

Mental Health

ROKITANSKY SYNDROME



INSTITUTO ROKI

Apoio a mulheres com
Síndrome de Rokitansky

Mental Health Guide for Women with Rokitansky Syndrome and their Families

The purpose of this guide is to assist in dealing with the impact of a diagnosis of Rokitansky Syndrome and to answer questions such as: “What is the syndrome?” “What are the treatment options?” “Questions about sexuality and motherhood” “How to deal with family, friends, and strangers when discovering you have a syndrome?” “Professionals who can help” “Why seek psychotherapy?” and “What are the works in therapeutic groups at the Roki Institute like?”

Considering these questions and the need for access to information, the team of psychologists at the Roki Institute has structured this guide in a “questions and answers” format based on frequently asked questions regarding the syndrome and its impact on mental health.

*With care,
The Roki Institute Team*



Discovering the syndrome

The Mayer-Rokitansky-Kuster-Hauser Syndrome (MRKH), better known as Rokitansky Syndrome, consists of the total or partial absence of the vaginal canal, uterus, and fallopian tubes (internal genital organs). However, the ovaries function normally, producing eggs and female hormones.

The syndrome can be subdivided into two classifications based on observed alterations:

- Type I - When there are no other malformations associated with the syndrome.
- Type II - When there are associated malformations, such as kidney abnormalities, bone abnormalities, mainly in the spine, cardiac problems, etc.

It is usually identified during adolescence, through the absence of menstruation (amenorrhea), difficulty in sexual intercourse, or pelvic pain, symptoms that lead the woman to seek medical/gynecological attention. Lack of knowledge about the syndrome by healthcare professionals, as well as a lack of someone to talk to about it, are factors that can lead a young woman to a painful and prolonged journey before she and her family receive appropriate care. In this phase, information is essential, as the more informed and supported

the young woman and her family feel, the better their psychological and emotional resources will be, as to guide them towards self-care and consequently, a significant improvement in their quality of life.

One of the first challenges for a woman diagnosed with the Syndrome begins with understanding her condition, which is still a topic that needs greater visibility and accessibility. Receiving the diagnosis can be painful and lonely because, even if the young woman is accompanied by her family, her condition concerns what is happening in her own body. Therefore, it is essential that she has greater knowledge about the subject. This is a stressful period in which she may feel vulnerable, as she will need to undergo clinical and imaging exams during gynecological appointments. The discovery of physical alterations is accompanied by feelings of low self-esteem, as well as psychological and social changes that impact her quality of life. There is a possibility of questioning her sexuality, her possibilities of motherhood, understanding her female body, and her own identity. All of this ends up impacting her way of life and how she relates with others, often contributing to social and emotional isolation.

What is the psychological impact for those who receive this diagnosis?

Studies on the psychological effects caused in women with Rokitansky syndrome are insufficient to draw conclusions about their emotional profile. There may be a variety of negative reactions, and the impact of the news can generate a state of shock, feelings of distress, reactive depression, fear, confusion, anger, a sense of strangeness regarding the body, fear of partner rejection, social isolation, distortion of self-image and the world around them. The reactions of young women receiving the diagnosis can be compared to those of people who have suffered trauma and to symptoms of Post-Traumatic Stress Disorder (PTSD), because there is indeed a rupture in their lives, between before and after the diagnosis.

Another important point is related to the absence of menstruation. Culturally, the presence of menstruation - seen as a rite of passage from childhood to adulthood - and the reproductive potential are important characteristics for "being a woman". Thus, it is necessary to give real importance to how we deal with feelings of shame and guilt, which may arise, as well as their relationship with the woman herself. We realize that the understanding of femininity goes through the young woman's body experience in the world, by living her social role. Any rupture in this construction cannot be rebuilt with technical interventions or motherhood, but with self-knowledge, self-strengthening, and recognition of one's own history through the process of life maturation. Therefore, it is advisable to receive help from individual psychotherapy and/or therapeutic groups.

I have Rokitansky syndrome. Am I a woman?

Yes, you are a woman, of the female sex, since the karyotype test indicates the presence of the 46XX chromosome. This makes you biologically a woman. However, being a woman in the society we live in is something intertwined with social roles and expectations. Some patients believe that to be considered a woman, they need to procreate. However, we understand - just like science - that the construction of femininity goes through the biological and psychological body, and the imaginary of each one.

The vast majority of young women with the syndrome feel their sense of gender identity threatened. Issues such as sexual preference and gender do not usually change due to the discovery of the syndrome, as they are related to the psychic structure. Being able to reproduce and carry a baby are not factors that define a woman under any circumstances. The syndrome does not define gender roles or identities. Young women need to be reassured about their gender identity, and if they have any doubts or concerns on the subject, they should seek help.



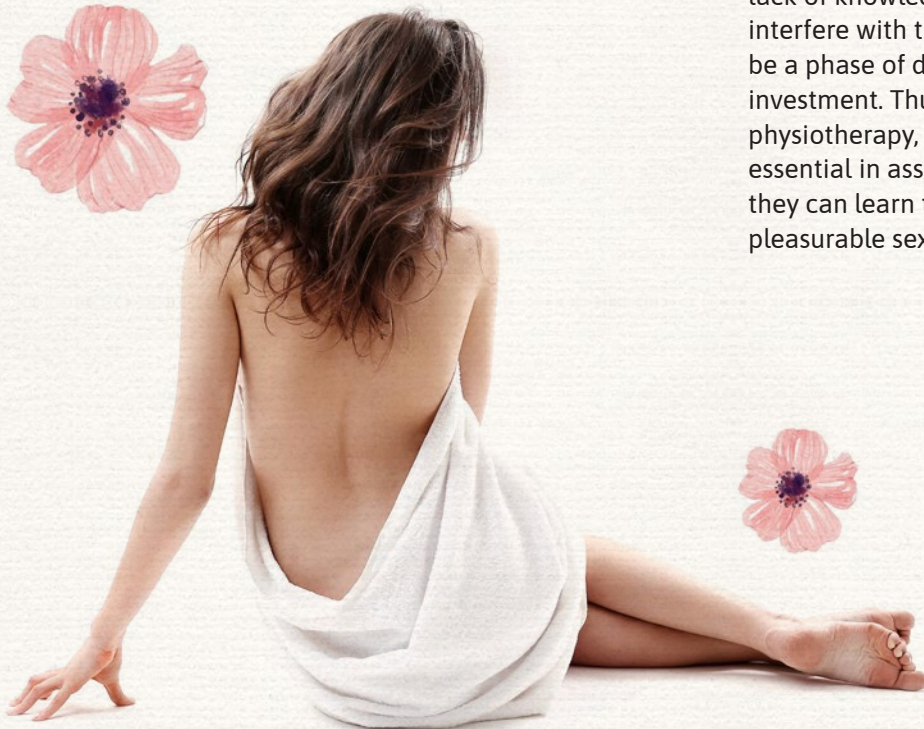
Living sexuality and pleasure

I have been diagnosed with the syndrome, can I have an active sex life? Will my sexual experience be different from that of a woman without the syndrome?

Most of the time, women diagnosed with Rokitansky syndrome feel their sexuality threatened until they receive adequate information and understand that yes, a fulfilling sex life is possible as long as they are willing to face some challenges, such as: telling their partners; using dilators, and demystifying the

mistaken idea that orgasm is achieved only through penetration. Having psychological support can help these women look at themselves with more confidence and well-being.

In the case of women with the syndrome, the female genitalia does not have a vaginal canal, which, however, can be reconstructed. The entire external genitalia is normal and capable of pleasure. Initially, the syndrome can affect sexuality because the vaginal canal through which penetration will occur may not be open enough or simply may not exist. After its construction, the woman will be able to have sexual intercourse. However, the lack of knowledge about their own bodies can interfere with the acquisition of pleasure. This will be a phase of discovery, requiring more emotional investment. Thus, we see the importance of medical, physiotherapy, and psychological support, which are essential in assisting these young women so that they can learn to allow themselves an active and pleasurable sexuality, if this is their desire.



Do I need to have a vagina to have a satisfying sex life?

Women do not “need” to have a vaginal canal if they do not want to engage in penetrative sexual activity. For those who wish to achieve a full sexual life, the construction of a vaginal canal - called a neovagina - is advisable. Women with Rokitansky syndrome, when treated with dilators or surgery, can have vaginal penetrative sexual activity. We know that there are many ways for women to achieve orgasm, not necessarily or exclusively through penetration. Often, an anatomically intact vagina alone does not guarantee a satisfactory or ideal sexual relationship. The goal is to achieve integrated health in its physical and psychological aspects. We know that women can enjoy sexual pleasure through erotic stimulation in various parts of the body, although orgasm is only achieved with clitoral stimulation and/or penetration.

What will my sexual relationships be like after surgery?

An important point to address is what we consider to be a sexual relationship. Typically, when asked this question, what is implied is sexual intercourse (penis-vagina penetration). It is worth noting that the vaginal canal is not the main source of sexual pleasure. The clitoris, an organ analogous to the

glans - the upper part of the penis, known as the “head” - is the main source of pleasure, in addition to psychological conditions. The vaginal canal can be reconstructed through the use of dilators, with regular penetration, or through surgery. Once the canal is ready for this encounter, you may experience some pain during penetration. This pain can be reduced through good communication with your partner and the use of water-based lubricants. It is important to remember that the “foreplay” phase, or the exchange of bodily caresses with your partner, will be essential to promote feelings of pleasure, contributing to the reduction of pain. It is important to emphasize, once again, that penetration is not the only way for you to achieve orgasm. Finally, another point to mention is that the use of dilators will continue to be important during periods of sexual abstinence.

Can I feel sexual desire if I have Rokitansky syndrome?

Yes. Desire is based on personal experiences that we are able to develop. Sexual desire occurs when a woman is attracted to another person. Therefore, if you have Rokitansky syndrome, do not think that the absence of a uterus will interfere with your desire. What can cause a decrease in desire is the fact that you do not accept your body, and therefore do not believe that others may be interested in it.

I'm afraid to tell my partner about my problem. Should I do it?

Indeed, it's not easy to share something that you may not fully accept or understand yourself. As intimacy grows, it's important to be able to share with your partner any and all experiences related to your body, and the pleasure achieved in this discovery process can be even greater. Any type of communication happens after the establishment of mutual trust. When you feel more comfortable with your partner, it may be time for a good conversation.

As a woman with Rokitansky syndrome, in addition to not menstruating, will I experience PMS?

Despite the malformation of the uterus, which results in the absence of menstruation, women with the syndrome have fully preserved ovaries. The ovary is responsible for the hormonal cycle and PMS. There is no difference, therefore, between a woman with Rokitansky syndrome and a woman without the syndrome.

As a woman with Rokitansky syndrome, how do I masturbate? Can I experience pleasure alone?

Every person can and should masturbate. Through masturbation, we get to know our body and the sensations of pleasure that we can achieve. It's important that everyone knows their own body, their own genitals, and knows how to manipulate them. The entire vulva area is composed of muscles

and nerve endings, so touching this area can produce sensations. We also know that it's through manipulation of the clitoris that most women can achieve orgasm. It's very important to learn how to touch yourself. Some women introduce vibrators into the vaginal canal and you can do the same, as long as it gives you pleasure. You can feel a lot of pleasure alone through masturbation, and with that be able to share and enjoy a pleasurable and satisfying sexual activity. If you have difficulties, there's nothing better than talking to your doctor and/or psychologist so they can guide you.



The dream of motherhood



Women with Rokitansky syndrome suffer greatly when they find out that they will not be able to bear a child, but motherhood is still possible. Women born with or without a uterus have very different experiences when it comes to procreation. Young women with the syndrome experience anxiety and worry about their reproductive function and femininity. With this in mind, we will talk about the possibilities of experiencing and living motherhood.

Why can't I be a natural mother?

Young women with Rokitansky syndrome are born with ovaries and ovulate every month, like any other woman. However, they have a complete or partial absence of the uterus, which prevents them from carrying a baby in their bodies, as the uterus is where the fetus will develop. Therefore, being a natural mother is NOT possible, unless the woman undergoes the process of uterus transplant, a procedure performed in reference hospitals, which has been carried out in recent years in Brazil and around the world. For more information about uterus transplant, contact the Roki Institute.

Could something happen and suddenly I discover that I can become a mother by carrying a baby in my own body?

No. A non-existent or partially existent uterus cannot carry a baby or develop itself throughout a woman's life.

What are the possibilities for me to become a mother?

Women with Rokitansky syndrome can become mothers through adoption, surrogacy, or by undergoing uterus transplant. If you have opted for adoption, you need to inquire about how to apply for the adoption process.

Regarding the surrogacy process, the accompaniment of a group of specialists will be necessary so that the journey can be as smooth as possible, since three people will be involved in the process: the mother, who is the egg donor; the father, who is the sperm donor; and the woman who will carry the baby as a surrogate. The surrogacy process involves artificial insemination in the woman who will receive the embryo.

Another option is uterus transplant. This procedure has already been successfully performed in Brazil. All the different paths to motherhood mentioned should be accompanied not only by the medical team, but also by psychologists who help these women to constitute motherhood in a different and special way.

The notion of a support network should be taken into account in these cases, as it should serve as a safe haven for the anxieties, fears, longings, and frustrations that will arise throughout any of these motherhood processes.

Involved in the Rokitansky journey

What if the professional who attends me doesn't have knowledge of the syndrome?

It is worth noting that, as it is a rare syndrome - affecting one in every 5,000 women - it is possible that the professional who assists you may not have knowledge about it. If this is the case, try to talk to him. Tell him about the existence of the Roki Institute. It is advisable that the professional can establish a partnership with the Institute to offer the most appropriate treatment. A good professional is always the one who is committed to helping, if he is willing to learn about it.

And what is the role of the family of someone with the syndrome?

Having the support of family and friends is very important and can be a fundamental support at this specific time. However, we understand that it can be very difficult to open up and express your feelings, emotions, insecurities, fears, and doubts, as these are all topics related to personal intimacy, which should be respected.

Sexuality is still a big taboo in our society and numerous families have great difficulties in dealing with these issues. We understand that, due to the fact that the diagnosis involves issues related to sexuality, motherhood, and self-esteem, it can further complicate an openness for family dialogue. It is up to the woman with Rokitansky to decide what she wants to share or not about her intimacy and, regardless of that, family support will always be recommended.



How can family members react to the diagnosis news?

This can vary depending on each individual's family structure. Family members may be impacted and surprised by the diagnosis news - just like you - and may feel like they have somehow failed. Therefore, all family members, to a greater or lesser degree, will seek a way to understand and assimilate the new situation. The amount of time the family needs to talk about the diagnosis may be different from your own time, and this should be taken into consideration.

Your family may try to avoid talking about the subject not to embarrass you or because they are still looking for ways to process the news. On the other hand, another family may interfere too much, making decisions for you and making you feel invaded and pressured. Another possibility is that the family shows availability to the subject but respects the necessary processing time.

Should it be my parents who decide on the type and duration of treatment?

We understand that dialogue, partnership, respect, and patience are fundamental to strengthen the family support network and make this process less painful. The decision about the type and duration of treatment should be yours. Your parents can have a dialogue, express opinions, and support you for your best journey. Remember that, like you, your parents/family members may also need help from therapeutic groups. The Parents/Partners or Mothers' Group can also be a resource to support them in their emotional issues and help them deal with the diagnosis in the best possible way.

Therefore, we conclude this guide by trying to convey a very important message: **YOU ARE NOT ALONE!** Come and get to know the Roki Institute. We want you and your family around! As painful as the diagnosis news of Rokitansky syndrome may be - and this pain needs to be validated - it is essential to have a space of support, to meet other girls with the same syndrome, and feel comfortable speaking freely with those who share the same issues. Whether for you, who have the syndrome, or for the family members involved, we will have open arms to everyone!



Seeking support and acceptance

The Institute offers psychological groups aimed at supporting, informing, and helping women in their search for self-understanding after diagnosis. To participate in support groups, simply contact the Roki Institute. The first step will be an interview with one of our psychologists, who will get to know you better and find the best way to assist you, such as participation in support groups, referrals to doctors, physiotherapists, etc.

In the groups, you will have the opportunity to meet other girls/women diagnosed with Rokitansky syndrome and share information, emotions experienced after diagnosis, and life experiences with them. It is a safe space created for women to share their fears and experiences, forming a support network and a group with which they can identify. Participation occurs in one group at a time, and you will always have the opportunity to join a new group if you feel the need to do so.

Can I have individual therapy while participating in a therapeutic group?

Yes, you can have individual therapy since, in addition to the syndrome, we all have existential issues that are worth being TAKEN CARE OF. The Roki Institute does not currently offer this resource, but we can refer you to SUS or some support network in your city.

What type of group does the institute offer?

The institute offers support groups for women with the syndrome and for family members, such as mothers, fathers, and others who may be involved.

What professionals are involved in treatment?

A comprehensive professional support is recommended, comprising a multidisciplinary team of doctors, physiotherapists, and psychologists.

Doctors will be responsible for diagnosis and the indication of the most appropriate treatment for your case. Several medical specialties are involved, such as gynecologists, urologists, cardiologists, and orthopedists. In some cases, consultation with an endocrinologist is recommended. It is worth remembering that each case has its singularities, so it is not always necessary to have consultations with all these specialties.

What is the importance of psychological support for those with the syndrome?

Women with Rokitansky Syndrome often present significant symptoms of anxiety, depression, family and partner relationships, sexuality, self-image,

maternity, and other issues that may involve their own sexual identity. Therefore, taking care of mental health is essential. Psychotherapeutic support can help, whether in individual sessions or through support groups.

The role of the psychologist is to welcome those involved in the Rokitansky journey, to understand their personal demands, and to guide them towards self-awareness. In therapy sessions, you will have the opportunity to talk about your fears, intimate themes, and relationships in general, whether they are family, romantic, or friendships. Therapy is a welcoming space where the professional listens to the patient without judgment. The goal is for the patient to get to know themselves better, developing conditions to understand and perceive existing dysfunctional patterns, and learning how to deal with them more lightly and effectively in various life issues.

Rokitansky Syndrome does not define who we are or who we are not. It is a part, a facet of who we are, among many possibilities and potentialities. Through studies and perception during the follow-up of patients who are part of the therapeutic groups at the Roki Institute, psychotherapy is strongly recommended.

The longer the delay in seeking psychological treatment, the more chronic and severe the psychological consequences caused by the syndrome may become.



Bibliographic references

Bean, E., et al. *Mayer- Rokitansky-Küster-Hauser Syndrome: Sexuality, Psychological Effects, and Quality of Life*. J Pediatr Adolesc Gynecol, 22:339-346, 2009.

Carrol, S., et al. *From Engulfment to Enrichment: Associations Between Illness Representations, Self-Concept, and Psychological Adjustment in Mayer-Rokitansky-Küster-Hauser Syndrome*. J Pediatr Adolesc Gynecol, 33, 639-648, 2020.

Delaine M., Ohl J. *Activité sexuelle et qualité de vie chez les patientes atteintes d'un syndrome de Mayer-Rokitansky-Kuster-Hauser Sexual activity and quality of life in patients with Mayer-Rokitansky-Kuster-Hauser syndrome*. *Medicine sexuelle feminine Gynécologie Obstétrique & Fertilité*, 42, 865-871, 2014.

Heller-Boersma J.G., Schmidt U.H., Edmonds D.K. *A randomized controlled trial of a cognitive-behavioural group intervention versus waiting-list control for women with uterovaginal agenesis (Mayer-Rokitansky-Kuster-Hauser syndrome: MRKH)*. *Hum Reprod*, 22(8):2296-2301, 2007.

Heller-Boersma J.G., Schmidt U.H., Edmonds D.K. *Psychological Distress in Women With Uterovaginal Agenesis (Mayer-Rokitansky-Kuster-Hauser Syndrome, MRKH)*.

This guide was developed by the team of psychologists at Instituto Roki:

Alessandra Santos

Claudia Gitti

Cléo Franco

Daniella Bauer

Iane Melotti

Rodrigo Romano



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If you have been diagnosed with Rokitansky Syndrome,
please contact the **Roki Institute**.

Our commitment is to welcome and assist you!

www.institutoroki.org.br



All information is educational in nature. This guide was created by the Roki Institute.
For diagnosis and treatment, please consult your doctor.