

Patient Journey Spina Bifida



Note: Might be detected in the womb at an ultrasound control, defect on the spine or an unnatural big head.

Note: Patient will be at the hospital/clinic/specialist center for 4-7 days so it is possible to do all the exams!









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... at birth at 16-19 wks of pregnancy ...

... diagnosis straight after birth ...

... from birth to departure from life. First time when the baby is born. After that needs a checkup every year ...

1. & 2. Pre-Diagnosis & 1st Symptom

The child is born with Spina Bifida which is showed as a malformation on the back. Information about Spina Bifida from HCP and a visit from another parent with a child with SBH after approx 4 weeks after birth. Depending on how the parents are coping.

Note: The parents can choose about proceeding with the pregnancy, surgery in the Ideally:

womb or leave it as it is and wait until hirth!

Ideally:

The parents feel their being well taken care of, having faith in the doctors. Being well informed on why and what to do next

2. Diagnosis

IF the malformation is low down on the spine = less damage

If the malformation is high up on the spine = more damage Measure the head to look for hydrocefalus

3. First Treatment

Surgery straight after birth within 24 hours.

Close up the back

If the patient has hydrocefalus.

Put in a shunt in the

5. Follow-Up Care

Peadiatric Nurologist as Clinical Lead and Urologist and/or Urotherapeut, Orthopedic,
Neurosurgeon and Radiologist

lly:

The parents have a patient responsible doctor who has all the information on the child and who is listening to parents concerns

Note:

Urologist/urosergeon – checks up the kidney, bladder and bowl movement. If there are any problems a discussion is needed for surgery.

Urotherapist – examine bladder control and bowl movement. Teach how to do clean intermittent catheterization with is very important to be able to do yourself.

Orthopedic – checks for defects on feet's, knees, hips, scoliosis, kufosis, etc. If needed – consult with an orthopedic technician or surgery.

Neurosurgeon – Hydrocefalus, Arnold chiari syndrom, tethered cord which can do a lot of damage like lost of feel, pain and so on. If problems there is a need of surgery

The Neurologist – is the patient responsible doctor who checks out the rest like epilepsy, eyes pressure, cognition, ability to swallow and eat, weight (to big /to small) etc and writes referrals to specialists in the area for further treatment.



