The Overt Consequences of Spinal Cord Injuries

ROLLING
INSPIRATION

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Introduction

When a person sustains a spinal cord injury or affliction, many other consequences follow. These need to be managed to maintain a quality of life and ensure longevity. The consequences and how they are managed will vary from person to person depending on the nature of their injury or affliction and the extent of the fallout.

Many of these consequences are hidden, such as bladder and bowel functions, which have been discussed in a previous booklet, that can be found on the QuadPara Association of South Africa (QASA) website.

Other consequences are overt, obvious, even if it takes some time for them to become visible (like the challenges of ageing with a spinal cord injury). These are the consequences that we strive to uncover in this booklet. As these consequences and their management are deeply personal, the advice given here should be considered a high-level overview to help guide you in the right direction.

The series of articles covers essential topics like spasticity, sausage feet, obesity and ageing – to name a few. We aim to explain each in simple terms while focussing on the management of the consequences, either by the person with the spinal cord injury or affliction, or their caregiver.

Whether you're newly injured or a veteran, we trust that this booklet will equip you to take better care of yourself (or your loved one) and live a long and fulfilling life!

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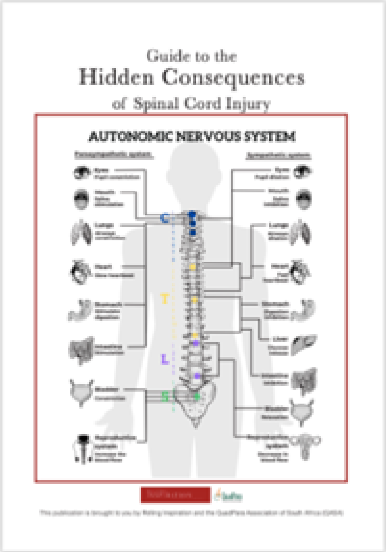

Spasticity

Spasticity affects more than two thirds of persons with spinal cord injuries (SCIs). It is more common in neck and upper chest-level injuries. It is caused by a breakdown in communication between the brain and the different parts of the body.

The spinal cord nerves are like a bundle of telephone cables that communicate messages between the body and the brain. Some of the nerves take messages from the body to the brain and other nerves take messages from the brain to the body.

> **Spasticity affects more than two thirds of persons with spinal cord injuries.**

When you want to move, muscles send messages to the brain, telling the brain where they are – their respective positions relative to other muscles. The brain sends return messages down the spinal cord telling the respective muscles what each of them must to do to move or balance or support the entire body.

When the spinal cord is damaged, these messages cannot be sent between the brain and the body. In flaccid paralysis, all communication is lost, and no movement is possible. In spastic paralysis, the lesion is usually partial; thus, muscles can't communicate with the brain, but the brain can send messages to the muscles.

Because the brain doesn't know where the muscles are, it can't tell them what to do. So, instead, it fires like a shotgun: contract, contract, contract. This causes a general stiffening in the part of the body that is affected by the SCI.

When some muscles are stronger than others they can pull the body into all kinds of abnormal positions. Without the brain being able to guide the muscles, they sometimes start contracting and relaxing rapidly, causing an arm or a leg to shake uncontrollably (known as clonus).

Or muscle bundles can gradually become tighter and tighter until they are too tight to contract any further. Then the muscles let go with force, causing an intense jerking movement (known as myoclonic jerks).

Spasticity is not a nice thing to have. As persons with spasticity and their caregivers get to understand the nature of their spasticity, they get to know what causes these spasms and how to manage them. In many cases, they can make life relatively comfortable.

THE TRIGGERS

It is important to understand how much tone (amount and severity of spasms) is normal for each person with spasticity and investigate possible triggers when there is an increase in the level of tone. Spasms can be triggered by something as simple as moving a limb, stretching a muscle or just being in the same position for a long time.

Spasms are often also a sign of something the matter with your body: A bedsore, an ingrown toenail, clothes that are too tight, etc. In the absence of pain sensation (often present in SCIs), spasms or jerks may be set off by contact with something very hot or cold – the body trying to protect itself.

Check when last the bladder was emptied or if there is a need for a bowel motion. A full bladder or constipation can also trigger spasms or jerks.

MANAGING SPASMS

In general, one should not try to fight or break a spasm. If possible, it is best to allow the spasm to pass before trying to move the spastic person. Generally, ways to break a spasm may be as simple as just moving the limb gently and slowly into a more comfortable or even just another position. This helps especially for clonus and for ongoing myoclonic jerks.

For sustained spasms, gentle but firm pressure on the area in spasm together with a gentle, slow, sustained pulling of the limb or trunk away from the direction of the spasm will often break the spasm. It is very important to not use rapid, jerking, pulling or pushing actions. These could easily trigger further spasticity.

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During the day, the person with spasms will most likely be in a wheelchair. Discomfort or any other trigger may cause spasms that can either pull the trunk forward (to the point of falling out of the chair) or it can pull on the back muscles causing the shoulders to arch backward and the pelvis to slide forward, resulting in the person sliding out of the chair.

In both instances, when caregivers notice this happening, gently but firmly push the trunk in the opposite direction to help break the spasm.

If spasms tend to cause the person with spasms to fall out of the wheelchair, it may be necessary to strap the ankles, thighs and trunk to the chair. However, this must not be done while they are in spasm.

First bring the spasms under control before you secure the person to the chair. If, however, the person with spasms tends to get frequent and severe myoclonic jerks while seated in the wheelchair, this needs to be investigated.

Are the spasms caused by poor positioning in the wheelchair? If so, then a seating assessment and adjustments needs to done by an experienced therapist.

Clonus is easier to manage. Just stroke the affected leg or arm with gentle but firm pressure while at the same time moving the limb into a different position will usually do the trick.

When transferring a person with spasticity, be very aware of spasms or clonus. Do not allow them to move into a position that triggers spasms or clonus.

If a spasm occurs, first deal with it and get the person relaxed and in a comfortable position before doing the transfer.

At night, it is best to sleep on your stomach if possible. Alternatively, sleep in an assisted position. Be sure to avoid any pressure points.

Day or night, if the spasms or jerks keep happening and are difficult to control, look for wounds, check when last the bladder voided or if there is a need for a bowel motion. Always place a person with spasms in a comfortable position. Fighting against discomfort invariably triggers spasms and jerks.

When putting the person to bed and before getting up in the morning, these are good times to go through the range of passive movements of all the limbs to prevent the muscles from contracting.

Passive movements and exercise are helpful in preventing spams as it maintains the flexibility in the muscles, nerves and joints.

In conclusion, the secret of successful management of spasticity is to get to know what triggers spasms and how best to relieve them. Spasticity does not behave the same in all people with a SCI, but hopefully these general guidelines will help carers to have a better understanding of what you are dealing with and how to help affected persons to cope with their spasticity. R

Pressure ulcers

People with paralysis can’t be complacent in the prevention of pressure sores. A tiny, but deep pressure ulcer, for example, could lead to septicaemia, multiple organ failure and eventually death.

When someone remains in the same position for long periods of time, their circulation becomes very poor. The skin thins. A lack of movement, thin skin and possibly poor nutrition all contribute to pressure sores.

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There are vulnerable areas on the body where pressure ulcers are more common. These include the buttock area, the side of the hips, heels, ankles, the back of the head and protruding areas such as the elbows.

The biggest concern with a pressure sore is the depth. Deep dark holes are always worrying. You don’t know what is happening inside. If there is a lot of dead tissue (skin and muscle) around and in the wound, it is a concern as bacteria loves to grow in the dead tissue.

To ensure good healing, this build-up of dead tissue (also known as slough) needs to be removed by either by scraping it off with a curette, using a de-sloughing agent (a special paste or cream) or by using special dressings to make sure the wound is clean right down the base of the ulcer.

Remember that a dressing is worth nothing if the pressure is not taken off the affected area. The best way to heal a pressure sore is direct contact with air. Leave it open to the air, keep the pressure off and clean with saline or even soap and water.

Anybody who can do their own pressure relief should be doing it routinely. Also consider your sleep position and ensure there aren’t any pressure points, turning every two to three hours. The right mattress can assist but can’t replace good pressure relief. It is still important to reposition and do daily checks.

Do a top-to-toes inspection once daily for paraplegics and twice daily for quadriplegics to catch any pressure ulcers early. The first sign is usually a telltale redness that does not go away.

On darker skin tones, look for dark spots that do not go away. The minute you see a blister, it is a pressure sore. People with an incomplete SCI might experience pain or discomfort that could also point to an ulcer.

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Autonomic dysreflexia may be a sign of a pressure sore. If you feel nauseous or have a headache for some unknown reason, check for pressure sores.

Seek medical assistance if there are multiple pressure sores, or if the ulcer is very deep (as soon as dressing is required). Also consider your living situation. If the environment is poor, it is better to be admitted to hospital early.

Be aware of your skin and look after it. All your skin really needs is not to be compressed and to be exposed to fresh air.

Sausage Feet

The pooling of blood in the feet and ankles result in the swelling of the feet and ankles – a condition called dependent oedema, or sausage feet in more common language.

This is a common problem among persons with spinal cord injury as their muscles cannot pump blood back to the heart as effectively as persons with working muscles; the contraction and relaxation of especially the calf muscles help to push blood upwards.

As a result, blood collects in our feet and ankles, and fluid from the blood leaks out of the vessels into the surrounding tissue. This type of oedema is known as dependent oedema because the legs are "dependent" or hanging down while sitting.

Medical conditions such as heart failure can also cause ankle oedema, but this is due to the heart not working as it should.

Oedema, whether due to sausage feet or to other causes such as heart failure, is easily confirmed by pressing a finger into the skin over the lower shin. If an indentation remains for several seconds after removing your finger (called "pitting"), oedema is present.

You can also examine the skin under your sock – a pattern left by the sock is an indicator of oedema.

RISKS OF SAUSAGE FEET

The major consequences of sausage feet involve the skin. Dependent oedema, especially if long-standing, can cause the skin to become thin and friable, and therefore more vulnerable to injuries and ulceration.

If your shoes are too tight, this could potentially lead to pressure ulcers. If you already have a pressure ulcer, oedema can prevent or delay healing. There is also a risk of infections of the skin of the legs, including cellulitis.

Be sure to consult your doctor if you notice newly developed redness and/or warmth associated with sausage feet, as this may be a sign of cellulitis. Pay particular attention to your toe nails. Long or sharp toenails that cut into adjacent tissue could be the start of a pressure ulcer or a serious infection.

MANAGING SAUSAGE FEET

Swelling in the legs after a SCI can be caused by a combination of factors, including dehydration, high sodium (salt) levels, physical inactivity and warm weather.

It is essential for fluid levels in your body to be well balanced as this allows blood to flow more efficiently throughout the body, causing more oxygen and nutrients to be delivered to where it is needed.

The following techniques can help reduce the swelling:

- **Move more:** Use passive movement exercises to move your legs more. If you can't do this independently, ask a caregiver or visit a physiotherapist or biokineticist.
- **Limit salt intake:** Too much salt can cause a build-up of fluids in the body. Try to eat less salty food and rather eat more fruits and vegetables. They have high water content and are low in salt.
- **Elevate your legs:** Just as gravity causes fluid build-up in your feet, elevating your legs allows fluid to drain away. Place your legs on pillows while you sleep or whenever you're laying down. Ensure there are no pressure points when the legs are elevated. Be prepared to potentially urinate more as the fluid drains.
- **Drink more water:** Swelling is caused by too much fluid in the body. It might seem a bit weird to drink more water, but

dehydration can cause the body to "store" water as a safety mechanism. By drinking enough water throughout the day, your body understands that there's no need to store it for later.

- **Wear compression socks:** Wearing compression stockings or socks helps to increase blood pressure in the legs and move some of the extra fluid out of your legs. Consult a doctor before using compression socks or stockings and have them fitted by a professional. Avoid these stockings if you have peripheral artery disease, active cellulitis or are prone to autonomic dysreflexia (AD). Too tight or wrinkled stockings can cause AD. When first using compression socks or stockings, monitor your skin for evidence of irritation or breakdown and remove it at the first sign of skin irritation.
- **Massage your legs:** Swelling can be reduced by massaging your legs. Massage your legs from the feet upward to move fluid upwards. If you are unable to do it yourself, teach your caregiver to do it.
- **Avoid hot temperatures:** Warm temperatures can cause your blood vessels to dilate to cool you off. Keeping cool will narrow the blood vessels and reduce swelling. Stay cool by staying out of direct sunlight, wear easy-to-remove layers, drink lots of water and have a spray bottle with water handy to help cool you down.
- **Inspect your body regularly:** Other complications can also cause swelling including deep vein thrombosis (blood clots in your leg veins) or heterotopic ossification (abnormal bony growths that can interfere with the return flow of blood to the heart and cause swelling). Frequent body inspections will help identify complications early and allow you to manage them before they progress. If you notice that one leg is much more swollen than the other (with or without pain), see your doctor immediately.
- **Medications to help:** There are diuretic medications that can help the body shed water. These should only be taken after consulting your doctor as it can cause blood pressure to drop.

REDUCE SWELLING

Managing sausage feet

Move more

Use passive movement exercises to move your legs more by gently moving and stretching your legs.

Elevate your legs

Elevating your legs allows fluid to drain away. Place your legs on pillows, but ensure there are no pressure points.

Limit salt

Too much salt can cause a build-up of fluids in the body. Try to eat less salty food and rather eat more fruits and vegetables.

Drink more water

Dehydration can cause the body to "store" water as a safety mechanism. By drinking enough water throughout the day, your body won't store any for later.

Compression socks

Wearing compression stockings or socks moves extra fluid out of your legs. Consult a doctor before using compression socks.

Massage your legs

Massage your legs from the feet upward to move fluid upwards.

Avoid hot temperatures

Keeping cool will narrow the blood vessels and reduce swelling.

Inspect your body

Swelling can also be caused by other complications such as blood clots in your leg veins or abnormal bony growths. Inspect your body to identify complications early.

Medication

There are diuretic medications that can help. Consult your doctor before using these.

Combating Obesity

For persons with a SCI, obesity is a common problem that cannot be passed off as the consequences of "sloth and gluttony". It is far more complex than that. Yet, the consequences of obesity are as dangerous to persons with a SCI as for the able-bodied, if not more so.

To combat obesity, we must first understand the types of obesity that afflict us, the dangers and complications.

TYPES OF OBESITY

The most common indicator of dangerous obesity is the measurement of your waist circumference. The complications of an excessive waist circumference are life threatening. So, what should you look out for?

Subcutaneous fat is fat that's found under your skin. Too much subcutaneous fat can be a sign that you have too much visceral fat, which lies deep within your abdominal cavity and surrounds your organs.

The loss of muscle mass in the afflicted part of the body (related to the level of the spinal cord lesion) is common in persons with a SCI. This is known as sarcopenia. When sarcopenia is associated with excessive body fat, it is known as sarcopenic obesity. This condition is increasingly recognised for complicating the management of obesity-related conditions both clinically and functionally.

DANGERS OF OBESITY

Complications of obesity, and particularly of an excessive waist circumference, includes diabetes, hypertension, heart attacks, strokes, and an increased predisposition to pressure sores and sleep apnoea, to name but a few.

Obesity also impacts on the routines of daily living where excessive weight make, for example, transfers, dressing and turning in bed difficult for carers (and yourself if you are still able to function independently). There is also additional weight on pressure points, which can increase your chances of developing pressure sores.

ADDRESSING OBESITY

Weight management is the best way to address and prevent obesity. This is done through diet, exercise and behaviour modification. These are supplemented by medications and surgical interventions, but both are fraught with complexities and should be kept as last resorts in instances of morbid (gross) obesity.

> **Weight management is the best way to address and prevent obesity.**

Adjusting your meals

Persons with a SCI are at a high risk of gaining weight because of reduced physical activity and loss of muscle mass. As a rule of thumb, the higher the spinal cord lesion, the greater the chance of becoming obese.

Dietary management is very individualised. To ensure that you get the appropriate nutrients and minerals as well as the appropriate balance of fat, protein and starch in your diet, it is advisable to manage your diet under the guidance of a dietician.

They will check your weight, hydration and test your blood to ensure your kidneys and liver is working well. From there, they will determine your ideal weight and the balance of protein, carbs, fibre and food supplements that is needed.

There is however some general advice that everyone can follow. First, avoid crash diets. They may result in rapid weight loss but are almost invariably associated with complications relating to loss of essential nutrients. It has been shown that, at best, the one-year outcome of a crash diet is equivalent to that of a controlled diet over a longer term.

However, in many instances, once the crash diet has achieved the desired weight loss, people return to their normal eating habits and regain the weight lost during the diet. This is because the hunger centres in the brain did not have time to adjust to a lower calorie intake, following on the diet.

So, unless there is good discipline following the crash diet, our brain's hunger centres entice us to eat as we did before the diet. Rather follow a diet prepared by a dietician and be patient with the weight loss. It is a lifestyle adjustment – not a quick fix.

If you are unable to reach a dietician, there are some general steps that can help. It is important to remember that as a person with a SCI, you require less calories per day than when you were able-bodied. You can reduce your overall food portion by about 10 percent.

Cut back significantly on fat, butter and cooking oils. Reduce your meat and starch (pasta, bread and mielie meal) portions. Increase your vegetable and fruit intake.

Drink at least two litres of water per day – over and above any tea or coffee. Fluid intake ensures that the kidneys continue to work optimally. Kidney failure is one of the main causes of death in persons with paralysis. The colour of your urine can indicate whether you are drinking enough water. A dark yellow is a sign that you need to drink more water.

Steer clear of fizzy cooldrinks and pure fruit juice, which is packed with sugars. Also avoid any sweets and chocolates.

If you feel healthy and full of energy as you slowly lose weight, all is well. However, if not, write down your diet and take it to a doctor or dietician for further guidance.

Building better habits

Behaviour modifications is all about identifying cravings and then addressing the triggers that result in over-eating, which contributes to weight gain. A few ways to change your behaviour includes:

- **Goal setting and self-monitoring:** Set yourself realistic weight-losing goals and a timeline with the help of your doctor or dietitian. Monitor your progress by recording your weekly progress. Weighing yourself may be a challenge for a person with a SCI. Instead, check your abdominal circumference to monitor your progress.
- **Stimulus control:** Recognise the temptations of your hunger centre and counter it with (for example) a glass of water rather than a slab of chocolate, which is also a much cheaper option.
- **Slow eating:** Take your time when eating. Chewing your food thoroughly helps to manage your hunger centre.
- **Increasing physical activity:** Formal exercise programmes are important. In addition, try to do as many of your daily activities independently as your abilities allow. Don't ask your carer to do things that you can do for yourself.
- **Social support:** Include friends and family in your weight-loss goals and ask them to encourage you in your efforts. Also invite them to celebrate your achievements with you.

LAST RESORTS

There are many adverts for wonder products. Steer clear! Also avoid the so-called weight-loss clinics that charge an arm and a leg for rapid weight loss. Rather work with a dietitian or your doctor.

Bariatric surgery has been shown to be successful, but only if performed by a select few multi-disciplinary units with proven track records. It is also not just a case of having the surgery and all is solved. The aftercare is intense and very expensive. It should only be considered in the morbidly obese.

In conclusion, diet, exercise and behaviour modification, all under expert supervision, is the ideal combination for successful weight loss. So, here's wishing you all the very best in your endeavours to shrink your abdomens and becoming healthier, more dynamic and sexier versions of yourself. R

Exercise and sleep

For almost all of the overt consequences of spinal cord injuries, exercise and sleep is vital as a way to prevent and manage the consequences.

SLEEP

The ideal position to sleep in is your stomach. This helps to prevent pressure sores and spams. Aim for at least four hours on your stomach a night. It is not necessary to turn a person if they are comfortable sleeping on their stomach. However, it can be uncomfortable to sleep on your stomach if you are not used to the position.

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In other sleeping positions, the trick is to get the entire body into a comfortable, supported position that will allow the person to be the most relaxed without needing any effort to stay in that position. This includes careful positioning of the head and neck.

As always, special care must be taken to ensure that potential pressure points are positioned in a way that prevents pressure sores. Make use of supports such as pillows at the back to prevent the person from rolling out of position. With any other sleeping position, be sure to turn every two to three hours.

EXERCISE

Both active and passive movements are very important. Active exercises can help relieve pressure points to prevent pressure ulcers, strengthen your arms, core and shoulders to keep you independent, and help you burn energy to keep you trim. It counters bone thinning and ensures healthy rotator cuffs – an injury here can turn a paraplegic into a quadriplegic.

Exercising can also help prevent bad posture or hunching in your wheelchair. Hunching can pinch the nerves that work your arms and hands, causing stiffness, pins and needles and loss of function.

Passive exercises help your prevent spasms and sausage feet while keeping your muscles, nerves and joints flexible.

When starting on any of these exercises, it is best to consult a biokineticist or physiotherapist to ensure the movements are done correctly and that the programme is step up for your particular needs and ability.

Passive Movements

If muscles aren't stretched, they will contract into non-functional positions. Tendons and joints stiffen until the entire joint becomes frozen. To prevent this, passive movements should be done at least once a day (ideally twice a day) for five to 10 minutes.

If there is a particular area where you are experiencing stiffness, passive movements should be done more often until the range of movement improves.

If the stiffness is severe, it is recommended to seek assistance from a physiotherapist as the bones can become thin and osteoporotic, causing them to break relatively easily.

Stiff, contracted muscles can also tear easily. Movements should be done with a lot of care to avoid over-stretching as the body doesn't resist and the person feels no pain.

Caregivers can first test their own range of motion and then not go beyond those limits when practicing passive movements on the person with the spinal cord injury.

The movements should be done rhythmically and within the range of movement of the joint, possibly with a little bit of a stretch at the end of the range of movement.

It is important to work against the pulls of the body. For example, if hamstrings are particularly spastic, working on the range of straight leg raises can help counter the pull of the hamstring.

A word of caution. A straight leg raise stretches the muscle and tendon, but also the nerves. If overstretched, this could cause pain, headaches, dizziness and feelings of nausea.

So, one needs to be gentle. If the knee buckles or the leg tightens up, you need to ease up and maintain that position. Be gentle, be alert and feel the resistance of the limb to the movement.

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If you are unsure of where to start, it is best to consult a physiotherapist for a session or two. They will be able to draw up a series of movements to be followed.

Changing your position often during the day is a great way of assisting with passive movements. For example, if you are sitting in your wheelchair most of the day, your hips and knees are bent and your ankles are stretched. When you get out of the wheelchair, make a point of lying on your stomach for a while. This allows your hips to stretch and your knees to straighten out.

It is important to be disciplined and do the movements regularly. If you pick up a problem, fix it as soon as possible. If you are not able to fix it, get professional help. The aim is to maintain your posture, your flexibility and your range of movement.

Active movements

There are various purposes and kinds of active movements that need to be practiced daily to build and maintain strength, independence and ideal weight, as well as removing pressure.

- **Strength:** Aim for 20 to 30 minutes of exercise, two to three times a week. The exercise should be intense enough to increase your heart rate and breathing. Aim for more repetitions with lighter weights or elastic bands. Use smooth, slow movements. Practice practical movements like forward leans, chair lifts, twists and rotating. These will help build and strengthen your shoulders, core and arms to help making transfers easier.
- **Pressure relieve:** A paraplegic with normal upper body function should relieve pressure every twenty minutes. Push yourself up with your arms and wiggle your backside for at least 20 seconds before sitting down again. This improves the circulation. Quadriplegics with upper body function can drop their chest onto their knees and rock from side-to-side or lean from side-to-side. Ask your caregiver for assistance if needed.
- **Posture correction:** To help your shoulder posture, try a straight arm stretch-swing from your knee to behind your ear. Reverse the movement from the front to back with straight arm, reverse bowling action. To assist your neck and back, lie on your back, look straight ahead, push your head back against the pillow. Hold it for 10 seconds and repeat 15 times. It is important to not look up!
- **Practice daily functions:** If you find that you are starting to struggle with things that previously came naturally, make a point of practicing that movement to activate the brain-limb connection. If this does not work, get utensils that will help; a tool to help with shirt buttons, a special fork or spoon that allows you to get food into your mouth. Don’t be proud, be proactive. R

Ageing with a SCI

For people with mobility impairments, the well-known saying “Growing old is not for *sissies*” can be accentuated by adding “most definitely not for sissies”. For those of us who suffered a spinal cord injury, the new normal that we settled into starts to change; yesterday’s norms fade away and next year’s norms become unpredictable. For those of us with progressive disabling disorders, shifting norms is our expectation.

As we grow older, we diminish in capacity. We may not believe it and we often do not accept it, but it is a reality, and we must manage it. This diminishment of capacity is often more prevalent in persons with spinal cord injuries or afflictions because our capacity diminishes from an already compromised baseline.

If we realise this and actively manage our diminishing capacities, we can slow down the process. If we shift our minds and actively work towards optimising whatever remaining capacities we have, our lives will remain fulfilled and continue to have purpose. Here are some things that we can do physically and mentally to achieve this.

EVERYONE AGES

As we grow older, for those of us who are fortunate enough to have a spouse, it is important to remember that they too age. They develop back problems, shoulder problems, knee problems. Their strength and agility decreases. They cannot help us as they used to be able to.

Don’t get mad at them. Consider them and ask for assistance from others. Take the lead where situations allow you to do so, don’t leave it to your spouse to look for help. People respond faster to requests from persons with disability. If you take charge, your spouse experiences that you care; that your spouse has not just regressed into being your carer.

STAY MOVING

As we grow older, exercise tends to be placed on the back burner. This is probably the worst thing that we can do. All persons with paralysis should continue to exercise all body parts either through active or passive exercises. It counters bone thinning, strengthens the core muscles of the trunk and shoulders and promotes general wellbeing. For self-propellers, it is particularly important to keep our shoulders strong and supple. Rotator cuff injuries tend to turn paraplegics into quadriplegics.

MANAGING THE COMPLICATIONS

The major causes of mortality in persons with mobility impairments include pressure sores, urinary tract infections and eventual kidney failure, and obesity-related conditions such as strokes, heart attacks and diabetes. Managing these are important to ensure quality of life and longevity.

Pressure Sores

As we grow older our skin tends to become thinner and more fragile. Our chances of developing pressure sores increases as a result. Regular pressure relief is important, as well as avoiding pressure points when sleeping and doing twice-daily examination for pressure sores.

Bladder and kidneys

In a nutshell, bladder and kidney health revolves around bladder care. The goal is to avoid urinary tract infections, which can cause damage to the kidneys. Often, these are caused by poorly managed bladders or unhygienic catheters. You should aim to empty your bladder regularly and completely.

Incontinence should be accompanied by indwelling or sleeve catheters, while urinary retention should be treated with intermittent catheterisation, preferably with hydrophilic catheters. Be sure to drink enough water to ensure you have a healthy bladder and kidneys.

Obesity

Obesity is common in people with spinal cord injuries. As we grow older, our bones tend to thin, and we become osteoporotic. Obesity and thinning bones are not a good combination and can worsen back problems such as collapsed vertebrae, kyphosis (hunchback) and scoliosis.

Over and above health issues, obesity also makes life difficult for caregivers. To manage your weight, it is important to eat balanced meals (ideally designed by a registered dietitian) and exercise.

CREATING PURPOSE

Morbidity or having a chronic illness to manage is what makes our lives miserable. These can also eventually kill us. Managing the complications of our disability (spasms, neurogenic bladder, etc) is half of the battle for fighting morbidity. Thereafter, we need to find purpose – especially if we are unemployed or retired and we can't depend on a career to create a sense of purpose.

Creating purpose is all about finding reasons to get up in the morning. It can be anything that grabs your attention, makes you feel like you are contributing or have value. We are human beings not human doings. We are defined by who we are more than by what we do. So, whatever makes you enjoy life is a good purpose to have! Here are some things to consider.

Start a hobby or challenge

Doing something that you enjoy or is a challenge can be a great way to spend your life! Ideally, you should do this within a community. Loneliness is more debilitating than a disability. Find people or a community who enjoy the same hobbies or challenges so that you can share it with them. If all else fails, consider building an online community.

Be a friend

Mobility impairment tends to make us lonely, particularly after retirement when we lose out on work-related socialisation. People are hesitant to invite us over because their homes are not wheelchair friendly and using their bathroom could be problematic.

Waiting for someone to strike up a friendship with usually gets us nowhere. So, reach out actively. If you come across someone that you feel you can connect with, make a date for coffee at a wheelchair friendly coffeeshop. Find places where you can visit on equal footing.

Focus outwards, don't draw into yourself. Look actively at how you can be a blessing to someone else, even if it is just a smile, a kind word, a listening ear or a shoulder to cry on.

Be quiet

Make time to be quiet and to meditate. Make place for me-time: Music, a good book or just stepping out of yourself to take stock of your circumstances and emotions.

Plan for your future instead of worrying about it. Stepping out of yourself usually brings perspective and mountains return to being mole hills.

STAYING SHARP

Finally, you want to keep your mind sharp into old age. Forgetting things does not necessarily mean dementia. As we grow older, we tend to forget things. We also don't listen as attentively as we should and then we make our spouses angry because we do not remember what they told us.

So, exercise your brains. I hate Sudoku and word puzzles, but I like woodwork and planning a new project; designing and measuring, figuring out what lengths and sizes of wood is needed, what else I must buy and how to put everything together. It keeps my mind active.

When everything comes together after fixing a few errors and the project is successful, the pleasure of accomplishment keeps my brain (relatively) sharp.

ENJOY BEING

We are so focused on being human doings that we forget that first and foremost, we are human beings. So, if we lack in the capacity to do, no matter what our disability, we have an unlimited capacity to be.

So, let us be there for one another. Be a human being. Become involved. Care actively. R

Resilient mindset

As a caregiver, friend or family of a quadriplegic, you may have wondered why people react so differently to their disabilities. Some give up, others become violent or aggressive. Some seem to have a sense of entitlement or helplessness. Then there are those who pick themselves up, pull through and become stronger, more compassionate and more grace-filled than before their injury or affliction.

To understand the mind of a quadriplegic person, you need to step into their shoes. Imagine your worst nightmare. You are captured and put in an iron cage with your feet shackled to bars with little or no space to move your arms. You are fed, clothed and washed by someone else. You are never allowed out of the cage. Not ever.

This is a reality for a quadriplegic, but instead of a cage of iron, it is one of their own bodies. How do you overcome this imposed bondage without going insane? The answer lies in resilience.

Resilience is having the capacity to bend without breaking, to bounce back. We place a lot of emphasis our bodies. When our bodies are "broken", we feel stripped of our identity.

This is not true. Our bodies are only a small part of who we are. Our real identity is found in our soul and spirit. This is what resilience is all about. If we cannot bounce back in body, we bounce back in spirit.

Much has been written about resilience. The reasons for why some people are resilient and others not varies. It includes facing reality, having a supportive community, changing your mindset, spirituality and much more. I believe the art of resilience can be encapsulated in three conceptions: Hope, optimism and a compelling "why" or purpose.

THE ART OF HOPE

Hope is believing that things can change for the better even when the chances are slim. It is the belief that we will learn to cope and eventually thrive. For some, our hope is placed in ourselves, trusting that we can do it. For others, this might be trusting someone (or something) bigger than us will help us.

REALITY-BASED OPTIMISM

Optimism rooted in reality can be powerful to help keep us motivated. False optimism might be believing that we can walk again despite all the contrary evidence. True optimism is trying to live as independently as possible within the constraints of our disability.

True optimism is the ability to accept our reality and then look broader and wider to positively reappraise our circumstances. It is the fuel that ignites resilience, and it is the cement that binds our hope for something better with our here-and-now reason for being – our purpose.

CREATING PURPOSE

A compelling "why" or purpose is our reason for living. It could be a small passion or interest that keeps us going.

Few will know Samuel Pierpont Langley, but many remember the Wright brothers. Samuel was contracted to build the first airplane. He was given all the resources he needed.

However, it was the Wright brothers who built and flew the first airplane – from a shoestring. The difference? To Samuel, it was doing a job. Orville and Wilbur Wright, however, wanted to fly. It was their purpose, their compelling reason why. All of us need a purpose. It focusses our minds.

LEADING OTHERS TO RESILIENCE

Knowing the importance of hope, optimism and purpose in creating resilience, we can have more compassion for those who falter, whether they are quadriplegics or not. We can sow a seed of hope, show them the bigger picture and help them find their reason for being. Thus, in a small way, you will help to restore value in a "broken" person. R

Boosting

Deploying Autonomic Dysreflexia in an unethical and highly dangerous manner

When discussing the consequences of spinal cord injuries (SCIs), it is important to talk about the dangers of abusing these consequences as is the case with boosting – a practice done by athletes with disabilities to improve their performance. There are ego-driven athletes who feel the need to win at all costs even when those costs are dire. They often become dopers, using forbidden performance-enhancing chemicals to push their bodies beyond its natural limits.

In the SCI community, ego has found another source of “extra energy” – self-induced Autonomic Dysreflexia (AD). When a spine is injured, it affects the Autonomic Nervous System (ANS), which is responsible for managing key functions like blood pressure and body temperature. As the system is already damaged, a painful or uncomfortable stimuli below the level of injury can cause the body to overreact as is the case with AD. Signs of AD includes excessively high and fluctuating blood pressures, pounding headaches, excessive sweating and more.

For athletes with a T6 or above injury, the damage to the ANS can be very frustrating. The body doesn’t respond to the demands of competition as it would normally. Their heart rate and blood pressure remain low even when exercising. This compromises the increase in oxygen uptake that is so necessary in sport. Performance is therefore lower, and endurance is reduced.

Boosting intentionally puts the athlete in AD to boost their blood pressure and improve blood flow to working muscles before a competition so that they have more energy, better performance and greater endurance. Of course, it isn’t just that simple.

The ANS is damaged and messing with it is dangerous – and illegal (those found out face expulsion). Aside from just feeling ill, AD can cause serious harm. It is not consistent in increasing the blood pressure and heart rate. It fluctuates. Here lies the danger.

If the athlete’s blood pressure spikes significantly during a moment of intense strain, it can cause an artery in the brain to burst. It only needs a fraction of a second for an artery to pop. That fraction of a second can change your life for ever … Imagine going from an active, sport-loving, highly competitive athlete to a stroke … or death! There are many ways in which athletes induce AD, but the premise is the same – pain or discomfort equals AD. Examples include:

- Clamping catheters resulting in bladder distension (Imagine taking a tumble with your chair and rupturing an overfull bladder!)
- Excessive tightening of leg straps (Imagine a non-functioning, osteoporotic bones breaking when you take a fall!)
- Sitting on your own testicles
- Breaking a big toe

Beyond just the danger of stroke, many of these tactics hold other risks. An overfull bladder can rupture if the athlete takes a fall. Non-functioning bones tend to become osteoporotic and frail. Leg straps that are too tight can increase the risk of breaking bones during a tumble. Damage to your testicles can impact your ability to bear children while the healing on a toe can be complicated.

All of the above methods are somewhat crazy, but a thought to hold onto is: “If boosting is not controlled, someone will die”. Boosting, as with doping, turns us into criminals. We start lying. We distrust. We become defensive and paranoid. The goals that we strive for become our slave masters. Is it worth it? Is the prize worth the deceit? Is it a life worth living?

Rather compete according to your natural abilities and make new friends as you go along. If you do happen to win gold, you will have the satisfaction of knowing that you achieved it honestly and with integrity. R

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