

INDIAN SPINAL INJURIES CENTRE

THE POWER OF THE MIND

VOL:2

NEURO-UROLOGY Magazine

Eradicate "Neglected Neurogenic Bladder" by 2030 Campaign
Caring for your Urinary Bladder and sexual health

A portrait of Major H.P.S. Ahluwalia, a man with a white beard and a white turban, wearing a dark blue suit and a dark blue tie. He is seated and smiling slightly. A gold watch is visible on his left wrist. The background is a plain, light-colored wall.

Major H.P.S. Ahluwalia

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20 POINTERS TO REDUCE RISK OF INJURY DURING INTERMITTENT CATHETERIZATION (CIC)

Reducing the risk of traumatic intermittent catheterization is crucial for maintaining urological health.

1. Use the Right Catheter: Ensure you are using a catheter that is the correct size and type recommended by your healthcare provider. Normally a 12/14F catheter should be good for an adult. People with narrow urethra and younger children may use 8/10F catheter.

2. CLEAN / No touch Technique: Maintain strict hygienic technique during CIC to prevent infections.

3. Proper Lubrication: Use a water-soluble lubricant on the catheter and instill lubricant in the urethra in men to reduce friction during insertion. Inadequate lubrication is most important cause of friction injury, pain, bleeding and subsequent urethral stricture formation.

4. Adequate Relaxation: Relax your pelvic muscles before attempting catheterization to reduce resistance and trauma. Take slow deep breath and learn to relax while inserting the catheter.

5. Gentle Insertion: Insert the catheter slowly and steadily, avoiding force or excessive pressure.

6. Pause for Resistance: If you encounter resistance, pause, breathe deeply, and attempt to gently advance the catheter again.

7. No Sudden Movements: Avoid sudden or jerky movements during catheterization to prevent injury. Slow and steady gentle onward insertion of the catheter.

8. Position Matters: Ensure you are sitting or lying in a comfortable and stable position for the procedure. A reclining position in men straightens the urethra for easy insertion. Aim the catheter slightly upward during insertion to follow the natural curve of the urethra especially in women. Adopt a convenient position to avoid urethral angulation.

9. Regular Catheter Inspection: Check the catheter for any kinks, bends, or irregularities before use.

10. Use a Mirror: If necessary, use a mirror or catheterization aid to assist with visualizing the insertion point of urethral meatus, especially in obese men and women.

11. Monitor Catheter Length: Be mindful of the catheter's length to prevent over-insertion, which can cause trauma. Excessive coiling of catheter can cause friction injury to opposing wall of the bladder and may cause pain and bleeding.

12. Maintain Hydration: Stay adequately hydrated to ensure a healthy urinary flow and reduce the risk of complications. Ensure 200-400ml of urine drained at each CIC. If bladder is over-distended it can cause high pressure injury. Major purpose of CIC is to timely empty the bladder to maintain low pressure storage.

13. Avoid Contaminants: Be vigilant about maintaining a clean environment and preventing contamination from stool or other sources. Keep catheter and lubricant jelly in safe clean place to avoid contamination. Wash hands thoroughly and cleans genitalia to prevent infections.

14. Regular Follow-Up: Keep regular appointment to monitor your urological health and catheterization technique. For patients at high risk, 3-6 monthly close urological supervision is required. For other patients who are at Low risk, 6 months to a yearly followup may suffice. Don't stop the prescribed treatment and CIC without your urologist's guidance. Stay in touch for an unforeseen problem encountered in between.

15. Know the Signs: Educate yourself about signs of urinary tract infections (UTIs) and other potential complications, and seek prompt medical attention if they occur. Don't rush for urine tests and take unnecessary antibiotics on slightest pretext unless prescribed by your doctor. Remember that the evaluation and management is required only in symptomatic UTI.

16. Good Hygiene: Maintain proper personal hygiene to minimize the risk of infection.

17. DISPOSABLE CATHETERS : use disposable catheter for CIC, as one time use, or change them frequently if they show signs of looking dirty or wear and tear.

18. Avoid Rush or hurry: Take your time during catheterization to reduce the likelihood of errors or trauma.

19. Psychological Support: Seek emotional support or counseling if you experience anxiety or stress related to CIC, as stress can impact your ability to relax and perform the procedure safely.

20. Remember, it's essential to work closely with your urologist and trained nurses to develop a safe and effective catheterization routine tailored to your specific needs and circumstances.

They can provide personalized guidance and monitor your progress to minimize the risk of trauma and complications.

What spine surgeons and spine units should NOT do..

In order to provide multidisciplinary comprehensive long term care and to safeguard the health and Quality of Life of their SCI patients. Spine units may develop broader focus and better compliance with following issues at hand.

Never Neglect the need for comprehensive Rehabilitation:

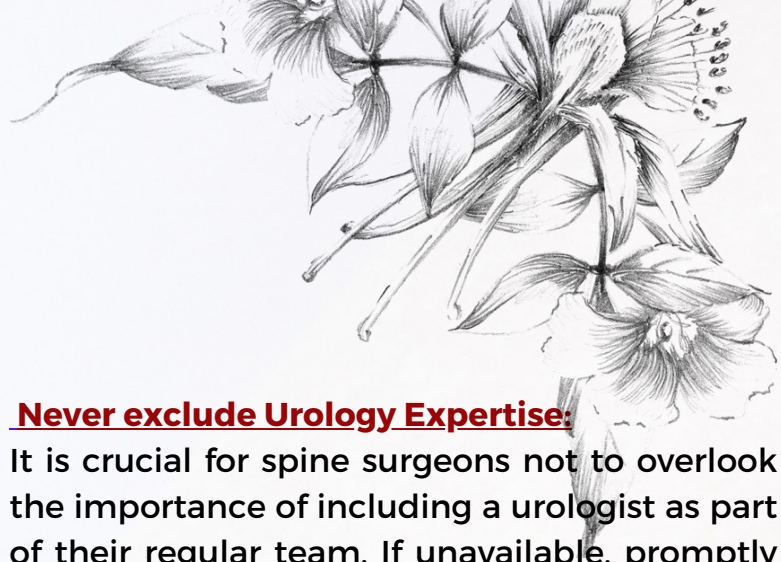
Spine surgeons should not neglect the importance of rehabilitation in the recovery process. Merely performing a successful surgery is not sufficient; they must actively encourage the role of proper and scientific rehabilitation in achieving functional improvement for the patient.

Never Overlook Multi-system

Dysfunctions: Surgeons should not overlook or downplay the possibility of urinary, bowel, and sexual dysfunctions that patients may experience after spine surgery. Instead, they must take the responsibility to educate patients about these potential issues and ensure appropriate evaluation and management by experienced urologists through proper referrals.

Never try to treat Bladder Problems all by

yourself: Spine surgeons should never attempt to personally treat bladder problems related to neurogenic dysfunction after SCI. Recognizing the specialized nature of care required, they should always refer patients to designated urologists, who can provide guidance for the life-long follow-up to prevent serious complications.



Never exclude Urology Expertise:

It is crucial for spine surgeons not to overlook the importance of including a urologist as part of their regular team. If unavailable, promptly refer patients to an appropriate urology center with expertise in SCI management from the outset. urological care begins from day one and continues life long.

Never Underestimate the role of Continence Nurses:

Spine surgeons should not underestimate the critical role of continence nurses in bladder, bowel, and sexual evaluation and management. Instead, they should ensure that nurses in their team receive specialized training to guide, educate, and train patients effectively.

Never Neglect SCI patient's need for long term Follow-Up

Urological Care: Surgeons should never neglect the importance of early evaluation and regular long-term follow-up for neurogenic bladder dysfunction after spinal cord injury. Implementing a reminder system through SMS, mail, or call-back is essential to organize follow-up consultations effectively, and telemedicine can be an effective tool to facilitate communication

Never Neglect SCI patient's Sexual Health:

Sexual and fertility health should not be grossly ignored in the treatment plan. Spine surgeons must prioritize referring SCI patients to appropriate specialized centers and Urologists for proper guidance, evaluation, and management, as sexual rehabilitation can significantly benefit the patient's self-esteem and overall well-being.

10 WAYS TO MANAGE URINARY LEAKS THAT OCCURS DESPITE DOING TIMELY INTERMITTENT CATH

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1. **Review your Catheterization Technique:** Consult your urologist or Urology nurse to ensure that you are using the correct catheterization technique and following the appropriate schedule. Some people delay CIC or keep it on demand. Some people may miss out night time CIC. Its important to adhere to defined schedule. Remember, its not just about urine leakage, its about the bladder pressure and saftey of urinary tract.
2. **Optimize Catheter Size:** Confirm that you are using the correct catheter size and type. Too small a catheter may leave bladder un-emptied. residual urine and debris may cause incomplete emptying and worsen urine leakages.
3. **Bladder Emptying Assessment:** Get an ultrasound to assess residual urine after your attempted catheterization. People with larger median lobe and bladder diverticulum or high grade reflux may fail to empty the bladder and retain urine despite CIC.
4. **Assess your Bladder Capacity:** Work with your healthcare team to determine if your bladder capacity is sufficient for your catheterization timings. You may need to adjust the timing or the frequency of CIC accordingly. A smaller capacity bladder may need more frequent CIC alongwith anticholinergics to manage it well.
5. **Pelvic Floor Exercises:** If you can, Engage in pelvic floor muscle exercises (Kegel exercises) to strengthen the muscles that control urination. sometimes you may need biofeedback devices and neurostimulation to exercise your pelvic floor muscles. Weak pelvic floor muscles can worsen stress relatd urinary leaks in all SCI patients.

10 WAYS TO MANAGE URINARY LEAKS THAT OCCURS DESPITE DOING TIMELY INTERMITTENT CATH

6. **Use Incontinence Products:** Wear absorbent pads, adult diapers, or specialized incontinence products to manage leaks discreetly. Some people may leak a small amount of urine occasionally which can be easily managed with the use of these accessories and one can maintain a confident socially active life without any embarrassment. Try different products and choose what serve your needs well.

7. **Medication:** In some cases, anticholinergics alone or in combination can help manage urinary leaks by reducing bladder spasms or increasing bladder capacity. Discuss this option with your Doctor. Newer anticholinergics and Mirabegron alone or in combination are highly effective. Use of Intravesical Botulinum is also useful in refractory cases.

8. **Adjust Fluid Intake:** Modify your fluid intake to reduce the frequency of urine production while still maintaining adequate hydration. Avoid excessive fluids close to bedtime. Watch out for tea, coffee and aerated drinks as they promote more urine output. Avoid consumption of large volumes of fluid at a time, rather spread your fluid intake over the wake hours for controlled urine output. Learn to keep watch over how much fluids you take in and how much urine you pass generally. Excess fluids intake and untimely CIC is the commonest cause of leakages in our country.

9. **Lifestyle Modifications:** Identify triggers for leaks, such as caffeine or certain activities such as pushing at exercise or lying prone, and make necessary lifestyle adjustments. It requires education and awareness of aggravating factors so that patients may adjust their life style accordingly.

10. **Consult a Urology Specialist:** If urinary leaks persist despite trying various management strategies, consult a urologist for a thorough evaluation and customized treatment. Discuss advanced neurostimulation techniques for added help.

It's crucial to work closely with your urologist to address urinary leaks effectively. They can provide tailored guidance, recommend appropriate treatments, and monitor your progress to improve your quality of life and overall bladder health.

Healing through Hope & Joy



10 WAYS TO SUSPECT IF YOU HAVE SYMPTOMATIC URINARY INFECTION OR NOT

Suspecting a urinary tract infection (UTI) is important so you can seek prompt medical attention and treatment if necessary.

Some common ways to help you suspect if you might have a symptomatic urinary infection:

1. **Frequent Urination**: If you suddenly need to urinate more often or need to do CIC more than usual, it could be a sign of a UTI.
2. **Urgency**: A strong, sudden urge to urinate or frequent leaks of urine that is difficult to control is a common UTI symptom.
3. **Burning Sensation**: A burning or painful sensation during urination or at CIC is a classic symptom of a UTI.
4. **Cloudy or Bloody Urine**: If your urine appears cloudy, bloody, or has a strong, foul odor, it may indicate an infection.
5. **Discomfort or Pressure**: Pain, discomfort, or pressure in the lower abdomen or pelvic region or the flanks can be indicative of a UTI.
6. **Lower Back Pain**: Some UTIs can cause lower back pain or discomfort in the kidney area.
7. **Fever or Chills**: If you develop high grade fever or experience chills along with urinary symptoms, it may be a significant, requiring prompt treatment.

8. **Fatigue**: Feeling unusually tired or fatigued can be a sign of an infection, particularly in young children and elderly frail persons, as your body is working hard to fight it off.

9. **Urine Odor**: A strong, unpleasant odor or clody turbid urine from your urine may suggest a UTI.

10. **Change in Mental State**: In older adults, a UTI can sometimes cause confusion or changes in mental clarity. Altered sensorium or deliriousness should not be ignored as it could be the first sign of sepsis in elderly and poor immune cases.

It's important to note that UTI symptoms can vary from person to person, and not everyone will experience all of these symptoms.

If you suspect you have a UTI or are experiencing any combination of these symptoms, it's crucial to contact a healthcare provider for proper diagnosis and treatment.

Left untreated, UTIs can lead to more severe complications, so early intervention is essential. Your healthcare provider can perform a urine test to confirm the presence of an infection and prescribe antibiotics or other appropriate treatments.



10 WAYS TO FIND OUT IF YOUR BLADDER AND URINARY TRACT ARE AT HIGH RISK FOR SUBSEQUENT DETERIORATION

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Identifying whether your bladder and urinary tract are at a high risk for subsequent deterioration is crucial for timely intervention and management.

1. **Medical History:** If you've had diabetes, previous urinary tract issues, bladder infections, or surgeries related to your urinary system.
2. **High Spinal Cord Injury:** High-cord injuries such as dorsal and cervical injuries often carry a higher risk of urinary complications.
3. **Neurological Symptoms:** Pay attention to any new or worsening neurological symptoms, such as increased spasticity, muscle weakness, or changes in sensation, which can indicate potential urinary tract issues or unbalanced bladder.
4. **Frequent UTIs:** If you experience recurrent urinary tract infections (UTIs), it may be a sign of underlying bladder and lower urinary tract dysfunction that require further evaluation.
5. **Incomplete bladder Emptying:** If you frequently feel that your bladder isn't emptying completely or you have to catheterize more often to achieve full bladder emptying, it could indicate reduced bladder capacity or compliance.
6. **Changes in Urinary Patterns:** Monitor changes in your urinary patterns, such as increased frequency, urgency, incontinence, or difficulty starting and stopping urine flow. Unusually high or low volume, frequent leaks, fever, blood in urine, pain in abdomen and flanks may indicate the risk of urinary complications.

7. **Pain or Discomfort:** Note any pain or discomfort in your lower abdomen, pelvis, or lower back, which may indicate urinary tract issues.

8. **Urine Leakage:** If you experience frequent and bothersome urinary leakage despite following proper catheterization techniques and regular medication, it could be a sign of unbalanced bladder and merits attention.

9. **Blood in Urine:** The presence of blood in your urine (hematuria) may signal an underlying issue in the urinary tract that requires investigation.

10. **Failure to regularly follow up with urologist:** Failure to regularly consult a urologist for evaluations of your urinary system, with the aim to preserve and prevent urinary complications by multimodal approaches leads to unexpected complications.

Early detection and management of potential urinary tract issues are essential for preventing further deterioration and complications. If you suspect any problems or experience changes in your urinary function, it's crucial to consult with a Urologist who can provide a thorough evaluation and a tailored plan for maintaining your bladder and urinary tract health.

NEGLECTED ASPECTS OF UROLOGICAL AND SEXUAL AND FERTILITY HEALTH IN SPINAL CORD INJURED PERSONS IN INDIA

Urological, sexual, and fertility healthcare remain neglected in over 90% of spinal cord injured patients in India,

NEGLECTED ASPECTS include :

1. Lack of Accessibility to Specialized Care: Majority of SCI population in India may not have easy access to such specialists. Its inherent duty of every spine unit to ensure proper referral to appropriate Urologist.

2. Lack of Reproductive Health Education: Providing education and information about reproductive health, family planning, and fertility preservation options for individuals with spinal cord injuries remains grossly neglected. Excellent outcome can be achieved in majority of SCI persons with apt and timely treatment/

3. Lack of Affordable Assistive Devices: Access to affordable assistive devices, such as catheters, erectile dysfunction aids, and fertility-related equipment, is crucial for improving quality of life. Get in touch with your urologist for safe use of appropriate devices for optimal functioning.

4. Lack of Psychosocial Support: Mental health and emotional well-being should be addressed, as the psychological impact of spinal cord injuries on sexual and reproductive health can be significant. Its advisable for every spine unit to have a psychologist. Cognitive and emotional changes need to be monitored on an on-going basis for a good quality life.

5. Lack of Rehabilitation Programs:

Comprehensive rehabilitation programs should include sexual health counseling and fertility assessment, focusing on improving overall quality of life.

6. Lack of Holistic Care: Treating urological and sexual health issues should be part of a holistic approach that takes into account the patient's overall well-being, including physical, emotional, and social aspects.

7. Lack of Female-Specific Concerns: The unique urological and sexual health issues faced by women with SCI need greater attention and specialized care. Besides concerns about menstruation, sexual activity, vaginal lubrication, and safe sex measures and avoidance of pregnancy and contraceptive issues need to be explained. In SCI patients with pregnancy the care and cautions during pregnancy need be highlighted.

8. Lack of Sexual Function Rehabilitation:

Rehabilitation programs should emphasize sexual function recovery and provide access to therapies, such as pelvic floor exercises and sensory training.

Addressing these neglected aspects of urological, sexual, and fertility healthcare in spinal cord injured patients in India requires collaboration among healthcare professionals, policymakers, and patient advocacy groups to ensure that comprehensive and patient-centered care is provided to individuals with spinal cord injuries.



THE POWER OF THE MIND

THE INDIAN SPINAL INJURIES CENTRE , VASANT KUNJ, NEW DELHI

SCI patients urological education and awareness program:

Educating patients with spinal cord injuries (SCI) to actively participate in their urological self-care program is crucial for their overall well-being and quality of life. Strategies to help patients become actively involved in their urological self-care and seek reliable information:

Building a Strong Patient-Provider Relationship:

- We value the trust and rapport with the patient. We make them feel comfortable while discussing their urological and personal concerns.
- We lay stress on open communication between the patient and healthcare team allowing patients to be free from undue stress and anxiety.

Education and Information:

- We provide basic information about their specific SCI-related urological issues and explain the potential risks and complications.
- We offer educational materials such as brochures, videos, or pamphlets that are easy to understand and are easily accessible.

Individualized Care Plan:

- We devise a personalized urological care plan tailored to the each patient's specific needs, level of injury, and medical history.
- We Clearly outline the steps, responsibilities, and goals of the care plan and share with the patients.

Demonstration of self care Techniques:

- We hold demonstrations of how to perform essential self-care tasks related to their urological needs, include catheterization, bladder emptying, or bowel management.
- We Encourage the patients and care givers to ask questions and take notes during demonstrations.

Encourage Independence:

We empower the patient to take an active role in their care. We train them to perform urological self-care tasks independently whenever possible.

Regular Follow-Up:

- We schedule regular follow-up appointments to assess the patient's progress, address concerns, and make any necessary adjustments to the care plan.
- We Keep the lines of communication open to monitor changes in the patient's condition.

Peer Support and Counseling:

We connect patients with SCI to peer support groups or counseling services. Hearing from others who have experienced similar challenges can be encouraging and informative.

Access to Reliable Resources:

- We provide patients with trusted sources of information, such as reputable medical websites, organizations dedicated to SCI care, and patient education materials.

Continual Learning:

- We encourage patients to stay informed about the latest advancements in SCI care and urological management by attending workshops, or webinars.
- We promote the importance of lifelong learning and adaptation to changing needs.

Family and Caregiver Involvement:

- We educate family members and caregivers about the patient's urological care needs. Ensure they understand their roles and responsibilities.
- We encourage a collaborative approach to support the patient's care.