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... Diagnosis ...

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First Symptom ...

## 1. First Symptom

During pregnancy, on echo: Bladder Exstrophy can be diagnosed before birth on echo, but is also missed often. Although no patient has the exactly the same severity of this condition and the variations can be hugely differ between persons, there can be made a distinction of 3 different types of Bladder Exstrophy – **Epispadias, Classical Bladder Exstrophy** and **Cloacal Exstrophy**.

**Note:** For (expecting) parents, need diagnosed and redirect in order to receive proper information about bladder exstrophy. Thorough information about the condition of Bladder Exstrophy and the impact on health and life is needed in order to prepare parents and give them realistic outlooks for the future of their child. People can be overwhelmed and have difficulty to assess this condition and the future expectation (e.g. they might think it is comparable to Down syndrome / Spina Bifida or other severe conditions, which might impact their choice to have a termination of the pregnancy.

## 2. Diagnosis

Bladder Exstrophy: During pregnancy, on echo: Bladder exstrophy can be diagnosed before birth on echo, but is also missed often.

When born: Bladder is open and is partly visible laying inside-out on outside of abdomen. Genitals are often open and gender is sometimes not easy to define by sight only.

**Note:** For parents: Parents need to be directed to medical centres and clinicians specialized in treating BE Patients. They also need to get clarity and answers to their questions and emotional / practical and psychological support. Parents need to be directed to a patient Bladder Exstrophy society / organization(s) for support, knowledge and connect to people with personal experience.

**Ideal:** Parents are directed to medical centres and clinicians specialized in this condition and a good diagnosis and treatment plan should be made available.

## 3. Treatment

Open bladder and abdominal wall; Genitals can be 'different looking'; Incontinence – difficulty controlling. Severity differs per patient.

**Note:** Patients will need extensive treatment and several surgical operations in order to solve the main issues. In a step by step process.

**Ideal:** Bladder inside the abdomen and abdominal wall closed. Although incontinence exists it is now only from the neo-urethra. Genitals are taken care of and reconstructed as far as possible in this age and stage.

## 4. Surgery

Main steps: Closing bladder, (bowels/rectum) and abdominal wall (0-1 years old). Solve incontinence problems (3-16 years or older) (bladder exstrophy). Functional and aesthetical reconstruction of genitals and abdominal wall. Fertility support and special treatments if needed.

**Note:** Baby has surgery straight after birth or some time in a later period shortly birth in the first year of life. More hospitals now recommend to not do surgery straight after birth, for better bonding of the newly born baby with the mother. Genitals function as normal as possible. Possibly aesthetic reconstructions later in life. Incontinence can be solved in different ways, depending on personal situation and personal choice of the patient. Reconstruction of genitals (possibilities vary and can be very complex. So far only possible at very few medical centers across Europe). Fertility is taken into account during all treatments. **Ideal:** Patient is informed about all options to solve main issues. Abdominal wall and bladder are closed. Genitals are reconstructed, both functional and aesthetic as much as possible.

## 5. Quality of Life

Regular checks and/or when health or mental / social problems arise such as: Incontinence problems; problems with infections; reflux, or other urine passage problem; Calcifications or Problems with scar tissue / inguinal hernia; Problems with permanent stoma; or any problems with social development / mental health.)

**Note:** Clinical monitoring and support  
Psychological support; Regular checks for stones, abnormalities etc.; Medicine (in case of infections); Medical support materials updates (diapers, catheters or other relevant materials etc.)  
**Ideal:** Regular clinical monitoring and support by specialised clinicians  
Psychological support by specialised psychologists; Regular checks for stones, abnormalities etc.; Medicine (in case of infections); Proactive medical material updates (diapers, catheters or other relevant materials etc.) by Nurse Specialists.