

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 help women and their families cope 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 do I deal with family, friends, and strangers after learning that I have the syndrome?" "Which professionals can help?" "Why seek psychotherapy?" and "What are the therapeutic groups at the Roki Institute like?" In response to these questions and the need for accessible information, the team of psychologists at the Roki Institute has structured this guide in a question-and-answer format, based on frequently asked questions about the syndrome and its impact on mental health.

*With care,
The Roki Institute Team*



Discovering the Syndrome

One of the first challenges for a woman diagnosed with the syndrome is understanding her condition, which still needs greater visibility and accessibility. Receiving the diagnosis can be painful and lonely because, even when the young woman is accompanied by her family, the condition concerns what is happening in her own body. Therefore, it is essential that she have access to information about the subject.

This is a stressful period in which she may feel vulnerable, as she will need to undergo clinical and imaging examinations during gynecological appointments. The discovery of physical changes may be accompanied by low self-esteem, as well as psychological and social changes that affect quality of life.

She may question her sexuality, her possibilities of motherhood, her understanding of her female body, and her own identity. All of this can affect her way of life and her relationships with others, often contributing to social and emotional isolation.

Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH), better known as Rokitansky Syndrome, consists of the complete or partial absence of the vaginal canal, uterus, and fallopian tubes (internal reproductive organs). However, the ovaries function

normally, producing eggs and female hormones.

The syndrome can be divided into two classifications according to the alterations observed:

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

It is usually identified during adolescence through the absence of menstruation (amenorrhea), difficulty with sexual intercourse, or pelvic pain—symptoms that lead the woman to seek medical or gynecological care. Lack of knowledge about the syndrome among healthcare professionals, as well as the absence of someone to talk to about it, can lead to a painful and prolonged journey before the woman and her family receive appropriate care. During this phase, information is essential. The more informed and supported the young woman and her family feel, the greater their psychological and emotional resources will be to guide them toward self-care and, consequently, a significant improvement in quality of life.

What is the psychological impact of receiving this diagnosis?

Studies on the psychological effects of Rokitansky Syndrome in women are insufficient to draw conclusions about a specific emotional profile. There may be a variety of negative reactions, and receiving the diagnosis can lead to shock, distress, reactive depression, fear, confusion, anger, a sense of estrangement from the body, fear of rejection by a partner, social isolation, and a distorted perception of oneself and the world around oneself.

The reactions of young women receiving the diagnosis can be compared with those of people who have experienced trauma and with symptoms of Post-Traumatic Stress Disorder (PTSD), because there is indeed a rupture in their lives between the period before and after the diagnosis.

Another important point concerns the absence of menstruation. Culturally, menstruation—often viewed as a rite of passage from childhood to adulthood—and reproductive potential are important characteristics associated with “being a woman.” Therefore, it is important to give proper attention to feelings of shame and guilt that may arise, as well as to the woman’s relationship with herself.

We understand that the construction of femininity is shaped by a young woman’s experience of her body in the world and by the social role she inhabits. A rupture in this construction cannot be repaired through technical interventions or motherhood alone, but through self-knowledge, self-strengthening, and recognition of one’s own history throughout the process of maturation. Therefore, individual psychotherapy and/or therapeutic groups are recommended.

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 46,XX chromosomes. However, being a woman in the society in which we live is intertwined with social roles and expectations. Some patients believe that, in order to be considered a woman, they need to have children. However, we understand—just as science does—that femininity is constructed through biological and psychological experiences of the body, as well as through each person’s own inner world.

The vast majority of young women with the syndrome feel that their gender identity is threatened. Issues such as sexual orientation and gender do not usually change because of the discovery of the syndrome, as they are related to the individual’s psychological structure. The ability to reproduce and carry a baby does not, under any circumstances, define a woman. The syndrome does not define gender roles or identities. Young women should be reassured about their gender identity, and if they have any doubts or concerns on the subject, they should seek professional support.



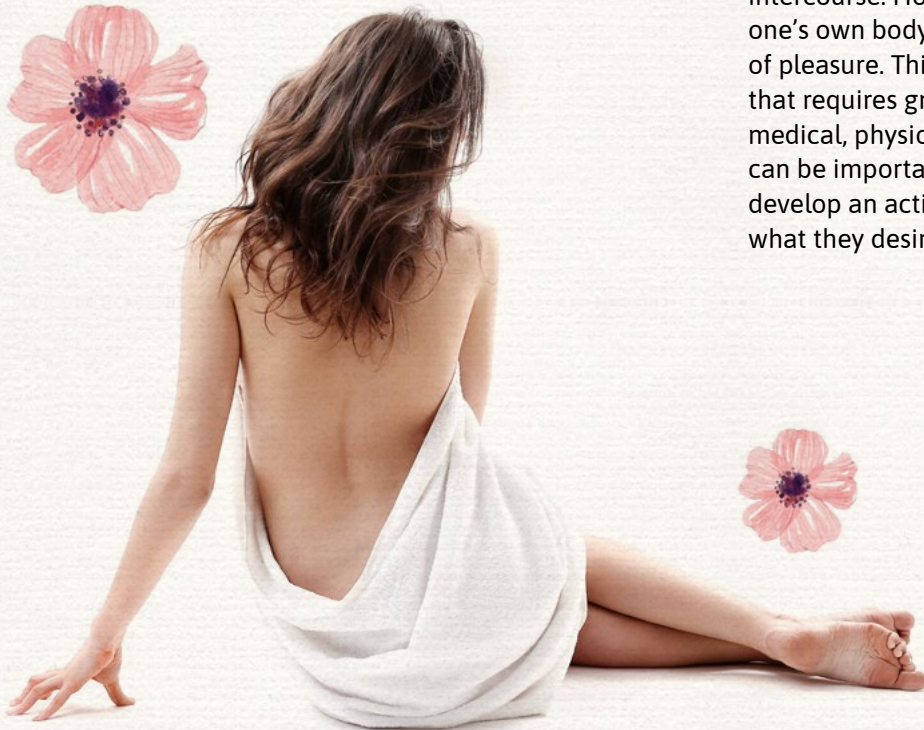
Living Sexuality and Pleasure

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 women diagnosed with Rokitansky Syndrome feel that their sexuality is threatened until they receive adequate information and understand that a fulfilling sex life is possible, although they may face some challenges, such as talking to

their partners, using dilators, and dispelling the misconception that orgasm can only be achieved through penetration. Psychological support can help these women view themselves with greater confidence and well-being.

In women with the syndrome, the vaginal canal may be absent, but it can be reconstructed. The external genitalia are normal and capable of producing pleasure. Initially, the syndrome can affect sexuality because the vaginal canal through which penetration would occur may be too narrow or may not exist. After the vaginal canal has been created, the woman may be able to have penetrative sexual intercourse. However, lack of knowledge about one's own body can interfere with the experience of pleasure. This can be a period of discovery that requires greater emotional investment. Thus, medical, physiotherapy, and psychological support can be important in helping these young women develop an active and pleasurable sex life, if that is what they 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 wish to engage in penetrative sexual activity. For those who wish to have penetrative sex, a vaginal canal—called a neovagina—may be created. Women with Rokitansky Syndrome who undergo treatment with dilators or surgery may be able to engage in vaginal penetrative sexual activity. There are many ways to experience orgasm, and penetration is not necessarily or exclusively required. An anatomically intact vagina alone does not guarantee a satisfactory sexual relationship. The goal is integrated health in both its physical and psychological aspects. Women can experience sexual pleasure through erotic stimulation of different parts of the body.

What will my sexual relationships be like after surgery?

An important point is to consider what we mean by a sexual relationship. Typically, this question refers to 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, commonly called the “head”—is a major source of pleasure, together with psychological factors.

The vaginal canal can be created through the use of dilators, regular penetration, or surgery. Once the canal is ready for sexual activity, some pain during penetration may occur. This pain can be reduced through good communication with your partner and the use of water-based lubricants. It is also important to remember that the “foreplay” phase, or exchange of bodily caresses with your partner, can be essential for promoting pleasure and helping to reduce pain. Penetration is not the only way to achieve orgasm. Finally, the use of dilators may continue to be important during periods of sexual abstinence.

Can I feel sexual desire if I have Rokitansky Syndrome?

Yes. Sexual desire is influenced by personal experiences and by the relationships we develop. If you have Rokitansky Syndrome, the absence of a uterus does not, by itself, prevent sexual desire. What may contribute to a decrease in desire is difficulty accepting your body and, consequently, difficulty believing that others may be interested in it.



I'm afraid to tell my partner about my condition. Should I?

It is not easy to share something that you may not yet fully accept or understand yourself. As intimacy grows, it can be important to share experiences related to your body with your partner, and the pleasure achieved through this process of discovery can be even greater. Communication develops after mutual trust has been established. When you feel comfortable with your partner, it may be the right time for an open 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 functioning ovaries. The ovaries are responsible for the hormonal cycle and are associated with PMS. Therefore, there may not be a difference in this respect 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 explore masturbation as a way of getting to know their body and the sensations of pleasure they can experience. It is important to become familiar with your own body and genitals and to discover what feels pleasurable. The vulva contains muscles and nerve endings, so touching this area can produce pleasurable sensations.

Stimulation of the clitoris is the way many women achieve orgasm.

Some women use vibrators in the vaginal canal, and this may also be possible after appropriate treatment, provided that it is comfortable and pleasurable for you. You can experience pleasure on your own through masturbation and, in doing so, become more comfortable sharing and enjoying satisfying sexual activity. If you have difficulties, talking with your doctor and/or psychologist can help provide appropriate guidance.



The Dream of Motherhood

Women with Rokitansky Syndrome may suffer greatly when they learn that they cannot carry a pregnancy, but motherhood is still possible. Women born with or without a uterus have very different experiences when it comes to reproduction. Young women with the syndrome may experience anxiety and concern about their reproductive function and femininity. With this in mind, we will discuss the possibilities of experiencing and living motherhood.

Why can't I be a biological mother by carrying a pregnancy myself?

Young women with Rokitansky Syndrome are born with ovaries and ovulate every month, as do many other women. However, they have a complete or partial absence of the uterus, which prevents them from carrying a pregnancy because the uterus is where the fetus develops. Therefore, carrying a pregnancy is not possible unless the woman undergoes a uterus transplant, a procedure performed at specialized hospitals that has been carried out in recent years in Brazil and around the world. For more information about uterus transplantation, contact the Roki Institute.

Could something change and I suddenly discover that I can carry a baby in my own body?

No. A uterus that is absent or only partially developed cannot carry a pregnancy or develop into a normal uterus later in a woman's life.

What are my possibilities for becoming a mother?

Women with Rokitansky Syndrome can become mothers through adoption, surrogacy, or uterus transplantation. If you choose adoption, you should seek information about how to apply for the adoption process.

Regarding surrogacy, support from a team of specialists is necessary so that the process can be as safe and well supported as possible. The process may involve the intended mother as the egg donor, the intended father as the sperm donor, and the woman who will carry the pregnancy as the gestational surrogate. Assisted reproductive techniques are used to create and transfer an embryo.

Another option is uterus transplantation. This procedure has been successfully performed in Brazil. All of these paths to motherhood should be accompanied not only by a medical team, but also by psychologists who can help women build their experience of motherhood in a different and meaningful way.

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



Involved in the Rokitansky Journey

What if the professional who treats me does not know about the syndrome?

Because it is a rare syndrome—affecting approximately one in every 5,000 women—it is possible that the professional assisting you may not have experience with it. If this is the case, try talking with the professional and tell them about the Roki Institute. It may be helpful for the professional to establish a partnership with the Institute in order to offer the most appropriate care. A good professional is committed to helping and is willing to learn about the condition.

What is the role of the family of someone with the syndrome?

Support from family and friends is very important and can be fundamental during this specific period. However, we understand that it can be difficult to open up and express feelings, emotions, insecurities, fears, and doubts, because these are all matters related to personal intimacy and should be respected.

Sexuality is still a major taboo in our society, and many families have difficulty dealing with these issues. Because the diagnosis involves sexuality, motherhood, and self-esteem, it can make open family dialogue even more difficult. It is up to the woman with Rokitansky Syndrome to decide what she wants to share about her intimate life. Regardless of that choice, family support is always recommended.



How can family members react to the news of the diagnosis?

This can vary depending on each family's structure. Family members may be affected and surprised by the diagnosis, just as you are, and may feel that they have somehow failed. Therefore, family members may need different amounts of time to understand and process the new situation.

Your family may try to avoid talking about the subject because they do not want 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 causing you to feel invaded or pressured. Another possibility is that the family remains available to discuss the subject while respecting the time needed to process it.

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

Dialogue, partnership, respect, and patience are fundamental to strengthening the family support network and making this process less painful. The decision regarding the type and duration of treatment should be yours. Your parents can talk with you, express their opinions, and support you on your journey. Remember that, like you, your parents and other family members may also need support through therapeutic groups. The Parents/Partners or Mothers' Group can be a resource to support them with their emotional needs and help them deal with the diagnosis in the best possible way.

We conclude this guide with a very important message: **YOU ARE NOT ALONE!** Come and get to know the Roki Institute. We want you and your family to be part of our community. As painful as a diagnosis of Rokitansky Syndrome may be—and that pain needs to be acknowledged—it is essential to have a supportive space, meet other women with the same syndrome, and feel comfortable speaking freely with people who share similar experiences. Whether you have the syndrome or are a family member, we welcome you with open arms!



Seeking Support and Acceptance

The Institute offers psychological support groups aimed at supporting, informing, and helping women in their search for self-understanding after diagnosis. To participate in a support group, 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 determine the best way to assist you, such as participation in support groups or referrals to doctors, physiotherapists, and other professionals.

In the groups, you will have the opportunity to meet other women diagnosed with Rokitansky Syndrome and share information, emotions experienced after diagnosis, and life experiences. It is a safe space where women can share their fears and experiences, build a support network, and connect with others who have similar experiences. Participation takes place in one group at a time, and you will always have the opportunity to join a new group if you feel the need.

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

Yes. You can have individual therapy because, in addition to the syndrome, we all have personal and existential issues that deserve care and attention. The Roki Institute does not currently offer individual therapy, but we can refer you to the Brazilian Unified Health System (SUS) or to a 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, including mothers, fathers, and others who may be involved.

What professionals are involved in treatment?

Comprehensive professional support is recommended, involving a multidisciplinary team of doctors, physiotherapists, and psychologists.

Doctors are responsible for diagnosis and for recommending the most appropriate treatment for your case. Several medical specialties may be involved, such as gynecologists, urologists, cardiologists, and orthopedists. In some cases, consultation with an endocrinologist may be recommended. Each case is unique, so it is not always necessary to consult all of these specialists.



Why Is Psychological Support Important?

Women with Rokitansky Syndrome may experience significant symptoms and difficulties involving anxiety, depression, family and partner relationships, sexuality, self-image, motherhood, and other issues that may involve their sexual identity. Therefore, taking care of mental health is essential.

Psychotherapeutic support can help, whether through individual sessions or support groups.

The psychologist's role is to welcome those involved in the Rokitansky journey, understand their individual needs, and guide them toward greater self-awareness. In therapy sessions, you will have the opportunity to talk about your fears, intimate concerns, and relationships in general, whether family, romantic, or friendships. Therapy is a welcoming space in which the professional listens to the patient without judgment. The goal is for the patient to know herself better, develop the ability to recognize existing dysfunctional patterns, and learn to deal with them more lightly and effectively in different areas of life.

Rokitansky Syndrome does not define who we are or who we are not. It is one part, one facet, of who we are, among many possibilities and potentialities. Based on studies and on observations made during follow-up with patients who participate in the therapeutic groups at the Roki Institute, psychotherapy is strongly recommended.

The longer psychological treatment is delayed, the more chronic and severe the psychological consequences associated with the syndrome may become.



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