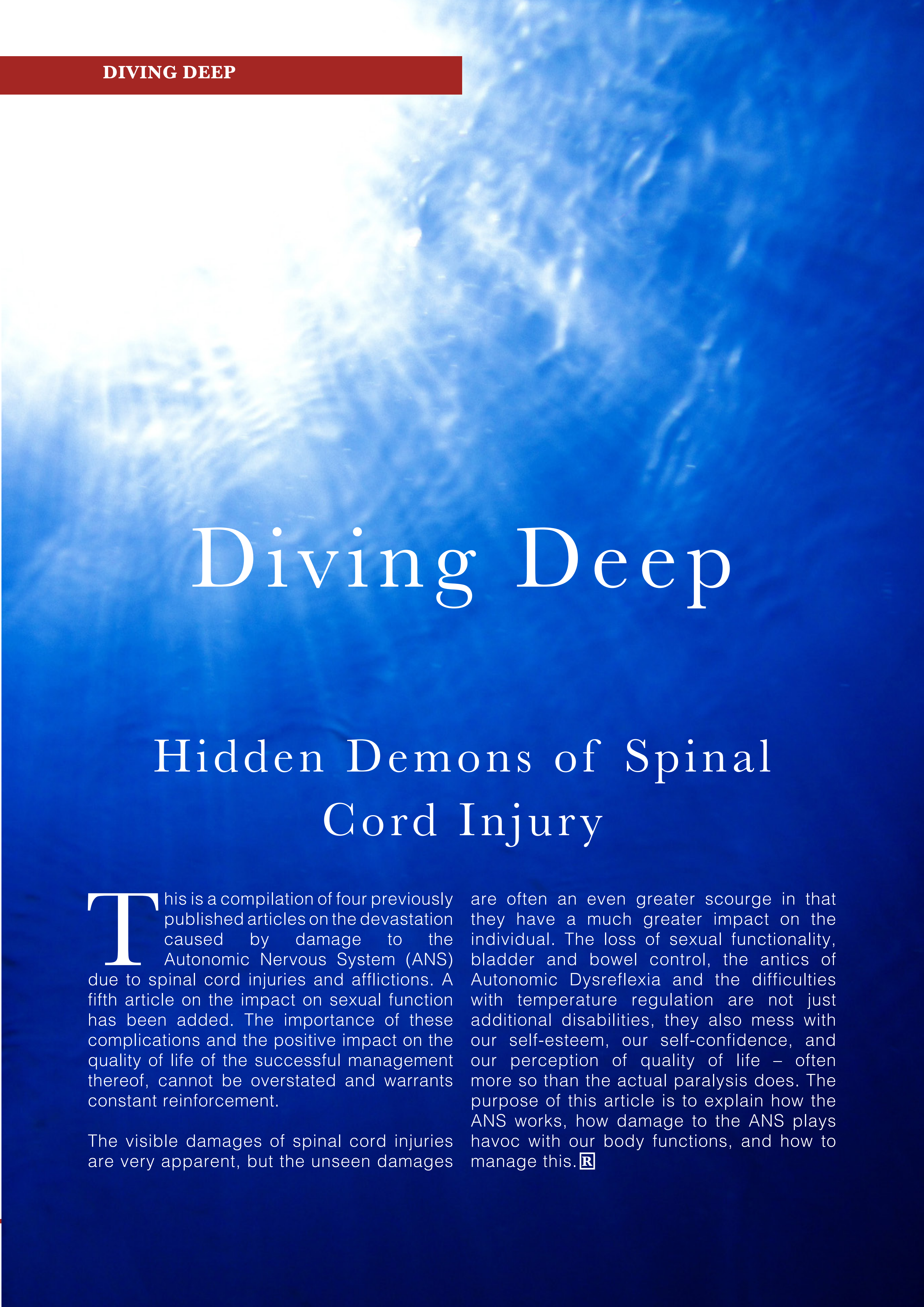


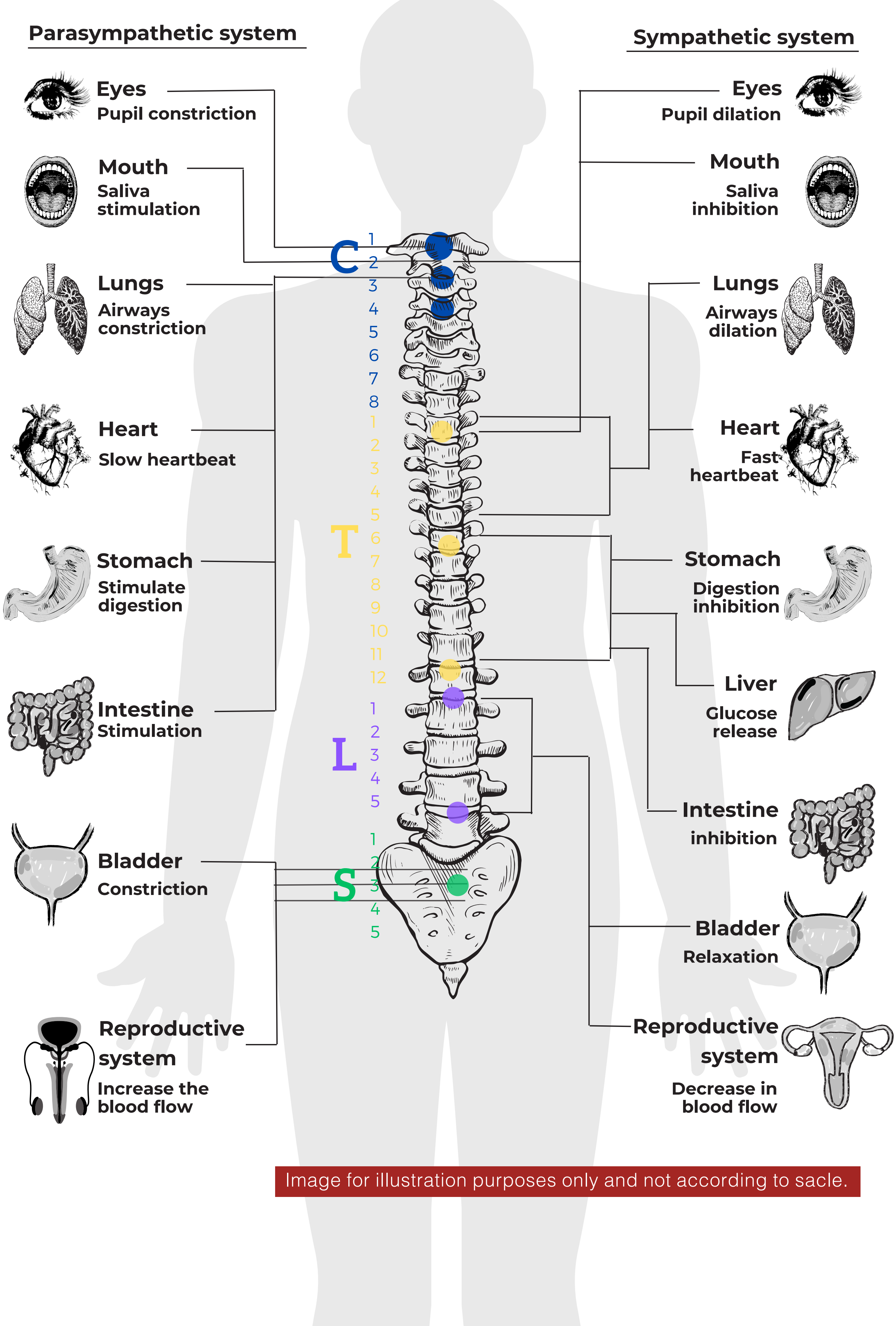
Diving Deep

Hidden Demons of Spinal Cord Injury

This is a compilation of four previously published articles on the devastation caused by damage to the Autonomic Nervous System (ANS) due to spinal cord injuries and afflictions. A fifth article on the impact on sexual function has been added. The importance of these complications and the positive impact on the quality of life of the successful management thereof, cannot be overstated and warrants constant reinforcement.

The visible damages of spinal cord injuries are very apparent, but the unseen damages are often an even greater scourge in that they have a much greater impact on the individual. The loss of sexual functionality, bladder and bowel control, the antics of Autonomic Dysreflexia and the difficulties with temperature regulation are not just additional disabilities, they also mess with our self-esteem, our self-confidence, and our perception of quality of life – often more so than the actual paralysis does. The purpose of this article is to explain how the ANS works, how damage to the ANS plays havoc with our body functions, and how to manage this.

AUTONOMIC NERVOUS SYSTEM



Parasympathetic system

Eyes
Pupil constriction

Mouth
Saliva stimulation

Lungs
Airways constriction

Heart
Slow heartbeat

Stomach
Stimulate digestion

Intestine
Stimulation

Bladder
Constriction

Reproductive system
Increase the blood flow

Sympathetic system

Eyes
Pupil dilation

Mouth
Saliva inhibition

Lungs
Airways dilation

Heart
Fast heartbeat

Stomach
Digestion inhibition

Liver
Glucose release

Intestine
inhibition

Bladder
Relaxation

Reproductive system
Decrease in blood flow

Image for illustration purposes only and not according to sacle.

Autonomic Nervous System

It must be stated at the outset that in my attempts to simplify explanations, I have taken some liberties with the very complex nature of the ANS as well as the consequences of ANS damage on the organs and other systems regulated by the ANS.

However, I trust that readers will be left with an understanding of why things are as they are; and that this understanding will give you empathy with the impact of these dysfunctions on the minds and emotions of afflicted persons.

The ANS make up all the nerves that regulate the function of our organs, including our urinary and digestive systems, our heart and blood vessels, temperature regulation and our sexual functionality. It has two components that work together, but largely with opposite functions.

The sympathetic system is responsible for quick responses and is commonly known as the "fright, fight or flight" system whereas the parasympathetic system is the more laid back, easy-going "breed and feed" or "rest and digest" system. The sympathetic system is the action component of the ANS while the parasympathetic system tends to look after the ongoing quiet slow processes.

In spinal cord damage, the parasympathetic component (which largely comes directly from the brain) tends to survive while the sympathetic system can be damaged in various ways. This is because the different sympathetic nerves leave the spinal cord between the first thoracic and the second lumbar vertebra. Thus, the extent of sympathetic nerve damage depends on the level of the spinal cord injury.

> **In spinal cord damage, the parasympathetic component tends to survive while the sympathetic system can be damaged in various ways.**

The outcome is that while the parasympathetic nerves largely continue to function as usual, the sympathetic system is either non-existent or it functions partially or erratically.

The result is that the interactive functionality of the two components of the ANS is disrupted, often with dramatic consequences for the organs that they regulate.

The exception to the above is a second parasympathetic nerve outlet from the spinal cord at the level of the sacrum. These nerves have some impact on bladder and bowel function, but the most significant impact is on sexual function.

So, with the above background, let's explore the hidden demons of spinal cord injuries (SCIs), starting with the impact of a disrupted ANS on the bladder. R

ABOUT THE AUTHOR

George Louw qualified as a medical doctor, but, due to a progressing spastic paralysis, chose a career in health administration. He has since retired, but still serves on the board of the QuadPara Association of South Africa (QASA), and is the managing editor of *Rolling Inspiration*. He has contributed to the magazine for over a decade.

Contents

DIVING DEEP • GEORGE LOUW

Neurogenic Bladder

The physiology of the bladder is an extremely complex interplay between the brain, the peripheral nerves (that manage our muscles and movement) and the autonomic nerves. I will not even attempt to explain this, so let's rather look at the various types of neurogenic bladders, the consequences of poor management of these bladders and some bladder management techniques.

In a nutshell, the bladder has two important muscles that interact with one another in normal bladder function; the detrusor muscle is in the wall of the bladder and the sphincter muscle is at the opening of the bladder where it joins the urethra (the pipe through which the urine flows out).

In normal bladder function, when the bladder is empty or partially filled, the detrusor is relaxed and the sphincter is contracted. This allows the bladder to fill up without urine leaking out.

When the bladder is full it sends a message to the brain and the brain in turn tells the detrusor to contract and the sphincter to relax. This message can be voluntary held back if you are not close to a toilet.

In a damaged spinal cord this messaging system is broken. Depending on the level of the injury, there are several possible malfunctions of the bladder, essentially disrupting the coordination between the sphincter and the detrusor muscles.

Effectively there are two types of outcomes: If the detrusor contraction is stronger than that of the sphincter, the result is a tendency to incontinence. If, on the other hand, the sphincter is stronger than the detrusor, there is a tendency to urinary retention. However, there are many individual variations of these two outcomes, depending on the extent of nerve damage.

Apart from the obvious embarrassment and discomforts of urinary incontinence and urinary retention, what are the dangers that must be guarded against?

The three important complications are urinary tract infections, strictures of the urethra because of poor hygiene, inappropriate catheterisation techniques and inappropriate catheter types, and, thirdly, hydronephrosis, which is caused by urine retention where a persistent overfull bladder pushes urine up the ureters into the kidneys, destroying the kidney structure. This can eventually cause kidney failure.

> **"Depending on the level of the injury, there are several possible malfunctions of the bladder.**

The type of bladder management required will depend on the nature of each individual person's neurogenic manifestations. If the problem is incontinence without evidence of urinary retention, then the choices are a schedule of bladder emptying, say every three to four hours, or incontinence wear, or condom catheters (in males).

If the problem is urinary retention, then the gold standard is intermittent clean catheterisation, preferably with a sterile pre-lubricated (hydrophilic) catheter. If the injured person is unable to self-catheterise then the caregiver will have to be trained to perform the function.

Surgically inserted suprapubic catheters must preferably be kept back as a last resort. Indwelling catheters are usually not recommended because they can cause complications in the long term.

Just a word on bladder percussion as a technique to stimulate voiding of the bladder. While this is a popular and often very effective way to trigger voiding, it is not without danger. Bladder percussion, especially robust percussion, can push urine up into the kidneys and can aggravate hydronephrosis.

The goals of bladder management are:

- To maintain continence and in so doing, maintain the injured person's self-esteem, self-confidence, and quality of life.
- Prevent urinary tract infections.
- Achieve regular and controlled bladder emptying and in so doing, preventing hydronephrosis.

So, select a technique that achieves the required purpose but that also suits your preference; as the person that has to live with your bladder.

I always joke that I have three bosses: God, my wife, and my bladder… But our bladders must never control our lives, we must take charge of our bladders and manage them.

And if persons with a spinal cord affliction or injury are not able to do this for themselves, their caregivers must step in and do it in a way that achieves the bladder management goals and at the same time respect the dignity of the injured person.

This is not a pleasant task but if it is done with compassion and empathy, you will be blessed for it.

Refuse to Reuse

Intermittent catheterisation users are urged to make the shift to single-use catheters. Even after washing a catheter, bio film (very small bacteria) can remain, which leads to urinary tract infections (UTIs). Single-use catheters greatly reduce the risk of contracting a UTI.

Members of medical aids can also have the medical expenses of single-use catheters fully funded under the prescribed minimum benefits (PMBs). QASA can assist with approaching your medical aid to get the correct funding. It is time to refuse to reuse!

TIPS FOR BETTER BLADDER MANAGEMENT

Improve your bladder health

Hydrate

Drink at least **2 litres of water a day**. On warm days, when exercising or sweating profusely, be sure to drink more.

Wash your hands

Hand sanitiser is not a replacement for washing your hands. Be sure to thoroughly wash your hands before emptying your bladder.

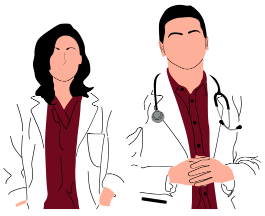
Regularly empty your bladder

Be sure to **regularly empty your bladder**. A bathroom schedule or routine can be helpful.

Completely empty your bladder

Be sure to always **completely empty your bladder** to avoid hydronephrosis (urine pushing back into the kidneys, which causes damage to the organ).

Consult your doctor



Speak to your doctor about your bladder management routine and methods. Be sure to ask about the pros and cons for each.

Neurogenic Bowel

Many persons with SCIs say that after the loss of mobility, the loss of bowel control is the next most distressing aspect of a SCI. It impacts on self-confidence, social interaction, recreational activities, sexual function, and most other activities of daily living. It creates an enormous psychological burden and substantially lowers quality of life.

Establishing an effective bowel management programme is essential for day-to-day wellbeing. The aim of a successful bowel management programme is not merely to ensure adequate bowel emptying, but also to establish control over bowel function at large.

To successfully manage a neurogenic bowel, we first need to understand the basics of the problem and, second, how it impacts specifically on the afflicted person.

BOWEL FUNCTION; BEFORE AND AFTER SCI

As with the bladder, there are muscles that aim to empty the bowel and muscles that prevent emptying until it is convenient to have a bowel movement.

The muscles that focus on emptying the bowel are controlled by nerves that react to the bulk of stool in the bowel. These nerves cause the bowel muscles behind the stool to contract and the muscles in front to relax, pushing the stool towards the anus.

The muscles of the anal sphincter always keep the anus closed to prevent leaking. When a stool approaches the anus and there is no toilet in sight, the sphincter works extra hard to keep the anus tightly closed until everything is ready for the big moment.

A SCI disrupts this process in several ways, depending on the level and the completeness of the injury. However, most injuries present with the following (to a greater or lesser degree):

- a loss of sensation that there is a need to pass a stool;
- incoordination of the muscles of the bowel causing a slow-down in the movement of stools to the anus;
- a loss of brain control over the function of the anal sphincter.

The major difference lies in the impact on the anal sphincter. In higher SCIs the anal sphincter remains in spasm, causing a build-up of faeces in the rectum. In lower-level injuries the anal sphincter is flaccid, and stool can easily leak out.

> “
> **It creates an enormous pscychological burden and substantially lowers quality of life.**

Caregivers need to have specific bowel function information of the person they are caring for, including the level of the SCI and the impact on the anal sphincter.

Aims of bowel management:

- Regular and predictable bowel emptying at a socially acceptable place and time.
- Avoidance of constipation, faecal incontinence and Autonomic Dysreflexia.
- Completion of the bowel routine in a reasonable time; preferably less than one hour.
- Trying to use the minimum physical interventions and medicines.

The overall aim is for the SCI individual, assisted by the caregiver, to be in control of bowel function in order to achieve confident integration into society.

THINGS THAT HELP STOOL MOVE THROUGH THE BOWEL

Activity and exercise, as far as the person with SCI is able. This includes passive movements where the caregiver moves the limbs and joints through their ranges of movement.

A well-balanced diet that is low on sugar and fat and that includes vegetables, fruit and serials together with fish, meat or dairy products. And lots and lots of fluids. (But stay clear of excessive fibre and raw bran. This is no longer recommended.)

Eating and drinking promotes peristalsis; the synchronized contraction and relaxation of the bowel muscles that move the stool along the bowel.

Abdominal massage with a half-closed fist or the heel of the hand; starting just above the pelvis on the right side, moving up to the ribs then across to the left just below the ribs and finally down to the left pelvis. This helps to move the stool along.

Laxatives are not essential to bowel management, but many SCI individuals use them as part of their bowel routine. Laxatives can be taken orally or as a suppository.

Suppositories work faster than oral laxatives. There are many different types of laxatives, and most persons have their personal preferences.

Digital stimulation of the rectum with a gloved finger generally causes the anal sphincter to relax. If contact is made with stool, manual removal may be tried, especially if there is a concern of impacted stool.

DEVELOPING A BOWEL MANAGEMENT ROUTINE; INDIVIDUAL VARIATIONS AND PREFERENCES

A bowel routine is a very personal and individual process with a lot of trial and error so:

- Keep a Bowel Motion Diary where you record what you did and how well it worked.
- Consider the pre-SCI bowel routine; do not try to force a daily routine if pre-injury there was a three-day routine.

TIPS FOR ENCOURAGING BOWEL MOVEMENT

Get your tummy going

Exercise

Activity and exercise, as far as possible. This includes passive movements where the caregiver moves the limbs and joints through their ranges of movement.

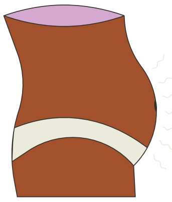
Healthy diet

A well-balanced diet that is low on sugar and fat and that includes vegetables, fruit and serials together with fish, meat or dairy products. Stay clear of excessive fibre and raw bran.

Hydrate

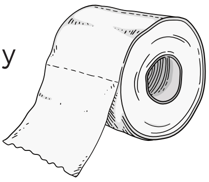
Drink at least 2 litres of water a day. On warm days, when exercising or sweating profusely, drink more.

Abdominal massage



Abdominal massage with a half-closed fist or the heel of the hand; starting just above the pelvis on the right side, moving up to the ribs then across to the left just below the ribs and finally down to the left pelvis.

Laxatives



Laxatives can be taken orally or as a suppository; the latter of which works faster.

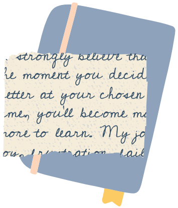
Stimulation

Digital stimulation of the rectum with a gloved finger generally causes the anal sphincter to relax.

TIPS BOWEL ROUTINE

Get into a routine to better manage your bowels

Diary

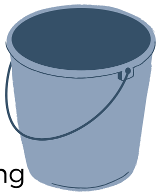


Keep a Bowel Motion Diary where you record what you did and how well it worked.

Don't force it

Consider the pre-SCI bowel routine; do not try to force a daily routine if pre-injury there was a three-day routine.

Bucket works, if preferred

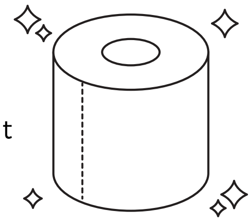


Using a commode with a bucket allows for the greatest versatility but consider the person with the SCI's abilities and preferences when deciding on how to go about the process.

Limit stimulation

Digital stimulation should not be attempted more than every 15 minutes and not more than four times per routine.

Follow instructions for Laxatives



The use of laxatives, suppositories and enemas should be guided by a doctor that is knowledgeable in SCI care.

Don't strain

Straining should be kept to a minimum and avoided completely if there is a history of high blood pressure, heart disease or diabetes.

- Using a commode with a bucket allows for the greatest versatility but consider the person with the SCI's abilities and preferences when deciding on how to go about the process.
- Digital stimulation should not be attempted more frequently than every 15 minutes and not more than four times per routine.
- The use of laxatives, suppositories and enemas should preferably be guided by a doctor that is knowledgeable in SCI care, but in essence it is also a trial-and-error process till you hit on something that suits your purpose.
- Straining should be kept to a minimum and avoided completely if there is a history of high blood pressure, heart disease or diabetes.

NON-BOWEL-ROUTINE MANAGEMENT OPTIONS

TRANS-ANAL IRRIGATION

This is a procedure where the person with SCI or a caregiver inserts a catheter into the anus and inflates a balloon to keep the catheter in place, while seated on the toilet.

Water is then pumped with a hand pump from a reservoir into the rectum (usually about 500ml would suffice). The increased volume in the rectum facilitates voiding of stool.

The procedure appears to be safe and apart from occasional reports of bowel perforation, side effects appear to be minimal provided that it is done with a recognised trans-anal irrigation product and following the supplier guidelines.

Advantages include fewer episodes of faecal incontinence, reduced time spent on bowel management and an overall improvement in the quality of life.

COLOSTOMY

Until recently colostomies were considered as a last resort procedure for failed bowel management in persons with SCI, but recent studies have found that the formation of a stoma can greatly improve the quality of life for some individuals.

It can reduce the time spent on bowel management and it increases the independence (and ease) of bowel care.

However, despite largely positive outcomes, colostomies are not without complications. These include herniation of the stoma, skin rashes around the stoma (causing problems with collection bags), inflammation of the unused bowel below the stoma and a mucus discharge from the anus, that may require the use of pads or even surgical closure of the anus.

However, there is a very effective stoma support service from the suppliers of stoma products to assist and advise on stoma care and side effects.

> **“The best kind of rectum is an empty rectum.**

A colostomy is a surgical procedure that brings one end of the large intestine out through the abdominal wall. During this procedure, one end of the colon is diverted through an incision in the abdominal wall to create a stoma.

A stoma is the opening in the skin where a pouch for collecting faeces is attached. People with colostomies have pouches attached to their sides where faeces collect and can be easily disposed of.

ANTEGRADE CONTINENCE ENEMA (ACE)

This is a procedure where a small stoma is created at the origin of the large bowel. The stoma is then used to instil an enema or bowel irrigation behind the stool.

Although commonly used in children with spina bifida, its use in adults with SCI has been proved to be generally unsuccessful and is seldom seen in clinical practice.

NERVE STIMULATION TECHNIQUES

This involves the surgical implantation of nerve stimulators that stimulate the nerves that cause voiding. Sacral Anterior Root Stimulators (SARS) have been in use for bladder management problems in SCIs for some years and has been found in some individuals to promote simultaneous bowel evacuation.

This procedure, however, seems to be unpopular as very few respondents to bowel management questionnaires report using this technique. Another procedure, Sacral Nerve Stimulation (SNS) has been found to be not effective in persons with SCI although limited success has been reported in persons with cauda equina lesions.

The collection of nerves at the end of the spinal cord is known as the cauda equina, due to its resemblance to a horse’s tail. The spinal cord ends at the upper portion of the lumbar (lower back) spine.

IN CONCLUSION

Remember, the best kind of rectum is an empty rectum. Whether the person you are caring for has a tight anal sphincter with constipation and build-up of faeces, or a flaccid anal sphincter and a tendency to leak stool, an empty rectum will prevent either complication.

However, there is no need to become obsessive and compulsive about daily bowel movements. If a good movement can be achieved every second or third day that is also okay.

So here’s wishing you bye-bye to constipation, consistently clean underwear and lots of happy crappies. R

FURTHER READING SUGGESTIONS

Bowel management in spinal cord injury patients. Click Here.
Guidelines for Management of Neurogenic Bowel Dysfunction in Individuals with Central Neurological Conditions. Initiated by the Multidisciplinary Association of Spinal Cord Injured Professionals. Click Here.
Exploring the benefits of anal irrigation. Nursing Times. Click Here.

Autonomic Dysreflexia

Caregivers, family, colleagues and friends of a person with a SCI need to be aware of issues that may need your assistance. For most issues you have time to ask around and look for help if you do not know what to do. Not so with Autonomic Dysreflexia (AD). This is a condition that could potentially cause strokes, heart attacks and even death.

Probably the most frustrating thing about this condition is that most doctors do not even know that it exists or, if they have heard of it, some just do not believe that it is a real condition. So, we need to be very aware of this condition and, if we see it happening in a person with SCI, we need to be confident enough to step forward and help.

We also need to be able to advise bystanders or even medical persons what is happening. To do this, we need to know who gets AD, what it looks like when it is happening, how to prevent it from happening, and what to do until medical assistance arrives.

Also very important, we need to know about the naughty tricks that persons with SCIs pull to actually bring on AD; and why they do such a ridiculously stupid thing. AD must always be foremost in our minds because if it isn't you may miss it when it happens. So, let's unpack Autonomic Dysreflexia.

FIRST, IN WHOM DOES IT HAPPEN AND WHY?

AD is only seen in persons with SCIs from the sixth thoracic vertebra and higher. It is caused by damage to the ANS.

HOW TO RECOGNIZE AD IN A PERSON WITH SCI?

The disrupted interplay between the sympathetic and parasympathetic nervous system can play havoc with blood pressure. It can push it up to very high levels with extreme risk of causing a stroke, a heart attack, or other complications.

If an AD attack is suspected, things to look out for include complaints of a pounding headache and nausea, a flushed red face, red blotches on the skin and sweating above the level of the spinal cord injury, as well as a cold clammy skin with goose bumps. Sometimes AD can also cause a fluctuating high and low blood pressure with a chronic headache.

WHAT BRINGS ON AD?

It is important to know what triggers AD, because, if we can fix the cause of the attack of AD, it should settle down (however, a doctor that understands AD must still be consulted).

It is interesting that many of the causes of spastic jerks or spasms also are potential causes of AD. So if there are uncontrolled spastic jerks or signs of AD check for the following:

- An overfull bladder or rectum are the first things for which to check.
- Pressure sores, haemorrhoids (piles), ingrown toenails or any injury, burn wound (including sunburn), sprain or fracture below the level of the SCI may trigger AD. These injuries cannot be felt as physical pain by the person with SCI, but the autonomic nervous system reacts to it and a damaged ANS results in abnormal responses, including AD.
- Suctioning of the upper airways may induce AD.
- If the person with SCI is sexually active, intercourse can also cause AD.
- If no obvious cause for AD can be found, consult a doctor because gall stones, kidney stones, renal tract infections and other hidden problems could also cause AD.

TIPS ON PREVENTING AD

A good and comprehensive care programme will go a long way to prevent or limit the incidence of AD:

- Good bowel and bladder care, including meticulous urinary catheter hygiene.
- Pressure relief to prevent pressure sores.
- Care with water temperature during showers or bathing.

- Avoid sunburn and use sunscreens.
- Maintain a reasonable body temperature; avoid environments that are too hot or cold and dress appropriately.
- Frequently check the entire body for injuries, burns and even fractures – anything that does not look right.

WHAT TO DO IN AN ATTACK OF AUTONOMIC DYSREFLEXIA?

- Sit the patient up – this helps to lower the blood pressure.
- Loosen all tight clothing.
- Check for all the things that trigger AD.
- Call an AD-knowledgeable Doctor – make sure your local GP is AD-savvy.

FINALLY, SOME WHACKY AD-RELATED SHENANIGANS OF WHICH TO BE AWARE

Persons with SCI that participate in sport events are just as competitive as any other person. However one of the problems of SCI is that their blood pressure is normally lower than that of an able-bodied person.

Furthermore the damage to the autonomic nervous system prevents the regulation of blood flow that carries oxygen to the muscles.

So, their performance suffers and they tire easily. But, these guys are clever and innovative so instead of taking drugs like some able-bodied sport stars, they boost their performance by pushing up their blood pressure through actions that cause AD.

Some common methods include tying down their catheters so that their bladders become overfull, or they injure themselves – like breaking a big toe. But, my personal favourite is the twits that sit on their own testicles to induce AD. As *Ouboet* from *Orkney Snork Nie* used to say: "*Ook maar lekker stupid…*".

Download the Autonomic Dysreflexia Emergency Care

Fold first before cutting out.

AUTONOMIC DYSREFLEXIA
(Medical Emergency Card)

Autonomic Dysreflexia (AD) results from a sudden rise in blood pressure in an individual with a spinal cord injury (SCI), with a neurological level of T6 or above.

The cause of AD is a pain stimulus below the level of injury, resulting in an unopposed sympathetic system discharge. Raising the blood pressure 20-40mm Hg systolic above the person's normal baseline blood pressure, may trigger the symptoms of AD.

Symptoms of Autonomic Dysreflexia

- Increased blood pressure • Severe headache
- Flushing & sweating above the level of the SCI
- Bradycardia • Anxiety • Cardiac irregularities
- Bronchospasm or respiratory distress • Goose bumps on skin above the level of the SCI

If left untreated, this condition can result in seizure, retinal hemorrhage, stroke or in extreme cases, death.

If any symptoms of AD appear, ensure the following:

- Keep the person in a 90° upright position.
- Check there is free urinary drainage.
- Check for distended bowel.
- Check for ingrowing toenails and skin sores.
- Assess for other possible noxious stimuli.
- Hypertension should be treated medically if it persists with prescribed Nitro Paste or Nifedipine.

Card Holder's Medical Information

Name: . . . .
Baseline Blood Pressure: . . . .
Level of Injury: . . . .
Emergency Contact: . . . .
Relationship: . . . .
Phone Number: . . . .

0860ROLLING

Body temperature management in persons with SCI

We all have a body temperature that runs at about 37°C. When it is hot, our bodies react in certain ways to help us cool down and we nudge it along by dressing in cool clothes. When it is cold, our bodies react to warm us up and we help by dressing warmly. This is a normal, everyday part of living.

But what happens if our bodies can no longer react to the surrounding temperature, or react inappropriately by wanting to keep us colder than we care for or hotter than what we are comfortable with? This is what happens in higher-level SCIs that involve the neck or the upper chest.

The inability of the body to react to the environment by cooling down or warming up can have very dangerous consequences and can even cause death. The fact that persons with a high-level SCI are more often than not unable to help themselves, makes it essential that caregivers understand what is happening and how to help.

So, before we go to tips on how to help, let's look at some physiology; how normal bodies work and what goes wrong in persons with high-level SCIs.

Humans and animals have been able to survive, live and thrive in extreme weather conditions from arctic ice to tropical heat. How do we do this? Temperature regulation is a balance between heat generation and dissipation of heat.

Our body heat is generated in our deep organs and in the contraction of skeletal muscles. Heat is lost mainly through the skin, but also by breathing. That is why dogs pant in hot weather. People also tend to breathe faster when hot.

The skin regulates body temperature in a number of ways; blood vessels under the skin dilate in hot weather so that heat radiates out through the skin. In cold weather the same blood vessels contract and direct blood away from the skin to conserve heat. The skin also has sweat glands that open in hot weather and push out lots of sweat to cool us down.

> “
> **What happens if our bodies can no longer react to the surrounding temperature?**

When it is cold, we sweat less and our hair follicles become erect so that our body hair lifts up and conserve heat by insulating the skin. That is why we get goosebumps. (This works better in hairy animals.) Our muscles also help to warm us in cold weather by shivering. This produces energy that warms us.

All these temperature regulating methods are controlled by a centre in the brain called the hypothalamus, the function of which is to maintain the body's temperature at 37°C. It does so by receiving information from temperature sensors under the skin and in deeper organs.

Based on the information received from these sensors, the hypothalamus sends instructions to the endocrine system to produce more or less energy (heat) as the circumstances require and giving instructions to the ANS, which regulates blood vessel contraction or dilation and sweating or shivering as needed. The hypothalamus also alerts the brain that we are too hot or too cold, so that we can do something about it.

In high SCIs, the normal connections between the hypothalamus and the temperature sensors are lost. So, there is loss of awareness below the level of the injury of being too hot or too cold. In addition to this, in high SCIs the sympathetic nerves' outflow of messages to the blood vessels, sweat glands and muscles, is broken.

This results in loss of blood vessel constriction or dilatation, so heat cannot be conserved or lost in response to temperature changes. In addition, heat production is limited in response to cold stimuli because of the loss of ability to shiver.

Sweating is also ineffective below the level of injury. So in effect, the brain does not get temperature-related information in from the body and it also cannot tell the body what to do about it. The brain is isolated from the rest of the body.

In a nutshell, persons with high SCIs have, to a greater or lesser degree, lost their ability to differentiate between hot and cold and have also lost their ability to compensate for too hot or too cold conditions.

To aggravate this, some persons with SCI, particularly if the SCI is associated with a traumatic brain injury, may also set their body temperatures at either higher or lower than 37°C, which drives them to want to compensate for this. This feeling may be continuous, or it may be triggered by an event that causes discomfort.

Now to our role in assisting with all of this. The point of departure is that we must know the person's situation. If there is a tendency for the person with SCI to feel colder or hotter than you do in a given situation, this needs to be accommodated.

So, for example, don't insist on a jersey just because you put on one yourself. But having said that, let's look at the practicalities of temperature regulation.

COLD CONDITIONS

The obvious is to dress the person with SCI warmly, taking particular care of the hands and feet as well as the head – gloves, warm socks, scarfs and cosy headgear. Dressing in three to four layers takes more time and effort initially, but often works better than a single very thick garment. It also helps with adjusting clothes as the day warms up.

However, the main challenges of protecting against cold happen at night when we are sleeping because unlike able-bodied persons, the person with SCI cannot feel the cold below the level of injury and being very cold can, apart from the usual complications, be a cause of AD in persons with SCI. So, here are some tips.

Dress in layers – vest, tee-shirt and bedclothes, including bed socks. When positioning persons with SCI and also after each turning, place them in the foetal position with legs up against the trunk. This helps to conserve heat.

However when doing so, be aware of clonus or jerks as these are indications that the body is experiencing discomfort. So, reposition until the limbs relax.

Also check pressure points to protect against pressure sores. Lastly, cover the person with SCI in a way that does not allow cold air to sneak in and settle between the shoulder blades or the legs.

HOT CONDITIONS AS WELL AS POST-EXERTION

Overheating in South Africa is dangerous as it can cause heat stroke and even death. Apart from the obvious precautions of cool clothing, protective headgear, lots of fluids and getting out of the sun, other tips include mist water sprays that mimic sweating, ice water and even sucking ice cubes to help cooling down from the inside. A wet cloth (especially from a freezer) on the head or back of the neck does wonders.

But most importantly, in hot weather or cold, use your initiative. Make use of what is available rather than grasping for methods that are not available.

You and the person that you care for are a team. Understand what works and what does not and figure out the best ways to solve tricky situations together. R

ANS and sexual function

The purpose of this short article is to explain how the autonomic nervous system manages sexual function in males and females, and what goes wrong in a SCI. The interplay between the ANS and the somatic nervous system, the impact of hormones, the roles of love and desire and lastly, the role of carnal urges, is hugely complex and still very poorly understood. So, the following description of events is a huge oversimplification of an as yet poorly understood enigma of love, desire and sexual intimacy.

The loss of sexual function is rated as one of the greatest losses experienced by persons with SCIs. Understanding the physiology of sexual function and where things went haywire with your injury will provide you with a steppingstone toward exploring alternative ways of achieving sexual pleasure and satisfaction. For techniques to explore and realise alternative ways of sexual intimacy, please defer to Dr Danie Breedt's column on sexuality.

Sexual function works differently in males and females, but in this brief review of functionality as well as the impact of injury on functionality, I chose not to go into the detail of differing functionalities, but to rather focus on the outcomes of injury. For more detailed reading, refer to the reference link provided at the end of the article.

The sexual act starts with arousal driven by desire and foreplay, causing blood to flow into the penis and clitoris, culminating in erections of both organs. This is driven by the component of the parasympathetic nerves that leave the spinal column via the sacrum.

So SCIs that damage these parasympathetic nerve pathways will result in an inability to achieve an erection – in males and females. Although in some instances, partial erection may be achieved.

Ejaculation in males is managed by a combination of somatic and sympathetic nerves. SCI generally causes a loss of natural ejaculation, but an interesting finding is that in levels of injury higher than T6, penile vibration techniques may achieve ejaculation. Unfortunately, this is not the case in injuries lower than T6.

The neurology of orgasm remains an enigma. The neural pathways and psychological brain activities that lead to orgasm is still poorly understood. What is known however, is that there are two ways to achieve an orgasm and herein lies the good news.

While genitally induced orgasm is totally dependent on the sacral parasympathetic nerves, a very satisfactory psychologically induced orgasm may be achieved by emotional interactions such as sexual intimacy. There are also non-genital triggers of orgasm such as the nipples and ears, that can become the focus of foreplay. In men, orgasm can occur without penile erection. Ejaculation may occur, but this is not always the case.

Sexual dysfunction after a SCI is, however, more than just due to nerve damage. A reduced self-image, loss of sexual drive and reduced or lost libido (the experience of specific sensations that motivate you toward initiating or becoming responsive to sexual stimulation), can result in an aversion to or fear of sex. But as you make peace with yourself and the "new you", this will improve and your need for sexual intimacy will return.

The beauty of this situation is that orgasm emanating from physical and hormonal origins has largely fallen away and opened the door for orgasm achieved by sexual intimacy, loving desire and a healthy self-image. Is this a message for the able-bodied? Is their sexual intactness as emotionally intact as it should be?

FURTHER RECOMMENDED READINGS

Neural Control and Physiology of Sexual Function: Effect of Spinal Cord Injury
Andrei Krassioukov, MD, PhD, FRCPC and Stacy Elliott, MD. Click here.

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