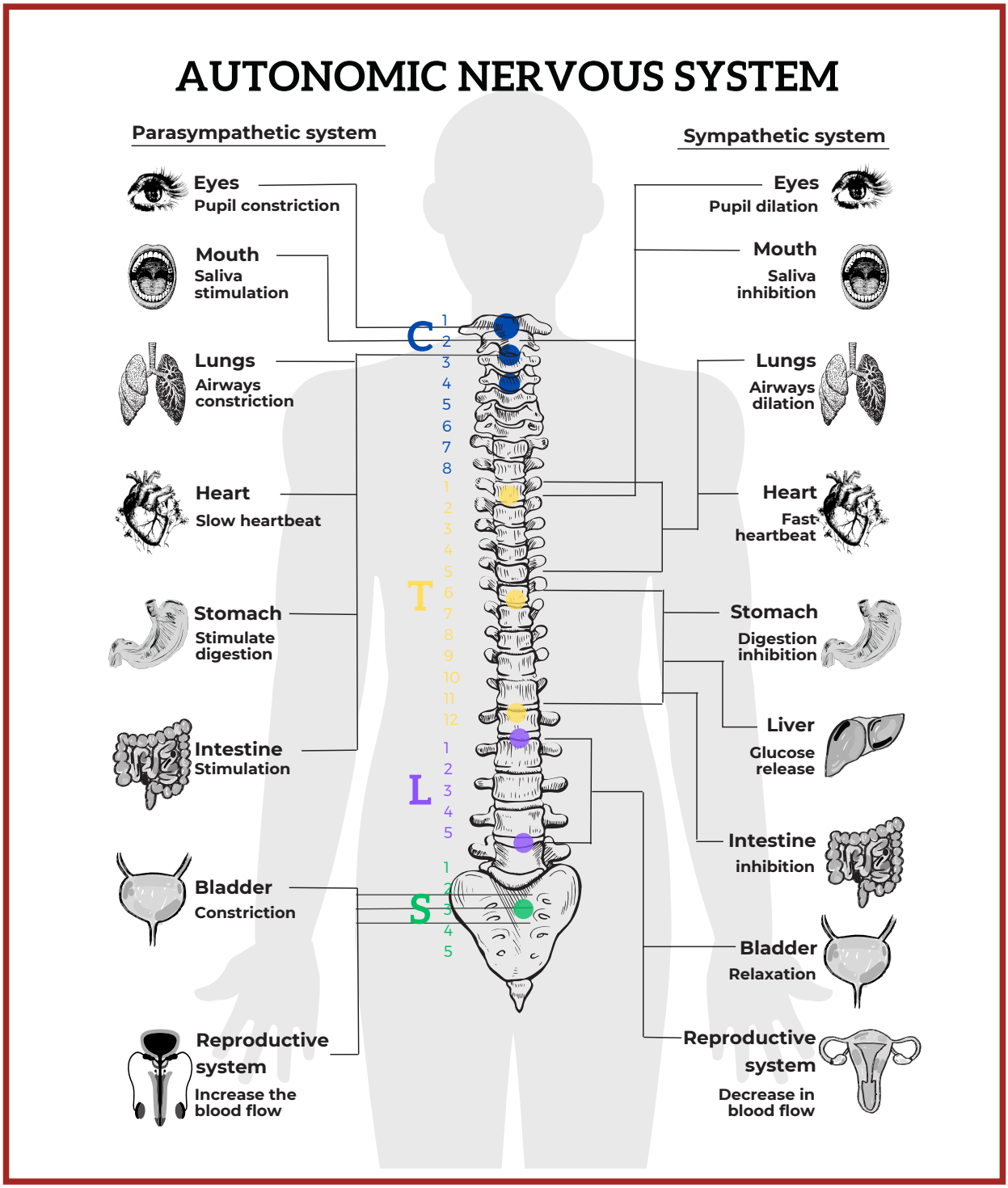
Guide to the Hidden Consequences of Spinal Cord Injury



This publication is brought to you by Rolling Inspiration and the QuadPara Association of South Africa (QASA)

Hidden Consequences

An introduction

This is a compilation of six articles on the devastation caused by damage to the Autonomic Nervous System (ANS) due to spinal cord injuries and afflictions. 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 guide is to explain how the ANS works, how damage to the ANS plays havoc with our body functions, and how to manage this. R

About the author



GEORGE LOUW

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

Autonomic Nervous System	3
Neurogenic Bladder	4
Neurogenic Bowel	6
Autonomic Dysreflexia	10
Body temperature management	12
Restful Sleep	15
ANS and Sexual Function	18

The publication is written and compiled by *Rolling Inspiration*. It is published and funded by the QuadPara Association of South Africa (QASA).

Contact us

ROLLING INSPIRATION

rollinginspiration@qasa.co.za
www.rollinginspiration.co.za

QUADPARA ASSOCIATION OF SOUTH AFRICA (QASA)

031 767 0352
info@qasa.co.za
www.qasa.co.za
17 Hamilton Crescent, Gillitts, KwaZulu-Natal, 3610

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 to 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.

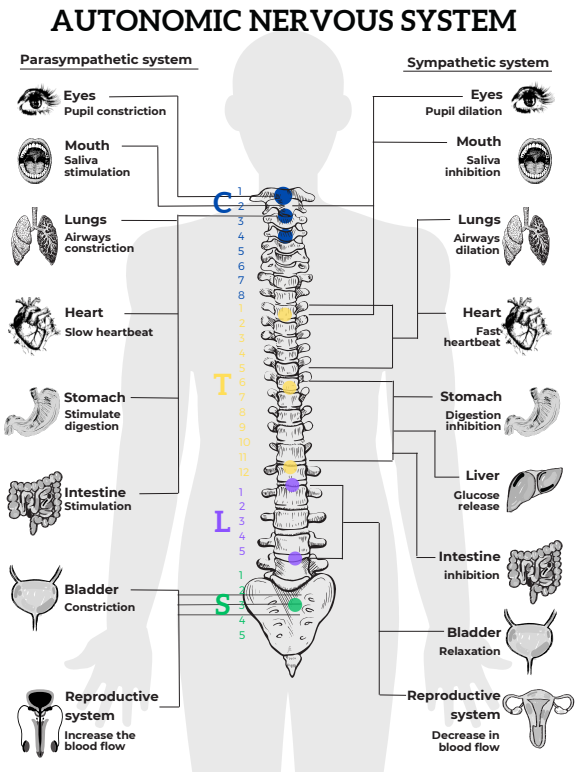
In spinal cord damage, the parasympathetic component (which largely comes directly from the brain) tends to survive while the sympathetic system can be damaged in various ways.

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.

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



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. R

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



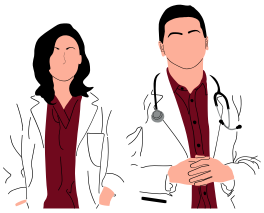
Be sure to **regularly empty your bladder**. A bathroom schedule or routine can be helpful.

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.

> **“Establishing an effective bowel management programme is essential for day-to-day wellbeing.**

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.

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.

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.



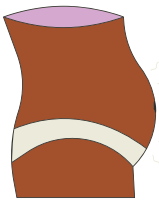
Healthy diet

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



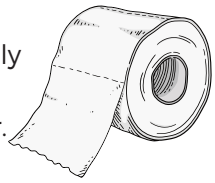
Drink at least 2 litres of water a day. On warm days, when exercising or sweating profusely, drink more.



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

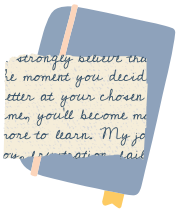
Digital stimulation of the rectum with a gloved finger generally causes the anal sphincter to relax.

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.



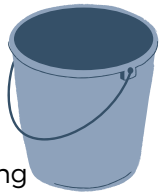


Don't force it

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.



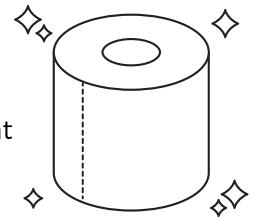


Limit stimulation

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.

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.
- 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.

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

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...*". R

Fold first before cutting out.

2nd Fold

AUTONOMIC DYSREFLEXIA
(Medical Emergency Card)

QuadPara Association of South Africa (QASA)

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

1st Fold

1st Fold

2nd Fold

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.

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

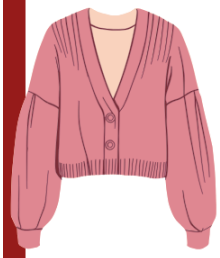


COLD WEATHER

Body temperature management



IN THE DAY



Dress in layers

Three to four layers of clothing is recommended. Rather do more layers of thin clothing than one thick layer. It is easier to regulate temperature by removing one or two thin layers.

Adjust layers

Be sure to check the temperature throughout the day and adjust the layers accordingly. Also consider the location and activity. If in doors or active, you might need to remove some layers.



AT NIGHT

Layers adjusted

The same daytime rule applies. You should ideally dress in layers and remove them if necessary. This can be done when turning takes place.

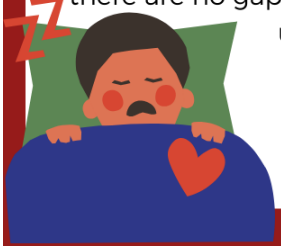
Foetal position when sleeping

After turning, be sure to return to a foetal position. Look out for **clonus or jerks that indicate discomfort**.



Cover up

Take care when covering up. Make sure there are no gaps for the cold air to get in underneath the blankets.



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 AND 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



HOT WEATHER

Body temperature management

Dress in cool clothing



Wear clothing made from light, breathable material like cotton or linen

Wear protective headgear

Make sure to take keep a hat or cap with you when you leave the house.





Drink lots of fluids

Be sure to drink a lot of fluids to stay hydrated. It is better to drink water than sugary or fizzy drinks.

Stay out of the sun



Where you can, avoid spending time in the sun, especially on warm days.



Keep a mist or spray bottle

Keep a misting or spray bottle handy to spray your skin when it gets hot to mimic sweating and help you stay cool.

Suck on ice cubes



Sucking on ice cubes is a sure way to help you cool down on a warm day and is better than sugary ice cream.



Wet cloth

Place a wet cloth (ideally from the freezer) on the head or back of the neck to help cool down.

Restful sleep

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

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

This compromises daytime functionality, including general alertness, concentration, and physical energy. In many instances, it can also lead to anxiety and depression. So, let's examine a few of the more common causes of sleep disorders in persons with SCI.

SLEEP DISORDERED BREATHING

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

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

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

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

A PERSPECTIVE ON OBESITY

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

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

> **"Sleep disorders are common in persons with SCI.**

PERIODIC LEG MOVEMENTS

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

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

Once again, the result is daytime sleepiness and all the other consequences described above. Treatment with medication appears to be somewhat

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

SLEEP-WAKE DISORDERS

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

> **"The Circadian Rhythm is a highly complex neurological process that is disrupted in cervical spine lesions.**

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

Finally, REM sleep takes the body out of deep sleep and prepares us for wakefulness, making waking up easier. It is also thought that brain development occurs during REM sleep. It is postulated that this is why new-borns spend most of their sleep time in REM sleep.

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

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

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

SCI AND INSOMNIA

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

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

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

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

PRESSURE SORE AND BLADDER CARE ROUTINES

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

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

There is no treatments or solutions for what is needed. We must just take it in our stride and find ways around it that work for us. I know the words of about six or seven songs off by heart and sing myself to sleep in my mind. Out loud is scary.

But if in your approaching sleepiness you

forget the words, just hum the tune. Trying to remember words wakes you up again.

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

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

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

IN CONCLUSION

There are many factors to consider in the management of sleep disorders in persons with SCI, including lesion related, obesity, environment, and care routines, to name a few.

Mostly a combination of factors is at work to disrupt sleep in affected individuals. This makes management highly personalised and includes caregiver understanding, medical intervention and psychological support.

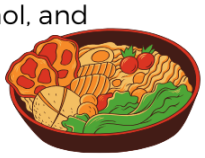
Trial-and-error is the name of the game and hopefully this article provides some insight and will help to focus management on an acceptable sleep routine. R

TIPS FOR BETTER SLEEP

Body temperature management

Watch what and when you eat

A big dinner can be harsh on your digestive system and interfere with sleep. Avoid caffeine, alcohol, and sugar 5 hours before bed.





Limit naps

Try to avoid taking naps later in the day, and even then, try to limit them to no longer than 30 minutes.

Melatonin supplements

The brain releases melatonin to help you fall asleep. Melatonin supplements can help your circadian rhythm.





Increasing physical activity

Physical activity promotes good sleep and relieves stress.

Medications

Prescription sleeping medications may help individuals fall and stay asleep throughout the night.



It is important to note that sleeping pills are addictive and have side effects. They are not recommended for long-term use.

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 in the *Rolling Inspiration* magazine.

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. 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? R

Read the ROLLING INSPIRATION magazine



FOR FREE

Scan the QR Code with your smartphone and read or download our latest magazine for free.



QuadPara Association OF SOUTH AFRICA

[QASA]

OUR VISION

All Quadriplegics and Paraplegics will live their lives to their full potential

Who We Are



As an NPO, we develop products, programmes and services for quadriplegic and paraplegic members to build their capacity and ensure opportunities for societal integration and empowerment so that they can live their lives to their full potential.

Programmes & Services

SKILLS DEVELOPMENT & EMPLOYMENT



QASA invests in programmes that up skills and supports members who pursue employment opportunities, whether this is through skills development, employment programmes that educate employers on the value proposition of our skilled members, or bursaries for tertiary or continued education.

ADVOCACY & LOBBYING



QASA advocates and lobbies on behalf of its members to ensure universal access and inclusion in the built environment and transport nodes. This includes disability awareness and sensitisation workshops, access audits, and the promotion of the White Paper on the Rights of Persons with Disabilities. Prevention of spinal cord injury forms part of our advocacy commitment.

MEMBER DEVELOPMENT

QASA supports the health and wellness of its members through educational programmes for members, caregivers and the healthcare sector. QASA provides better mobility, assistive devices and accessibility for its members to ensure a barrier-free environment. This includes assisting with accessible housing, independent living solutions and even driver training programmes.

GET IN TOUCH

031 767 0352

info@qasa.co.za

www.qasa.co.za

17 Hamilton Crescent, Gillitts, KZN, 3610