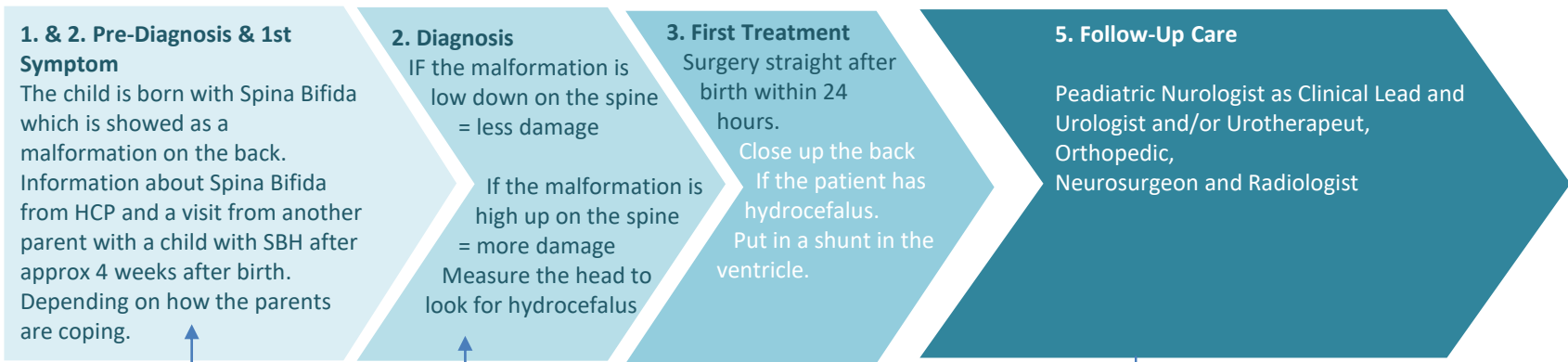


Note: Might be detected in the womb at an ultrasound control, defect on the spine or an unnatural big head.

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



... at 16-19 wks of pregnancy at birth diagnosis straight after birth from birth to departure from life. First time when the baby is born. After that needs a checkup every year ...



Note: The parents can choose about proceeding with the pregnancy, surgery in the womb or leave it as it is and wait until birth!

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

Ideally: 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 – Hydrocephalus, 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.

This patient journey has been completed following a methodology developed by EURORDIS. EURORDIS cannot be held responsible for any use which may be made of the information contained herein.