

Overview

Menstrual dysfunction has long been a complaint of women with IBD and ostomies. A variety of factors, ranging from malnutrition/malabsorption to certain medication options, can impact menstrual health. With this being said, there is still a significant need for further research and focus on menstrual dysfunction and disorders as associated with IBD and ostomies. Below are several common menstrual complications of IBD and ostomy (although some have more research backing than others):

Types of amenorrhea

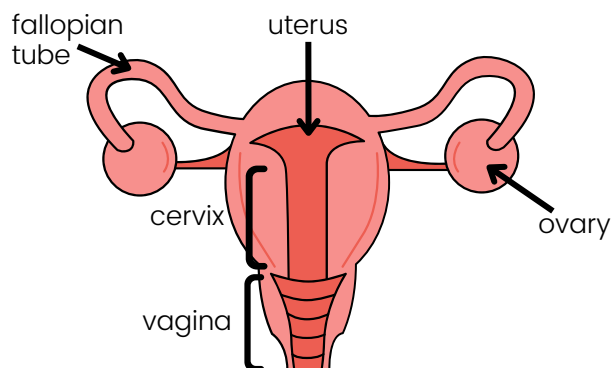
Primary amenorrhea

- Inability to start one's period by age 15 or within 5 years of the first signs of puberty
- In this type of amenorrhea, one never actually begins their period

Secondary amenorrhea

- Loss of one's period for 3+ months or irregular periods for 6+ months
- In this type of amenorrhea, one loses their period despite having it regularly in the past

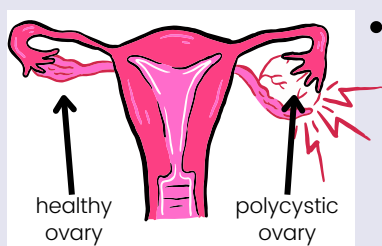
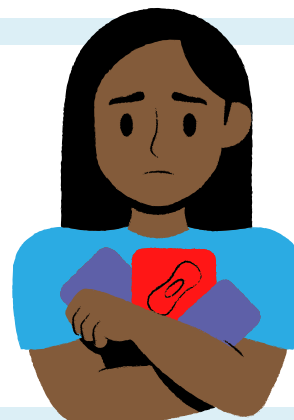
- **Amenorrhea:** Amenorrhea can be classified as either primary or secondary. In primary amenorrhea, an individual is unable to start their period by age 15 or within 5 years of the first signs of puberty (e.g. breast development, pubic hair growth, etc.). In secondary amenorrhea, an individual who has previously had normal menstrual cycles loses their period for three or more months or experiences irregular periods for six or more months. In primary amenorrhea, an individual is never actually able to begin their period whereas in secondary amenorrhea, an individual starts their period but then loses it or experiences irregularity. In one study, 10.1% of young female participants were shown to have delayed puberty and menstruation. For those who had a normal start to puberty and menstruation, 25.8% then experienced secondary amenorrhea (Jin). In another study evaluating the impact of IBD diagnosis on menstrual regularity, 24.8% of participants experienced a change in the interval of their menstrual cycle in the year prior to a diagnosis of IBD. With each year following IBD diagnosis, women were more likely to restore a regular menstrual cycle (Saha).



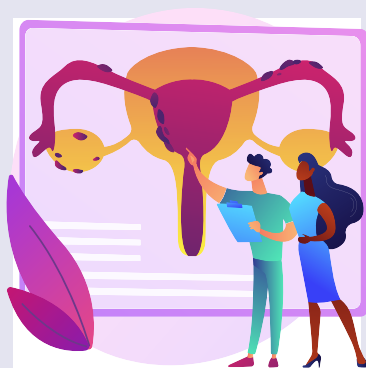
- **Increased pain/symptoms during and around menstruation:** A common frustration of many women with IBD and ostomies is an increase in pain and symptoms in the time immediately prior to and during menstruation. In one study, 53% of Crohn's patients reported worse symptoms during their period, while 51% of UC patients reported worse symptoms during their period (Rolston).

50%

Approximately 50% of women with IBD report worsened symptoms during their period



polycystic ovarian syndrome

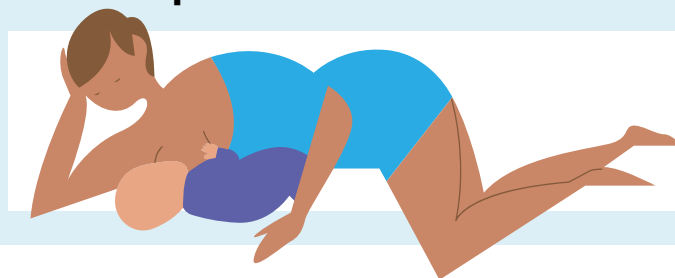


endometriosis

- Although more research is needed to establish whether there is a connection or not between IBD and other menstrual/reproductive disorders, **endometriosis** and **polycystic ovarian syndrome (PCOS)** are important to note. In endometriosis, tissue that typically lines the uterus begins to grow outside of the uterus. In one study, individuals with endometriosis were shown to have IBD at a rate of 2-3.4% as compared with the general population at a rate of 0-1%. Bowel endometriosis can be difficult to differentiate from IBD, and there are thoughts that these two conditions may be somehow related (Chiaffarino). PCOS is a hormonal disorder in which the ovaries produce higher-than-normal amounts of male hormones. This can lead to irregular menstrual patterns, excess hair growth, acne and weight gain around the abdomen. There are several cases of women with coconimant IBD and PCOS; however, the research behind whether there is a link between the two conditions is absent. For the sake of the fact sheet, we chose to include PCOS due to its prevalence in the general population and lack of public awareness.

Causes and Risk Factors in the General Population

- **Pregnancy/breastfeeding:** Loss of one's period if pregnant/breastfeeding is natural. Women who breastfeed can typically expect to lose their period for 3-6 months.



Causes and Risk Factors in the General Population (continued...)

- **Menopause:** Loss of one's period as a result of menopause is natural. Many women will begin to experience irregular periods (either with variation in cycle length or duration of bleeding) beginning sometime in their 40s with complete cessation of periods by approximately age 50. It is important to note some individuals may experience premature menopause in which they enter menopause earlier than expected.
- **Certain health conditions:** Particular health conditions are associated with increased risk of menstrual dysfunction. For example, diabetes (type I, type II and gestational) are associated with increased risk of PCOS. Endometriosis and PCOS can also lead to amenorrhea and increased pain during menstruation.
- **Eating disorders:** In individuals struggling with disordered eating/eating disorders, loss of one's period can be common. Because disordered eating restricts energy intake, the body may begin to shutdown certain organ systems to conserve energy for the most vital bodily processes. Typically, the first organ system to become dysregulated is the reproductive system – your body is not going to want a baby if it thinks you are in a food deprivation state as this would be negative for both you and the baby. Dysregulation of the reproductive system in this case frequently first presents as loss of one's period.
- **Excessive Exercise:** Similar to individuals struggling with disordered eating/eating disorders, individuals who engage in excessive exercise without appropriately fueling their body can experience a low energy state which then leads to a condition known as relative energy deficiency in sport (RED-S). As with disordered eating, in RED-S, the body must conserve energy by dysregulating certain organ systems. The first system to become dysregulated is typically the reproductive system leading to loss of one's period.
- **Genetics:** A family history of endometriosis or PCOS can elevate the risk of developing endometriosis or PCOS.
- **Stress:** High stress can lead to temporary alterations in the function of a small area in the brain known as the hypothalamus. Dysregulation of the hypothalamus can lead to altered hormone release which then impacts the menstrual cycle inducing a loss in menstruation.
- **Uterus/pelvic damage:** Conditions that cause damage to the uterus or pelvic area (e.g. uterine fibroids, pelvic inflammatory disease) can lead to amenorrhea or pain surrounding menstruation. Chronic damage to the uterus and pelvic area is thought to also increase risk of endometriosis and PCOS.

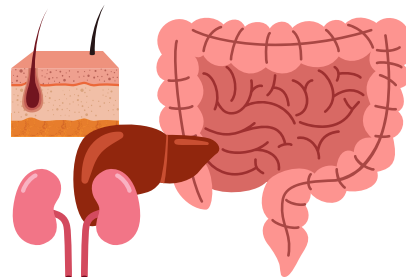


Causes and Risk Factors in IBD/Ostomy Patients

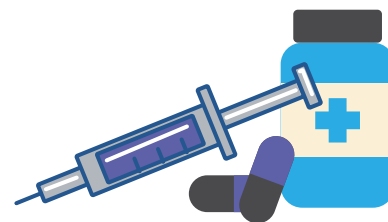
- **Certain extraintestinal manifestations:** Women suffering from extraintestinal complications, such as fistulae (particularly enterovaginal fistulae), or vulvar involvement from Crohn's may also experience more painful periods.
- **Certain medications:** Steroid usage has been associated with irregular menstruation patterns; however, it appears concurrent use of steroids with either thiopurines or anti-TNF agents may reduce this risk (Saha). Medication options used to treat extraintestinal manifestations of IBD and ostomies (e.g. antidepressants for mental health conditions) may also be associated with irregular menstrual patterns.
- **Malabsorption:** Depending on the location of active disease or type of ostomy, individuals may be consuming enough food, but because of their condition, not be absorbing nutrients from the food they consume appropriately. In this case, despite eating what would seem to be an appropriate amount of food to support function and health, an individual may still be undernourished because of malabsorption issues. This can precipitate loss of one's period.
- **Malnutrition:** For individuals with IBD and ostomies, there can be significant fear in approaching eating or an overall inability to eat based on disease activity. Malnutrition can be a common occurrence contributing to a loss of one's period. As with those struggling with disordered eating or excessive exercise patterns, malnutrition can lead to dysregulation of the hormones involved in induction of the menstrual cycle. Disruption of these hormones presents as irregularity or loss of one's period.
- **Surgery:** Surgical procedures of the abdomen and/or pelvic area may be correlated with increased pain before and during menstruation.

Certain factors, specific to IBD and/or ostomy, can influence menstrual dysfunction or pain

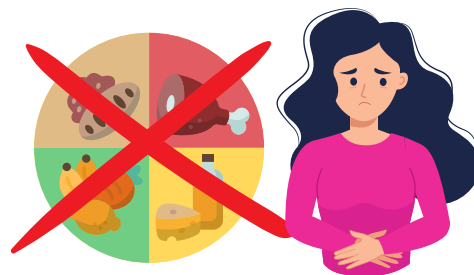
1 Certain extraintestinal manifestations



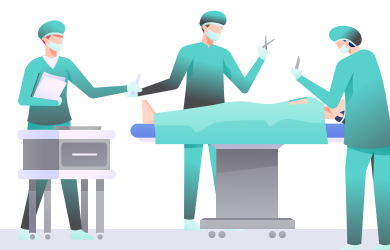
2 Certain medications



3 Malabsorption and Malnutrition



4 Surgery



Signs and Symptoms

While amenorrhea, as defined from a healthcare standpoint, is either the inability to start one's period within a generalized timeframe, the loss of one's period for three or more months or irregularity of one's period for six or more months, you do not need to wait to reach out to a physician if you are not having your period for shorter than the above recommendations. It is important to note that the clinical definition of amenorrhea does not always match up with when you should be seeking care from a healthcare provider. In recognizing the needs of your own body, it may be important to reach out about loss or irregularity of your menstrual cycle immediately. The same can also be said of increased pain or symptoms during menstruation. You do not need to wait till your pain or symptoms reach a certain level of severity in order to feel comfortable seeking care from your physician.

Signs and symptoms of endometriosis often include irregular menstrual patterns (e.g. abnormal or heavy flow), excessive menstrual cramping (often felt into the back or abdomen), painful urination or bowel movements during menstruation, pain during intercourse and increased gastrointestinal issues.

With PCOS, individuals will often notice irregular menstrual patterns (e.g. missed periods, irregular periods or very light periods), excess body hair (on the chest, stomach, back or face), acne, weight gain around the abdomen and thinning hair/baldness.



Because menstrual disturbance and pain can be caused by numerous factors, a wide array of diagnostic tools may be utilized.

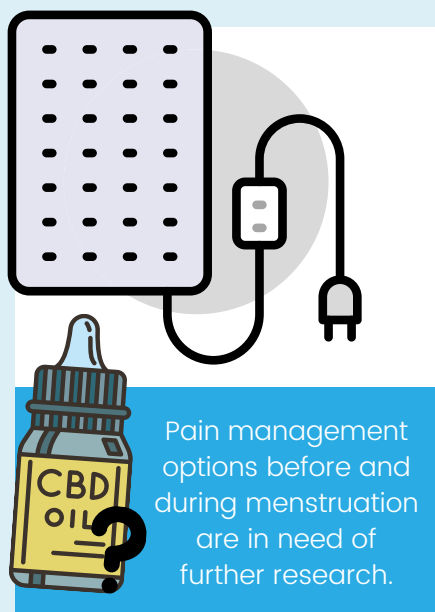
Diagnosis

Menstrual disturbances and pain can have numerous causes, and as thus, may require a number of diagnostic modalities. Your physician will likely start by taking a medical history and performing a physical examination. Specifically, a pelvic examination will be done to identify any abnormalities such as cysts or scarring. Labs can be drawn to evaluate hormone levels and better establish a specific cause and/or diagnosis. Abdominal or transvaginal (via the vagina) ultrasound may be used to identify cyst formation as well. It is important to note that menstrual conditions are often identified through the process of elimination which can feel frustrating for the patient.



Treatment

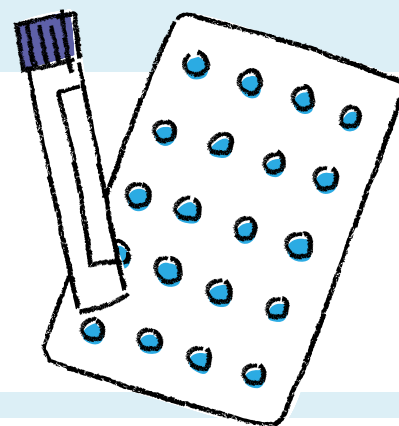
Just as with diagnostic modalities, treatment options for menstrual disturbances and pain will vary widely dependent upon the specific condition and cause. It is important to note that while oral contraceptives may often be prescribed for different menstrual conditions, these modalities induce a synthetic period. Essentially, oral contraceptives may help to regulate the cycle via a medication-induced period, but this does not necessarily treat the underlying issue. For example, individuals struggling with amenorrhea due to disordered eating or excessive exercise can take birth control and regain “regular cycles”; however, these cycles are only medication-induced and underlying hormone issues in the body are not addressed. An individual with disordered eating or excessive exercise would need to also make lifestyle changes, such as increasing nutrient intake and reducing exercise, in order to stimulate a real (rather than synthetic) period and truly address underlying health issues.



Recommendations for pain management before and during menstruation often include NSAIDs (e.g. ibuprofen) or acetaminophen (Tylenol). It is important to keep in mind that NSAIDs are not recommended for individuals with IBD as they can irritate the digestive tract lining and increase risk of flare. With this being said, sticking to pain management options outside of NSAIDs is advised for those with IBD. Many women find relief with heat packs in addition to acetaminophen use. Although there is no current research on the efficacy of CBD use for menstrual pain, many individuals still find this to be an effective option for pain management. Unfortunately, at this time, management options for painful menstrual cycles are limited and in need of further focus and research by the medical community.

With endometriosis and PCOS, other hormonal therapy options (besides oral contraceptives) may be utilized as well to regulate hormone levels. Regulating hormone levels with menstrual conditions can be important in preventing further endometrial growth, cyst formation or risk of endometrial cancer.

Hormone therapy options can be utilized in management of endometriosis and PCOS.



Treatment (continued...)

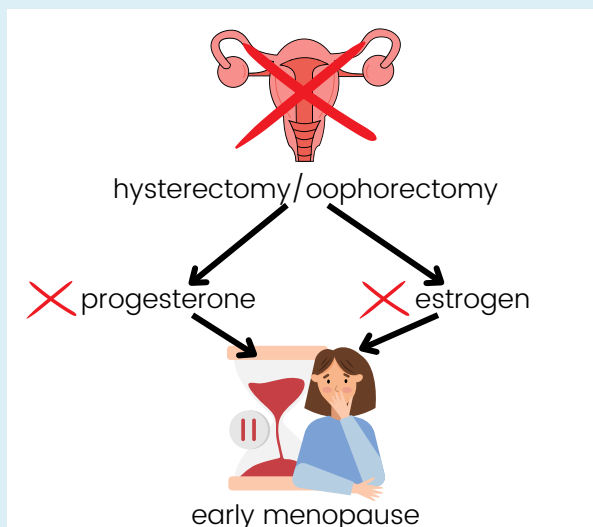
In particular, PCOS is often associated with excessive hair growth which can be treated with a variety of treatment options including spironolactone (blocks deposition of hormones called androgens on the skin), eflornithine (a topical cream that can slow hair growth on the face and under the chin) and electrolysis (hair laser treatment that destroys the hair follicle).

In certain cases, endometriosis may require surgery.



Individuals with endometriosis may require surgery to remove endometrial growths. Surgical procedures can be done either laparoscopically (a small incision is made and a thin tool called a laparoscope is inserted to navigate the surgery) or traditionally with open incisions (which is less common). Women looking to conceive will be more likely to undergo surgery for endometriosis in order to ensure a healthy pregnancy and delivery.

In the past, hysterectomy (removal of the uterus) and oophorectomy (removal of the ovaries) were considered a first-line treatment for endometriosis and PCOS. By removing the uterus and ovaries, further endometrial growth and cyst formation cannot occur. In recent years, the medical field has moved away from this practice in young individuals as removal of the uterus and ovaries induces early menopause as the ovaries are no longer present to produce certain hormones. Not only are the hormones released from the ovaries involved with reproductive health, but also a number of other aspects such as bone health. Individuals who have hysterectomies/oophorectomies at a young age will enter premature menopause and increase their risk of other health conditions (e.g. osteoporosis). Because of this, hysterectomy/oophorectomy as a treatment modality for endometriosis and PCOS must be highly individualized with the risks and benefits weighed.



In the past, removal of the uterus or ovaries was a frontline treatment for endometriosis and PCOS. The medical field has now moved away from this practice as it is associated with early menopause and other health risks (e.g. bone health problems). The risks and benefits of this treatment should be discussed with a healthcare provider.

Prevention

Menstrual disturbances and conditions can be difficult to prevent – there is still a large amount of unknowns surrounding the intricacies of menstrual conditions which makes identifying prevention measures difficult. With amenorrhea, focus on a balanced diet and regular exercise habits can ensure regular menstrual cycles. Because poor nutrient intake and excessive exercise are associated with amenorrhea, monitoring lifestyle habits can help prevent menstrual disturbances. Balanced and sustainable nutrition and exercise has also been shown to reduce risk of developing endometriosis and PCOS. Excessive alcohol consumption and high caffeine intake may also be risk factors in development of endometriosis. As with any health conditions, it is important to note that while preventative factors can be taken into consideration, the development of health conditions is a complexity of genetic and environmental factors – many of which can be beyond an individual's control.

Further Resources

- Crohn's and Colitis Foundation: Women's Health and IBD Presentation
(https://online.crohnscolitisfoundation.org/site/DocServer/IBD_Women_Health_Gupta2019.pdf?docID=35835)
- Crohn's and Colitis Foundation: Women and IBD Fact Sheet
(<https://www.crohnscolitisfoundation.org/sites/default/files/legacy/assets/pdfs/womenfactsheet.pdf>)
- Crohn's and Colitis UK: Reproductive Health and IBD
(<https://www.crohnsandcolitis.org.uk/about-crohns-and-colitis/publications/reproductive-health-and-ibd>)



Citations

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Citations (continued...)

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