Caregiver Wellness

A guide to caring for your carer

ROLLING INSPIRATION

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Introduction

Persons with mobility impairment draw attention (often unintentionally) to themselves. They receive compassion, sympathy (a useless emotion), empathy (much more constructive) and even admiration for perceived fortitude, courage and resilience.

> **Their needs are very real and, if ignored, may have dire consequences.**

On the other hand, those who care for us, including professional caregivers, spouses, family or friends, live on the fringes of the mobility-impairment drama and their needs, more often than not, remain unrecognised. However, their needs are very real and, if ignored, may have dire consequences.

Possibly the greatest asset of a competent caregiver is a compassionate mindset. But compassion is born from agony and sorrow for the person cared for. This agony can impact the mindset of the caregiver destructively in many ways.

Caregivers and those they care for need to be aware of the influences that can derail the caregiver's mindset and must actively strive to remedy the situation.

Taking care of a person with mobility impairments is very "up close and personal" from dressing, toilet routines, feeding, transferring in and out of wheelchairs to many other activities of daily living that are largely taken over by the caregiver.

A healthy mindset and a mutually trusting, positive and respectful relationship must be developed, nurtured and cherished from both sides. One way traffic will not work, the relationship must be reciprocal.

This series of articles addresses selected aspects and circumstances that impact the psyche of caregivers and the consequences thereof. It is by no means comprehensive but I trust that it will provide insight. R

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

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Basic caregiver wellness

Care giving is emotionally draining work. The irony is that the more a caregiver becomes attached to their care receiver with a disability, the more emotionally draining the work becomes. Good caregivers also recognise and respect your mood swings and the emotional outbursts that we are all guilty of at one time or another. They realise that they cannot respond or defend themselves. As one caregiver once explained to me.: "I cannot also become sad or cross; then there will no laughter anymore…"

So, we as quadriplegics, paraplegics and other users of caregivers have a moral and a "condition of service" obligation to look out for the emotional and physical wellbeing of our caregivers. We should actively promote and ensure that our caregivers look after their stress levels. We should provide the time, opportunities and empathic support for our caregivers to de-stress and maintain their physical and emotional health. Here are a few pointers for you and your caregiver to consider together:

PREVENT YOUR CAREGIVER FROM ISOLATING THEMSELF

Care giving can easily result in 24 hours "on call", causing a caregiver to become very lonely. Allow and actively encourage your caregiver to contact or visit family and friends. If possible, allow your caregiver access to the internet and encourage participation in online chat groups, Facebook groups and online support groups, which also help to reduce feelings of isolation.

GIVE YOUR CAREGIVER "TIME OUT" TO ACTIVELY DE-STRESS

Encourage your caregiver to exercise, to go for a run, join a gym, a yoga class, karate class (if you can afford it). If they are battling emotionally, consider consulting a counsellor or therapist to offer support to your caregiver.

ENCOURAGE YOUR CAREGIVER TO ACCEPT SUPPORT

If friends or neighbours ask how they can help, give them the opportunity to help you and in so doing give your caregiver some time out. You could also consider intermittent adult day care for yourself if you are not working.

If you are employed, please be careful not to tie your caregiver down with tasks that limit or prevent personal time out.

ENSURE YOUR CAREGIVER GETS ENOUGH SLEEP

This is probably the most important support that you can provide for your caregiver particularly if you are a quadriplegic or any other form of disability who requires attendance at night. Make sure that your caregiver gets eight hours sleep every day, which could include afternoon naps.

Encourage your caregiver to stay away from caffeine drinks later in the day and evening. Encourage discussing concerns or "setting matters straight" before bedtime to ensure a good night's sleep.

ENSURE YOUR CAREGIVER PAYS ATTENTION TO THEIR OWN HEALTH

Ensure that your caregiver (and you too) eat regular meals including fruit and vegetables, drink lots of water and takes a brisk walk every day if there is no time for their regular exercise programme. Look after their basic health and dental care as well.

ALLOW TIME FOR PERSONAL GROWTH

Allow your caregiver time for hobbies and general relaxation. If your caretaker is enrolled in an adult education programme, please recognise and support them in this and accommodate it as far as possible.

In conclusion, care giving is a very difficult and draining occupation. Good caregivers are rare and special people. We should do everything in our power to support them in having a life that is as close to normal as possible. This will build loyalty and respect and will lay the foundation for a long and mutually beneficial relationship. R

Trauma phases for partners

Spinal cord injuries are hugely traumatic. We deal with the death of a part of ourselves and disappear into ourselves. There is the battle to survive followed closely by the battle to rehabilitate, then there is the life-long battle to live our lives in a reduced state. In all of this, many of us have support infrastructures and the focus is on "me" and how to make the most of what remained of "me".

But what about your spouse, your life-partner? How does all of this impact on them? Physically … Mentally … Emotionally?

In their article, "The experience of being a partner to a spinal cord injured person", Sanne Angel and Niels Buus follow the lives of seven spouses from the moment of their partner's injury, over a period of two years. I have based this article on the research findings, interspersed with a few insights gleaned from (fairly robust) discussions with my wife of fifty years.

MUTUAL SUPPORT

At the outset it must be emphasised that couples who have faced spinal cord injury (SCI) together survive better in all walks of life than an individual with a SCI trying to go it alone. So, do not become disheartened, work hard at building and strengthening your relationship. The key words are mutual support. The giving of yourself must flow both ways to the utmost of the ability of both partners.

However to this end, just a word of warning: The older we get, the more challenging the circumstances become. Both partners move into reduced abilities. Particularly the partner with an SCI must appreciate and respect this of their spouse.

TRAUMA PHASES FOR SPOUSE

The trauma and challenges experienced by the spouse are described in the research article in three phases, namely:

- To be harmed by the partner's injury;
- To find oneself on the outside of their partner's life; and
- To struggle for the injured partner and re-establishing life as a couple.

The three phases relate to the injured partner's movement from the acute phase of recovery to the extended phase of rehabilitation and finally into the "home straight" of returning home and rebuilding life together.

PHASE 1: TO BE HARMED BY THE PARTNER'S INJURY

The entire focus is on the injured partner from the healthcare professionals, the concerned family and friends to the non-injured partner. Struck by the brutality of the injury, the spouse's own needs fade into the background. Their world comes to a standstill.

> **"Struck by the brutality of their injury, the spouse's own needs fade into the background.**

They realise that they have not lost their partner, but they mourn the loss experienced by their partner. They feel the loss and pain of the partner, but are absolutely powerless to do anything about it.

As much as the injured partner needs physical care, so the spouse needs emotional support and care. The support of friends, family and pastoral care is (usually) great, but professional care must be sought and offered.

If we do not take care of ourselves, we lose the ability to care for others. Note the safety talk before take-off on an airplane: "First place the oxygen mask over your own face, then attend to others."

The shock of the injury has a profound impact on the spouse that leaves them with a sense of vulnerability. The physical pain of the injured partner becomes the emotional pain of the spouse. The physical struggle for survival is mirrored as an emotional struggle for survival in the spouse. They become lost in space…

This needs to be recognised and managed for the sake of the immediate need of the spouse and the long-term survival of the relationship.

PHASE 2: TO FIND ONESELF ON THE OUTSIDE OF THEIR PARTNER'S LIFE

Once the physical injuries are healed, rehabilitation starts. A team of professionals support and train and exercise the injured spouse throughout a long period of intense and very hard work. The injured person becomes part of the team and the common goal is to recover as much functionality as possible. But where does the spouse feature in all of this?

Certainly they have a place in the physical recovery processes and are meant to be an integral part of the training process. And, as with their spouse, they also have to learn the skills of coping with disability.

But unlike their spouse, this is not their whole life. They still have a home to run and often a job to uphold. They have to juggle their time between the needs of their spouse, household responsibilities, children and their job. They become torn apart by the conflicting demands.

The processes of rehabilitation carries on with or without them. They start to feel like an intermittent onlooker rather than an integral part of the rehabilitation.

They find it difficult to share the pressures of work, the demands of children and the drain of household responsibilities and chores with their life partner who had always shared this, but is now absorbed into another world.

They become lost in space…

PHASE 3: TO STRUGGLE FOR THE INJURED PARTNER AND REESTABLISHING LIFE AS A COUPLE

Finally the day arrives. Discharge. Going home. All of a sudden, both are faced with the realities of the situation. Unconsidered normality's become major obstacles: Small, unnoticed steps, a too-narrow doorway, a blown ceiling light bulb that needs changing, the homes of friends that are no longer accessible and entertaining in your own home falls squarely on the shoulders of the uninjured spouse.

Children need to adapt. Authority is often shifted. Holiday planning takes on a whole new meaning. Then there is the mutually embarrassing issues around a neurogenic bladder and bowel that need to be managed. And the brunt of it all falls on the able spouse…

> **"The brunt of it all falls on the able spouse.**

Re-establishing a life together after one partner's SCI is a long and troublesome process that couples have to manage by themselves. Two people, both in a deep existential crisis, are supposed to overcome challenges in their relationship, their circumstances and their emotions, which often are more than couples living a normal life could handle.

The challenge is to jointly focus on regaining independence, removing unnecessary dependencies, for the injured spouse. In this process "Ag shame" does not cut it. Empathy is great, but there is no place for sympathy. It is a matter of taking the bull by the horns.

Discover abilities, define roles and fulfil roles to the utmost of your combined abilities. Love one another deeply, support one another as fully as you are able but place sympathy on a shelf to gather dust. And eventually you will both find your place in space again. R

Reinventing purpose

A man tragically lost his wife in a car accident. His life was shattered, but he tells of how he consciously made the wellbeing of his children the new purpose of his life; how this helped him to pull the pieces of his life back together again.

Losing the physical vitality of your spouse through a spinal cord injury (SCI) is a life shattering experience for both partners and to rebuild requires purpose.

In a previous article, I wrote on how the acute care and rehabilitation often leaves the spouse lost in space, travelling on the fringes of the recovery journey but torn by personal responsibilities and embroiled in roller-coaster emotions, unable to be actively part of the restoration journey.

This article proposes a process toward establishing a purpose for the spouse of a recovering SCI patient by carving out an active role, setting priorities and managing your time.

Immediately after the injury, there will most likely be an information overload that your emotionally traumatised brain cannot digest, or worse, that just escalates your anxiety. Clinicians explaining things, information leaflets, your own research, well-meaning friends, support groups … the list is endless and just leaves you more confused and emotionally drained.

So, the first step towards redefining your purpose is to take a step back. Look at yourself, look into your own immediate needs and cater for them. Be selfish. Put yourself first. Because if you crash, you are of no use to anyone, least of all your injured spouse.

Remember that while your spouse is in ICU, they are fairly zonked out and not all that aware. While it may be emotionally gratifying to sit and mope in the ICU visitors' room, it is not exactly productive and certainly not fair to your children or other loved ones.

Rather use the time to shift your mind from "why us" to embracing your new spousal realities and figuring out what your new challenges are and how to overcome them so that when your spouse resurfaces, you are in a position to contribute toward rebuilding your lives.

Look into resting well, eating regular proper meals and exercise (moderately). If there are children, take care of them, make that an active and immediate purpose.

Once your emotions have settled and you can think rationally again, start making lists:

- Priorities that need your time and input (personal time, children, home, work and spouse) and a manageable schedule delegating what you can. If possible, make arrangements with your employer to work from home or work flexitime.
- Questions for which you need answers and the best persons to ask.
- The contact details of relevant persons including healthcare providers, support groups, pastoral care, and so on.

Organise your life. Don't isolate yourself. There will be people who want to help so make use of them. Here are some pointers:

- It is emotionally draining to tell the same story over and over to concerned persons. Accept a living-in support person like a mother, sister or brother and ask that person to be a spokesperson on your behalf.
- Ask well-wishers and concerned persons to rather use SMS, WhatsApp or Facebook to communicate. In this way, you can respond to the messages in your own time and share it with your loved one in hospital.
- Stay in touch with your case manager who is the best source of your spouse's progress and will guide you along the way to eventual discharge and

post-discharge needs.

- Get to know the nature of your spouse's injury and the expected fallout such as limitations in mobility and the required mobility aids, bowel and bladder issues and how best to manage these. In this way, you will develop a sound knowledge of your spouse's post-discharge needs and whether you will be able to cope together or if you will need the services of a caregiver.
- Start a journal. It helps to channel your grief and it illustrates progress; your own as well as that of your injured loved one.
- Encourage your loved one to talk to other patients, especially those who are further along on the road to recovery. It engenders a feeling of "I am not alone in this. There are others too and some are worse off than me". Friendships and camaraderie around shared hardship tends to inspire.
- If you feel the need, let your emotions out, cry, scream, shout or talk to those who are prepared to listen, including councillors.

When your loved one moves into rehabilitation, become a support resource to the rehab team and an emotional support to your loved one. This can include simple things like bringing comfortable training clothes from home to make rehab like going to the gym.

If your spouse's feet start swelling (as often happens with paralysis), get shoes that are one size larger, preferably rubber-soled training shoes. Remember toiletry items and bring along comfort items such as books, magazines, music or a favourite pillow.

In this way, your participation is active, supportive and constructive. Your loved one will take courage from this and together you can plan you future together.

Search your minds together to discover a new purpose that will bind you together so that you will rise to the challenges that await. Then live the journey. We make the road by walking, or in this instance, by rolling. R

GETTING ORGANISED

While your partner recovers, get organised to better support them

Accept offered support

Let your family or friends support you by, for example, acting as a spokesperson for when your community reaches out.

Encourage text messages

Ask well-wishers and concerned persons to rather use text to communicate so that you can respond in your own time and share it with your loved one in hospital.

Communicate with case manager

They are the best source of your spouse's progress and will guide you along the way to eventual discharge and post-discharge needs.

Know the condition

Get to know the nature of your spouse's injury and the expected fallout. You'll develop a sound knowledge of your spouse's post-discharge needs and whether you will be able to cope together

Journal

It helps to channel your grief and it illustrates progress; you're own as well as that of your injured loved one.

Encourage peer support

Encourage your loved one to talk to other patients, especially those who are further along on the road to recovery.

Find a healthy release

If you feel the need, let your emotions out, cry, scream, shout or talk to those who are prepared to listen, including councillors.

Proactive patience

Grace, compassion and empathy are important qualities for caregivers to practice when working with your clients, but what is the practical application of these mindsets.

I have given this some thought and I want to propose proactive patience as a way to apply these virtues to your day-to-day caring.

"Proactive" is taking the initiative by acting rather than reacting to events, while "patience" is the ability to endure waiting, delay, or provocation without becoming annoyed or upset.

So, at first glance it would seem that these two mindsets do not sit together all that well. But let's look a bit closer at each one and then put the two together.

"You have to stay calm and professional. You cannot react as you often would like to react.

PATIENCE IS A VIRTUE

Patience is possibly the more difficult of the two. In managing your client, you are faced with a body that cannot do what bodies are supposed to do, but often there are also attitudes of anger, aggression and sarcasm to deal with.

On occasion, there is despondency or depression that leaves your client without the will to want to do anything at all.

Through all these negative mindsets, you have to stay calm and professional. You cannot react as you often would like to react. You have to persevere and be calm when faced with these situations.

But nowhere in the definitions and descriptions of patience does it tell us to sit back and do nothing. This is where "proactive" comes to the fore.

PLANNING AHEAD

Managing challenges like pressure ulcers and practicing disciplines like passive movements require a caregiver to be proactive. You need to build a routine, design the passive movements with a biokineticist, prevent triggers and respond to spasms if they occur. You don't wait for your client to ask for help, you just go ahead and do it.

"Learn to anticipate the needs of your client and try to respond to them before being asked or told.

Getting to know your client's emotions and emotional triggers is similar, especially the things that frustrate. Learn to anticipate the needs of your client and try to respond to them before being asked or told.

In short, learn to read the mind of your client and deal with needs before they become issues.

PUTTING IT TOGETHER

So, putting the two together: Living grace, compassion and empathy practically as a caregiver is to be patient with the brokenness of the body of your client and to be tolerant of the emotions of your client when they boil over.

At the same time, be proactive with the needs of your client by recognising emotions for what they are and maturely responding to them with grace, empathy and with compassion. R

Managing stress and exhaustion

The old saying, “Don’t do to others what you don’t want them to do to you”, could just as well also say: “Don’t do to yourself that you don’t want others to do to you”. The first article in this booklet was for employers on caring for their caregivers. This article is directed at you, the caregiver.

Caregivers become caregivers because you care. Because you care, you sacrifice yourself, your time, your energy but also your emotions. Your reasons may include that you want the best for your client, but also being afraid of losing your job.

So, if your client is in a bad mood, you take it and say nothing. When they sleep, you try to sleep as well, but you sleep lightly because if something happens, you need to be there fast. Your client’s needs take priority and your own needs get pushed away. You tell yourself that you will deal with it later … all the while you become more and more stressed, and more and more exhausted.

This is the reality of the work that you chose. The circumstances and situations will not go away. However, they can be managed. To do so, you firstly need to understand what is happening to you. You need to realise that you are not being weak or going mad. What is happening to you is a normal reaction of your body and your mind to the stresses of the job. Most importantly, you must not be afraid to ask for help because if you crash, you and your client are in trouble.

Here are some identifiers of stress: Do you lie awake at night worrying about things that seem silly the next morning? Are you “too tired” to go out with friends? Have you stopped laughing? Are you cruising in “emotional neutral” where you do not allow yourself to become angry, but you are never happy either? Or do you become irritable with everyone except your client, lashing out for no reason? Has caring for your client become the one and only priority of your life that nothing else matters anymore?

Other causes of exhaustion may include: The mental strain of sleeping “with one ear open” in order to ensure that nothing happens to your client while you are sleeping; the physical strain of picking up, turning and positioning your client; and the emotional strain of remaining calm and professional and friendly in the face of your client’s frustrations and irritations – even taking abuse because you need the job.

The double whammy is that stress feeds exhaustion and exhaustion feeds stress…

So what to do? Before anything else you need to understand what is happening. Understanding the causes of stress and exhaustion is probably the greatest reliever of stress. Once you understand, you overcome the fear of the unknown.

The next step is to actively manage your stress and exhaustion. There is no magic formula that works for all, but here are a few pointers:

- Talk to your client so they know how you feel (Do so even if you feel scared.)
- Accept support if someone asks to help.
- Visit friends even if you don’t feel like it.
- Exercise to build your strength and your stamina.
- Eat healthily and regularly.
- Read books to help you relax (and make you drowsy). If your mind is running away with you, a good book settles you down in no time.
- Don’t drink alcohol or energy drinks, and don’t do drugs. They seem to relieve stress and give you energy in the short term, but in the long run they just make things worse.

If all else fails, talk to a professional about your situation. If you are not able to afford psychiatric or psychologic consultations, seek out pastoral counselling. Even a good friend, especially one with a positive uplifting personality, can help. Venting with laughter is a great reliever of stress. R

Compassion fatigue

Have you ever felt so tired, despondent and angry that you wished that your caregiving responsibilities would just go away?! Have you ever secretly wished in a moment of extreme tiredness and frustration that the one you are caring for would just die so that this torment could become over and done with?!

You are not a heartless monster. In all likelihood you are suffering from compassion fatigue.

Dr Charles Figley of Tulane University in New Orleans describes compassion fatigue as "a state experienced by those helping people or animals in distress; it is an extreme state of tension and preoccupation with the suffering of those being helped to the degree that it can create a secondary traumatic stress for the helper."

In short, it is the cost of caring for others because caring too much can hurt. When caregivers focus on others without looking after their own emotional and physical wellbeing, destructive behaviours such as withdrawal, bottled up emotions and substance abuse can surface.

Researchers have discovered that caregivers who are overstressed by the nature of their work begin to show symptoms that are very similar to that of their clients, including difficulty in concentrating and feelings of hopelessness, exhaustion and irritability.

Difficult home and personal circumstances and challenges in the working environment can all contribute to compassion fatigue. It is a major cause of professional caregivers leaving this field to look for other, less stressful work. (This option is however not that easy for those who look after family members.)

RECOGNISING COMPASSION FATIGUE

How do I recognise compassion fatigue in myself? The simple answer is that if you feel like you have it, you probably have it.

Symptoms to look out for include poor self-care (personal hygiene and appearance), bottled up emotions, withdrawal from colleagues and friends, always blaming others for things that happen and compulsive behaviours such as overspending, overeating, gambling and even sexual addictions.

Persons with compassion fatigue tend to become apathetic and withdrawn into themselves with difficulty in concentrating, feelings of sadness and a lost joy of life.

Persons with compassion fatigue tend to become apathetic and withdrawn into themselves.

They feel mentally and physically tired and drained. They may experience nightmares and even get sick more frequently, typically with irritable bowel and related problems.

Compassion fatigue in a formal environment such as a self-help centre that involves a number of caregivers could result in major problems for the centre, including absenteeism, high turnover rates, friction between caregivers or caregivers and management possibly leading to strikes.

Behaviours to look out for include the inability of teams to work well together, a tendency to break organisational rules, loss of respect, loss of flexibility, resistance to change and outbreaks of aggressive behaviour.

At first glance, compassion fatigue appears to be the same thing as burnout. There are similarities, but there also are major differences.

In a nutshell, compassionate fatigue is an overwhelming emotional and physical drain that presents with changes in the way the sufferers see and experience circumstances and how they react emotionally to these circumstances.

> **Compassion fatigue is an overwhelming emotional and physical drain.**

Burnout on the other hand describes the physical and emotional exhaustion that workers can experience when they have low job satisfaction and feel powerless and overwhelmed at work.

However, burnout does not necessarily mean that our view of the world has been damaged, or that we have lost the ability to feel compassion for others. Burnout is also not limited to persons that work in caregiving environments.

MANAGING COMPASSION FATIGUE

How do we manage compassion fatigue? Recognising that you have compassion fatigue is the first step to recovery, but remember that compassion fatigue is a process that develops over time so healing from its effects will also take time.

LR Knost noted: "Taking care of myself doesn't mean 'me first', it means 'me too'". Mother Teresa understood compassion fatigue.

She wrote in her plan to her superiors that it was mandatory for her nuns to take an entire year off from their duties every four to five years to allow them to heal from the effects of their caregiving work.

Some dos for managing compassion fatigue includes:

- Find someone to talk to;
- Understand that the pain you feel is normal;
- Exercise and eat properly;
- Get enough sleep;
- Take some time off;
- Develop interests outside of caregiving; and
- Identify what's important to you.

Some don'ts for managing compassion fatigue includes:

- Blame others;
- Make big changes like finding a new job, buying a car or getting divorced;
- Fall into the habit of complaining;
- Work harder and longer;
- Self-medicate;
- Neglect your own needs and interests;

> **Taking care of myself doesn't mean 'me first', it means 'me too'.**

You can follow the ABC of prevention, which includes:

- **Awareness**: What situations contribute to your stress level increasing your vulnerability to compassion fatigue?
- **Balance**: Self-care, fun events, exercise and do things that enthuse you. Take care of your soul.
- **Connect**: Establish a support system and talk out your stress with someone else such as a coworker, therapist, clergy, friend, family or a supervisor.

Compassion fatigue and burnout can lead to very serious problems, such as depression, anxiety and suicidal thoughts.

When this happens, you deserve to have help. Talk to your doctor about options such as counselling. R

Saying no

Often caregivers (specifically non-professional caregivers like family or friends) are burdened with a sense of obligation. For the caregivers, obligation is born out of love, a sense of responsibility, or many other reasons.

But obligation can also come from outside including the expectations and demands of others. Siblings, friends and others might say something like, "You are the best person for the job because", which is followed by a multitude of reasons – some are realistic, others serve only to absolve the other persons from taking up the responsibilities themselves.

For the person with the disability, it is what it is. They have to live with it. For the voluntary caregiver, it is a choice. This is the crux of caregiver stress. It is optional. It is a choice. I choose to care out of love, out of compassion, out of a sense of responsibility or even out of a sense of obligation.

Now here I am a year or two later, exhausted, demoralised and frankly, just plain *gatvol*, not so much of the person that I care for, but because of the situation I find myself in – isolated, frustrated, no time of my own. My temper is frayed and my tears are just below the surface.

I live on "cruise control" doing what needs to be done. But for myself, I am slipping…

There are many research programmes and articles that examine and describe the effects of overburdened caregiving on caregivers. Most of these articles define the labels, the condition and describe the fallouts.

But when it comes to solutions, one word encapsulates all proposed solutions. The tiny little word "No".

It is okay for caregivers to say "No". No to the person you are caring for. No to all those who cheer you on so that they do not have to become involved themselves. And an especially loud and emphatic no to yourself.

But what does "no" mean?

"No" is not giving up and walking away. "No" is not throwing your love and compassion into the trash can. "No" is not cruel and heartless. "No" preserves the caregiver's health and sanity. "No" paves the way for long-term caregiving. "No" is the caregiver's toolkit for survival.

We don't have to feel guilty about saying no. If you feel that you are getting lost in caregiving, if you feel that you can no longer provide caregiving in this way, if you feel that the current demands of caregiving cannot be sustained for much longer, it is more than okay to say no. In fact you must say no.

No means taking stock of your current situation. No means questioning, "What can I change in order to cope?". It asks, "where can I get help?". It is the beginning of formulating a strategy for sustainable caring without losing yourself. "No" allows you to continue to love and care without being weighed down by the burden.

So, now that we have taken the plunge to say "no", what now?

First and foremost, don't wait until you are ready to crash before saying no. The earlier in the caregiving relationship you step back, take stock and plan a routine for caring, the better for you and the person you are caring for. Ask yourself two questions, "What are the needs of the person I am caring for? What are my own needs?". Write down the two lists of needs.

Next, it is time for a chat with the care recipient. Keep the conversation calm and supportive. The disability in question is a given. It is not something to feel guilty about or sorry for. It is something that needs to be

managed in a manner that satisfies the needs of both parties as far as possible. As the caregiver, show your love and allow time for both of you to share your concerns. Add any new concerns to your list.

Thereafter, agree on structure and boundaries. As the caregiver, you are in charge of setting up structures and boundaries because you are the active person, but remember that your care recipient is the affected person.

To prevent resentment, there needs to be good communication and mutual agreement on the proposed structure and boundaries.

To build structure, consider the daily and the weekly routines. Remember to include breaks and "me-time". For boundaries, remember to set both physical and emotional boundaries.

This is not a world where the care recipient can just load everything onto the caregiver who with boundless energy and limitless love just absorbs everything in their stride. It is a relationship of give and take.

The caregiver's physical limitations must be taken into account and emotions must be talked through by both parties. In this way, understanding, fortitude and resilience is developed and the relationship becomes more solidified.

When boundaries are challenged with unreasonable demands or emotional outbursts, an assertive "no" comes into play, but with empathy and understanding. Be careful that the care recipient's emotions do not infect you to respond in kind.

If you maintain control, it will help to sustain your physical health and your emotional state of mind. If you need a good cry or a loud scream to vent your frustration, do not hold back. Cry and scream to your heart's content, but do so in private.

There is an old saying, "It takes a village to raise a child". We can also say, "It takes a village to care for a person with a disability". So, say "no" to going it alone and to social isolation.

Don't let siblings and mutual friends tell you that you are the best person for the job and then step back from their responsibilities. Say to them, "thank you for the compliment, but if I am to remain the best person for the job, I am going to need your help". This is where you do not accept "no" for an answer.

Make a point of facilitating social contact. Invite friends and family over. If the care recipient's mobility allows for it, go out for lunch, coffee or other social events. Social isolation can be devastating – to both of you.

> **"By setting structure and boundaries, caregiving can become an expression of love.**

By setting structure and boundaries, and with the constructive use of "no", caregiving can become an experience of privilege; an expression of love that builds the caregiver's sense of self-worth and the recipient's experience that life is there for living and enjoying despite the limitations of disability. "No" need not be a negative. It can also be a reality check and a means of survival.

On a personal note, my wife, her sister and I shared the heart-breaking privilege of, over a period of five years, guiding both my parents-in-law through dementia aggravated by psychotic episodes until their eventual passing in 2019 and 2021 respectively.

We suffered many of the stresses, anxieties and heartaches of caregiving, but we came through because we shared the burden between ourselves, and when it became necessary, also with a frail care facility. There were many instances when we said "no" and there were instances where the frail care staff said "no" to us. R

Partner as a caregiver

Common wisdom advises strongly against spousal caregiving because it is notorious for destroying marriages. However in a competition where persons with mobility impairment motivated the excellence of their spouses as caregivers, the winner turned out to be a biker who converted his motorbike to accommodate his wife's physical challenges caused by Multiple Sclerosis so they could go on road-trips together.

As chance would have it, at the same time, I received a response to my article on caregiver burnout. Tony has been caring for his wife Crystal for the past 20 years after she became hemiplegic following a stroke. He now recognises that much of what he thought was anxiety and depression could have been burnout. To quote from his e mail: "I am just coping with nothing left over at the end of the day…"

So, here we have two perspectives. Both are long-term relationships, and both are husbands caring for wives but one couple seems to be coping better than the other. Is there a magic formula? Of course not. Relationships are as complex and diverse as the genes that make us what we are. At best I can give a few pointers. As with any challenge we have three options: We can fight against it, run away from it or embrace it. Many caregiver-marriages suffer the fate of the first two options. Even when love and faith urges us to embrace the challenge, we embark on a very rocky road.

How we respond will determine where we end up. Will we be tired, scared and despondent, or spiritually strengthened and bonded in love; not merely persevering with gritted teeth, but with a sense of purpose and a joy of life, despite.

The crux of this journey is that we must travel it as a team. We cannot fight one another (but invariably we will). Managing our attitudes toward life and toward one another lays the foundation. A team must also be absolutely honest to one another about how they feel, how they experience their situations, their sorrows, their fears and their anxieties. For a team to succeed, it must also be stretched – no "*ag shame*, you poor thing", but rather "let's go for it!". Of course be realistic about one another's limitations, but supplement and encourage rather than say, "We cannot do it because it will be too difficult for you".

A very real issue in a spouse-caregiver situation is the matter of sex. I am not even going to attempt any advice here because it is a veritable minefield where every relationship is unique. However, just an observation. In marriage love, friendship and companionship are far more enduring than "good sex". Especially as we get older and the driving passions start to settle, we tend to realize that a comfortable cuddle is very gratifying as well.

So, if active sex seems to have disappeared off your radar, weigh it up against love and companionship before you make up your mind. (And if you still have a strong urge to behave like a bunny in the bedroom, put yourself on a diet of carrot sticks and celery…)

Lastly, we are all created with the ability to choose. Probably the greatest burden of the caregiver spouse and the greatest fear of the spouse with a disability is the option to simply call it a day and walk away from it all. I cannot tell you what to choose, but I can say that once you choose to commit to one another, put all the other options out of your mind and focus on the life that you chose.

If you feel sorry for yourself, focus away from yourself; focus on the needs of your spouse, your children, family, friends … whatever. This goes for the both of you, not just the caregiver. Focusing outward on the needs of others gives a wider perspective and tends to lift you out of your funk.

So, love one another, talk to one another, take on life with one another and go break a leg! R

Managing caregiver guilt

Non-professional caregivers such as spouses, family members or close friends take on the caregiver role out of necessity and compassion. Usually a full-time caregivers cannot be afforded or the family does not want to sacrifice personal privacy by contracting a live-in stranger. This voluntary commitment is therefore a choice. However, this comes with baggage that underlies the compassion and financial constraints that drove the initial decision to serve as caregiver.

Initially, the associated baggage is contained. As the stresses and strains of long hours, closely intimate care requirements, and the loss of personal time start to take its toll, the baggage start to surface. Your physical inability to do what is required is frustrating and scary. The need to periodically call on friends and neighbours to help when you become truly stuck is embarrassing.

The heartache of daily seeing your loved one reduced to a shell of what they once were is emotionally draining. The pent-up resentment of having to live with the situation at the expense of your me-time starts to bubble over. In times of deep distress, anxiety and depression, you wish your loved one would just die so that all of this would go away and you can live your life again... All of this culminates in guilt, "I am not this person, how could I be so heartless and callous?". When you meet with your support group of other caregivers, the others seem to cope better than you so you also put up a brave front, but inside of you the guilt is gnawing away.

Be assured, you are not alone in this. There are literally tens of thousands people across the globe who are in similar positions, who share your agony and guilt. As proof, visit the website www.caregiver.com, and check out the large array of support articles on this and related topics. I have selected a batch of articles from the website as resource material on the management of caregiver guilt.

FINDING ACCEPTANCE

In "Dealing with caregiver guilt", Malika Brown lists a number of ways to deal with guilt. Three stand out to me:

- "Know that you have made the best decision possible for you and your loved one". You explored your options and, although it is exceptionally tough, it is what it is. If circumstances change, rethink your situation and make a new best decision.
- "Accept that you are human and that you have flaws". We all make mistakes. We have different strengths and weaknesses. Learn from your mistakes, build on your strengths and don't mope about your weaknesses, find ways to deal with it.
- "Deal with unresolved issues or accept them for what they are". Work through issues that bother you with your loved one and with other relevant people. If a workable solution can be found, great. If not, accept it for what it is and work around the issue.

GUILT IS A GUIDE

Dr Vicky Rackner, in her article "Eight tips to managing caregiver guilt", explains: "For caregivers, painful feelings – such as guilt, sadness and anger – are like any other pain. It's your body's way of saying, 'Pay attention'. Just as the pain of a burned finger pulls your hand from the stove, so too guilt guides your actions and optimises your health." If guilt is making you feel miserable, Dr Rackner advises to look into yourself and recognise the guilt for what it is. Once it is recognised and the source identified, you have a new perspective to work with.

If you need "me"-time, find someone to stand in for you and take time out for yourself. If you feel your behaviour is in conflict with your values, change your behaviour. Reinvent yourself to become the "ideal you" by balancing your needs with your commitment to your loved one. She further advises that you should be compassionate with yourself. If you are feeling down, recognise it, but don't let it control your actions. She concludes:

"Understand that you will be a more effective caregiver when you care for [yourself] first. Loved ones neither want nor expect selfless servants. As a caregiver, when you care for yourself, you increase and improve your own caring. Yes, guilt is part of caregiving, but this guilt can help you become the caregiver you and your loved one want you to be."

Remember the airplane safety speeches before take-off, "Place the oxygen mask on your own face before helping others".

COUNT ON YOUR COMMUNITY

Carolyn Schultz takes a more proactive pragmatic approach in her article: "Lessen The Squeeze: Caregiver Coping Skills". She notes how planning ahead can help lessen the chances of guilt setting in. Have an open, honest discussion with your loved one and those who support your commitment to care. Work out a system that will cover your care responsibilities and your normal activities of daily life from work and home to social and me-time. This will help you to take control of your caregiving commitments and your "normal" life. (I find that a "year-plan" tick-list that lists daily, weekly and monthly routines helps to prevent things falling through the cracks. Note that such a plan is a living document that must be updated as needs and routines change.) To help keep your head above water, know your resources including available time, financial affordability, stand-in support, and so on. When planning ahead, do so with due consideration to the availability and constraints of your resources.

CHERISH THE WINS

Recognise and celebrate achievements; your own and those of your loved one. A pat on the back, a congratulatory card, a special treat or even a celebratory get-together lifts spirits and negates guilt and dejection. Be aware that the more you give of yourself, the higher you set the bar of the "expected normal". So set your limits. Never do for your loved one what they can still do for themselves, no matterhow difficult.

FRUSTRATION IS A SIGNAL

In her article "Releasing Resentment", Lisa Hutchinson's opening paragraph cuts to the chase: "Caregivers love to help people. It is a good feeling to comfort and give aid to someone in need. This support can also take its toll. There is a great responsibility, and at times a burden, that is felt in the caregiver role. It is important to find a way to express and channel the frustration that naturally occurs in helping relationships over time."

Lisa explains that venting our anger and frustration is difficult and she proposes a change in mindset. Rather, see your anger and frustration as signals to restore balance to your life. Take a step back from your emotions and look for ways other than venting to release your pent up emotions. Over and above taking time out to spoil yourself and making a point to connect with friends, Lisa adds two vital recommendations: Forgive yourself for the anger, frustration and consequent guilt that built up inside of you and take your negative emotions to God (whatever is appropriate for your religious or spiritual beliefs).

THE VALUE OF NO

Deborah Colgan, in her article "When and How to Say No to Caregiving", admits that saying "No" may seem like a harsh statement to a caregiver who prides herself on being a helpful, kind and loving person. But saying no is not a cop-out. It is setting reasonable limits that you and your loved one agree to in order to make caregiving more sustainable.

Saying no takes into consideration your own (in)abilities and your emotional wellbeing. Healthy emotional boundaries are important in helping you as caregiver distinguish between your own needs and the needs of the person being cared for. Set these boundaries as early as possible. Do not wait for emotions to boil over. Objective boundaries work better than highly emotional ones.

A FINAL WORD

Don't see caregiver guilt as a negative. See it as a warning that something is wrong and needs to be dealt with. Examine your feelings and find the source of your guilt. Discuss it openly with your loved one and seek solutions together. Well-managed guilt will bring progress and sustainability to caregiving. R

Tipping your caregiver

When I stop at my regular shopping centre, the car guards know me. One of them, Eric, will always come to the car and assemble my chair for me, bring it to my car door, help me into my chair and push me into the shopping centre. On my return, he helps me back into my car and stows my chair. For this little service I give Eric five Rand. In the process we have built up a good relationship. He appreciates the tip and, in a way, it motivates him, but it seems the act of service brings him a joy that is a bigger motivator.

In a self-help centre, a few residents got into the habit of tipping their caregivers; not just for little add-on services but also for routine aspects of the caregivers' work and for preferential treatment over the other residents. After a short while, the attitude of the caregivers started to change. They became surly, they often were rude and it happened that some of them even refused to attend the residents in certain routine tasks. What went wrong?

To find an answer, consider research in human behaviour that found there is a large divide between how businesses motivate staff and what research shows actually works. Businesses believe that motivation comes from outside a person (external), and thus reward good performance and punish poor performance, usually with bonuses or increases being awarded or withheld.

However, research has found that this method only works well for tasks with fixed protocols and specified steps. When it comes to heuristic work, creating something new, creating something out of nothing or looking for new ways to do things better, challenges that required innovative thinking, motivation comes largely from within the person. In these persons financial rewards had exactly the opposite effect. It diminished performance.

Research found that making innovation a transaction removed the joy of the challenge. Innovators are more interested in being given the freedom to create, to chase after something larger than themselves than in monetary rewards. As long as their salaries are in line with the nature of their work, bonussing is of little consequence to them.

How does this apply to the changing attitude of caregivers who received tips? Surely, caregiving requires routine tasks with defined protocols? Surely, "bonussing" should have the desired effect? My contention is that tipping changed a labour of love into a financial transaction. Just as innovation is driven by an inner passion, the work of a caregiver requires an inner devotion. It is not something that one can do for a long time just because "the money is good". It requires compassion, a caring attitude, anguish … David Wilkerson said: "All true passion is born out of anguish". A person sees something that is not right (anguish) and develops a passion for making it right.

Tipping destroys all of this. It converts devotion into a financial transaction. The inner passion is replaced by an external motivator. It becomes a means to extort more out of the person on whom the tasks are performed. (Note, not the person who is cared for, but the person on whom the tasks are performed.) It pushes love, compassion and caring into the background and brings scheming and greed to the fore. The passion born from anguish is replaced by calculating manipulation.

So, how do you show your appreciation? The point of departure is that your caregiver's salary should be market-related and the conditions of service must be fair and fully agreed upon with your caregiver. This puts your caregiver's mind at ease and allows them to focus on compassion and the inner anguish that begets their passion for caring. With this in place, create a kitty of contributions. With funds from the kitty, organise periodic events such as an appreciation party or gifts to the caregivers. Such public recognition does far more for morale and job satisfaction than tipping ever will. R

Managing frustration

As persons with a disability, we do become frustrated with our own inabilities. Frustration and pent-up anger are very much part of our lives. The irony is that we vent to those who we love most, those who truly care about us, and those who care for us. If those who truly love us become our carer, this becomes a double whammy. When we take out our frustrations on the ones we love the most (and who love us most), love usually prevails but at what cost?

A lot has been written about "caregivers" who abuse care-recipients, but I recently found a study on the effects of abuse by care-recipients with severe disabilities on close-family caregivers. The study included 147 family-member caregivers of which 129 were women. Just over half were mothers. The rest included husbands, spouses, grandparents, daughters, sisters and aunts. The average age was 56. They were largely well-educated with various racial background. The common factor was that all the caregivers were novices. They found themselves in the deep end of an intensely emotional and physically challenging circumstance with no training and often little or no support. In fact, sources of abuse included the family and friends who they looked to for support.

The study evaluated experiences over 12 months and divided the caregivers into two groups: Those who suffered abuse, and those who experienced more amicable circumstances. In the first group, the extent and intensity of the abuse was measured on a scale and included aspects such as "demanding and bossy", "hateful attitudes" and physical assaults. The findings showed that there were no recorded incidents of the caregivers abusing their family care-recipients and 71 caregivers reported that they were not abused.

Of the 75 caregivers who reported abuse, 45 percent experienced being "yelled at or insulted"; 12 percent received "threats to hit"; and another 12 percent were actually hit. The majority of the perpetrators were care-recipients. Members of the family collectively accounted for the remaining (28 percent) incidents of verbal and physical abuse reported by the caregivers.

For both groups the outcomes were evaluated. Depression was evident in both groups, but more so in the abused group. Both experienced reduced life satisfaction, but this was more evident in the abused group. The abused group also showed greater evidence of increased burden and physical ailments. So, the service of caregiving had a definite impact on all the caregivers in the study and this was exacerbated in the group who suffered abuse. The study implies that a relatively large percentage of family caregivers may experience abuse and that this has an adverse effect on the family caregiver's wellbeing and psychological adjustment. Parallel research suggests that care-recipients may be at risk of abuse when care-recipients require intensive support and/or when caregivers have high levels of depression, ill health, and distress.

So, after all this, what needs to be done? A comprehensive plan, should be developed to better assist family caregivers in their role. This additional support has the potential to ease the stress and burden experienced by family caregivers by effectively providing them an outlet to express their questions and concerns.

By working closely with family caregivers and being attentive to the stressors and issues they face, professional support would help to reduce conflicts and subsequent caregiver health and wellbeing-related problems. With proper health-related and interpersonal training, family caregivers have the potential to help reduce and prevent early or unnecessary entrance into assisted living facilities and could reduce the high costs of formal health care over time.

To those of us who are frustrated with the limitations imposed on us, let's try and work on our frustration and anger issues. R

Quality of life

We all want to live lives that are worthwhile. We like to measure ourselves on how worthwhile we think we are. Our measures of worth tend to include our qualifications, our careers, achievements and our strengths physically, mentally and emotionally. When we look at one another, we tend to compare the other person to ourselves. We often value our own worth by how we compare to others. When we first meet the quadriplegic person that we have to rehabilitate or care for, we say to ourselves, "*Ag shame*, you poor thing…"

Jeff Blackmer from the Canadian Medical Association once spoke on the "Quality of Life – Ethical Considerations". The talk started with how we measure quality of life and what contributes to a person's sense of wellbeing – emotionally, socially and physically. Factors such as our physical abilities, our expectations for our lives, and our own happiness and satisfaction with our ability to realise these expectations were covered.

Then came a study of self-esteem ratings relating to persons with severe spinal cord injuries (SCIs). There were a series of statements on self-esteem that included: "I feel that I am a person of worth"; "I feel I have a number of good qualities"; and "I am satisfied with myself on the whole". There were also statements on negative self-perception that included: "I feel sometimes that I am a failure"; I feel useless at times"; and "I do not have much to feel proud of".

The people who were treating the patients with an SCI were asked to answer these questions about themselves. Then they were asked to answer the same questions on how they believed their SCI patients felt about themselves. Lastly the SCI patients were asked to evaluate themselves on these questions.

The results were fascinating. The persons who were treating the patients with an SCI were very positive and upbeat about their own quality of life, but significantly down scored their SCI patients. When it came to the patient's opinions of themselves, they were equally positive and upbeat about their own quality of life.

They were realistic in that the negative questions tended to score higher, but that did not detract from their overall sense that life was indeed worth living. They felt that it was good to be alive!

What is the message in this for us as caregivers of SCIs and other afflicted persons? Quality of life is not determined by our circumstance, physical abilities and agility, by our intelligence or our talents or our wealth. Quality of life is determined by how we respond to our circumstances.

The world is full of people who have nothing, but are exceedingly happy. There are also a multitude of examples of persons who seem to have it all, yet are unhappy, disgruntled and miserable. If we respond to those we care for in an "*Ag shame*" manner, doing everything for them (even the things they can do for themselves), we will work against their self-esteem and push them down.

There are many stories about winners; people who have "made it" in life. We must recognise that all persons with an SCI who made it through rehab and are now in a position to return to life are already winners. As caregivers, we need to realise that while we are there to care for the physical needs of our SCI wards by helping them to build their self-esteem; by challenging them to actually do for themselves those things that they are able to do; by encouraging them to stretch themselves.

We are by these simple deeds helping our wards to build self-esteem, rediscover meaning and to celebrate the victories of life, however small. We will have helped our wards to become winners and together we with them, will have become winning teams. R

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