



ERN eUROGEN Common Needs



ERN EUROGEN Patient Journeys Completed

Completed Patient Journeys for the following ERN EUROGEN rare diseases:

1. Bladder Exstrophy
2. Interstitial cystitis
3. Anorectal malformations
4. Penile Cancer (under development)

Anorectal Malformation



Bladder Exstrophy



Penile Cancer

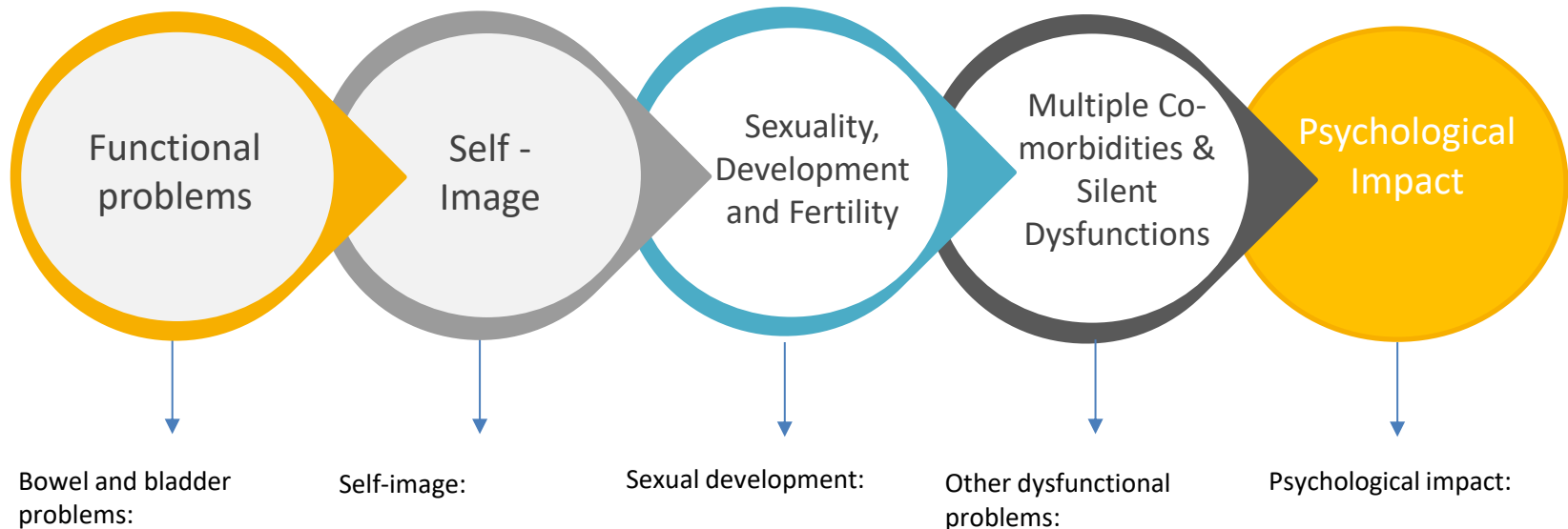


Interstitial Cystitis



Common Needs Rare & Complex Urogenital Anorectal Conditions

Surgical correction is the key for many rare and complex uro-genital- anorectal malformation however it is only one aspect, care needs to go beyond the surgery and be a holistic, life-long approach to optimise childhood development, confidence and independence.



Diagnosis – Common needs

Accurate and timely diagnosis can be difficult to secure. Can be give during pregnancy, immediately at birth or later in life.

Following diagnosis, referral to the right specialty and centre is essential.

Parents can be overloaded with information and are faced with many difficult questions.

Step-by-step, proactive information given on treatment options is essential including on surgery options and psychological support.

Diagnostic information including time of diagnostic examinations should be given to the parents – who to call and what to expect in the first 6 months.

Directing parents and family to a patient organisation can be a huge support.

In other syndromes that are diagnosis later in life with chronic and degenerative disease (such as interstitial cystitis), women can see many doctors and can be ill-treated before securing the right diagnosis, causing significant distress.

Surgery – Common needs

Corrective surgery - closing of the bladder or correcting the malformation.

Information on possibility of reconstruction surgery.

Proactive bowel and continence management is essential from day one.

Parent education on self-care for the child including skin care .

Information and advice on managing the incontinence or soiling, including management of colostomy or catheterization.

Follow up care plan with contact details for support, e.g. specialized nurse and case manager for support.

For some conditions, there is no surgical intervention and standard treatments do not take away the problem nor the pain.

Ongoing Treatment – Common needs

After surgery, optimising bladder and bowel management from the word go is essential!

For example, following reversal and closure of the stoma that is when problems with the bowels can start.

Functional and aesthetic problems need to be proactively managed and individual given long-long support.

Treatment should be under an expert centers and by a multi-disciplinary team.

Families should be given a 'road map' or care plan so they know what to expect and when.

Advice on who/speciality to see when needed as an adult/older person when potential further problems may develop.

Communication – Common needs

Good communication and expectation management.

Clinicians should use support tools, trigger questions, written information (like individual transition protocols) to aid effective, person-centred communication.

Important to have good communication with local services and coordination and timeline for care (including with primary care services and for teachers and schools).

Self-image and emotional well-being – Common needs

All affected individuals want to have a normal life and good expectations on management and life choices.

Bladder and bowel disorders touch on the most intimate parts of the body. So much impacts on image...

Individuals need to know how to cope with the pain which can trigger depression. Despite 'flare-ups' of pain, there are ways to maintain a good quality of life and sex-life.

Clinicians should ask trigger questions including about body-image and social and sexual problems

Patient organisations can help parents navigate the challenges in how to talk about the disorder and help it be normalised. Help is being able to phase and ask questions ... 'can I have sex? And how when communicating. This helps confidences of the person.

Life-long Follow Up & Transition – Common needs

Long-term care with future guidance and life stage advice.

Bowel management problems and bowel management follow up needed, however needs may change.

Care needs to be coordinated and followed up with regular clinical review so issues are identified earlier, in a timely manner.

Care needed throughout the whole life of the person. Problems are always there, but silent and can come back to impact on the person's quality of life.

Transition is a process not a 'one off' event and should start early working towards the child becoming more independent in their engagement with health care professionals

Individual transition plans should be developed and put in place .