

# Meningomyelocele (MMC) or Spina Bifida

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## Symptoms of Meningomyelocele (MMC) or Spina Bifida in children

- Defect of spine formation.
- Visible bulge, dimple or tuft hair on the back.
- Deformation of the spine or limbs.
- Weakness in the limbs.
- Lack of control on bladder and bowels.
- A continuous leakage of urine or stools.
- Frequent urinary tract infections leading to high fever.
- Lack of sensations in the limbs leading to frequent injuries.
- Learning and speech difficulty

## What is Meningomyelocele (MMC) or Spina Bifida?

- MMC is a serious congenital spine development defect that affects a large number of children.
- This unrecognized health scourge affects around 4 children of every 1000 live deliveries, which is a very large number of patients.
- With a massive population, India sees a significantly number of children born with MMC.
- The ill effects of MMC continue from birth through the patient’s life to affect their health in several serious ways. As the child grows, the symptoms may change.

- MMC patients require regular monitoring, treatment and management of their symptoms for extended period.
- These children need specialist care to function independently and integrate with the society.
- Often the MMC patients come from an underprivileged background and the required treatment is beyond their reach.
- Due to a variety of socio-economic reasons, the ratio of MMC in India is several times higher than the global average.
- MMC is easily preventable with adequate nutrition during the gestation period, pre-natal scans, specialist monitoring and pregnancy management.
- Ultrasound scans can detect a spinal defect. However, medical termination of pregnancy is possible only in the early part of the gestation, due to India's medico-legal norms.
- Awareness for MMC is not common knowledge, even with healthcare professionals.
- Scanty information is available about MMC and its practical treatment in the public domain.

### **Effects of MMC**

- Meningomyelocele (MMC) or Spina Bifida is a congenital (birth) defect where the baby's spine does not form correctly resulting in a defect in the bony arch that protects the spinal cord and its coverings.
- The spinal gap exposes part of the spinal cord and its protective membranes. The damage to the spinal cord often resulting in paralysis of the lower limbs and developmental difficulties. Other symptoms vary, depending on the location of the spinal gap.
- While the focus is mainly on the spinal cord, MMC affects the function of the urinary bladder and subsequently the kidneys, resulting in serious health complications.
- As MMC patients reach puberty, they need sexual counselling as well as social rehabilitation.
- Usually, MMC is evident as a large bulge over the lower back of the neonate at birth. This becomes a surgical emergency and needs early closure of the exposed neural tissue and its coverings.
- In some cases, the spinal defect is not obvious at birth but may present on the skin above the spinal defect as a tuft of hair, a birthmark or a dimple. As they attain puberty and have a growth spurt, these affected children start showing symptoms like incontinence of urine and/or stools, clawing or arching of feet and wasting of the muscles of the lower limbs.

### **Effect of MMC on Urinary Tract and the Kidneys**

- While the public focus of MMC is on orthopaedic and neurological treatment, the damage to the spinal cord also affects the urinary bladder and the kidneys.
- The damage to the critically important kidneys leads to severe health complications in the patient.
- The damage to the kidney starts as soon as the infant is born, hence quick urological assessment and treatment is essential.

### **About Spine and Child Centre (SCC)**

Spine and Child Centre [SCC] is a specialized medical facility for treatment and management of Meningomyelocele (MMC) or Spina Bifida in infants, children and young adults.

Located at Pune in Maharashtra, SCC uniquely offers all the expertise and equipment needed to mitigate the effects of MMC, under one roof and one management.

- Despite the large number of MMC patients, India lacks dedicated medical facilities to deal with this disorder.
- The MMC patient requires care and counselling in a variety of medical disciplines. Typically, the patients lack adequate information, qualified guidance and means to the required treatment.
- SCC is an attempt by experienced and qualified team of doctors to integrate all the MMC treatment and management skills with facilities under one roof.

## **Objectives of SCC**

### **Education**

MMC is easily preventable with focusses pre-natal care, diagnostics and nutrition. Education, awareness and training will help in removing the scourge of MMC from India.

- Education of citizens and healthcare professionals on prevention.
- Identification of MMC and its immediate management.
- Seeking help and support for long term treatment and management.
- Online library of MMC related information for patients and healthcare professional.
- A public outreach program through print, radio, television and social media to make MMC an easily recognized word in the society.

### **Facilities**

- A well-organized facility with efficient workflow to accept, identify, treat and advise MMC patients.
- Comprehensive laboratory and investigations.
- Surgeries and other therapies.
- For those located away from Pune, remote counseling and telemedicine to patients and healthcare professionals.

### **Treatment Verticals**

- Spinal and neurological (nervous system).
- Orthopedic (bones) treatment.
- Urology (urinary tract), nephrology (kidneys) and andrological (sexual and reproductive) treatment.

### **Typical Patient Workflow**

- Pre-visit counseling
- Registration on arrival
- Diagnostic tests
- Evaluation by specialists
- Treatment
- Rehabilitation and training

### **List of specialists and their roles**

- Urologists
- Neurosurgeons
- Neurophysicians

- Orthopaedic Surgeons
- Psychiatrists
- Sexual Counsellors
- Physiotherapists

### **Leadership**

SCC is led by Dr. Shirish Yande, who is one of the leading Urologists from Pune, India. With over 40 years of intensive practice in India and abroad, he has handled thousands of cases covering a wide area of expertise. He is the Chief Urologist at Ruby Hall Clinic and the Director at Institute of Urodynamics in Ratna Hospital, both in Pune.

### **Dr. Yande's expertise**

- Surgery of the Kidney and the Bladder
- Kidney Transplantation
- Urodynamics
- Bladder Dysfunctions
- Male Sexual Dysfunction
- Teaching and training of Urology students at undergraduate and postgraduate levels
- Organising Medical Conferences, Teaching Sessions and other Academics activities for Pune as well as for the Zonal and National Urology Societies.

### **Why is a Urologist heading the treatment of MMC?**

During his long career Dr. Shirish Yande regularly sees patients with urological issues resulting from MMC. The patients visit Dr. Yande after having met other medical professionals who are not able to solve the myriad visible and invisible problems caused by MMC.

As an experienced and well-connected surgeon, Dr. Yande is aware about the lack of specialized care for MMC patients. His expertise in Functional Urology would be invaluable to treat the less obvious connection between MMC, urinary tract and the kidneys. He aims to help the MMC patients, especially from the underprivileged section of the society who have no access to the specialized treatment.