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From the desk of the President



Greetings on the occasion of World Spinal Cord Injury Day. The Executive Committee decided to launch the first Newsletter of Spinal Cord Society on this very important Day and I am very happy that the Editorial Board of Spinal Cord Society led by Prof Sanjay Wadhwa and ably supported by Dr Dinesh Suman have not only edited and compiled a very good newsletter with content contributed by members but also got it designed very well. Compliments & Congratulations.

We are all aware that Spinal cord injury (SCI) has devastating physical, psychosocial and economic consequences. Even today it is recognised as *“one of the most devastating ailments that can afflict mankind.”* However, with advances in management and proper comprehensive management, persons with SCI can get back to a normal lifestyle.

There also are innumerable examples of individuals who have not only overcome the challenge using the power of the mind, their special abilities and staying positive, but also come out stronger and more successful achieving great goals. They are great examples of what can be achieved by tapping the *“Power of the Mind”* and are role models who continue to inspire and motivate not only persons with disabilities but able bodied as well. They help prove *“Where there is a will, there is a way”*.

Such wheelchair achievers also make the able bodied believe that there is an ability within each individual to overcome any challenge using the power of the mind and staying positive. It is possible to not only overcome the challenge, but also to tap any opportunity which helps one to come out stronger and more successful. They strengthen the conviction *“Anything can be achieved with the Power of the Mind”*.

On World Spinal Cord Injury Day, let's join hands to create awareness not only on prevention and management of spinal cord injuries but also to take a cue from the wheelchair achievers and start believing in their abilities and the power of the mind.



Dr Harvinder Singh Chhabra

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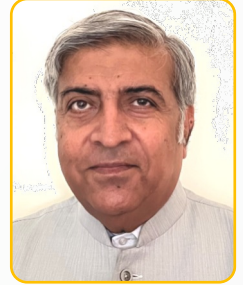
Editorial

Improving Access to SCI Services: Strengthening Rehabilitation

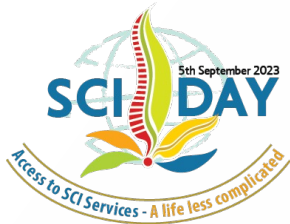
Greetings on behalf of the Spinal Cord Society from the desk of Editor-in-Chief!

September is an important month for SCI individuals and SCI management. In many parts of the world, it is observed as Spinal Cord Injury Awareness Month.

International days are powerful tools to promote public awareness and to activate authorities on certain issues of concern. In 2016, the International Spinal Cord Society (ISCoS), under the Presidentship of Prof JJ Wyndaele decided to observe 'Spinal Cord Injury Day' on 5th September every year. Each year it is celebrated with different slogans and theme that highlight the most current issues of concern for SCI individuals. This year's theme is very important, "**Access to SCI services; a life less complicated**".



For eight years in a row, the world Spinal Cord Injury Day has been celebrated worldwide on 5th September.



Access to spinal cord injury (SCI) services is critical for individuals with SCI and their families. However, access to these services can be complicated due to various factors, such as lack of available resources, geographic location, financial constraints, and a lack of knowledge about the services available. This can lead to a life that is unnecessarily complicated, adding more challenges to an already difficult situation.

Working towards improving access to SCI services involves advocating for increased funding and support for SCI services, promoting awareness about the services available, and working to remove any barriers that prevent individuals from accessing these vital services. By focusing on this year's theme, we can make significant strides towards ensuring that individuals with SCI have access to the resources they need to achieve optimal recovery and live a fulfilling life. (Source: <https://www.iscos.org.uk/sci-day>)

It has been recognised world over that an important barrier in improvement of quality of life of persons with SCI is lack of or limited access to SCI services. If this issue is addressed satisfactorily and on priority, life of persons with SCI will become less complicated.

This inaugural issue of the Spinal Cord Society Newsletter is brought to coincide with and commemorate the important occasion of the World SCI Day 2023!

There is another important fact worth recalling and appreciating. It was 101 days ago when on 27 May 2023 the World Health Assembly endorsed the historic resolution on **strengthening rehabilitation in health systems**. The resolution calls for expanding and integrating rehabilitation into health systems as part of Universal Health Coverage (UHC), emphasizing the importance of rehabilitation in primary care and as part of emergency preparedness and response. The resolution expresses deep concern that rehabilitation needs are largely unmet globally, particularly in Low- and Mid-income countries which includes India. The resolution sends a clear message that urgent action is required to address the lack of access to quality rehabilitation services, an important point which is also included as part of this year's SCI Day theme!

This SCS Newsletter contains useful information on a variety of topics. In this issue you will be taken down the memory lane by Dr Dinesh Suman, a very eminent and experienced Urologist, Director Neuro-Urology at ISIC New Delhi. It is a humble beginning by Spinal Cord Society, and we hope to grow with your active support and participation. Through this SCS Newsletter, we hope to interact with you, inform you, update you, and involve you at regular intervals during the coming months and years.

Please read it, enjoy it, share it among your friends, peers, fellows, professional and contribute information to enrich it. Your suggestions are important and always welcome. You can also reach us by simply sending a mail at contact@scs-india.org

Enjoy reading this inaugural issue!

Dr Sanjay Wadhwa

Editor-in-Chief, Spinal Cord Society



My Journey with Spinal Cord Society (SCS) ...a perspective by Dr. Dinesh Suman

"I am talking about 1999 when I first visited the Indian Spinal Injuries Centre, which I saw incidentally on my way, and curiosity led me inside. The building was still under renovation, and admissions for the patients had yet to begin, but still, there was an aura of its own. When I was interviewed by Major HPS Ahluwalia, the visionary founder whose endeavors started the revolution of modern state-of-the-art spine surgery and rehabilitation in India, Air Marshal Chahal, who was the first spine surgeon of India and later devoted his life to furthering the cause, it was a moment whose excitement and awe still thrive in my heart. They welcomed me to join immediately, and hardly did I know that it would become the devotion of my life. The more I learned with them, the more empathy, concern, and appreciation for the hitherto neglected needs of the urological and sexual health of SCI became evident to me. After my MCh, I knew so little about Neurourology and spinal cord injury, but with time, my patients and their needs became my teacher, and I studied hard to gain requisite awareness. I still carry the burden of faith Major Ahluwalia and Air Marshal imposed on my young shoulders. I imbibed not only the knowledge required to treat my patients but more - the spirit of service and the vision to expand the modern state-of-the-art service to the hitherto neglected SCI brethren across the country. I continue to remain in awe of the legends for their vision, perseverance, and dedication to the service of spinal cord injury persons.

I am talking about the times when the term 'spine surgeon' had not yet taken root. It was the orthopedic surgeons and the neurosurgeons, who would do a few spine surgeries in addition to the rest of the routine orthopedics procedures too. Gradually as they evolved, they focused on spine ailments only, and slowly SPINE SURGERY became a niche. From the early days when only the posterior approach and Harrington rod fixation surgery were done, it gradually evolved into anterior, posterior, and combined approaches, the use of implants, prostheses, minimally invasive, endoscopic, and subsequently Robotic and O-arm guided spine surgeries. Soon, we had state-of-the-art SPINE UNITS and dedicated SPINE SURGEONS spread across the country. Today, we are proud to say that in such a short span of time, spine surgery has reached such a pinnacle that we are second to none in the world.

As young surgeons, Dr. Sunil Katoch, Dr. HS Chhabra, and I conceived the concept of having some form of association or society of people

interested in spine care. So, we thought of having a spinal cord society. Can you imagine? It was so difficult those days to have members from each region across India and multiple states to actually make an All-India society. So first, it was conceived as a local society. I contacted an acquaintance and drafted the memorandum and articles of association and went to the Registrar's office in Kashmiri Gate to get it registered. I still remember the warm sense of appreciation from Major Ahluwalia and Air Marshal Chahal when we presented the society registration to them. It was our dream to unite spine services and create a network so that every SCI person could be served well. Slowly the efforts gained momentum, and its educational and awareness activities became the tool to spread the good work of ISIC across the country. ISSICON attracted the great legendary spine surgeons, rehabilitationists, psychologists, nurses, and other professionals from across the world and became the catalyzing tool for the development of spine services as we see them today.

However, we all have failed to deal with the consequences of spinal cord injury in the aftermath of successful spine surgery. We certainly have done well to excel in surgical techniques but have failed to imbibe the essence of care that Donald Munroe emphasized in the 1930s: that the surgeons have to be not just the surgeons but also complete rehabilitationists for the well-being of their patients. It was his philosophy that for the first time saw a deadly 'ailment not to be treated' becoming manageable and people could survive SCI. Ludwig Guttmann demonstrated the same comprehensive care principle to the world when he took up the roles of surgeon, physiotherapist, nurse, psychologist, and just about everything to his patients and brought a ray of hope in the lives of SCI persons. John Young revolutionized Comprehensive Care as a MODEL system of SCI care that serves as the pinnacle of SCI care.

In India, hardly 2% of the SCI persons have access to proper rehabilitation care, and over 90% of patients continue to be neglected for their urological, sexual, fertility, pressure sore care, psychological concerns, and other assistive technological and advanced treatment options. The efforts of individual doctors and institutions continue to remain scattered and fragmented. Given the longevity of SCI persons, we can expect to have more than a million SCI patients across our vast country and imagine just over 35 rehabilitation centers to cater to their needs with barely a few dedicated neuro-urologists, rehabilitation specialists and the psychologists etc. working with the SCI persons.

It's high time that every spine unit owns up to its comprehensive responsibilities towards the SCI person, going beyond the surgery. Until there is cohesive multi-professional teamwork, the quality of life of the SCI persons will not improve much.

Contd...



Surgery is not the end of the treatment; rather, it's the beginning of a new life full of its struggles, adaptation, learning, and finding newer meanings and ways of living. We have waited for 20 years, and little has changed since then.

We hope that SCS shall catalyze the transformation urgently and strongly among all its members and coordinate with fellow spine surgeons as part of ASSI so that we in India may formulate a cohesive comprehensive model care-like system in the true service of the SCI persons.

With the emergence of technology, the concept of outreach has become so much simpler. The aspects of counseling, education, and training can largely be imparted through online tools, where patients may have free and easy access from the comforts of their home.

Similarly, telehealth, including remote consultations, may make the lives of SCI persons less complicated. The development of easily available good quality wheelchairs and their modified versions may make the lives of SCI persons much more convenient.

Communication with patients about creating awareness of the latest technological and medical breakthroughs may allow even more patients to approach for advanced care to improve their health and QOL.

ISIC has launched an ambitious campaign to "Eradicate the neglected neurogenic bladder among the persons with SCI by 2030", utilizing a multipronged approach. Support and adoption of such timed campaigns by the SCS may allow an energetic thrust to our combined efforts in realizing the vision and ambition of accessible and affordable comprehensive state-of-the-art care for every SCI person across the country.

When this is seen to have happened, we would feel our dream of having a Spinal Cord Society was worth having. However, a long painful journey still lies ahead..."

Dr Dinesh Suman

Director, Neuro-Urology
and SCI Andrologist

Indian Spinal Injuries Centre, New Delhi



Depression and Gut Health

SCI is a major trauma, psychologically and physically to the patient, for the patient the fight has to be at both fronts. The psychological impact of depression has a wide spectrum of symptoms of depressed mood, loss of appetite, fatigue, insomnia, poor quality of socio-cultural life.

Currently, it is appreciated that depression is linked to Gut dysregulation: therefore, to fix up depression one has to fix up gut. Rather, a generic statement can be given too that the gut is the root cause of all epigenetic illnesses. Conventionally, depression is treated in modern medicine by anti-depressants, preferably by SSRI's which have their own drawbacks and side effects.

The Gut's nervous system, called as the Enteric nervous system is the second brain of the body. Most of the body's serotonin is found within the Gastro-intestinal tract and is produced primarily by diet (the Amino acid Tryptophan is the precursor), exercise, Vit D in gut cells and positive emotional state. This metabolism occurs in the specialized cells of the gut, the Enterochromaffin cells. The microbiomes, around 10,000 species inhabit our gut, contributing towards our health if their ecosystem is not disturbed.

To maintain the healthy bilateral communication of brain and gut through neural, neuroendocrine and neuroimmuno pathways, a set of Do's and Don't's have to be followed, the correct Lifestyle suggestions.

The practical tips are:

- 1) Follow the circadian rhythm of the body i.e., dinner, preferably before sunset. The metabolism of the body slows down thereafter and only milk or something very light, if need be, should be taken.
- 2) The body absorbs undigested food also, hence, eat only when one is hungry so that the gastric juices are secreted optimally. The appetite simulants are lemon soaked ginger pieces before a meal. The facilitators of digestion are 'ajwain' seeds, fennel seeds and ginger powder.
- 3) Avoid food stuffs having synthetic corn syrup (sauces, ice-creams, curd etc.) as they lead to fatty liver.
- 4) There is a list of incompatible food combinations e.g. Milk-banana (it is heavy on the digestive system), Honey cooked items (heated honey becomes toxic) etc. which are mentioned in Ayurveda.
- 5) Millets are gluten free and far healthier than wheat (its gluten is the cause of coeliac disease)
- 6) Best oils are traditional indian oils, mustard, sesame, peanut).

The list is long...

The message is while treating/avoiding depression pay attention to gut health by diet, lifestyle changes and de-stressing The mind relaxes exponentially if focussed on a single thought e.g. on breath, listening to beats in the music, Pranayam etc.

Dr Neera Vyas

Asstt. Director

Central Council for Research in Ayurvedic Sciences
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Empowering Lives: The Vital Role of Early Bladder Rehabilitation and Sexual Health Counseling for Spinal Cord Injured Individuals

Introduction:

When it comes to spinal cord injuries (SCI), the journey to recovery and well-being is a multifaceted one. In this path, two critical components stand out – the early institution of bladder rehabilitation and comprehensive sexual health counseling. These aspects not only contribute to preventing serious urological complications but also play a profound role in enhancing an individual's quality of life (QOL) post-SCI.

Bladder Rehabilitation: A Preventive Approach:

The impact of spinal cord injury on the bladder function cannot be understated. Neurogenic bladder, a common consequence, can lead to severe complications such as urinary tract infections, kidney damage, and even life-threatening sepsis if left unaddressed. However, there is hope – **the practice of early bladder rehabilitation**. This approach involves a holistic strategy encompassing education, counseling, training, and consistent follow-up with urology teams. It also mandates that **all high-volume spine units must include a comprehensive rehabilitation program and a urologist as an essential part of their team** to provide optimal long term care to the spinal cord injury persons.

Education and Counseling:

Empowerment through knowledge is paramount. **Early education about bladder function changes, appropriate hygiene practices, and potential complications sets the foundation for proactive management**. Counseling sessions provide individuals with a safe space to discuss concerns, fears, and questions related to their bladder health.

Training and Follow-up:

Bladder rehabilitation includes training individuals in **proper hygienic catheterization techniques, bladder emptying schedules**, and maintaining a bladder diary. **Consistent follow-up with urology** teams ensures that any emerging issues are promptly addressed, preventing the escalation of problems. Untreated urinary problems have historically been responsible for recurrent morbidity and even causing the risk of death in sizeable number of untreated patients. Thus, **prevention and early prompt diagnosis and management** is the key to good health in spinal cord injury persons.

Sexual Health Counseling: Nurturing Emotional and Physical Well-being

The impact of spinal cord injury extends beyond the physical realm, affecting emotional and psychological aspects as well. It's crucial to recognize that sexual health is an integral part of a person's identity and well-being.

Early sexual health counseling after SCI can make an incredible difference in an individual's journey towards acceptance, adaptation, and renewed intimacy.

Unfortunately, in India these concerns remain grossly neglected due to lack of physician's training and awareness and other social, cultural and religious reasons.

Sensitize all persons, men and women in sexually active age group about their sexual and fertility potential and educate and provide them with the varied scientific options available today to mitigate these concerns. We believe that in the coming times most spine care centres would include an experienced urologist in their team to timely deal these concerns and add great value to the patient's overall Quality of life.

Psychological Adjustment:

Sexual health counseling addresses psychological and emotional challenges that may arise post-SCI. This includes body image concerns, self-esteem issues, and anxiety related to sexual activity. Through counseling, individuals can gain a more positive perspective on their bodies and their ability to experience pleasure and intimacy.

Adaptive Strategies:

Sexual health counseling introduces adaptive strategies, techniques, and assistive devices that enable individuals to explore and engage in fulfilling sexual experiences. Open communication with partners about desires, fears, and boundaries is emphasized, nurturing a deeper emotional connection.

Improved Quality of Life:

Addressing sexual health concerns enhances overall QOL. Intimacy is a vital component of human relationships, and acknowledging and catering to these needs leads to greater emotional well-being and satisfaction in life.

Conclusion:

In the journey toward recovery after a spinal cord injury, early institution of bladder rehabilitation and sexual health counseling stand as pillars of empowerment.

By proactively addressing urological challenges through education, training, and follow-up, individuals can prevent severe complications that might adversely affect their health and well-being. Moreover, embracing sexual health counseling fosters emotional resilience, adaptive strategies, and improved relationships.

Both these interventions not only extend life but also enhance its quality – reminding us that healing encompasses both the physical and emotional dimensions of the human experience.

Dr Dinesh Suman, MCh

Director, Neuro-Urology and SCI Andrologist
Indian Spinal Injuries Centre, New Delhi

◀◀ Right to Healthcare for Persons with Disabilities ▶▶

Persons with disabilities have the right to access medical insurance coverage like any other individual. The Rights of Persons with Disabilities Act, 2016 recognizes the right to health of persons with disabilities and mandates the provision of necessary healthcare services, including insurance coverage. However, this right was being denied to India's over 2.7 crore citizens until recently.

Only on instruction of the Delhi High Court in December 2022 did the IRDAI issue orders on February 27, 2023, asking private insurers to design instruments for the disabled.

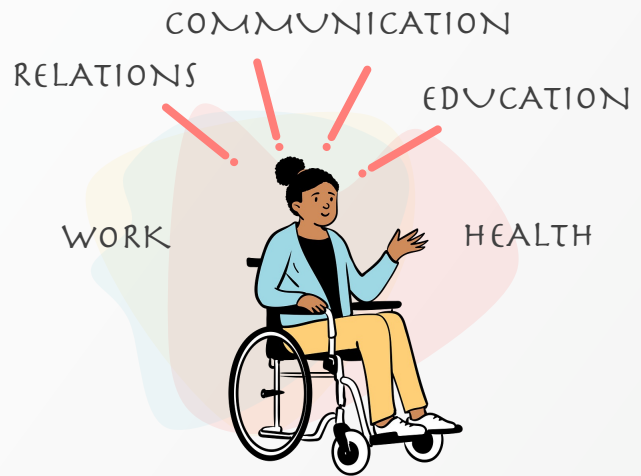
“In the light of the above provisions incorporated in the respective Acts, and with the objective of making available an appropriate product offering health insurance cover for certain vulnerable sections of society, like persons with disabilities (PWD), persons afflicted with HIV/AIDS, and those with mental illness, all general and health insurers shall offer a specific cover for persons with disabilities (PWD), persons afflicted with HIV/AIDS, and those with mental illness”.



This Delhi High Court order came after a person with spinal cord injury filed a writ petition in the Delhi High Court. The IRDAI asked all insurers to design a product which will cater to all the basic recommendations of people with disabilities for them to be inclusive in the health insurance cover of disabled people. Few insurance companies have now launched products for PwD's but policies under this category remain capped at 5 lakhs cover only. This is a miniscule amount for medical insurance cover in today's age. The annual premiums are also exorbitantly high and do not justify the cover provided.

Many countries like the Philippines, Germany, Ireland, Japan, France and many more have health policies for disabled people. In the Philippines, PhilHealth, automatically covers all disabled people under the National Health Insurance Program (NHIP) of the Philippines Insurance Corporation (PhilHealth).

A start has been made but there is still a long way to go for persons with disability to get their rightful necessary healthcare services including insurance coverage.



Shishir Bhatnagar

Peer Mentor with The Spinal Foundation
Disability rights advocate and DEIB awareness

An Important Event Held Recently

A Brief Report on 4th Annual Summit of SPINE20 - Dr Sanjay Wadhwa

Traditionally, the World Health Organization (WHO) has focused on the mortality of communicable diseases; however, in 2018 the WHO acknowledged the impact of NCDs and called for action through **rehabilitation 2030**.

SPINE20 is an advocacy group founded in 2019 by EUROSPINE, the North American Spine Society, the German Spine Society, and the Saudi Spine Society, to improve spine care and prevention on a global level. In 2020, two new partner societies joined SPINE20, the Italian Spine Society and the Association of Spine Surgeons of India. SPINE20 decided to develop evidence-based policy recommendations for the G20 countries and the global community to alleviate the burden of spine disease, disability, and injuries.

SPINE20 was registered in 2020 under the C20 official engagement groups of G20 (<https://civil-20.org/>). The C20 is a platform of Civil Society Organizations around the world bringing forth political dialogue with the G20. At present, 33 societies from across the globe are partner societies of Spine20.

The inaugural meeting of SPINE20 took place in Riyadh, Saudi Arabia on 10 and 11 November 2020. The 2nd Annual SPINE20 was held in Rome, Italy on 16 to 18 September 2021. The 3rd Annual SPINE20 Summit was held in Bali, Indonesia on 4 and 5 August 2022, and the most recent 4th Annual SPINE20 Summit has been held at New Delhi, India on 10 and 11 August 2023. Each time the Annual SPINE20 Summit has been held just prior to the G20 meetings. Association of Spine Surgeons of India (ASSI), one of the partner societies, was the host of Spine20 2023. Dr HS Chhabra served as the Chairman of this Summit. Shri Amitabh Kant, the G20 Sherpa also addressed the 4th Annual SPINE20 Summit.



An Important Announcement



International Spinal & Spine Injuries Conference (ISSICoN), the Annual Conference of Spinal Cord Society, has always been a right platform for knowledge sharing and attracts interdisciplinary participation from across the globe.

This year ISSICON 2023 will be organized by K M Patel Institute of Physiotherapy, Bhaikaka University, Karamsad, Anand, Gujarat at Dr Kurien Auditorium, National Dairy Development Board (NDDDB), Anand, Gujarat from 1st -3rd December 2023.

The scientific content of this conference would be a right mix of keynote talks, live lectures/presentations, workshops, instructional courses, case based discussions and posters. There will be special focus on and rewards for the best research and innovations.

scs-issicon.org

Glimpses of Wheelchair Rallies on World SCI Day organized since 2016 with Involvement of SCS at India Gate, Delhi - Compilation & Collage by Dr Sanjay Wadhwa

