Diastematomyelia

Patient Information Series – What you should know, what you should ask.

What is the diastematomyelia?

Diastematomyelia is a complete or partial clefting (a longitudinal split) of the spinal cord that is divided into two hemi-cords.

How does diastematomyelia happen?

The spinal cord and the intradorsal nerve roots are split into two columns. This mass may be a bony, fibrous or cartilaginous septum that subdivides partially or completely the vertebral canal. The cleft may be found at any level, but in most cases is found at the lower thoracic or upper lumbar regions. Thoracic region is the one that runs from the base of the neck down to the abdomen and the lumbar region is the lower part of the back.

Diastematomyelia acts as a restraint that slows the normal growth of the spinal cord by impeding the upward migration of the neural elements, with progressive neurologic deficits (abnormal function) in the limbs.

Should I have more tests done?

The tests available depend on where you are. Tests to ask about include an amniocentesis to look for problems of the number of chromosomes and some genetic underlying conditions. When an amniocentesis is done, a needle is inserted in your abdomen to collect some fluid from around the baby and test it.

Because diastematomyelia has been described in association with other various anomalies (such as open spina bifida, scoliosis, kyphosis, hemivertebrae, cutaneous manifestations and orthopedic deformities of the feet, especially clubfoot), you should also ask for a detailed ultrasound examination.

What are the things to watch for during the pregnancy?

What you should know is that the outcome is usually favourable, but neurosurgical and orthopaedic surgery may be necessary, and there is a chance of neurologic compromise.

What does it mean for my baby after it is born?

When diastematomyelia presents as a closed neural tube defect, the prognosis for neurological function may be enhanced by early surgical removal of the septum, so it is important to refer to an orthopaedic center to plan the correct timing of the surgery.

Will it happen again?

The risk of recurrence is unknown. Autosomal dominant transmission has been described in rare cases so a genetic counselling is recommended.

What other questions should I ask?

- Is diastematomyelia isolated or associated with other anomalies?
- Is spina bifida present?
- Is it possible to terminate the pregnancy?
- How often will I have ultrasound examinations done?
- Is surgery after pregnancy available?
- Where and how should I deliver?
- Where will the baby receive the best care after delivery?
- Can I meet in advance the team of doctors that will be looking after my baby following delivery?

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