# What is MRKH syndrome and what does it involve?

BEZPESTKOWE

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MRKH syndrome is a genetically determined aplasia (organ failure) or hypoplasia (significant underdevelopment) of the uterus and vagina in a person with a female phenotype (ed. note: phenotype most simply explained means the appearance of a person) with karyotype 46.XX. It belongs to the group of rare diseases because, according to statistics, it affects about 1 in 4000 to 1 in 10 000 live born female newborns (most often it is said that it is about 1 in 4500 live born female newborns). In Poland there are approx. 4400 people with MRKH, and about 40 Bezpestkowe are born each year.

**MRKH syndrome looks different in each person.**

It ranges from a complete absence of the uterus, to residual non-functioning uterine horns or residual uterine horns with a residual cavity with endometrium. Similarly, in the case of the vagina, it may be completely absent, present in a vestigial form or in the form of a recess, which in some individuals is large enough to become a fully functional vagina without medical intervention when intercourse is attempted.

MRKH syndrome is complex – in medicine, anything called a syndrome is made up of many components. Defects of the uterus and vagina can therefore be accompanied by defects in other organs. The two systems most commonly affected are the urinary system and the skeletal system; in some cases there are also defects of the heart and great vessels, and some patients have hearing loss.

There are therefore two types of MRKH syndrome: the first is diagnosed when the defect is limited to the reproductive system, i.e. the uterus and vagina, and the second when other defects coexist, such as congenital absence of a kidney and/or spinal defects

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## MRKH syndrome: menstrual cycle and menopause

**Although Bezpestkowe do not menstruate, this does not equate to the absence of a menstrual cycle.**

People with MRKH syndrome have functioning ovaries that secrete hormones and produce ova, so Bezpestkowe ovulate and, hormonally speaking, go through all the stages of the cycle. The only difference is that there is no bleeding, although in the presence of a vestigial endometrium „micro-menstruation” may occur. Bezpestkowe will also go through menopause and may experience the many discomforts associated with it.

## MRKH syndrome and sex

Having MRKH does not equal being unable to have sex. Each person defines sex in their own way, and penetration is not necessary. Remember to check with your health care provider before doing this. Whichever option you choose, successful and satisfying sex despite MRKH is possible.

**The quality of sex does not depend on whether your vagina is 4 or 7 centimetres long, but on who you choose to have sex with.**

However, if you choose to have penetrative sex, there are three ways to create a vagina.

The first option is vaginal stretching with a partner – if you have someone you feel comfortable enough to do this with (in an atmosphere of tenderness and mutual trust), consider this option. It can give you a lot of pleasure.

The second is non-surgical vaginal shaping using dilators (known as dilation). It involves regular, gradual stretching of the existing vaginal canal. This option requires patience and determination, but is very rewarding. You can adapt the exercises to suit your needs. Remember that you are doing this for yourself, so you should enjoy the process.

The third option is surgery.

As you can see, there are many possibilities, so it is advisable to familiarise yourself in advance with the method proposed by your doctor. Don't be afraid to ask questions, be inquisitive, demand care and attention as well as accurate information and a holistic approach to your body and health. Whichever method you choose, the decision is entirely yours.

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Remember about looking after your health – once a year Bezpestkowe, just like cis women, should have a gynaecological examination with ultrasound, a vaginal assessment with cytology, and once every 5 years they should have a panel of hormonal tests.

## How to talk about MRKH?

It is important to vet the people with whom we share our experiences, as there are some people who may not understand this and/or react in a negative way.

**Remember that your comfort and safety is most important, and that you are the one who sets the boundaries.**

If you need to talk to someone about MRKH and you don't know how to get started, we recommend repeating in your head selected points you'd like to discuss so that in a real-life situation you're fluent and the words you say don't sound unfamiliar or feel awkward. It's up to you to decide who you will be sharing your story with: a loved one, a fellow person with MRKH, a mental health professional (sexologist, psychologist, psychotherapist).

You can reach out for different forms of support to suit your needs - look for supportive people in your immediate environment, consider joining a dedicated support group and/or receiving psychological support or psychotherapy.

The most important issue of allyship (i.e. being a supportive person) is empathy, listening to the other person and sensing (or asking directly) if they even want to talk about the topic - not every person with MRKH wants to talk about it and not everyone needs to be an educator and activist. Therefore, asking (accompanied by the possibility of withdrawing from the conversation) is important: „Would you like to talk about it and are you comfortable with having this conversation?".

It is important to give space, not to impose yourself with too many questions and to respect the boundaries set by Bezpestkowe. People with MRKH syndrome have the right to be tired of being asked, to not want to answer questions and to keep their experiences just to themselves.

Language matters! Because as a society we are not open to diversity or diverse sexual development, and MRKH is one of many cases of this diversity, an adequate narrative is important. If we talk about MRKH openly, without stigma or stigmatisation, we show that having MRKH is nothing bad and/or scary. It is not a sign of ‚incompleteness' and it does not dictate someone's worth.

We try to avoid terms such as „'suffering', "ill" or "diagnosed with MRKH syndrome". Instead, we say that one simply has MRKH.

**An extremely important aspect is the way information about MRKH is communicated by the attending doctor.**

You can't tell a patient in a hurry that she won't menstruate, can't have intercourse, can't have children because it's... not true. Unfortunately, not only as Bezpestkowe, but as people in general, we most often remember exactly what we were told at our first gynecologist appointment.

That's why it's important to be presented with alternatives as early as the identification of MRKH syndrome and not to treat being Bezpestkowe as a bad thing. It is important to talk rather than mechanically take action so that the patient is in control of the situation and aware of the decisions they is making that affect their body.

## Relationships and parenthood

MRKH puberty (up to the point of diagnosis) follows the same patterns as a cis women's puberty, so Bezpestkowe usually take on female gender roles (because of their physical appearance, not MRKH syndrome).

The role of a therapist is to support people with MRKH in engaging in sexual contacts, or to jointly identify the reason why they do not. Talking through the mental blocks and finding solutions to them helps achieve sexual satisfaction.

Each person, regardless of having or not having a seed, is built differently – our bodies, their appearance and functionality are different. If you are concerned that your sexual partner(s) will recognise that your vagina has been produced, we assure you that there is no need to worry – from a layperson's point of view, we are unable to recognise whether we are having sexual contact with a person who was born with a vagina or a person who has a neo-vagina.

Another consequence associated with MRKH syndrome is the inability to get pregnant and give birth. Usually when MRKH is identified, this information is more difficult for parents/carers of Bezpestkowe to accept.

**Of course, having MRKH does not preclude you from becoming a parent (that is of course if you want to become one at all). There are different ways to do this:**

The first option is uterine transplantation, which is still considered an experimental treatment and for anatomical reasons cannot be performed on all patients with MRKH syndrome. Currently, there are more than ten children born to patients with MRKH in the world. To date, the best-known precedents are those of 2014 and 2017, when, in Sweden and Brazil respectively, patients with MRKH gave birth – in the first case from a uterus transplanted from a living donor, in the second from a deceased donor. The uterus is not a vital organ and is only transplanted for one pregnancy (it is removed after birth). Although the operation is very complicated and burdensome for both the donor and the recipient, it is possible.

A second option is surrogacy, which involves ectopic fertilisation with transfer of the embryo to a surrogate mother. In this way, a patient with MRKH syndrome can be a genetic parent, since from an ovarian point of view Bezpestkowe are fertile.

The third (and currently the only legally available in Poland) option is adoption, but in order to initiate the adoption procedure, one must be married for at least four years.

It is worth noting that there are individuals who fulfil the need for parenthood in other ways, e.g. by bonding with a person who has a child/children, by becoming involved as a carer, a close family friend, etc.

## A note from Bezpestkowe:

Harmful stereotypes still persist in our society - gender is often defined by the condition of our bodies. Those of us who feel feminine are well aware that the absence of a uterus does not take anything away from us, does not make us ‚incomplete'. Our condition therefore proves that gender identity has no right to be defined by what our bodies have and don't have.

MRKH syndrome does not subjugate Bezpestkowe's femininity – it is about time for this to ring loud and clear, especially since as Bezpestkowe we are often excluded from the so-called ‚women's circles', where bonds are often established on the foundation of shared experiences of menstruation and motherhood. Knowing what it feels like to be excluded from communities, we do our best to avoid creating a similar atmosphere within our own.

Just as among the general population, there are non-binary, transgender and non-heteronormative people among us. For this perhaps small but no less significant group of Bezpestkowe, the preconception that we are all heterosexual women leads to an even stronger sense of exclusion. Out of respect for our diversity and the desire to create a community where everyone can be themselves regardless of gender identity and psychosexual orientation*, we use the words ‚patient' and ‚person' interchangeably and refrain from specifying the gender of Bezpestkowe's potential partners.

There are also intersex people among us. What is intersex? Inter-sex is an umbrella term for people who are born with a body that does not fit into social and/or medical definitions of typical female or male bodies. People with MRKH can (but don't have to) identify under the intersex umbrella.

*Gender identity and psychosexual orientation are terms commonly confused with each other, but they mean two completely separate things. Gender identity is a personal sense of belonging to a gender, an awareness of our inner self. Psychosexual orientation, on the other hand, describes our emotional, romantic or sexual attraction to people of a certain sex.

Bezpestkowe (pl. “seedless”) is a project founded in 2018 that aims not only to actively support people with Mayer-Rokitansky-Küster-Hauser syndrome, but also to raise awareness and educate the public.

The name refers to the seed of fruit and compares it to the uterus – stone fruit differs from seedless fruit only by having a seed, which after all does not define anything.

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