

A MONTHLY PUBLICATION OF

## PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's

### MESSAGE

PRESIDENT'S

The phrase "The Lazy Days of Summer" does *not* fit the Parkinson's Resource Organization model. As the annual "season" in the Coachella Valley closes, the team at PRO is gearing *up* for a summer of planning exciting events, making **BIG** changes. It was one year ago when we planned to launch our new website. With the help of The H.N. & Frances C. Berger Foundation grant and our staff—a group of wonderful volunteers and contracted individuals—our NEW website is expected to relaunch July 1. We are also welcoming a variety of **NEW** members into our Wellness Village. **All** in the interest of serving our community better.

The management and creative team at PRO is growing and bursting with inspiration, energy and boundless talent. Again, thanks to The H.N. & Frances C. Berger Foundation grant, the help of supportive staff, a team of techy volunteers and contracted individuals, we are converting our database from an old, non-supported program to cloud-based, customer relationship management software that will help us communicate better and easier with everyone. We'll be asking you to update your contact information with us so we can reach you better and easier.

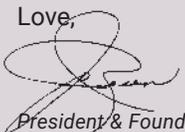
This month's jammed packed newsletter includes **HELP! I'VE FALLEN AND I CAN'T GET UP: RAIZER BY LIFTUP** on this page; **CAMPTOCORMIA: THE BENT SPINE SYNDROME: A Parkinsonism** on page 4; **GLUTATHIONE TREATMENTS FOR PARKINSON'S DISEASE: IS IT EFFECTIVE ENOUGH?** by Kimberly Hubenette, DDS on page 3; **PARKINSON'S DISEASE & INFECTIONS** on page 4; and our **INSPIRATIONAL: THE BUTTERFLY** on page 8.

We are so incredibly grateful for your tax-deductible donations giving us the opportunity to help **MORE** people, **MORE** often, **MORE** timely, with **MORE** information in a **MORE** compassionate way. We are providing valuable information and support in the Parkinson's community. Keep giving, we continue to appreciate your monthly or general donations through our safe PayPal donation page at [ParkinsonsResource.org/contribute-2/](https://www.parkinsonsresource.org/contribute-2/) or by mail to our office in Palm Desert, California.

Communicate with us through Facebook at [facebook.com/parkinsonsresourceorganization/](https://www.facebook.com/parkinsonsresourceorganization/) or on Twitter at [@ParkinsonsPRO](https://twitter.com/ParkinsonsPRO), on Linked-In at [Linkedin.com/in/jorosenpro/](https://www.linkedin.com/in/jorosenpro/) and now on Instagram at [Instagram.com/parkinsonsresourceorg](https://www.instagram.com/parkinsonsresourceorg). There's no reason not to stay in touch with us now. We would love to receive your social media handles so we can be more easily in touch with you as well.

Until next month, REMEMBER, Nat'l Best Friend day on the 8th, Flag Day on the 14th; Father's Day on the 17th, and Summer Solstice on the 21st. The flower is the Rose, and the birthstones are the Alexandrite, Pearl, & Moonstone. ALWAYS remember to CELEBRATE YOU and PRAY FOR OUR TROOPS!

Love,



President &amp; Founder

### HELP! I'VE FALLEN AND I CAN'T GET UP: RAIZER BY LIFTUP

Lifting a person who has "fallen and can't get up" with the use of one's own back and legs is nearly a thing of the past, thanks to a new medical device called the Raizer. A caregiver who was otherwise concerned about hurting him/herself while lifting a fallen person can accomplish the lift much safer for both themselves and the fallen person. A device that seems to be revolutionizing the ease of caregiving is the Raizer which is a simple battery operated mobile lifting chair that helps a fallen person up to an almost standing position within a few minutes. The Raizer can, with ease, be assembled and operated by only one assistant/caregiver and does not require any physical effort besides a supportive hand.

Many caregivers have experienced that the Raizer provides for a better physical and psychological working environment. In general, they state that their physical working posture is better as they use less effort in supporting the person during the lift.



When discussing the Raizer lift, a department manager said: "The caregiver's physical working posture is better. They still have to go to their knees, but it's a completely different working posture". A social and healthcare assistant adds: "It's very positive that you don't have to exert yourself physically. There are merely a few buttons you need to press, and then the Raizer performs almost the entire lift".

A caregiver can feel more in control of the situation. Not only do they feel calmer performing the lift they feel like they have

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# Our Wellness Villagers

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- Dr. David Shirazi

## ANIMAL-ASSISTED THERAPY

- Canine Companions

## AROMA THERAPY

- Renee Gauthier

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- California Phones

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## RAIZER – cont. from page 1

effectuated the lift far more safely and thus more professional. The Raizer puts the patient in the center. It all revolves around them. Consequently, the patient gains a feeling of participation and less like an invalid. They're more empowered to feel at ease when they get to the near standing position allowing them to access their walker, cane or even be seated in their wheelchair. A patient can feel more a part of their fall recovery.

In most cases, Raizer will contribute to reducing the number of lift risks by the caregiver when a patient has had a fall. It makes it possible to lift a fallen person while protecting their head, upper body, legs, etc. and also protecting the back and legs of the caregiving lifter. It reduces the risk of dropping the patient while executing a manual lift.

A person who has fallen and cannot get up again is raised comfortably to a sitting or almost standing position in a way that is safe and comfortable for the patient by supporting the entire body throughout the process. This way of lifting shows consideration for the importance of being helped up in a dignified and safe way.

If they fall, patients find that the Raizer meets their needs for getting up from the floor with a much more humane and dignified process. It's an overall nice experience for them. One patient states: "It was a good and pleasant lift. Quick, and a nice help".

Most patients are being very positive and want to be lifted by the Raizer, should they fall. A patient has stated: "It's one of the

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## GLUTATHIONE TREATMENTS FOR PARKINSON'S DISEASE: IS IT EFFECTIVE ENOUGH?

Kimberly Hubenette, DDS

The loss of Glutathione in the brain of individuals with Parkinson's occurs years before the onset of motor symptoms. Glutathione has been proposed as a neuroprotective therapy in Parkinson's for decades, but the therapy has been limited by the lack of oral availability and the invasiveness of intravenous administration. Recently, a Phase I Study of glutathione nasal spray concluded the therapy is safe and tolerable.

**But, What is Glutathione and What Does it do?** Glutathione is a naturally occurring co-enzyme (antioxidant) that is made in the human body to reduce free radical damage. Free radicals (Oxidative stress) are often the byproduct of normal cellular metabolic oxidation and toxic overload. They can lead to chronic inflammation, which is associated with many disease processes and linked to autoimmune diseases, diabetes, cardiovascular disease, several types of cancer, and even heart attacks. Oxidative Stress is not a disease; every mammal has oxidative stress building up daily. Healthy cells can rid themselves of free radicals with the help of enzymes such as Glutathione.

Glutathione is a combination of three simple building blocks of protein or amino acids—cysteine, glycine, and glutamine—and it is produced naturally in the body. Glutathione is one of the most powerful and effective antioxidants that our body creates. Often it is called "the master antioxidant" because it can regenerate itself in the liver after each fill-up of free radicals and go back to work. Glutathione is also essential for maintaining healthy cellular mitochondria. Along with Superoxide Dismutase (SOD) another master regulator, Glutathione keeps our cells in balance and regulates health inside our body.

Free Radical damage is the largest source of electrons damage in cells. A normal human creates over 32 sextillion free radicals per day. Between the ages of 1 to 20, our bodies are growing and have an abundance of naturally occurring enzymes and growth factors that can keep up with balance and remove toxins before they can damage our cells.

When we age, our bodies slow down the creation of enzymes that break down free radicals in our bodies. When the channels producing Glutathione and SOD are "clogged" up, our body slows down the processes. There is a daily build-up of free radicals. Thus chronic inflammation and disease is the ultimate breakdown of a cell. Glutathione is one of the main antioxidants that slow down the process of cellular damage.

Parkinson's Disease is associated with oxidative stress, and thus, Glutathione treatments have been researched in trials as a treatment of the disease.

As natural health author, Paul Fassa wrote "*Glutathione is critical for one simple reason: It recycles antioxidants. You see, dealing with free radicals is like handing off a hot potato. They get passed around from vitamin C to vitamin E to lipoic acid and then finally to glutathione which cools off the free radicals and recycles other antioxidants. After this happens, the body can "reduce" or regenerate another protective glutathione molecule, and we are back in business.*"

Dr. Richard Cutler, Director of the National Institute of Aging, had this to say about Glutathione, "The amount of antioxidants in your body is directly proportional to how long you will live." And anti-aging specialist and New York Times best-selling author, Dr. Don Colber, put it best when he says: "Optimizing our Glutathione levels is very important if we want to live to be over 100. I would add to this statement by stating extending quality of life if I lived to be over 100."

Although Glutathione treatments are controversial, there are Parkinson's patients that go weekly to get glutathione injections and pills for treatment. Although injections are most effective, they are very dangerous on an ongoing basis. The onset is fast, effective, yet expensive and transient. When taken orally, acidic digestive tract enzymes destroy most of the Glutathione in the pill form. No matter what you pay for Glutathione treatments, research has shown that synthetically made glutathione is not the same as the Glutathione manufactured in our bodies. Finding ways to stimulate cells to produce more

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## PARKINSON'S DISEASE & INFECTIONS

Staff Writer

**URINARY TRACT INFECTIONS (UTIs)** - Be aware when as a caregiver you notice your charge (PWP) has suddenly become lethargic, cognitively impaired, fatigued and can't or won't respond to normal activities of daily living he or she may have a UTI. Get them to their doctor for urinalysis as quickly as possible. More often than not, a PWP does not feel a UTI or bladder infection.

Urinary tract infection (UTI) is a common ailment that involves inflammation of the urinary system. A group prone to developing urinary tract infections is those who have Parkinson's disease, a serious nervous system disorder.

The urinary system consists of the kidneys, ureters, bladder, and urethra. Together, these structures work to remove waste from the circulating blood, convert it to urine and then express it from the body. The kidneys filter the blood for waste products and create urine with the urea, excess water and other impurities they remove. The ureters continuously draw the urine from the kidneys and dump it into the bladder. The bladder stores the urine until it is full and then releases the urine into the urethra. The urethra leads the urine out of the body.

Sometimes, bacteria that are normally present on the skin, in the intestinal tract or the stool spread into the urinary system. The spreading of this bacteria normally occurs through the urethra, the tube through which urine leaves the body. In many cases, your body's immune system will disarm any foreign bacteria. However, when it does not, the bacteria begin to colonize the urethra. As the bacteria reproduce, they travel up the urinary system, infecting the bladder and sometimes the kidneys. As a rule, the higher up the urinary tract that the bacteria travel, the more serious the infection has become.

Parkinson's disease patients are prone to urinary tract infections. When the bladder is full, it alerts the brain through nerve cells, and the brain uses additional nerve cells to tell the muscles to relax and allow the urine to excrete. On the other hand, the patient may be able to urinate but does not have enough muscle control to empty all urine from the bladder completely. Thus, Parkinson's disease patients have a hard time emptying their bladder, creating a breeding ground for bacteria.

There is no cure for Parkinson's disease, and scientists are still unsure of what causes it. However, the disease is typically managed through medication, and the condition causes UTIs. Valient hygiene might help in preventing UTIs. The patient's genitals should be kept clean and dry. After bowel movements, wiping front to back will help prevent bacteria from being spread to the urethra. Many Parkinson's disease patients also use a catheter, which is a tube inserted through the urethra and into the bladder. The catheter allows the bladder to be completely drained and reduces the risk of UTIs.

UTIs are treated with antibiotics. After treatment, it is best to get a laboratory

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## CAMPTOCORMIA: THE BENT SPINE SYNDROME

### A Parkinsonism

For many years camptocormia, designating a forced posture with a forward-bent trunk, has been considered as related to psychiatric manifestations. Times have changed, and it is now well-known that somatic factors can produce this chronic abnormal curvature of the lumbar spine in standing position. Since the early wartime literature many developments have taken place, and it is now possible to establish a more precise etiologic diagnosis.

Camptocormia is an abnormal flexion of the trunk that appears when standing or walking and disappears in the supine position. The origin of the disorder is unknown, but it is usually attributed either to a primary or a secondary paravertebral muscle myopathy or a motor neuron disorder. Camptocormia can also be observed in a minority of patients with parkinsonism.

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**GLUTATHIONE TREATMENTS** – cont. from page 3

naturally occurring Antioxidants and enzymes to breakdown Oxidative Stress is the answer.

Can it be done? The answer is YES.

The naturally occurring antioxidant, Glutathione is generated via a process known as the Nrf2 activation Pathway. This pathway activates our cells to create our Glutathione. Your body is the most effective glutathione-producing machine on earth. By supplying your cells with Nrf2 activation pathway, you can use your body's natural ability to produce Glutathione. What are ways to get our body to create more Glutathione you ask? Well, there are several ways to do this.

Nrf2 activators are not all created equal; some faster and more efficient than others. Some are natural while others synthetic to try to mimic naturally occurring ones. The main goal of a Nrf2 activator is to open channels in our body to create our own molecules to break down free radical damage, antioxidants, anti-inflammatory, anti-aging.

Some Natural occurring Nrf2 activating supplements that help create Glutathione are Selenium and Sulfur. Research has found Icelanders live the longest on earth, eating a diet rich in Selenium and Sulfur, which activates our cells to create more Glutathione.

Another Nrf2 activator, among the scientific world, would agree that the strongest natural activator on the market today is called Protandim. It has several patents, and it claims that the proprietary blend of 5 herbal ingredients has a synergistic quality; the five together surpass multiple times beyond the capabilities of each ingredient on its own. In fact, one study showed Protandim to increase production of Glutathione by as much as 300%. While research keeps getting better and better, I feel there still has to be more clinical trials before Protandim becomes mainstream.

Weekly injections of Glutathione is extremely expensive and dangerous. The effects, Dr. Perlmutter a neurologist that has dedicated his life to this research, has also stated that GLUTATHIONE is one of the body's key antioxidants. But beyond the effect of glutathione serving as a powerful antioxidant, it does a lot of things such as:

- *Glutathione plays an absolutely key and critical role in the liver in a process called Phase II Detoxification, where things that reside in the body that have been modified by what is called Phase I Activity then, through the action of glutathione, are excreted*
- *Glutathione is important for the way the body repairs tissues. Glutathione allows for the regenesis of other antioxidants, like vitamin C and vitamin E. (glutathione makes them more water soluble so they can be excreted more easily). In our very toxic world, having healthy amounts of glutathione in the liver available for the process of detoxification is critically important.*
- *Glutathione allows for the regenesis of other antioxidants, like vitamin C and vitamin E.*

"It is just a remarkable fit of elegance that is impressive in its simplicity, and its effectiveness and clinical efficacy," Dr. Perlmutter said. "Protandim is just in its infancy. There is going to be a global impact of this".

To learn more about Nrf2 Activation of Glutathione go to PubMed.org the National Institute of Health digital database for the leading clinical trial research.

To learn more about Protandim and [Dr. Kimberly Hubenette](#) visit the Wellness Village under [Healthy Products](#). Watch the video, read her bio and visit her website. Dr. Hubenette has been a member of the Wellness Village since July 2017.

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WE INTEND IT TO SERVE AS  
AN INFORMATION GUIDE.

**RAIZER** – cont. from page 2

better lifting aids. Next time I fall I'll ask the caregiver to lift me with the Raizer".

Being lifted by the Raizer makes the patient feel very safe and secure. The great majority of staff and managers in nursing homes or care facilities find that the patients prefer being lifted with the Raizer. A social and healthcare assistant says: "The patient was calm and less defeated. She was positively surprised when she was lifted in such a comfortable and dignified way. She hardly noticed that she had been lifted."

**Technical Details**

The Raizer can be conveniently stored at home or in a car. It comes in two carry bags weighing a total of 28.6 lbs. The bags can be carried using a shoulder strap or as a backpack. The unit can then be assembled around the person who needs assistance. Assembly is easy with color-coded pieces and a loud click that lets you know the pieces have been properly attached. Easy and safe assembly makes the Raizer an ideal lifting aid, not only for professional caregivers but family and friends will also be able to use the Raizer to help their loved ones.

The Raizer is battery operated with the battery unit located in the seat. To fully charge the battery takes approximately six hours. A full battery will provide from 40-100 lifts depending on the load. The total lifting capacity is 330 lbs, and a lift takes between 20-30 seconds to reach a near standing position.

Care and maintenance of the Raizer is simple using a damp cleaning cloth to clean the unit and an alcohol-based disinfectant if necessary. The Raizer has a service life expectancy of five years or more with regular maintenance.

**Overall benefits from using the Raizer**

There is a strong request from both patients, staff members, and facility administration, to use the Raizer. For the patients, the Raizer provides a comfortable and safe lifting situation both at a care facility, or in their own private homes. For the spouses or caregivers in the private homes or in a care facility the Raizer provides an improved work environment with less physical risks during the lift of a patient. Lastly, facility administration benefits from improved efficiency and safety as the Raizer support decreases staff injuries, more effectiveness, and less sick days.

*For more information about Raizer by Liftup, visit them in the Wellness Village under Mobility Products. Watch their video and visit their website or give them a call. Raizer by Liftup has been a Wellness Village member since April 2018.*

**INFECTIONS** – cont. from page 4

re-evaluation to make certain the infection is COMPLETELY gone.

Taking an antibiotic isn't the only way to get over symptoms of a urinary tract infection.

Some remedies don't require a prescription, and they can be done right at home in addition to any treatment your doctor has recommended.

But it's important to be cautious with do-it-yourself home solutions, and be sure to check in with your doctor before trying a new strategy on your own.

The following viable home remedies—from drinking lots of water to applying heat and wearing loose cotton clothing—may ease your agonizing UTI symptoms or prevent them in the first place.

1. **Get Your Fill of Water** – One of the first things to do when you have a urinary tract infection is drink plenty of water. That's because drinking water can help flush away the bacteria that's causing your infection, according to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). It puts you on the right track for recovery.

Most people can be assured they're getting the water they need by simply drinking water when thirsty, according to the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine. General recommendations have suggested that women get about 91 ounces of water daily and men get about 125 ounces each day, including water from food, as also noted in that group's report.

2. **Load Up on Vitamin C for a Healthy Urinary Tract** – Getting plenty of foods high in vitamin C is important because large amounts of vitamin C make urine more acidic. This inhibits the growth of bacteria in your urinary tract, according to Johns Hopkins Medicine's health library. If you have an active UTI, taking vitamin C supplements may help, too, advises Kandis Rivers, MD, a urologist in the Henry Ford Health System in West Bloomfield, Michigan.

3. **Soothe UTI Pain With Heat** – It is rare that a person with Parkinson's FEELS their UTI; however, if they do, Inflammation and irritation from UTIs can cause burning, pressure, and pain around your pubic area. Applying a heating pad can help soothe the area. Keep the heat setting low, don't apply it directly to the skin, and limit your use to 15 minutes at a time to avoid burns.

4. **Cut Bladder Irritants From Your Diet** – When you have a UTI, caffeine, alcohol, spicy food, nicotine, carbonated drinks, and artificial sweeteners can irritate your bladder further, making it harder for your body to heal. Focus on healthy foods, like high-fiber carbohydrates (such as oatmeal or lentil soup), that are good for your digestive health.

5. **Go Ahead, Empty Your Bladder Again** – Every time you empty your bladder—even if it's just a small amount—you rid it of some of the bacteria causing the infection. Keep making those bathroom runs, advises Rivers.

*cont. on next page*

**INFECTIONS** – cont. from previous page

6. Consider Herbal Remedies – You may find some relief from taking the herb uva ursi (bearberry leaf), which is sometimes used as an herbal remedy for lower urinary tract infections. But caution, it should be taken only for short periods of time—five days or less—as it could cause liver damage. Also, the herb goldenseal may be used as a remedy for UTIs, according to the National Center for Complementary and Integrative Health.

It's important to note that even though these herbs may help some, there have been no large randomized controlled trials (the gold standard when it comes to proving the effectiveness of a drug or treatment in medicine) testing either of these remedies for this purpose.

And always be sure to check with your doctor before taking goldenseal or other supplements. Supplements, herbs, and other medications you might be taking can cause side effects or may interact with one another. The effects can sometimes be serious.

7. Change to Healthier Habits – Lifestyle changes matter because they can help you recover from a UTI and might prevent another infection.

Wear loose cotton clothing and underwear.

Wipe yourself clean from front to back.

Choose only fragrance-free personal hygiene products.

**Cranberry Juice and UTIs** – For years, unsweetened cranberry juice was thought to help flush away bacteria and keep them from sticking to the bladder wall, possibly helping to prevent or reduce recurrent UTIs. But a review of 14 studies published in December 2013 in American Family Physician showed that cranberry juice might not have real benefits.

While more studies may clear up this issue, for now, cranberry juice is no longer recommended as a UTI fighter.

**SEPSIS** – Many chronic or progressive diseases, such as Parkinson's disease, put you at risk for developing infections. The diseases themselves aren't fatal, but their effects can be. For example, as Parkinson's disease progresses, it can become increasingly difficult for you to swallow food and drink without choking. You may aspirate the food or drink, which means it goes into the lungs instead of your stomach. When you aspirate, you can develop pneumonia, an infection that can trigger sepsis.

People with movement disorders like Parkinson's disease are at risk of falling and their skin being cut or scraped. These injuries can become infected. Falls can also cause fractures, such as a broken hip. If a fracture breaks through the skin (an open fracture) or needs surgery for the bone to be set, again, there is the chance of infection.

When you have a chronic or progressive illness, being admitted to a healthcare facility, a hospital or rehabilitation facility, isn't unusual. This puts you at risk for developing healthcare-acquired infections (HAIs), most frequently, infections such as MRSA and C. difficile.

Sometimes incorrectly called blood poisoning, sepsis is the body's often deadly response to infection. Sepsis kills and disables millions and requires early suspicion and treatment for survival.

Sepsis and septic shock can result from an infection anywhere in the body, such as pneumonia, influenza, or urinary tract infections. Worldwide, one-third of people who develop sepsis die. Many who do survive are left with life-changing effects, such as post-traumatic stress disorder (PTSD), chronic pain and fatigue, organ dysfunction (organs don't work properly) and/or amputations.

There are many ways someone with a chronic or progressive can develop an infection, so it's important always to be aware of the possibility and to watch for the signs and symptoms of sepsis. Quick recognition and treatment is the key to survival.

**CAMPTOCORMIA** – cont. from page 4

Patients with parkinsonism and camptocormia (excluding patients with multiple system atrophy) prospectively underwent a multidisciplinary clinical (neurological, neuropsychological, psychological, rheumatological) and neurophysiological (electromyogram, ocular movement recording) examination and were compared with age-matched patients with Parkinson's disease without camptocormia.

The camptocormia developed after 8.5 years of parkinsonism, responded poorly to levodopa treatment (20%) and displayed features consistent with axial dystonia. Patients with camptocormia were characterized by prominent levodopa-unresponsive axial symptoms (ie, axial rigidity, gait disorder, and postural instability), along with a tendency for greater error in the antisaccade paradigm. (The anti-saccade (AS) task is a gross estimation of injury or dysfunction of the frontal lobe.

Neurologic disorders affecting both the frontal cortex or the basal ganglia have shown impaired performance on the anti-saccade task. These include schizophrenia, Huntington's disease, Parkinson's disease, and progressive supranuclear palsy. Additionally, disseminated brain disease such as Alzheimer's disease or AIDS dementia also have an increased number of errors. We suggest that (1) the salient features of parkinsonism observed in patients with camptocormia are likely to represent a specific form of Parkinson's disease and camptocormia is an axial dystonia and (2) both camptocormia and parkinsonism in these patients might result from additional, non-dopaminergic neuronal dysfunction in the basal ganglia.

Camptocormia is characterized by an abnormal flexion of the trunk appearing in standing position, increasing while walking and abating in the supine position. The term camptocormia is sometimes referred to as "bent spine syndrome" (BSS). The abnormal curvature must be a lumbar kyphosis. An anterior flexion of 45° or more is required to differentiate BSS from the kyphosis starting from the dorsal spine, frequently observed in elderly individuals.

